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**Girls/women in inverted commas –
facing ‘reality’ as an XY-female**

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**PhD Thesis
Gender Studies**

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Far from being natural or inherent, concepts of the psychologically or physiologically normal or abnormal have been crafted since the mid-1800s, when the British scientist Francis Galton put forth his eugenic principles and the term *normal*, which had previously meant “perpendicular”, began to be applied widely to the human body and psyche.

Katrina Karkazis *Fixing Sex: Intersex, Medical Authority and Lived Experience* (2008: 295) Duke University Press.

Declaration

I declare that this thesis, whether in the same or different form, has not been previously submitted to this or any other university for a degree. It has not been submitted as part of required coursework at any university. It has not resulted from joint work with other persons.

(Candidate's signature)

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Summary

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MARGARET SIMMONDS– PhD GENDER STUDIES – SEPTEMBER 2012

GIRLS/WOMEN IN INVERTED COMMAS – FACING ‘REALITY’ AS AN XY-FEMALE

XY-women with conditions such as Androgen Insensitivity Syndrome (AIS) have male sex chromosomes, internal (abdominal) testicular or gonadal streak tissue, and no ovaries or (usually) uterus, but are otherwise female in body form and gender identity/role. Many have no reason to doubt a female sex until they are investigated for failure to menstruate. Using mixed-method (quantitative and qualitative) empirical methodology, the study reveals how XY-women discovered their diagnosis, with an in-depth analysis of the medical and societal discourses that shaped the labels/identities to which they have been subjected or they have assumed. Data was collected by questionnaire from 114 women recruited via a peer support group. The study is interdisciplinary, spanning medicine, psychology, sociology and feminist gender theory. It is informed by a range of theories including patriarchy and medicalisation (including terminology issues), sexual dimorphism, sex versus gender, social construction, abjection, self-surveillance and performativity, and sexual difference and corporeality.

Many participants had experienced diagnostic secrecy by doctors, particularly in N. America. Younger participants had benefited from a recent move to truth disclosure. Participants had found the androcentric medical discourse/terminology difficult to reconcile with their female appearance, identity and social role; and did not approve of the degree of medicalisation. Infertility was the greatest personal concern but most thought that possession of a vagina was society's main criterion for womanhood. Most seemed secure in their female gender, although some were aware of a degree of performativity. Knowledge of their male biological attributes seemed problematic for many (especially those with Swyer Syndrome¹), with expressions of inauthenticity, fraud or freakishness by some. Participants showed little awareness of gender theory and even the idea of a sex versus gender conceptual split seemed confusing for many, but clearer to those in N. America. The majority seemed to construct a totally female sex, although some entertained the idea of an intersexed sex, particularly those in N. America and those with a lesbian or bisexual orientation. The lesbian/bisexual sub-group, and those with a PAIS diagnosis, also showed the greatest awareness of gender performativity. Advocacy is a key aspect of the project, developing the argument that the androcentric focus of intersex medicine and the poor provision of clinical psychology restricts the opportunities for these patients to explore alternative discourses and non-medical meanings of their diagnosis.

1. But needs clarifying using a larger sample.

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1 Introduction

This chapter provides some medical background to the phenomenon under study, sets out my research topics, and outlines the structure of my thesis.

Overview

In 1953 American gynaecologist John Morris reported on a group of patients who, whilst otherwise appearing to be regular females, had sparse pubic and under-arm hair, had never menstruated, and were found to have testes inside their abdomen where ovaries would be expected to lie (Morris 1953). These patients had a condition now known as Androgen Insensitivity Syndrome (AIS), although Morris assigned it the name Testicular Feminization Syndrome.

AIS is an *intersex* condition,¹ in which a person's genotype (sex chromosomes) and gonads (ovaries or testes) do not match up with what is expected in terms of external genitalia and general body form (phenotype) for a female, or a male. This thesis is a study of the psychosocial issues faced by women with AIS and related XY-female conditions such as XY Gonadal Dysgenesis (Swyer Syndrome), 5-Alpha-Reductase Deficiency and Leydig Cell Hypoplasia. My broad aim is to examine the social factors that influence how women with AIS and related XY-female conditions discover their medical diagnosis, and how this affects their gendered identity/subjectivity.

Intersex has been known about since early times and AIS has been extensively reported in the medical literature, often using its older name (Testicular Feminization Syndrome) or under an even more archaic umbrella term (male pseudo-hermaphroditism) introduced in 1876, terms that are only now starting to disappear from medical texts. But it is only since the early-mid 1990s that it has been studied and talked about outside the clinical arena, with the arrival of patient advocacy/activist groups such as the UK-originated Androgen Insensitivity Syndrome Support Group (AISSG)² and the Intersex Society of North America (ISNA)³, and through attention from social scientists. Until then a clinical paradigm of secrecy had operated, with a generalised lack of disclosure of diagnostic information to patients, and lack of awareness in society as a whole.

1. Becoming known in clinical circles as a Disorder of Sex Development (DSD) since 2006.

2. See 'AISSG' in Bibliography. The group's name originates from the fact that the founder was the mother of an AIS child, but the group supports all XY-female conditions (and some XX-female conditions such as Mayer Rokitansky Küster Hauser (MRKH) syndrome that exhibit similar symptoms, e.g. lack of uterus and/or vagina).

3. See 'ISNA' in Bibliography.

AIS occurs when a genetically male (XY) foetus cannot respond to the ‘male’ hormones (androgens) produced by its newly formed (intra-abdominal) testicular tissue during gestation. The bodily development (phenotype) proceeds along female lines but with no ovaries, uterus or upper vagina being formed. If the tissues are completely insensitive (Complete AIS, or CAIS) then the external genital appearance will be female. If the tissues are partially sensitive (Partial AIS, or PAIS) the genital appearance can lie anywhere across the spectrum between female and male. The incidence of CAIS (the commonest of the XY-female conditions) is estimated to be 0.0076% of live births (Blackless et al 2000) with PAIS being less frequent. Some AIS individuals are diagnosed at birth or in early childhood, either because of the under-developed abdominal testes herniating through the abdominal wall in an apparently female infant (in some cases of CAIS) or because of clitoral enlargement or so-called genital ambiguity (in some cases of PAIS). However, for many with CAIS a lack of menstruation at puberty is the first sign of anything unusual.

The other XY-female conditions have different bio-medical aetiologies from AIS (i.e. not involving hormone insensitivity), and different presentations with respect to body hair, uterus (is present in Swyer Syndrome) and so on. Since I am defining my study participants as XY-females, I am focusing on individuals who have a female external genital anatomy (e.g. CAIS, Swyer Syndrome, Leydig Cell Hypoplasia), or maybe a slight clitoral enlargement (e.g. some with PAIS or 5-Alpha-Reductase Deficiency), and who have lived as females since birth. The study does not include any of those with PAIS, for example, who may have ambiguous genitalia and may have started life in a male assignment. My main criterion is that in a world where no attention was drawn to their unusual internal reproductive anatomy and physiology, my participants would believe themselves to be XX-women. I wish to look at the dilemma they are placed in when they discover themselves to be otherwise. The title of my study (*Girls/women in inverted commas – facing ‘reality’ as an XY-female*) refers to some clinicians’ use of quotation marks to describe XY-female patients as ‘girls’ and ‘women’ in textbooks and research papers,⁴ and with my own use of inverted commas around ‘reality’ giving recognition to the mediated nature of this concept in a postmodern world.

4. I am indebted to Marilen J. Dañguilan MD for prompting this idea with the title of her 1997 book about reproductive rights, population and development etc. *Women in Brackets: A Chronicle of Vatican Power and Control* (pub. The Philippine Center for Investigative Journalism). Her book, she explains, is “a chronicle of how the Catholic Church and some men in the Philippine government control women and seek to put them in their ‘proper places’ – in brackets” (p.xii). Committees preparing for a UN conference will generate a pre-conference document in which passages placed in square brackets are those to which one or more delegates have objected. Negotiations will then have to focus on those bracketed sections until a consensus is reached and the brackets are lifted.

John Morris's original paper, identifying the clinical features of AIS, advocated withholding the diagnosis on the paternalistic assumption that patients could not handle the truth (Morris 1953, Conn et al 2005), and John Money's (now discredited) paradigm of infant surgery (usually feminising) in cases of ambiguous genitalia viewed the hiding of the patient's medical history as necessary to ensure a stable assigned gender of rearing (Money 1955a, 1995b). Although such surgery is not directly relevant to those with no external genital ambiguity (in CAIS, for example), the way that society and medicine 'treat' them is directly coloured by taboos about the blurring of boundaries of a binary sex/gender system; and they have routinely been subjected to gonadectomy surgery without their informed consent (Dreger 1998c, Murphy 2000).⁵ Secrecy by the medical profession (and within families) has involved the liberal use of euphemisms such as 'twisted ovaries', and terms such as 'hysterectomy' in explaining what is in fact a gonadectomy or, more specifically, an *orchidectomy* or an *orchiectomy*⁶ (orchis = testis in Greek). Those who do discover their diagnosis may do so as a teenager (from a doctor when seeking medical advice for lack of menstruation, or from their parents if diagnosed in infancy/childhood) or as an older woman discovering the full story behind half-truths or lies told earlier in life. A late revelation may come from a magazine article, the internet, catching sight of medical correspondence/records or when a maternal relative gives birth to an AIS child. The other XY-female conditions present almost the same issues as AIS in psychosocial terms.

Support/advocacy groups have campaigned for truth disclosure with psychological support, for revisions to the medical terminology, for delaying surgery to allow informed consent, and for recognition that intersex is not, in general, an illness or a disease. My study comes at a time of transition for intersex. The combined efforts of patient advocacy groups and certain key clinicians have, since the mid-1990s, raised the profile of the subject, with changes in clinical practice (increasing truth disclosure and multi-disciplinary care) coming into being since the early 2000s at some major hospital centres (see Appendix B). And media speculation about whether public figures such as the South African athlete Caster Semenya might have an intersex condition has brought the subject into public consciousness.

The 'XY-female' diagnoses

This section provides a brief overview of the medical aspects of the conditions under study. But first, a word about two key elements of medical terminology/discourse:

5. From AISSG UK's enquiry list of some 1000 people (as of early 2012) the number who have escaped gonadectomy could probably be counted on one hand.

6. Doctors often use 'gonadectomy', which refers to the removal of either ovaries or testes, to cover up the fact that it is testicular tissue that is being excised.

- a) The word ‘gonad/s’ frequently appears in medical literature on intersex. The term is used by clinicians both to describe the primitive undifferentiated structure (anlage) which, prior to eight weeks gestation, has the potential to become either an ovary or a testis, and also as a generic or collective term to describe the mature generative organs (ovaries or testes).
- b) In conventional medical discourse, the active intervention of so-called male sex hormones or androgens (such as testosterone) produced by the foetal testes is needed, from around this eight week point, in order for an XY (male) foetus to develop a male genital morphology.

The various XY-female diagnoses can be divided into groups, based on their aetiologies and resulting body organs and features, as follows.

XY diagnosis with streak gonads

Those with *Swyer Syndrome* (pure XY gonadal dysgenesis) will have failed to develop testes in utero (just streaks of primitive gonadal tissue instead). In conventional medical discourse these conditions represent a problem with the *formation of testes*. As a result, they do not produce any androgens in utero. But, unlike those with other XY-female diagnoses, they also fail to produce another foetal testicular hormone, Müllerian Inhibitory Factor (MIF) or Anti-Müllerian Hormone (AMH) which, in those diagnoses (as in regular XY males), suppresses the formation of a uterus and Fallopian tubes. Those with Swyer Syndrome can therefore have a (usually small and possibly non-functional) uterus, and a normal vagina (but still have no ovaries). They may menstruate under hormone treatment and in some cases can carry a pregnancy via IVF using a donated egg.

XY diagnoses with testes

Underdevelopment of cells in testes

Those with *Leydig Cell Hypoplasia* (LCH) have intra-abdominal testes in which the androgen-producing cells have not developed properly. In conventional medical discourse this condition represents a problem with *androgen production*. They too have no ovaries, and the fact that the testes *are* able to produce MIF/AMH means that the formation of a uterus is suppressed. The vagina may be shorter than normal (vaginal hypoplasia).

Enzymatic defects in testosterone biosynthesis

Those with *5-Alpha-Reductase Deficiency* (5-a-RD) have internal testes and, as with the above mentioned diagnoses, a normal tissue sensitivity to androgens but they lack an enzyme that, during gestation, would have helped them convert their testosterone to a more powerful form (di-

hydro-testosterone or DHT) needed to masculinise their external genitalia. In conventional medical discourse this conditions represents a problem with *androgen biosynthesis*. They too have no ovaries or uterus, and possibly a shortened vagina.

Insensitivity of genital tissues to androgens

Those with *Androgen Insensitivity Syndrome* (AIS) have internal testes that produce androgens, but the body tissues cannot respond to their masculinising action, to a greater or lesser degree, because the tissue androgen receptors have not formed properly (this is controlled by a gene inherited on one of the mother's two X sex chromosomes). Like the other diagnoses, they have no ovaries or uterus, and have a shortened vagina. In conventional medical discourse AIS represents a problem with *androgen action*.

Those with CAIS (*Complete AIS*) can be expected to have a completely female external genital appearance, although the 'Complete' refers not to this morphological feature, but to the fact that they are completely insensitive at a cellular level to androgens. The newborn appears female, with no sign of its intersexuality until menstruation fails to occur at puberty; unless, that is, an inguinal (groin) hernia occurs in infancy/childhood (50% of cases) due to the testes attempting to descend through the inguinal canal. Otherwise they stay hidden in the abdominal cavity. The only other sign will be absent or sparse pubic and underarm hair, this growth being dependent on androgen action. Other female secondary sex characteristics develop at puberty, because the testosterone is converted to oestrogens in the body tissues, and many medical textbooks comment on the good breast development in CAIS patients. Older medical textbooks sometimes referring to them as being examples of 'sex reversal'. A clear skin may be mentioned (no androgen action to cause spots or acne-like conditions) or an above average height for a female.

In some cases of AIS the tissue insensitivity may not be complete, and this will allow some external masculinisation. This ranges from a clitoris that is slightly larger than average, through an ambiguous genital appearance, to genitals that are almost fully male in morphology. These individuals are said to have *Partial AIS* (PAIS). And unlike those with CAIS they will have normal pubic hair (regular XX-women, who, like men, are sensitive to androgens, develop body hair as a result of androgens produced by their adrenal glands).

The range of genital appearance in AIS forms a continuum, to which some clinicians apply a grading scheme, running from Grade 1 (PAIS male with minimal insensitivity) to 5 (PAIS female with clitoral enlargement) then Grade 6 (PAIS female, no clitoral enlargement, with pubic/axillary hair) and Grade 7 (CAIS female, hairless, completely insensitive) (ALIAS Newsletter 1996). While those with Complete AIS are almost invariably female in their gender

identity and in general are attracted to males, PAIS may be associated with a greater identification as intersexed or male, and with attraction to females. All the participants in this study, whatever their diagnosis, fall into the category of XY-female in as much as they are at, or very close to the female end of the female-male genital spectrum.

AIS is usually passed on via an X-linked recessive inheritance pattern. The altered gene (that controls the development of the tissue androgen receptors) is on one of the mother's two X sex chromosomes and in a given pregnancy there is a 1 in 4 chance of a carrier XX-woman giving birth to either an affected XY child, a carrier XX child, a 'normal' (unaffected) XY boy, or a 'normal' (non-carrier) XX girl. But some cases of AIS arise as a result of a spontaneous (de novo) mutation, with no family history. There is no known inheritance pattern in the other XY-female conditions.

Medical terminology

It seems useful to summarise the historical development of the umbrella terms used in intersex medicine, because medical terms can have such a hugely traumatising effect on patients. The way AIS and similar conditions are viewed in society has been greatly coloured by the naming conventions introduced in the era before modern clinical methodologies were put to use in clarifying the aetiology of such conditions.

Mythology-based terms

In 1876 Klebs derived a classification scheme for patients with ambiguous genitalia based on the nature of gonadal tissue (evaluated in cadavers) and using a 'hermaphrodite' based nomenclature (Klebs 1876). He postulated three types of hermaphroditism:

True hermaphroditism, in medical terms, is the coexistence in one individual of ovarian and testicular tissue: for example, an individual with an ovary on one side and a testis on the other, or the presence of both ovarian and testicular tissue in one gonad (an ovotestis).

Female pseudo-hermaphroditism occurs when only ovarian tissue is found in a person with some male morphological criteria of sex; for example an enlarged clitoris that looks like a penis. The commonest cause is a condition called Congenital Adrenal Hyperplasia (CAH).

Male pseudo-hermaphroditism, in contrast, is the presence of only testicular tissue in a person with some female morphological criteria of sex; for example, a baby with female-appearing external genitalia but who internally has testes.

The majority of intersex patients fall into one of the two ‘pseudo’ categories (signifying that the gonads are not mixed but are *either ovaries or testes*). ‘True’ hermaphroditism is *extremely* rare.

All the diagnoses discussed from page 5 onwards have, until recently, been grouped by medicine under the umbrella term of ‘male pseudo-hermaphrodite’ (essentially bringing together all those with XY sex chromosomes and male gonads, but varying degrees of feminisation in terms of genital appearance).

The history of medicine in this area, as in many others, is characterised by a gradual moving inwards into ever finer levels of detail, from the outwardly observable body to the minutiae of cells and DNA. The arrival of chromosomal analysis (karotyping) in 1960 enabled the genetic characteristics of these conditions to be established. In true hermaphroditism, where there are both male and female gonads (testes and ovaries) present, there is also an unusual mix of male and female sex chromosomes. The difference between male pseudo-hermaphroditism (e.g. AIS/TFS) and female pseudo-hermaphroditism (e.g. CAH) is that in the former a genetic male (XY) is feminised, whereas in the latter there is ambiguity of the genitalia resulting from masculinisation of a genetic female (XX) foetus.

Intersex

The term ‘intersex’ was introduced in 1917 by biologist Richard Goldschmidt (Goldschmidt 1917, Reis 2007: 536). This, like the hermaphrodite terms, is an umbrella term, encompassing a number of discrete medical conditions/syndromes. Intersex can be considered as a misalignment or cross-over of elements between the usual ‘XX-ovaries-female genitalia’ or ‘XY-testes-male genitalia’ axes, resulting, for example, in:

XX and ovaries and uterus, with masculinised external genitalia (for examples, Congenital Adrenal Hyperplasia or CAH)

XY and abdominal testes, with feminised external genitalia (for example, Androgen Insensitivity Syndrome or AIS)

Between these extremes of so-called ‘sex reversal’ there may be individuals with mixed elements at the genetic and gonadal level and varying degrees of ambiguity of the external genitalia. So intersex can include both those with ambiguous genitalia and those without (e.g. CAIS).

However, some professionals use the words ‘intersex’ and ‘ambiguous genitalia’ as synonyms, even though the latter is not always a feature of the former. For example, there are papers with the terms ‘intersex’ and ‘psychological outcome’ in their title, which would lead the reader to

suppose they might cover CAIS and emotional health, when in fact they focus on children with ambiguous genitalia and questions related to their gender identity (for example, Slijper 1998).

Disorders of Sex Development (DSD)

In the early-mid 1990s some patient advocacy groups, in particular the Intersex Society of North America (ISNA) took up the ‘intersex’ term and politicised it, as a personal label/identity of which to be proud; and a sector of ISNA also tried for a while to reclaim the hermaphrodite term, e.g. by publishing a newsletter titled *Hermaphrodites with Attitude*. By the early 2000s ISNA had shifted their view somewhat and decided that although the social use of the term intersex had been embraced as a positive identity by some adults affected, it was not popular with parents, for whom it had become associated with activism and represented something ‘in-between’ or a third gender (even though ISNA had never advocated raising children in a third gender, but merely a delay in carrying out surgery). It was at this time that ISNA started promoting the term Disorders of Sex Development (DSDs).

A conference in Chicago in 2005 (commonly referred to as the ‘Intersex Consensus’ conference), jointly organised by the US-based Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology, was important in producing official guidelines for improving the treatment of intersexed patients, with recommendations for inter-disciplinary care and truth disclosure with psychological support (Hughes et al 2006). But it also introduced a new system of terminology, sited under the overall banner of Disorders of Sex Development (DSDs). The scheme overcomes many of the disadvantages of the hermaphrodite-based umbrella terms, yet still provides for subsidiary terms like ‘46,XY DSD’ and ‘46,XX DSD’ to give the specificity required by clinicians to refer to subsets of conditions, but its introduction has been controversial amongst some parties outside the medical profession, as discussed on page 241.

Incidence

A review of sexual dimorphism (Blackless et al 2000) takes published estimates of the frequency of CAIS and of inguinal hernias in girls (some 1-2% of which may be due to AIS) and arrives at an incidence figure of 0.012% of female births. Combining this with estimates for male births gave an overall frequency of 0.0076% of live births. The most recent data used in these estimates was that of Bangsboll (1992) which used a nationwide Danish patient register and suggested an incidence for CAIS of 0.0049% (“hospitalised cases only, so the true incidence is probably higher”). Blackless et al point out that there are no solid figures for the frequency of PAIS but that Griffin and Wilson (1989) suggest it is one-tenth as common as CAIS. The complete form is

often referred to as ‘classic testicular feminization’, supporting the general view that it is the more common of the two forms. Looking at intersex conditions overall, they estimate that a grand total of 1.728% of live births deviate from the Platonic ideal of sexual dimorphism.

Medical interventions

Genital surgery

Appendix A explains why gender (re)assignment surgery is not of direct relevance to my participants but indirectly is of great significance.

Gonadectomy

In those XY-females born with intra-abdominal testes and some sensitivity to androgens (e.g. those with Partial AIS) an early gonadectomy (removal of testes) will prevent any surge in androgen production at puberty that would cause further masculinisation (usually considered undesirable in the case of a female upbringing/identity). However, early gonadectomy for babies with CAIS (where there is ‘by definition’ no issue of masculinisation due to their tissue insensitivity to androgens) has also been heavily promoted to parents, ostensibly to forestall a very slight risk of testicular cancer in adulthood, but no doubt partly to avoid having to confront a teenager with certain facts about her body when advocating gonadectomy at that stage. Some adult AIS women regret losing their testicular tissue (a source of natural oestrogen) and can have trouble adjusting to HRT. Moreover, androgens may play a role in bone health, with CAIS women being prone to osteoporosis. The cancer risk may have been overestimated in some XY-female conditions, with the risk in CAIS, for example, being lower than that of breast cancer in women as a whole. However, in some other XY-female diagnoses the risk can be considerable, as discussed on page 26; and intra-abdominal testes are more difficult to monitor for pre-cancerous changes than is breast tissue.

Vaginal lengthening

The conventional medical wisdom is that in AIS the upper third of the vagina is missing (it develops from different primitive tissues during embryological development than does the lower two-thirds). However it can actually be considerably shorter than this, even so short as to be referred to as “a dimple”, verging on complete absence (vaginal agenesis). Doctors do not seem to have an explanation for this variation in vaginal length in AIS, which has been observed even between sisters with CAIS. It seems not to be a topic of interest to clinical researchers, unlike the compelling issue of male genital anatomy.

The surgical creation/extension of a vagina (vaginoplasty) is something that medical science has not yet perfected. The sheer number of different methods, named after their proud originators, and none of them ideal, tells us that the quest is still on. Gynaecologists and surgeons, who on the whole like to ‘fix things’, often overlook the non-surgical method of pressure dilation in which the patient uses dilators (tube-like devices) in graduated sizes to apply steady pressure at regular intervals over a number of months. Ideally this needs the support of a clinical psychologist or specialist nurse with experience in motivating and monitoring progress, so a multi-disciplinary clinical setting is required, something that is not yet in place at many centres.

Research topics

My study spans social science and clinical psychology, engaging with sociological and feminist gender theory debates around intersex. In broad terms, I am asking how and when XY-women discover the various elements of their medical diagnosis, how this affects their gendered identity as women, to what extent they accept or reject the male/intersexed elements of their make-up, and whether exposure to alternative discourses of sex and gender might help them to deal better with their situation.

In relation to the discovery phase I am asking what part is played by doctors, parents and other sources of information, what role is played by stigma and shame, resulting from the possible treatment of their condition as taboo by clinicians and by family, whether younger affected women experienced more openness and transparency, what XY-women’s feelings are about the medical interventions they experienced and what their views are on medical terminology and discourse.

In terms of the impact of diagnostic information on gendered identity I ask what biological factors have the most influence (e.g. the presence of a Y chromosome and testes, the absence of ovaries and uterus, the lack of menstruation, infertility). I am interested to explore how these things might affect participants’ perceived authenticity as women and to what extent they consider their female status to be different from that of regular females.

In looking at the intersexed or male aspects of these conditions, I am enquiring whether XY-women have a heightened sense of sex versus gender (and whether such a distinction is helpful to them) and whether they perform their gender at a more conscious level than XX-women. I am interested in how they deal with knowledge of their Y chromosome and internal testicular tissue and how they would label themselves. How many would affirm that they are intersexed at a morphological level?

Finally, I am speculating as to how a feminist gender theory framework might assist the adjustment of XY-women to their diagnosis, whether a re-valuing of their unusual status might place more, or less emphasis on biology and the body, whether discursive models might help and what the possibilities are for agency and empowerment.

Identification of authors

I decided to use a <First name> <Surname> convention when introducing authors in this thesis, in order to identify the gender of those working in this gender-related field.

Structure of thesis

Chapter 1 (this chapter) has summarised the context of my study.

Chapter 2 (“Theoretical context and literature review”) outlines the feminist and advocacy framework within which my study is sited, the theoretical foundation on which it is based, and examines what has been said on the subject in the literature.

Chapter 3 (“Methodology and research material”) describes the strategy I adopted for my research, how I selected my study sample and went about collecting, processing and coding my data. It explains why I am studying this subject and sets out my claim to originality and the limitations of the study. My participants’ demographic characteristics are presented.

This is followed by four main data chapters. Their content is based on the premise that my study participants, in discovering and adapting to their situation, may pass through or adopt (or have imposed upon them) a number of medical and social phases or identities:

Chapter 4 (“The initiate and the patient”) covers participants’ experience of taking on the mantle of a medical condition as a patient.

Chapter 5 (“The failed male and the super female”) covers two other identities similarly coloured by medical discourse and terminology.

Chapter 6 (“The disordered woman and the outsider”) moves my participants towards the non-clinical realm and looks at identities based on cultural views of ‘femaleness’.

Chapter 7 (“The gender savant and the intersex woman”) explores the intersexed or male elements of my participants’ biology and alternative discourses of sex and gender that may be particularly relevant and useful to them.

Chapter 8 (“Discussion and conclusions”) brings together the analyses from preceding chapters and provides my discussion and overall conclusions.

This is followed by several appendices and a list of bibliographic references.

This introduction has provided the medical background needed to understand the remainder of this thesis. The next chapter sets out the theoretical framework in which my study is situated and reviews the relevant literature. But before moving on to that chapter it may be useful to read Appendix B which provides a historical summary of attitudes to intersex, including important changes that have taken place in the last 20 years or so, and some of the literature related to this.

2 Theoretical context and literature review

This chapter presents, in a combined form, the various theories around which my thesis is built and the recent literature on my subject area. My study engages with different theoretical concepts and different genres of literature as it moves through the main data chapters. The early chapters (Chapter 4 and Chapter 5) mainly cover issues related to *medicine*, whereas the later chapters (Chapter 6 and Chapter 7) mainly cover issues raised by *sociological/feminist gender theory*. However, there is some overlap, and in this chapter I have not necessarily established a separation between medical/psychology studies and sociological and other types of study (since my project sets out to cross boundaries and bridge divides) although I have tried to identify the discipline of each author, or team of authors mentioned. Firstly, though, I provide an introduction to the theory and to the literature aspects of this chapter.

Introduction to theoretical context

Feminist (gender theory) framework

My overall framework is feminist in orientation. It privileges experience as a valid source of data, it allows women's voices to be heard (Gluck and Patai 1991). The original feminist intervention in social science research was in the area of deficient knowledge/perspectives. It was an attack on positivism with its a value-free approach. The critique was that knowledge is linked to, and reproduces power relations, with the researcher gaining access to subjects, obtaining data, and producing knowledge to which the subjects don't get access. It was thus said that research should try and break down power relations (Harding 1987). From an initial preoccupation with the need for shared experience between researcher and researched, recent practice has been preoccupied with developing conceptual tools to arrive at situated knowledge that recognises difference, and with debates as to whether *qualitative* research is intrinsically more feminist than *quantitative* research (Gergen 2008). Mine is a mixed methods study, employing both types of research, which should provide opportunities for a rounded interpretation of the field of enquiry (Yardley and Bishop 2008).

For a study examining unusual bodily configurations, Alexandra Howson's observation is particularly relevant: that "the meaning of the body (including the sex assigned to it and its reliance on distinctiveness, opposition and hierarchy) is greatly determined by the interpretive framework through which it is viewed" (Howson 2005: 56). The bases for my theoretical framework are the concepts of medicalisation, and of patriarchy, phallocentrism and paternalism (see Appendix A) and the way in which these uphold binary divisions and bio-political controls,

whilst casting women as lacking or ‘other’. It is also constructed around concepts of sex and gender and the way in which intersex challenges dimorphic categorisations and heteronormativity. Intersex medicine brings these social mediators of bodily differences into focus. In the light of these over-arching biopolitical paradigms I will bring in theories of sexual dimorphism, social construction, abjection/stigma, cultural mediation/discourse, social disciplining/surveillance, performativity, sexual difference theory, and corporeal feminism.

Advocacy framework

One of my aims is to empower my participants. I seek to highlight the ways in which XY-women conceptualise and deal with their situation, and to identify ways of assisting those who may be restrained by a narrow focus of what their status means. My participants are not just women (although even that categorisation might be a matter of discussion during the study) but are additionally bound together by virtue of a very specific and unusual issue. My study concentrates on the lived experience of a group of XY-women and channels their voices on a number of topics that have not previously been subject to research. The voicing of XY-women’s experience has hitherto been very much subject to a patriarchal ‘gagging’, through the imposition of secrecy, stigma and shame (Scott 1991).

Feminist research has, by its nature, a political objective and yet seeks adequate and non-distorted accounts of women’s position in society. As citizens we are bound up with power relations and political action. Victoria DeFrancisco (DeFrancisco 1997) talks of Michel Foucault’s observation that power and knowledge are inextricably interrelated and that ultimate social control happens not through physical force but through the social control of knowledge perception (Foucault 1980a) and of Judith Butler’s assertion that knowledge gained from a marginalized group’s perspective is relevant to the larger society too (Butler 1990). Political companionship is limited in today’s world and it is particularly difficult for members of a stigmatised group to stand up and be counted. DeFrancisco recommends the study of resistance rather than power, to work against invisibility and silence, and talks about placing non-dominant resisting groups at the centre of analysis rather than at its margins.

Appendix B provides an account of how intersex has crept out of the shadows in the last 15-20 years, aided by patient advocacy groups and interest from clinical psychologists and scholars in sociological disciplines.

Introduction to literature review

The age of secrecy

Until the mid-1990s discussions of intersex were largely confined to medical texts, where it had been talked about for several centuries in anatomical, embryological, hormonal and (more recently) genetic terms. Until that time any focus on psychological issues were confined to gender identity. Early coverage of psychosexual matters in, for example, the 1950s publications of John Money and colleagues, concentrated on this particular aspect of identity, which had become an issue of great concern to clinicians in relation to so-called gender reassignment/reinforcement surgery. Gender identity could be evaluated via questionings and voyeuristic observations that did not require diagnostic disclosure to the patient or an awareness on their part of being studied. But it was not so easy to evaluate other aspects of an intersex status (the degree of understanding of the diagnosis, the emotional impact, ontological issues etc.) in patients who were supposed to be ignorant of the nature of their condition.

Caroline Brain and colleagues (members of the modern day multi-disciplinary clinical teams at the UCLH and Great Ormond Street Hospital NHS Trusts) summarise the current situation in a recent paper on the holistic management of intersex/DSD (Brain et al 2010):

Many adults with DSD have been lost to follow-up and historically this may, at least in part, have been due to insensitive or inappropriate care by clinicians. Delayed or even non-disclosure of the diagnosis was standard medical practice until relatively recently. As a result, it has often been difficult (both practically and ethically) to recruit into follow-up studies older patients who may not be aware of their karyotype. In addition, the original diagnoses may be incomplete or even incorrect. More recently, however, the advent of well-organised and better-informed patient peer-support groups, together with easy Internet access, has led to increasing numbers of older adult patients seeking information on every aspect of their condition. This should in turn increase our store of knowledge when advising younger patients, particularly as they approach adolescence.

My study aims to make visible the experiences and views of some of these adult support group members; and recent moves towards more diagnostic transparency on the part of clinicians should enable future projects to study a generation who have been fully informed about their condition from the start.

Emerging scholarship

Until the works of Suzanne Kessler, Anne Fausto-Sterling, and of scholars associated with patient advocacy groups such as Morgan Holmes, Alice Dreger and others, started to appear in the mid-1990s (see page 233) the sociological aspects of intersex had received virtually no attention, other than perhaps in the work of Michel Foucault discussing the 19th century case of Herculine Barbin, who in medical parlance was a “true hermaphrodite”. And even the emerging

interest seemed, with some exceptions, to be theoretical or anecdotal in nature, tended to focus on the issue of ambiguous genitalia, sometimes also providing commentary on the increasing intersex patient activism. Articles that discuss gender theory sometimes *use* intersex to illustrate certain points (relating to sexual dimorphism or the social construction of gender for example), without intersex being their main focus. Otherwise, feminist gender theory has not featured greatly to date in intersex scholarship and there are very few feminist-oriented studies built around data gathered from an affected population. But as the new millennium arrived some sociologists (e.g. Sharon Preves 1999) started to study individuals recruited via patient advocacy groups.

By the early 2000s clinical psychologists were also contributing to the emergence of intersex from the shadows. Clinical psychology studies come from a heritage of empirical and positivist measures such as evaluations of ‘brain sex’ or gender identity, questionnaire data on ‘well-being’, standard indices of sexual function, and so on; data that can be collected in a clinical setting. A recent paper gives an appraisal of the situation with respect to clinical psychology (Marta Berra et al 2010):

It is something of a paradox that although the discipline of Psychology has been profoundly implicated in the lives of people with DSD for half a century, psychological interventions targeting emotional and social adjustment in XY women can at best be described as embryonic. For some 50 years, psychologists in the field have mainly been academic researchers working within a neuroscience perspective. Academic interests in DSD has concentrated almost exclusively on their potential to help researchers determine the relative contributions of nature versus nurture to the gendered attributes and behaviours. The way and extent to which this type of psychological research has benefited or harmed people with DSD will remain a contentious topic for debate.

Some clinical psychologists have moved towards studying existential issues or personal narratives to do with adapting to diagnostic information and living with an intersex condition, issues on which patient groups had been campaigning for attention to be focused (the earliest being Julie Alderson 2000 and Lih-Mei Liao 2003) but the number of studies remains small.

Bridging divides

Articles on intersex in medical journals and textbooks tend not to mention studies published in the social science field, even when touching on issues of ethics and truth disclosure; and doctors on the whole do not have the time/inclination to read outside their particular medical specialty. Unfortunately this means that front-line clinical personnel who are carrying out irreversible interventions such as genital surgery, and who often manage the gateway to other services such as clinical psychology, do not become aware of discussions/findings in this area. In 2000, two AISSG UK members took part in a round table discussion at a meeting of the British Association

of Paediatric Urologists (BAPU), during which they questioned the wisdom of genital surgery. One of them reported afterwards (ALIAS Newsletter 2001):

I was really quite surprised at how unknown the social/feminist/philosophical intersex stuff seemed to be to them. I really think clinicians who are making these life-directing decisions [genital surgery] on behalf of other people should be aware of these discourses and I really wished I'd plugged books like Kessler's and Dreger's because I think they should have read this material.

Intersex(ed) scholar Iain Morland makes a similar observation; that paediatric surgeons only cite medical texts, by their peers, and not sociological works like those of Suzanne Kessler, in justifying gender reinforcement surgery (Morland 2001, p.545, note 13).

This review, and my study as a whole, seek to bridge that polarity – between positivist scientific knowledge of medicine on the one hand, and individual lived experience on the other – by considering both clinical and non-clinical academic studies in the psychosocial field. Social psychologist Katrina Roen recommends working across disciplines and epistemological frameworks – those that assert the need for medicalisation and those that interrogate the imperative of normative embodiment – in order to fundamentally rethink clinical practice in intersex medicine (Roen 2004, 2008). To look at intersex from an interdisciplinary perspective, including feminist gender theory angles, is an emerging trend, especially in journal 'special issues' (e.g. Liao and Boyle 2004, Morland 2009) and in books on intersex (e.g. Sytsma 2006, Holmes 2008, Karkazis 2008), the latter arriving on the scene from 1998 (see page 290 for a list). Morgan Holmes however, provided a downbeat appraisal of the general state of play at the time her most 2008 book was published (Holmes 2008: 116):

Outside of the medical specialities involved, there has been only a handful of ethics essays devoted to the issue of management, and there is an overwhelming absence of cultural work on intersex in humanities disciplines.

I now move on, under my two main categories of "Issues related to medicine" (below) and "Issues raised by sociological/feminist theory" (on page 31), to consider the theoretical frameworks and the published studies that are relevant to my main data chapters. In general, for each sub-topic under these two headings, I first discuss the general theoretical framework, where applicable, and then move into a discussion of how previous studies have used this in relation to my particular area of interest.

Issues related to medicine

The theoretical contexts and literature covered in this section are of particular relevance to the first and second of my main data chapters (Chapter 4 “The initiate and the patient”, and Chapter 5 “The failed male and the super female”).

The majority of XY-women assume the identity of ‘patient’ quite early in life, and will be subject to clinical investigations at diagnosis and to treatments throughout life ranging from surgery of various kinds to regular reminders of medicalisation via check-ups relating to bone health¹ and long-term HRT.

‘The initiate’

The first part of Chapter 4 examines how my participants discovered the various elements of their medical diagnosis, and is concerned with issues of disclosure versus secrecy.

Disclosure vs secrecy

The protocol used by the medical profession for the last 50 years until, say, the new millennium had been informed by a paternalistic belief that girls/women with AIS would be unable to handle the disclosure of their chromosomal (XY) and gonadal (testicular) make-up (Conn et al 2005). The origins of this paradigm are discussed on page 231. The twentieth century attitude to truth disclosure is highlighted by a 1996 article in a Canadian medical journal, asserting that it was acceptable to lie to an AIS patient about her diagnosis (Natarajan 1996). It won its medical student author, Anita Natarajan, an essay prize and caused an uproar in the emerging patient advocacy circles. In 1998 the web site of the British Association of Paediatric Surgeons displayed an Ethics Advisory Committee statement titled “How much to tell families of [AIS] girls with inguinal herniae regarding the possible diagnosis” (MacKinnon 1998). It adopted a paternalistic attitude, with clinicians acting as guardians of diagnostic information, implying that it was appropriate to tell half-truths or omit information, and failing to consider the involvement of a clinical psychologist in the disclosure process and thereafter, a provision that intersex patient groups were by that time calling for. Alice Dreger considered the ethical issues involved in the treatment of intersex and doubted that all, or even most of surgeries done at that time had involved legal and ethical informed consent, and she could find little in the literature on these issues (Dreger 1998c).

A particularly enlightened paediatric endocrinologist, Garry Warne, summed up the situation at a time when medicine was starting to wake up to the idea of truthful disclosure (Warne 1998):

1. Women with CAIS seem to have an increased risk of osteoporosis compared to women in general.

Members of the intersex community have been largely unmoved by what the biomedical researchers regard as significant achievements - the cloning of the AR [androgen receptor] gene, the detection of many mutations, the development of tests to identify carriers and to permit prenatal diagnosis. They are more concerned about issues of personal and sexual identity, and about understanding the influence that other people have had on their lives. Even now, most women with AIS regard their condition as a dark secret, reflecting the paranoia of their parents before them. In a recent television documentary about AIS,² one woman said of her condition: "It is... a monster in my life".

By the new millennium patient groups were influencing clinicians, those at specialist clinical centres at least, and the notion of diagnostic truth disclosure was being discussed within clinical taskforces, at conferences, and in the literature. Jennifer Conn and clinical colleagues discuss the pros and cons of telling a 40 year-old CAIS woman the details of her diagnosis that had been withheld at age 17. They discuss the historical rationale for widespread non-disclosure and the ethical issues of beneficence, non-maleficence, autonomy and justice, concluding that the greatest harm would result if the patient found out her diagnosis by chance in an unsupported environment (Conn et al 2005). Non-clinical researcher Margriet van Heesch interviewed Dutch women with intersex conditions in order to look at the management of knowing and unknowing in their life narratives (Van Heesch 2009). She considers how asymmetrical knowledge regimes and a hetero-normative gender binary have meant that gendered assumptions had consistently controlled knowledge and informed the medical ethical conviction that unknowing was better than knowing.

In the early 2000s a few clinical teams were also starting to evaluate patients' knowledge/ understanding of their diagnosis. Clinical psychologists Frouke Slijper and colleagues in Holland (Slijper et al 2000) and Amy Wisniewski and colleagues at Johns Hopkins³ in the US (Wisniewski et al 2000) all reported a poor understanding of their condition on the part of XY-women patients, as did US clinician Claude Migeon (Migeon et al 2002). The current UK clinical psychology expert in helping intersexed adults is Lih-Mei Liao. She reported many clients at UCLH's interdisciplinary clinic⁴ as being distressed by non-disclosure of crucial aspects of their condition or non-discussion of the implications, and about discussing atypical genitalia with sexual partners (Liao 2003). She recommends that psychological formulation of adult clients' difficulties should take account of dominant ways of conceptualising sex and sexuality in society, and suggests that psychotherapeutic intervention within a feminist-discursive framework could help increase clients' expertise about their conditions and their control of decisions about treatment and disclosure. Information delivery would need to draw on

2. Probably the BBC's 1996 *XY Women* documentary (in a series called *Dark Secrets*).

3. The medical institution where John Money developed his influential theories.

4. See 'Middlesex Centre' in bibliography.

alternative and subordinated discourses, allow further exploration of meanings of aspects of the condition and challenge notions of normality.

The statement that came out of the Chicago ‘Intersex Consensus’ conference in 2005 set out internationally agreed standards of care, which included diagnostic truth-disclosure (Hughes et al 2006). At a follow-up conference in 2007, Franco D’Alberton, a psychologist/psychoanalyst working in the clinical intersex field in Italy, spoke of the importance of speaking about one’s trauma, of the transformative potential of psychic pain, and the nature and timing of truth disclosure to children (D’Alberton 2007). He refers to the three-phase theory of trauma of Michael Balint, a psychotherapist who has studied the way in which medical conditions ‘disturb’ and how they involve being open to ‘the other’ (Balint 1969). In a subsequent paper D’Alberton talks of a horizontal fragmentation between the activities of medical and psychological practitioners, and a vertical fragmentation between paediatric and adult perspectives in terms of outcome knowledge. He discusses the importance of teamwork, and the challenges that disclosure and support place on clinicians’ own emotional barriers in relation to intersex/DSD (D’Alberton 2010).

By ten years into the new millennium a new paradigm of truthful disclosure had been in place, at some centres, long enough to enable some retrospective evaluation. Liao and colleagues surveyed 100 DSD patients⁵ (aged 16 to 62 years) attending the UCLH clinic with respect to their receipt and sharing of diagnostic information (Liao et al 2010). Participants were asked about their primary amenorrhoea (absent periods), infertility, absent uterus and ovaries, lifelong oestrogen, vaginal anomalies, clitoral anomalies, genital surgery, presence of testes and XY karyotype, in terms of age of discovery and satisfaction with the receipt of information. The patients were most likely to say they’d been appropriately informed in relation to amenorrhoea and infertility and least likely in relation to the presence of testes and a Y chromosome. Participants aged under 27 were more likely to have been appropriately informed than older patients, with 49% being fully informed by age 15 (compared with 0% of older participants). 59% had stumbled upon information unintentionally (70% in the older group).

My project studies a larger sample group than many of the above-mentioned studies, it includes participants aged from 15 to 76 years, and should provide useful supplementary and comparative data.

5. Made up of 56 XY-women and 44 women with the XX conditions Congenital Adrenal Hyperplasia (CAH) and Mayer Rokitansky Küster Hauser (MRKH). MRKH is a congenital condition in which an XX-female is born with vaginal agenesis and a rudimentary to absent uterus. It was not previously considered an intersex condition, but now comes under the Disorders of Sex Development banner introduced in 2006.

'The patient'

The second part of Chapter 4 evaluates my participants' experience of the medical system once they have been diagnosed, so is concerned with medicalisation in general, and with specific medical procedures/practices (surgery, display to doctors, clinical photography, psychological counselling/support etc.).

Medicalisation

A general poll might reveal a view of medicine as focusing on bodies and their biological workings, a privileging of form and function over meaning and experience, but medicine also plays an important role in social processes, referred to by Donna Haraway as "biomedicine's production of bodies and selves" (Haraway 1999). Deborah Lupton discusses the "orthodox medicalisation critique", which claims that medicine has increasingly attracted more power and influence, and that social life and social problems have become more and more 'medicalised' (Lupton 1997) with medicine having become "the contemporary authoritative belief system/'religion'" (Sylvia Walby 1990: 101). Supporters of the critique argue that becoming 'medicalised' denies rational, independent human action by allowing members of an authoritative group (doctors) to dictate to others, especially members of disempowered and exploited social groups, how they should behave. Feminist critics have viewed the medical profession as a largely patriarchal institution that uses definitions of illness to maintain the relative inequality of women. Most critics also advocate the empowerment of patients (often renamed 'consumers') encouraging people to take back control over their own health, by challenging the decisions and knowledge of doctors, joining patient advocacy groups etc.

The writings of Michel Foucault have challenged many central assumptions of the orthodox medicalisation critique, especially in relation to power and medical knowledge, by emphasising the positive and productive rather than the repressive nature of power (Foucault 1976-1984). Medical knowledge and practice participate in the very constitution, understanding and experience of bodies and subjectivities. This perspective fits into the broader social constructionist approach in understanding medical knowledge not simply as a given and objective set of 'facts' but as a belief system shaped through social and political relations. This is not so far from the orthodox medicalisation critique, says Lupton, particularly where medicine is said to transform social issues into 'diseases', but the Foucauldian approach goes further in contending that there is no such thing as an 'authentic' human body that exists outside medical discourse and practice. Rather the body and its various parts are understood as constructed through the 'clinical gaze' exerted by medical practitioners (Foucault 1963). From the Foucauldian perspective, power operates in the medical encounter as a disciplinary power that

provides guidelines for how patients should understand, regulate and experience their bodies; not through direct coercion or violence, but rather through examination, measurement and comparison with an established norm, thus persuading its subjects that certain ways of behaving and thinking are appropriate for them.

In 1991, just as intersex started entering discussions outside medicine, feminist scholar Elizabeth Grosz observed in an article titled “Freaks” (Grosz 1991: 30) that:

.... there has been a remarkable medicalisation of the hermaphrodite, so that today, virtually the only discourses available on intersexuality are those provided by clinical and scientific disciplines.

And in 1999 (by which time ISNA had started reclaiming/politicising the ‘hermaphrodite’ term as a social identity) bioethicist Carl Elliott, in a chapter titled ‘You are What you are Afflicted By: Pathology, Authenticity and Identity’, reflected on the development of intersex both as pathology and as identity, and on whether it belongs in the realm of medicine (Elliott 1999).

Medicine has a front-row seat at the demonstration that humans naturally exist with a range of reproductive anatomies and yet has been first in the queue to erase or hide this variability, by surgery and secrecy. Morgan Holmes discusses how medical practices obfuscate *social* interests, referring to the work of Julia Epstein on medicine and culture, and speculating on its application to intersex (Holmes 2008: 136):

Julia Epstein (Epstein 1995, 21) argues that when bodies do not meet up with social expectations, regardless of how normal their variation may be within “nature”, they have traditionally been perceived by families and physicians as *profoundly unnatural* and absolutely intolerable; furthermore, patients are diagnosed and managed with the specific goal of making their bodies match “normal social categories” (80). The goal of medical intervention in cases of atypical bodily appearance, then, is not to make bodies more natural, but to make them provide a cultural surface that coincides with larger cultural ideals and expectations. This is especially, though not exclusively, true with intersex, which medicine has recognized for several centuries as a natural variation, but for which law and culture have no room.

Suzanne Kessler too argues that the way in which the medical profession manages intersexuality in babies/children is guided by our culture’s beliefs about gender and genitals rather than by the needs of the child. Clinicians claiming to uncover an intersex baby’s ‘real sex’ actually rely on social factors in their decision-making (Kessler 1998). Holmes asks whether intersexed children are not in fact made *more* intersexed by surgery, presumably in the sense that surgical feminisation of an XY child moves the child even further from male end of spectrum that its chromosomes might seem to have ‘intended’. And the difference between intersexed and not intersexed, she points out, can be only a few millimetres (in length of phallus), so maybe no one is truly intersexed, and we are all, in our infinite differences from each other, intersexed (Holmes 2002, 2008). Moreover, as Cheryl Chase points out, a phallus can change from being a small

penis to being a large clitoris, without any actual change in its dimensions, merely as a result of redefining its owner as female rather than male (Chase, quoted in Holmes 1995, 2000).

Holmes sums up the state of play regarding the place of intersex within medicine and culture (Holmes 2008: 31):

Intersex, contrary to the dominant medical story currently in play, is a historical phenomenon and not a neutral biological fact. Intersex, as a set of bodily possibilities, has been both an object and product of knowledge for scientists and researchers who have made careers out of first identifying and then “fixing” the “problem”. Whatever else intersex may be at a biological level, at a cultural level it is a category that results from particular scientific and medical commitments, commitments linked to larger social means of ordering and organizing sexuality.

The categorization of intersex, she says, is related to ideological commitments to a presumed binary “nature” of male and female, coupled with a paradoxical assumption that gender is so fluid that we are entitled to make of infants and children whatever we will. She points out that most people have no knowledge of their chromosome profiles, and many millions have never heard of the concept, so it seems absurd to make chromosomes the determinants of one’s “true” sex, or to maintain that gonads and hormones are the first source and final site of subjectivity. The use of surgery to accomplish subjectivication of some individuals is also culturally contingent, and is only the most *recent* method of dealing with intersex.

But what of the effects of medicalisation on those who are intersexed? Women’s Studies researcher Lesley Gallacher uncovered invariably negative reactions to intersex medicalisation in individuals recruited from UK support groups for AIS and CAH (Gallacher 2005). Tamara Alexander, who has an intersex condition, even compares the medical management of intersexed children to childhood sexual abuse, by discussing shame, embarrassment, secrecy and silence, misinformation, dissociation and bodily estrangement, and ‘betrayal trauma’ (Alexander 1997). And even in 2008, following some 15 years of campaigning by patient groups, Katrina Karkazis’s book, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, refers (in a chapter titled ‘Growing Up under the Medical Gaze’) to:

...the disease-model approach to intersexuality, which broadly includes conceptualizations of, treatment practices for, and anxieties about gender-atypical bodies and creates a profound insecurity about the body and being, and one’s right to ownership of both...

She links this to psychiatrist R.D. Laing’s phrase “ontological insecurity”, meaning a compromised sense of self where the ordinary circumstances of living threaten one’s security and being (Laing 1960). Iain Morland, moreover, has put forward the interesting notion of “trauma by design” in relation to the effects of intersex management, i.e. ‘gendering’ by surgery, diagnostic secrecy and a resulting sexual dysfunction (Morland 2011). Treatment, he argues, is *designed* to be psychically overwhelming and incomprehensible, to prevent conscious reaction/

contemplation/memory or the gaining of a critical distance that might allow a reframing of its meaning.

The effect, on intersexed individuals, of society and medicine's defence of a dimorphic/binary system (male versus female, hetero- versus homosexuality etc.) – one that is shown to be based on untenable categories that are culturally and socially conditioned – has not been fully examined. My study aims to play some part in addressing this deficiency.

Medical interventions

Part of my study aims to uncover XY-women's experiences of, and views about surgical procedures, photography and psychological support within the clinical context, topics on which there is very little by way of personal testimony. The surgical procedures of most relevance to my study are those to remove intra-abdominal testes (gonadectomy or orchidectomy) and to lengthen/create a vagina.

Most of my participants will have undergone gonadectomy, many as infants/children, thus losing potentially fertile testicular tissue; and in many cases being advised later that it was infertile ovaries that they lost. The standard clinical approach has been that gonadectomy before adulthood is a necessary procedure, to offset a risk of cancerous changes in tissues that are immature and are situated in a (warm) part of the body (the abdomen) that they are not supposed to occupy. Pleskacova and colleagues summarise what is known from various studies of the prevalence of testicular cancer (Carcinoma In Situ and invasive type II GCT seminoma and nonseminoma) in intersex conditions (Pleskacova et al 2010). Prevalences ranged from 0.8% in CAIS to 12%-40% in conditions with dysgenetic gonads such as pure XY gonadal dysgenesis (Swyer Syndrome) and mixed gonadal dysgenesis. So an accurate diagnosis is important when weighing up the pros and cons of gonadectomy.

Gonadectomy is occasionally discussed in ethical terms, particularly in relation to Complete AIS, where a) the cancer risk is lower than in other intersex conditions, b) there is no issue of virilisation at puberty (because of the androgen insensitivity), and therefore c) informed consent might be advocated. But the procedure has had minimal attention in terms of how affected people feel about it. To my knowledge, only one study has specifically asked XY-women about their experience of, and feelings/views about gonadectomy surgery. Diamond and Watson reported that 33 (85%) of a group of 39 CAIS women were content that they had been gonadectomised (Diamond and Watson 2004) and that they were aware that tumour formation was a possibility. But their data was gathered from 1998 (six years before publication) when patient support/advocacy groups were just starting to raise the profile of intersex conditions and to question

medical practices. Reasons for *discontent* varied. One woman had an older sister who had AIS and was living satisfactorily with her testes, another believed that she was more self-confident before the surgery (which only “confirmed” that there was something “wrong” with her), a third would have preferred watchful waiting, and a fourth believed that the resulting scars required too many difficult explanations.

Vaginoplasty surgery is a procedure that is still in the dark ages; judging by the number of clinicians who have named variant techniques after themselves. Evaluative studies in the past have focused on the objective dimensions of the resulting neovagina, in terms of whether it is of appropriate size to accommodate a penis. There is very little published work on patients’ subjective experience of these procedures or their subsequent sexual function, but studies are starting to suggest that having an appropriately sized vagina is not, of itself, sufficient to ensure a good psychosexual outcome in these patients, who have many other anxieties about their condition, and that a psychosocial rather than a medical understanding is needed, as argued by gynaecologist Cathy Minto et al (2003), clinical psychologist Sue Smith (Smith 2000, Boyle et al 2005), and social workers/psychologists Bean et al (2009).

Related to medicalisation in general is the taking of medical photographs, the display of patients to trainee clinicians, the sampling of tissue for research purposes under the guise of patient diagnosis/care, and the use of patient data without consent. A power differential (a gendered relationship involving unequal power positions in clinical interactions – often male doctors and women patients or mothers), and until quite recently a lack of transparency with respect to intersex, has facilitated an atmosphere in which clinicians held all the cards and could do this with impunity. Diamond and Watson (2004) found that the difficulties of their study participants were often compounded by the health care system; by being treated as medical oddities, subjected to repeated examinations, displayed to other clinicians, photographed without permission, being labelled using outdated terminology such as Testicular Feminisation Syndrome, and by ignorance on the part of nurses and other staff (“When was your last period?... cervical smear test?”).

UCLH clinician Sarah Creighton and colleagues used childhood medical photographs of, and adult comments from AISSG members to explore the trauma caused by this practice (Creighton 2000). The authors recommend that whole-body naked photographs of intersex children or adults should not be taken and that other photographs (of the genital area, for example) should only be taken with informed consent and under general anaesthesia (Creighton 2002). And in a paper titled ‘Jarring Bodies: Thoughts on the Display of Unusual Anatomies’, non-intersexed academic Alice Dreger describes her experience of being photographed naked, in the manner of clinical

photography, for inclusion, with other photos, on the front cover of *Intersex in the Age of Ethics* (a book of which she is the editor) and traces the history of exhibiting patients and parts of their anatomies (the reference to specimen *jar* of the paper's title) whilst outlining the course of her own involvement in intersex advocacy (Dreger 2000).

Myra Hird points out the lack of psychological therapeutic help for intersexed people (most of it being given by consulting physicians rather than specifically trained psychotherapists) and the emphasis placed on maintaining a stable gender identity, *as determined by clinicians*. This, she suggests, limits the degree to which patients can explore other issues and is linked to a valuation of hetero- over homosexuality (Hird 2003). Only 16% of those in the Diamond and Watson study had been offered counselling by their physician and more than half subsequently sought out a psychiatrist or other therapist (Diamond and Watson 2004).

The second of my main data chapters (Chapter 5) that come under the broad category of "Issues related to medicine" is devoted to "The failed male and the super female".

'The failed male'

The first part of Chapter 5 examines the standard medical paradigm of "failure to masculinise" that underlies the conditions under study and how this, and the accompanying medical terminology, impacts on the psyche of those at/towards the female end of the spectrum.

Standard biomedical discourse says that in embryological terms a female body form (phenotype) is the default outcome for human beings, the active intervention of androgens being required at around eight weeks gestation for an XY foetus to develop with a male body (the 'Eve's Rib' principle). As John Money et al express it, "[In AIS] cellular insensitivity to androgen *permits* the 46,XY fetus not to masculinize" (my italics) (Money 1984a). Androcentric discourses of sex development have been dissected and critiqued in some detail by Iain Morland (2001), Nelly Oudshoorn (1994), and Marianne van den Wijngaard (1997). But is the notion of a female body form as nature's default outcome of any value to XY-women? Nuria Gregori and colleagues (social anthropologists/psychologists) point out that this is just another example of 'woman as lacking' (Gregori et al 2007). Medical terminology has played a key role here, with the use of terms that are a) based on archaic mythological concepts (e.g. various 'hermaphrodite'-based terms), or b) convey an outdated view of how the conditions arise (e.g. 'testicular feminisation syndrome'), or c) reflect the genetic and androcentric emphasis in intersex medicine (e.g. 'genetic male', 'male pseudo-hermaphrodite', even 'androgen insensitivity syndrome').

Money may be the *bête noire* as far as his influence on infant genital surgery is concerned,⁶ but he had some useful insights in other psychosocial aspects of intersex. He talks of ‘five universal exigencies’ or ‘pressing human necessities’ and mentions *ycleptance* as being the other exigency, apart from pairbondage, that has particular significance for patients with a birth defect of the sex organs. This is a recycled Elizabethan term which comes from the verb *to clepe*, meaning to name, call or style (Money 1984b). He says:

Human beings have named and typecast one another since recorded time. The terms range from the haphazard informality of nicknames to the systematic formality of biomedical nomenclature and diagnostic terms that prognosticate our futures and shape our lives. They affect our self-image, and all too often can be brutally stigmatizing.

From the mid-late 1990s members of intersex patient support/advocacy groups started to discuss and challenge the incumbent terminology amongst themselves (AISSG Web 1997b) and Jo Williams surveyed the terminology, language and information relating to AIS found in medical textbooks, scientific papers and the media (Williams 1996). Although such discussions have included complaints about the older terminology and the ‘failed male’ paradigm that it reflects, there is no published survey of the views of a group of XY-women. There is much interesting philosophical discussion of intersex terminology issues in Iain Morland’s key 2001 paper (Morland 2001) but otherwise, until the mid-late 2000s, when discussions/criticisms of the newly introduced DSD nomenclature emerged, virtually no attention was given in the clinical or sociological literature to the terminology used in this field.

Morland’s paper discusses intersex in relation to sexual difference, subjectivity, performativity, medical classifications, autonomy, ‘knowing’ and ‘telling’, androcentrism, corporeality and so on. He posits that labelling someone as a ‘pseudo-hermaphrodite’ suggests a lack of bodily authenticity, a naming through a *defining negation* which confines the patient’s subjectivity within medical discourse. It constitutes not only the truth about their body but also its falseness, as objects of medical knowledge. These terms have abounded in clinical notes and professional literature, but not in patient consultations. Such labelling, Morland says, deprives the patient of their autonomy because it constructs the patient as one who cannot know their own body: it may only be known by medicine (Morland 2001). As Suzanne Kessler framed it: “Medical professionals name intersexuality in order to eradicate it.” (Kessler 1990: 25).

The advent, in 2006, of the new DSD nomenclature means that some of the archaic terms are disappearing from current medical discourse, but there will be people, including many in my study, who continue to live with direct experience of their alienating and stigmatising effects. Many in younger generations will come across these older terms during online searches for

6. See footnote on page 231.

information; and the DSD terminology is not without problems, as discussed later. An example of the sort of title that a young girl might come across when searching for diagnostic information is a 1974 paper by Leinzinger titled ‘Hairless woman’, the male pseudohermaphrodite with testicular feminization’. Material published in medical circles has even been known to refer to a CAIS woman’s gonadectomy as ‘castration’, albeit by Italian clinicians, so possibly a linguistic misjudgement (Silvio Bertelloni et al 1998). So it seemed useful to capture the views and feelings of those subjected to such labelling, as it could provide insights into how stigmatising labels or categories in general impact on individuals’ sense of self and authenticity.

‘The super female’

The second part of my second data chapter (Chapter 5) discusses what some might regard as a damage-limitation exercise employed by some doctors (e.g. adult endocrinologists, gynaecologists) to counteract the ‘failed male’ discourse promoted by some of their colleagues in other disciplines (e.g. paediatric endocrinology).

One of the rhetorical devices sometimes used by doctors in talking to XY-women patients is the notion that those whose condition involves an inability to react to so-called male hormones (i.e. Complete AIS) are somehow inherently *more* female than regular, XX-women, in whom the growth of pubic/under-arm hair is evidence of the action of androgens from their adrenal glands. Even if the girl/woman with the rare condition sitting in front of them is the first they have encountered face to face, the doctor will have read in the medical literature about these patients’ invariably normal female appearance and gender identity, or (in the older literature) about how they marry and become good adoptive mothers or how, being tall and ‘well-endowed’, they supposedly enter glamour professions such as fashion modelling or movie acting (Netter et al 1958, Marshall and Harder 1958). Or they may in the past have been influenced by melodramatic declamations like that of Shearman who announced that “If the target cells lack this (androgen) receptor, testosterone passes like a stranger in the night and neutral female absolutism reigns supreme.” (Shearman 1985: 346-361).

Such ‘reassurances’ from doctors are the subject of some discussion in online discussion forums run by patient support/advocacy groups, with opinions being divided as to whether they are helpful and empowering, or unhelpful and patronising. Clinicians have also been known to advise young CAIS women to take advantage of the fact that their childlike lack of certain secondary sex characteristics (at least in the days before a shaved pubic area became widespread) and the fact that they can’t become pregnant, will make them particularly attractive to men with a leaning towards pre-pubescent girls. Urban myths/rumours also flourish online about certain

well-known movie actresses supposedly having AIS, with some ill-informed members of the public offering dubious insights such as “It just goes to show that the ideal woman is an androgen-insensitive man!”.

An over-emphasis of femaleness during consultations no doubt reflects, in part, a well-intentioned desire to ease the patient’s path towards acceptance of her condition, but perhaps also reflects an anxiety in the clinician about – and an inclination to push under the carpet – the intersex or male aspects of these condition: issues which, like any discussion of the patient’s prospects of having sexual relations, have until quite recently seemed taboo in many clinical discussions. In many ways it is also a perpetuation of the ‘woman as lacking’ viewpoint, even if issued with a positive/supportive intent. The use of this rhetoric with patients is not something that has been discussed in academic texts, as far as I am aware, possibly because it’s a CAIS-specific phenomenon taking place in clinics and consulting rooms and which probably isn’t well-known outside support group circles. The AISSG UK newsletter reported on an email discussion in 1997 between two AIS women about the words used by clinicians in medical textbooks and consultations (AISSG Web 1997b). A PAIS woman suggested that “some of the overemphasis on gender identity in such conditions possibly stems from prudish avoidance of the real issue – sexuality – in dealing with a child”, and a CAIS woman asked whether she was referring to “the ‘mythologizing of CAIS by overemphasising the patient’s femininity’ i.e., the way in which medics/parents throw up a smoke-screen of gender identity rhetoric/reassurance in order not to have to talk with youngsters about sex/sexuality?”. The PAIS woman’s response is shown as a section-head quotation on page 139.

I give my participants an opportunity to air their opinions and to reveal whether this concept forms part of the way they construct their identity.

Issues raised by sociological/feminist theory

Having considered the “Issues related to medicine” relevant to the first two of my data chapters (Chapter 4 and Chapter 5) I now move on to the theoretical concepts and literature that apply to the third and fourth such chapters (Chapter 6 “The disordered woman and the outsider”, and Chapter 7 “The gender savant and the intersex woman”).

‘The disordered woman’

The first part of Chapter 6 looks at the impact of diagnostic information related to participants’ ‘disordered’ sex development and at their’ psychological coping mechanisms. It also evaluates the recently adopted ‘DSD’ medical taxonomy which reinforces the notion of ‘disorder’.

Biophysical issues

Whilst there is a certain amount of literature on the general psychological effects of receiving an intersex diagnosis (as discussed in the next section) there is very little on how XY-women negotiate their differences from XX-women in terms of individual bodily components or functions. I am not aware of any published studies of how AIS women cope with their congenital lack of ovaries and consequent infertility, or on the significance assigned by XY-women to their lack of menstruation. There is a single paper by clinical psychologists Rachel Holt and Pauline Slade on the experience of seven women with MRKH (defined in footnote on page 22) in living with an incomplete vagina and womb. Four themes emerged from their interpretative phenomenological analysis. Participants struggled to understand the meaning of their diagnosis and to incorporate it into a new sense of self; contact with medical services enhanced feelings of uncertainty and isolation; emotional distress was managed through cognitive strategies and choices about disclosure to others; and experience of loss recurred over time in different ways depending on the salience of their sexual and reproductive identities (Holt and Slade 2003). Another study, of data from 55 non-intersexed women, evaluated the link between having a vagina and being a woman. Some affirmed a link, some questioned the inevitability of a link and some attempted disruption of a link, although this frequently served only to reinstate the normativity of it (Braun and Wilkinson 2005).

The influence of possessing certain male biophysical attributes is addressed in a later section (page 55). My study does not set out to study individual biophysical attributes (or lack of them) in detail, but is probably unique in looking at the relative impact of these on affected individuals' sense of their own womanhood and in relation to what is expected by society.

Psychosocial issues

Studies of psychosocial aspects of intersex can be grouped into:

- a) studies by non-clinical psychologists (e.g. 'brain sex' researchers) based on standard questionnaires and psychological scoring conventions and which usually focus on gender identity/orientation/behaviour and general quality of life measures (e.g. Hines et al 1998, 1999, 2003),
- b) clinical psychology studies based on clinical practice/experience, possibly aided by questionnaire data (sometimes from support group as well as patient respondents). Some focus on gender identity and sex (re)assignment surgery, others on emotional/cognitive reactions to diagnostic information (e.g. *in parents/children*: Slijper et al 1994, 1998, 2000, Le Maréchal 2001, Carmichael and Ransley 2002, Berenbaum 2003, Feder 2006, Duguid

2007, Cohen-Kettenis 2010; *or in adults*: Liao 2003, 2005, Liao and Boyle 2004, Liao et al 2010, Meyer-Bahlburg 2004, Kennedy 2006, Brinkmann et al 2006, Johannsen et al 2006),

c) studies by clinical psychologists and by sociologists based on interviewing affected adults recruited via support groups and which look at wider life issues/phases in relation to intersex (e.g. Alderson 2000, 2004, Preves 1999, 2000, 2003, 2008, Diamond and Watson 2004, Kerry 2005), and

d) analyses of writings/discussions by/amongst affected people or meta-analyses of published material (e.g. Nahman 2000, Hester 2004a, Bean et al 2009, Wisniewski and Mazur 2009).

Category (a) is not of direct relevance here. Key works from category (b) relating to adult patients were covered in “Disclosure vs secrecy” on page 20. Here I will focus on categories (c) and (d).

In category (c) clinical psychologist Julie Alderson conducted two semi-structured interviews with each of eight UK-based AIS women, recruited via AISSG UK, with qualitative analysis using grounded theory. ‘Meaning units’ were identified in the text and a conceptual model for understanding ‘AIS Distress’ was developed in which a pivotal concept was ‘Fear of Devaluation’. This was connected to participants’ level of ‘Adaptation’ and a perception of ‘Compromised Womanhood’, these in turn being related to ‘Medical Management’ and involvement with others (‘Support Group’ and ‘Talking about AIS’). Open communication was recommended, with sensitive pacing of information, to allow young women to make informed decisions about treatment and a realistic adaptation to life with AIS, together with further research on the role of support groups (Alderson 2000, 2004). The notion of compromised womanhood is a key concept also in my study (and my participants talked a lot about peer support at Q58 and Q59 but this material has been set aside for future analysis).

One of the earliest non-clinical sociological studies of a group of intersexed women is that of sociologist Sharon Preves who evaluated life history interviews with 37 intersexed adults (recruited from patient support/advocacy groups in the US) in relation to Erving Goffman’s work on stigma or ‘spoiled identity’. She highlights the way in which medicine alienates and objectifies intersexuals in its efforts to uphold sex/gender classification, and charts how individuals move through phases of shame, the gaining of knowledge of their condition, followed by a more positive identity. Preves identified the ‘coming out’ stages as: 1) recognition of one’s non-conformity, 2) acknowledgement of one’s difference to self and others, 3) seeking and socialising with others, 4) pride in one’s marginal identity, and 5) integration of one’s identity within a prevailing sociocultural context (Preves 1999 PhD, 2000 and 2008 articles, 2003 book).

Milton Diamond⁷ and Linda Watson are non-clinical psychosocial researchers at the Pacific Center for Sex and Society (University of Hawai'i Medical School). They collaborated with AISSG (UK and US chapters) to examine the psychological features of AIS and gathered data by interview and questionnaire from 39 CAIS individuals and 18 with PAIS (Diamond and Watson 2004). The most common problems were a) secrecy, shame and stigma b) being different in general c) concerns with infertility d) identity, and e) how to resolve personal questions of masculinity and femininity. Their detailed findings are discussed in various parts of this thesis.

Social scientist Stephen Craig Kerry interviewed eight intersexed Australians by post/email about their condition, their surgical/hormonal treatment, their gender and sexual orientation (Kerry 2005). Kerry's stages were: 1) feelings of shame, stigmatisation and secrecy, 2) questioning and disruption of sex/gender identities, 3) 'passing', self monitoring and 'doing' gendered behaviour, 4) reactions to clinical procedures, 5) relationships with parents and family members, 6) acceptance of difference, political empowerment and mobilisation, 7) spirituality, 8) sexual orientation, 9) "you can always adopt", and 10) analogies of sexual abuse. He compared the Australian experience with that of the US, as conveyed by Sharon Preves. Kerry's study, and that of Lesley Gallacher (Gallacher 2005) mentioned earlier, consider some postmodern/feminist theories such as social construction, 'doing' gender, and so on.

In category (d) we can mention social anthropologist Michal Rachel Nahman who uses Pierre Bourdieu's theory of dispositions/habitus in tracing some of the developments in online communication by and among intersex-identified people in general, including XY-women (Nahman 2000). She looked at activities within ISNA, AISSG, Intersex Voices, EZKU and CAH organisations/resources, focusing on expressions of embodiment in intersex body narratives as a way of thinking about feminist theories of the body. The narratives suggested a dissolving of the dichotomy between the biological, concrete body and the discursive body and are, it is suggested, an integration of and an engagement with epistemologies of the body.

David Hester, a researcher in rhetorics and hermeneutics, in one of his several studies of intersex, reviewed the responses of intersexed individuals and their parents available to researchers through web sites, forums, discussion groups and first-person published essays. He considers the 'rhetorics of healing' – the discursive and concrete strategies which intersexes themselves employ in their own efforts at 'healing'. These are compared with medicine's presumptions of the way they are 'supposed' to heal – through medical intervention to help the individual

7. Who, with a colleague, de-bunked John Money's famous 'gender neutrality' theory (see footnote on page 231).

conform to community values, with successful integration into the gender norms of the society into which she or he is born (Hester 2004a).

Also in this class of studies are, from 2009, some large scale clinical reviews of what had been published to-date in terms of quality of life (QoL) outcomes. These reviews considered XX-female conditions such as MRKH (defined in footnote on page 22) (Bean et al 2009) and XY-female conditions such as AIS (Wisniewski and Mazur 2009). Social workers/psychologists Bean et al analyse the extant literature on sexuality, psychological effects, and QoL in MRKH published from 1955 to 2007. In citing a paper by Hughes et al that evaluated the consequences of the Chicago ‘Consensus Statement’ (Hughes et al 2007) they report that the Chicago statement itself (Hughes et al 2006) had stimulated much dialogue, particularly in relation to the lack of long-term outcome studies and with calls for a shift in emphasis from the physical issues to the psychological aspects of how individuals adjust to their condition.

The review by clinical psychologists Wisniewski and Mazur, like other recent studies, points out that most studies have so far focused on gender identity, gender role, and sexual orientation and that few have focused on other domains, such as physical and mental health, and sexual function, or on how a DSD diagnosis and related treatment impact on QoL for affected individuals, despite the fact that patients and families often enquire about such topics. They reviewed 35 studies that included outcome information other than gender for individuals with AIS, 5-a-RD, and 17-b-HSDD, and found that reported psychological well-being varies greatly across investigations, probably due to the very small samples in studies to-date and the lack of accounting for developmental stages and the potential impact of medical and surgical procedures associated with those stages. All of the conditions included in the review were under-studied, and the authors could find no data pertaining to individual adjustment to the various intersex/DSD diagnoses included in their review and concluded that “we have a long way to go before we have a full appreciation of the mental, physical, social and spiritual domains that contribute to quality of life of people affected by XY intersex/DSD”.

The analysis of Bean et al suggests that reports of MRKH subjects’ compromised “sexual identity” and doubts about “female identity” most likely do not mean a dissatisfaction with their female gender or identity. They suggest that the term “gender role insecurity” would better describe their concerns; that an expected female gender role, one that includes menstruating, engaging in sexual intercourse, bearing children, may go unfulfilled. The women were questioning whether they can adequately perform the roles that biology typically equips them to fulfil and that society historically has expected them to perform, and the authors question whether this has been looked at in QoL studies. The authors point out that the way in which

professionals' use language to discuss the condition may positively or negatively influence a woman's experience of MRKH, and that although some studies recommended the vital psychological counselling, very few made specific suggestions regarding the type of intervention or its timing. No study had looked at how a woman's level of knowledge about her condition affected her ability to cope with it, or offered any suggestions about disclosure to others, and how and when this might be done. They conclude, again referring to Hughes et al 2007, that "there is scant research on the disclosure of any DSD" (Bean et al 2009: 345). I too am not aware of any literature on how XY-women might handle disclosure on a face-to-face basis to family, friends and sexual partners. My survey document questioned participants on their experience of talking to other people about their condition (Q41 and Q42) but I have set aside that material for future analysis.

Morgan Holmes comments on the psychological impact of medical practice as it appeared in 2008. She asserts that intersexed persons assigned female often experience the political and social world in much the same way as do typical females, "but there are parts of an intersexed woman's past that must not be addressed, thought of, or mentioned – even to oneself – if one is to walk in the world as a woman" (Holmes 2008: 146). She points out that intersex narratives often refer to how this sense of having been lied to, and then lying, about one's status as a woman has led to years of self-doubt, anxiety and fear. Doctors, she says, assume they can create subjects who will not think about their diagnoses, or their surgeries to create or remove body parts, and who will identify quite seamlessly and simply as female. They overlook the fact that these supposedly happy patients have to negotiate a set of bodily facts and procedures that are decidedly unusual, and unlike any experienced by their nonintersexed peers. She concludes (Holmes 2008: 146):

Children with a form of intersexuality are not just like everyone else, because the methods through which they acquire gender identity/sex assignment are outside the norm, even though those methods serve the same normative functions as less "obvious" measures of acquiring gender and subjectivity. Medical experts have seriously neglected the psychological impact of traditional diagnosis and medical treatment. Intersexuals assigned female are not "just like the other women", even when they have male partners and children.

DSD terminology

The recently implemented DSD (Disorders of Sex Development) medical terminology has been introduced in Chapter 1 (page 10) and in Appendix B (page 241). As mentioned there, the new terminology and the way it was introduced, has been controversial in some circles. Although certain advantages were recognised in the new terminology, it seemed to some affected people that in promoting the new scheme the Intersex Society of North America had come full circle, now demoting 'intersex' (a term that ISNA itself was largely responsible for foregrounding/

reclaiming, and which some intersexed people had adopted as a political/cultural identity) in favour of a return to terminology based on pathology (DSD Letters 2006). The advocacy group Organisation Intersex International (OII) has been particularly outspoken in criticising the new system (OII-DSD 2006).

Nuria Gregori and colleagues discuss controversies over the new nomenclature (Gregori et al 2007), and Robert Davidson (2009) and Susannah Cornwall (2010) discuss the differences in opinion on the issue amongst patient advocacy groups. Elizabeth Reis, a US-based women's and gender studies academic, comments on the drawbacks of previous terms based on 'hermaphrodite' and 'intersex' but criticises the use of 'disorders' in the newer term, advocating 'divergence' as being more appropriate (Reis 2007). Alyson Spurgas also takes a cautionary stance, taking up the issue of the new initiative being a largely US-centric affair with no opportunity for consensus⁸ being extended to patient groups outside the USA (Spurgas 2009). In fact, the term 'sex development' can, in French-speaking countries, mean something rather different (related to sexual orientation, paedophilia, fetishism, masturbation etc.) with no possibility in French to distinguish between 'sex development' and 'sexual development' (Hinkle 2008). The word 'disorder' "has a particularly unfortunate German equivalent, *Störung*" that carries overtones of 'disturbed' and it has also been suggested that the term 'disorder' was chosen partly because of its greater acceptability to US health insurers compared to a term based on something like 'variation' (personal communication with, and report by German-speaking Chicago delegate, Thomas 2006). Furthermore, the term is now being widely misquoted as Disorders of *Sexual* Development, after the originators had gone to great pains to specify 'Sex', rather than 'Sexual' (which was thought to suggest sexual orientation/practices).

Articles defending the new nomenclature also started to appear (Feder and Karkazis 2008, Karkazis and Feder 2008, Feder 2009, Hughes 2010). Arguments in favour include the fact that unlike 'intersex' (which can imply an identity, or a political stance, or a sexuality, and which is not popular with parents) DSD labels the medical condition and not the person, and that DSD emphasises the need for proper treatment of some medical aspects of the conditions such as HRT, osteoporosis (that is, it is transformed from "a disorder like no other" to "a disorder like many others", thus supposedly reducing stigmatisation). However, sociologist Georgiann Davis (who has CAIS⁹) asserts that scholarly support for DSD is based only on anecdotal evidence, rather than on any systematic empirical research, and presents a recent study based on interviewing adults with intersexuality, parents, medical professionals, and intersex activists. She argues that the shift from 'intersex' to 'DSD' "allows medical professionals to reassert their authority and

8. The 2005 Chicago conference was promoted as an 'Intersex Consensus' conference.

9. Has given permission for this to be mentioned here.

reclaim jurisdiction over intersexuality in light of intersex activism that was successfully framing intersexuality as a social rather than biological problem” (Davis 2011). This theme is developed further by Davis in a journal special issue where she argues that support for DSD is mixed amongst affected individuals and that “the power in a name” can govern which identities are adopted/rejected, and thereby impact on relationships with family and clinicians (Davis in press 2013). My participants’ views on this topic should usefully supplement the small amount of data available from the patient viewpoint.

‘The outsider’

The second part of my third data chapter (Chapter 6) consider what constitutes a woman in the eyes of society and looks at whether my participants see themselves as included within the standard categories of male or female human subject. It is therefore based around gendered attributes of men and women, sexual dimorphism, sex versus gender and social construction. It examines the extent to which my participants feel genuine in their sex/gender, and thus considers issues of abjection or outsider status, and authenticity.

Sexual dimorphism

To insist on binary divisions is part of human nature according to Robin Fox (Fox 1989), yet Thomas Laqueur tells us that our current two-sex (sexual dimorphism) model was preceded by belief in a one-sex system. Until the Renaissance there were no anatomical terms for female genitals, which were considered the same as the male’s but differently organised. There was thought to be a single type of genital structure or anatomy, one that was exteriorised in men and inverted in women (in whom it could even ‘pop out’ sometimes, when mythological shepherdesses were hotly pursued by shepherds, for example). The differences between men and women were pictured in a vertical and hierarchical fashion, rather than the polar, oppositional and complementary way that we now have. Man was near the top and woman towards the bottom of the same scale of values, and biology didn’t ground the social and cultural differences between men and women. As Laqueur explains, if the social order was a manifestation of God’s plan for mankind then there was no need to appeal to biology to explain why women could not preach or inherit property. Looking back, and using the more recently introduced terms ‘sex’ and ‘gender’, we could, with hindsight, say that before 1800 it was gender (i.e. how men and women appeared in the social realm) that was more foundational than people’s sex (their genital anatomy). As Laqueur suggests, in that situation gender preceded sex.

But the emergence of science, to challenge religion as the major belief system, meant that by the late 19th century male and female bodies had come to be seen as opposites, rather than two

arrangements or layouts of the same components. It became customary to “no longer...[...].regard woman as a lesser version of man along a vertical axis of infinite graduations but rather as an altogether different creature along a horizontal axis whose middle ground was largely empty” (Laqueur 1990: 148). But, interestingly, this is some 100 years before scientific ‘discoveries’ are brought to bear to support this new view. After 1800 bodies are being *thought of* in a different way; as the foundation and guarantor of certain types of social arrangements. We might say that sex was an *idea*, as much as an *anatomy*. As Laqueur puts it, “No one was much interested in looking for evidence of two distinct sexes until such differences became politically important”.

Anne Fausto-Sterling’s ‘Five Sexes’ article points out the inadequacy of a two-sex system for conceptualising intersex (Fausto-Sterling 1993), and Sue Vice points out that Freud suggested humans could have ended up divided into more than two sexes, perhaps following various psychological drives (Vice 1998). Had this happened, perhaps much of the medical intervention in intersex, and the associated stigma, might not have occurred?

Sex versus gender

In *Le Deuxième Sexe* Simone de Beauvoir famously stated: “One is not born, but rather becomes, a woman” (de Beauvoir 1949), or as Toril Moi puts it, “A woman defines herself through the way she lives her embodied situation in the world, or in other words, through the way in which she makes something of what the world makes of her.” (Moi 1999). However, the concept of gender, as opposed to sex, wasn’t introduced until the 1960s. The distinction has its roots in intersex medicine, being originally proposed by John Money (Money 1965) and theorised by Robert Stoller, a psychologist working with individuals born with ambiguous genitalia (Stoller 1964, 1968). Following Stoller, feminist scholar Ann Oakley defined sex as the anatomical and physiological characteristics which signify maleness and femaleness; and gender as socially constructed masculinity and femininity (Oakley 1972). My study aims to discover what a sample of XY-women makes of a ‘sex versus gender’ division and how useful or otherwise they regard this as being. This is new territory for intersex research, and I am interested to determine whether or not they are particularly attuned to such categorisations. Oakley’s schema could allow an XY-woman, if so inclined, to claim an intersexed or male sex but a female gender.

Oakley, Gayle Rubin and their contemporaries contributed to a critique of what is now called ‘essentialism’, which treats social phenomena like gender and sexuality as if they are fixed by nature, and exist prior to and outside the social and cultural discourses, practices and structures which give rise to them, instead of being historically and culturally variable (Rubin 1975, 1984). The meanings we give to the sexual organs, as well as our understandings of what it means to be

a man or a woman, are a product of social agreements. In 1978, prior to her interest in intersex, Suzanne Kessler (with Wendy McKenna) had drawn attention to the presumption that biological markers (genitals) are unequivocal under clothing; with male and female being *cultural* events that are ascribed via a 'gender attribution' process (Kessler and McKenna 1978). You look at someone and make a judgment of their sex or gender based on the genitals that you *presume* they have (or ought to have) under their clothes (their so-called 'cultural genitals').¹⁰

But from the 1970s onwards there was much discussion about sex and gender, and whether men and women's bodies have natural differences that pre-determine a specific gender, which in turn leads to a corresponding sexuality (sexual orientation). A separation of sex from gender is not always possible, or endorsed. Romance languages have no concept of gender, and the Anglo-American term 'gender' is not so popular in France, where 'sex' or 'social sex' is preferred. Psychoanalytic theorists often see sex, gender and sexuality as too closely entwined to be separated out and Tina Chanter argues that the sex/gender distinction makes it impossible to understand French psychoanalytically inspired feminism, especially the work of Luce Irigaray (Moi 1999: p.1, footnote). Gatens pointed out that the term 'gender' originated outside feminism, and questioned whether the dichotomy could aid the understanding of women's embodied experience (Gatens 1983). And some have questioned the distinction by arguing that we should not perpetuate the traditional dualism between nature (female) and culture (male).

On the other hand there are those who say that the sex-gender separation does not challenge essentialism enough, since it still assumes a natural sex onto which gender is superimposed. Some suggest that the chain of influence works in the opposite direction, so that rather than gender being a social expression based on sex, sex is itself a product of society and culture. The French materialist feminists of the 1970s such as Christine Delphy and Monique Wittig, asked whether, if gender is social, we should not consider how it shapes our ideas about biological sex. Delphy claims that *recognizing* a difference is a social act, as opposed to the differences being a self-evident fact. They postulate a Marxist class-like relationship, in which patriarchal society is said to take certain features of male and female biology and turn them into a set of gendered characteristics that serve to empower men and disempower women, and which are then presented as natural attributes of males and females. Delphy suggests that gender creates anatomical sex, and that sex has no inherent social implications until transformed by a power-based hierarchical division of humanity into two *classes* of person, men and women (Delphy and Leonard 1992,

10. Wendy Cealey Harrison has pointed out that Kessler's "cultural genitals" meant, in practice, a single genital, the penis, with women being defined as lacking one. But she suggests that Kessler's 1998 book, *Lessons from the Intersexed*, provides some evidence for vaginas emerging as cultural genitals; although there are no cultural clitorises which, she suggests, is in keeping with views of women's genitals as being tied to reproduction (Cealey Harrison 2006).

Delphy 1993). Wittig, following Delphy, even argues that those such as lesbians, who opt out of social relations that make us men and women (heterosexual relations and the male/female marriage contract) are thereby *not* men and women (Wittig 1992). This somewhat proscriptive view has been criticised, but on a theoretical level it opens up the interesting idea that XY CAIS individuals with internal testes who are attracted to men would be classed as women, whereas XX-female lesbians would not.

So these scholars question the very existence of *gender* categories, arguing that ‘women’ and ‘men’ are *social* categories defined *in relation to each other* rather than on the basis of a pre-social biological essence. These questions were elaborated further by poststructuralists and postmodernists, such as Denise Riley (1988) and Judith Butler (1990). Butler is arguably the best known of the more recent scholars who, building on ideas of Delphy (and of Foucault) have questioned the linkage of the two categories. She positions sex as a *discursive* product of gender, as described later in this chapter. This schema could allow an XY-woman to claim a female gender and, in doing so, to create a female sex.

So the sex/gender dichotomy, so central to feminism in the 1970s and early 1980s, entails a problematic dissociation between the two which can lead the body to be seen as irrelevant to an individual’s gendered cultural identity. It failed to question how society constructs the ‘natural body’ itself. Ultimately, sex becomes no more natural than gender, given that speaking of both is mediated by our existence as social beings and historical agents.

Some of the scholars/researchers who challenge the sex/gender dichotomy have also been engaged in debates relating to intersex (e.g. Fausto-Sterling 1999, 2003, Diamond 2000). Myra Hird explores Delphy’s notion that sex as well as gender is a social construction (Delphy 1993) – that gender precedes sex, that sex is the point of arrival not of departure – and the idea that this challenges their separation into distinct entities. Intersexuality and transsexuality are put forward by Hird as two bodily forms that support this view. She argues that “feminist theory needs to ascertain whether the artificial emphasis, contra nature, on male/female sexual difference is better able to effect social change than conjoined efforts to expose “sex” as a construction intended to ground divisions” (Hird 2000: 360). John Hood-Williams’ paper, ‘Goodbye to Sex and Gender’, describes how after disappointments in locating the switch that turns on maleness (with female being ‘other’) researchers found the SRY gene on the Y chromosome. But they still referred to XX-males as “males”; so they must already know what is it to be a man before they can confirm it genetically, says the author, who describes the work as circular, and seeking to ground in sex what is already defined in gender (Hood-Williams 1996).

Margaret McLaren, in her book on feminism and Foucault, bases her coverage of intersex mainly on the 19th century case of Herculine Barbin, but she does outline the feminist theories that impact on intersexed persons in today's world. "Theories of gender and sex have practical implications", she says (McLaren 2002: 127), and sums up (p.135):

The case of Herculine Barbin makes apparent the damage that can be done by accepting rigid gender distinctions and compulsory heterosexuality and imposing them onto a sexually ambiguous body. The case of Herculine Barbin can be more than a history lesson for feminists. The ambiguity of an intersexed body challenges strict divisions into male and female... ...The issues surrounding sex, gender and sexual orientation are complex. A feminism that seeks to be inclusive must negotiate these complexities, rather than rely on standard categories.

So feminist scholarship, unlike medicine, does at least give recognition to non-standard categories, even if it tends to *use* intersex to make points about normal bodies.

Alexandra Howson suggests that "Sociology's emphasis on the mutability of gender tends to 'fix' the body as a biological found" (Howson 2005: 55). In contrast, Nuria Gregori and colleagues state, in relation to intersex, that "the *fluidity* of sexed bodies made possible by technology [surgery] is used to guarantee the staticity of gender duality in a social *black-boxing* process" (Gregori et al 2007:3). The fact that these two viewpoints both hold some currency or validity is a good example of Howson's assertion, mentioned earlier, that meaning depends on the interpretive framework through which the body, and sex are viewed.

At this point in my thesis, I am keeping an open mind on the possible value of a sex/gender distinction for XY-women. It might afford them some detachment from their intersexed biology but can also result in an unsatisfactory abjection of this from their subjectivity.

Subjectivity/abjection

Whilst my participants are not outwardly indeterminate in body form, psychological theories of 'the exception' or 'the abject', and of 'monstrosity' are relevant in a study involving the disruption of norms and the crossing of boundaries (Kristeva 1982, Creed 1993, Butler 1993, Costera Meijer and Prins 1998). Feminist gender theory tells us that recognising a sex/gender involves not only identifications, where the discourse of sexual difference enables some identifications and not others, but also abjection, where some bodies form *the constitutive outside* which borders the domain of the subject and which will 'circumscribe the subject's own claim to autonomy and to life' (Butler 1993). Julia Kristeva's original concept of the abject draws heavily on Mary Douglas's influential 1966 work *Purity and Danger* and discusses three broad categories of abjection, namely: abjection towards food and thus bodily incorporation; abjection towards bodily fluids/waste and the extreme horror of the corpse; and finally, abjection towards signs of sexual difference. Abjection generally indicates elements of the body that fall away from

it, 'while remaining irreducible to the subject/object and inside/outside oppositions' (Grosz 1994: 192). The abject retains qualities of both aspects of these two dichotomies but 'cannot be clearly identified with either' (ibid). Hence, that which is abject is that which is part of and also not part of the body in question. Kristeva states that: "It is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions, rules" (Kristeva 1982: 4). Kristeva's text finds the abject "where meaning collapses" (Kristeva 1982: 2) and Creed's in "the place where 'I' am not" (Creed 1993: 9).

Barbara Creed's notion of the "monstrous feminine" (Creed 1993) was initially developed in relation to the depiction of women in horror films but is relevant to intersex scholarship.

Amongst Creed's various female 'monsters' is the 'monstrous boy-girl', which is akin to the archetypal phallic female. Catherine Harper puts this into the context of intersex (Harper 2007: 27):

The binary of sex is so rigidly constructed and perpetuated in culture and medical science that 'meaning collapses' (Kristeva 1982: 2) at the appearance of bodies whose morphology differs from the 'norm'. Here, fundamentally, is the threat of the chaotic, the destructive, the meaningless that intersex – irrationally considered – poses. However civilised is the 'management' of intersex, and however powerful are the promises to 'fix' aberrant genitalia, reconfigure errant organs, relocate doubtful sex, the implication remains that the consequences of inaction are fearful. Creed's words point us to a critical issue in the discourse of intersex: the 'I' is the person who is not intersexed. That is, intersex resides in the place of 'the other', for which read peripheral, the discounted and the objectionable. The threat of the 'abject intersexual' is a perceived threat to life itself, and all that life stands for. The abjection – in this discourse – of intersex is then to be 'radically excluded' (Kristeva 1982: 2). Permission is granted for surgical/hormonal intervention where intersex is detected in newborns because culture perceives an enormous threat from the 'hermaphroditic' body. That body – as abject – 'crosses or threatens to cross the "border"' (Creed 1993: 11) of reason, acceptability, appropriateness and the 'normal'.

Theories of abjection are closely bound up with psychoanalytic theory and with biopolitics (Agamben 1998, Edenheim 2003, Guidotto 2007). Medical science, in collusion with the state, renders visible those bodies that neatly fit the mould, while the exception is made invisible (via secrecy, esoteric medical terminology and so on) and controllable (via surgery) as a result. Notions of the abject, in effect, help to create what in Foucauldian terms would be called 'docile' bodies. Through curtailing excess, casting out and maligning improprieties and 'impurities', the social subject is constructed. Nadia Guidotto considers treatments of the hermaphrodite and its relationship to other despised groups in history and shows how biopolitics creates and regulates populations of monsters in order to establish and sustain a particular structure in society (Guidotto 2007). Sara Edenheim discusses the 'impossible' body in relation to the heterosexual matrix, interpellation and abjection. The intersexed body, she says, is not defined or treated as a subject until after a physical change has occurred (Edenheim 2003). Even in CAIS, where gender (re)assignment surgery does not play a direct role, there has traditionally been quite strong

pressure to remove abdominal testicular tissue, with an anxiety about hybrid sexual anatomy (testes in an outwardly female body) arguably providing at least part of the rationale for this. Educational sociologist Bronwyn Davies illustrates Kristeva's notion of abjection or exclusion with the example of science curricula in education making unspeakable and unthinkable the possibility of viable intersexed subjects (Davies 2006).

Elizabeth Grosz (Grosz 1991: 25) refers to "the freak" as:

.... an ambiguous being, a being whose existence imperils categories and oppositions dominant in social life. Freaks are those human beings who exist outside the structure of binary oppositions which govern our basic concepts and modes of self-definition. They occupied the impossible middle ground between binary pairs... ..Freaks cross the borders which divide the subject off from all ambiguities, interconnections and reciprocal classifications.

Grosz had just suggested that "a perverse kind of sexual curiosity" was at work concerning the sex lives of "siamese twins, hermaphrodites, bearded ladies and midgets" and her use of the past tense ("occupied") above seems to imply an *historical* cultural treatment of freaks; as circus exhibits and the like. Her 1991 quote given on page 23 (about discourses on intersexuality being confined at that time to clinical and scientific disciplines) shows that much has happened in around 20 years to bring intersex out into the open. However, one might ask whether Grosz wasn't engaging in a similar practice to that of many clinicians at that time, in writing about such individuals as objects of fascination (even if appropriated for use as a psychological figure) on the assumption that "viable intersexed subjects" cannot exist, and that if they did, then none would actually set eyes on her words?

Authenticity

In 1999 Germaine Greer published *The Whole Woman* where, in a chapter titled 'Pantomime Dames', she argued that women with AIS were not entitled to call themselves women but were "damaged males" (p.70) or "spurious females" (p.71), and defended the category of 'women' against being used as a bucket category. AISSG members and sympathisers engaged her in dialogue about this (Greer 1999).¹¹ Greer seems here to have in mind the view of XY-women which foregrounds vestigial male genetic and embryological elements, rather than the many ways in which these individuals manifest and function as women in legal terms, in appearance and social presentation, and in relationships.

11. E.g. Feminist scholar Celia Kitzinger challenged Greer's views in a book review (Kitzinger 1999); and in March 2000, at a public meeting to publicise the paperback edition of the book, Dr. Cathy Minto (Gynaecology Research Fellow at UCLH) challenged Greer to provide evidence of her own possession of an XX karyotype!

Issues of authenticity – and of belonging to, or exclusion from, particular groups – in relation to sex or gender have long been a subject of discussion. Liz Stanley quotes Garfinkel (1967) concerning Agnes (a young transsexual) ...”passing’ or achieving and security... ..rights to live as a normal natural female” and posits the implication that ‘passing’ is a feature of gender for normal males and females (Stanley 2002). Myra Hird discusses whether in order to ‘know’ yourself as female you need a) a particular morphology, and b) the experience of growing up as a woman under patriarchy; and compares intersex (implied to be authentic) with transsexualism (implied to be non-authentic) (Hird 2000: 349).

Herman E. Stark poses questions about authenticity and intersex in relation to Heidegger’s philosophical ideas (Stark 2006). He refers to a sense of “self-estrangement”, a feeling of having “failed at existence” in some intersexuals. He draws parallels with psychoanalyst Alice Miller’s theme of the repression of the true self in gifted children (defined in terms of sensitivity, alertness, and range and depth of feeling) rooted in their focusing on their *parents’* needs, thereby blocking access to authentic individual feelings (healthy narcissism). This, he says, could apply to intersexuals, who are often intensely sensitive and also probably aware of not having met expectations (of society, as well as parents, I suggest). It is an existential or ontological, rather than a moral matter and helps to capture what it is like to exist as a human. We find ourselves *thrown* into a world that has carried us along from birth, but we can break away from its current, to forge our own course. Authenticity demands truthfulness (why do many intersexuals doggedly track down medical information) but sometimes truth is hard, especially ontological truth about ourselves. Stark says that existential/ontological *authorship* is bound up with authenticity. The inherently temporal structure of stories makes them best suited for grasping authenticity. An authentic self cannot be explained in non-temporal terms, as if there exists a static, finished, immutable entity, “self”. An authentic self is rather a matter of authoring one’s own story, a process of “projecting a way of existing from within one’s thrownness”.

A number of the studies discussed earlier, some based on interview data, looked at how knowledge of their intersex condition affects individuals’ self-view, and could be said to explore how they construct or adapt their narrative identity. And the book *Intersex in the Age of Ethics* edited by Alice Dreger contains a number of chapters by intersexed people telling their stories. But the only study that claims to use narrative theory in its analysis is that of Australian Women’s Health researcher Cameryn Garrett. She analysed personal stories from the AISSG UK website through narrative theory to see what helped and hindered XY-females in revising their narrative identity. Acceptance of their condition was impeded by stigma, by the dominant discourse of womanhood and by the absence of an alternative narrative. In time, many did succeed, aided mainly by finding a collective narrative, by seeing acceptance of their identity by others, and by a

reinterpretation of the meaning of womanhood (Garrett 2007, Garrett and Kirkman 2009). In this thesis I report on my participants' thoughts about their gendered authenticity but I have set aside for future analysis some additional questions (Q40 and Q43-Q45) that asked about the construction/maintenance of a coherent personal narrative.

The second of my main data chapters that come under the broad category of "Issues raised by sociological/feminist theory" is devoted to "The gender savant and the intersex woman". The theory and literature pertaining to this is presented next.

'The gender savant'

The first part of my fourth data chapter (Chapter 7) examines the extent to which my participants are aware of, and use, devices such as a sex versus gender dichotomy, and gender-awareness practices such as self-surveillance and performativity. This is the phase in which my participants might take a pro-active role in fashioning alternative identities using discourses of sex and gender, so is where cultural mediation becomes particularly relevant.

Cultural mediation/discourse

Materialist and postmodern feminists differ in their respective modes of analysis. As discussed on page 39, materialist feminists emphasise *social* structural relations, treating men and women as social groups founded upon unequal, exploitative relationships. Postmodern feminists emphasise *cultural* factors, seeing 'men' and 'women' as discursively constructed categories, and would argue that there is no such a thing as an unmediated knowledge of the world, coming straight from things in the outside world into our understanding of those things. Arguably, all knowledge is filtered by cultural assumptions and created as a result of discourse. Discourses are not a reflection of an already ordered reality; but are that with which reality becomes ordered.

The most influential version of the concept of discourse is that derived from the work of Michel Foucault. The concept of discourse follows from the 1970/80's 'turn to language'. The assumption that language provided a set of unambiguous signs with which to label internal states and describe external reality was challenged. Language was re-conceptualised as productive, as *constructing* versions of social reality and achieving social objectives. The focus shifted away from the individual and his or her intentions, to language and its productive potential. For Foucault, discourses are anything that can carry meaning (languages, images, stories, scientific narratives and cultural products) but are also things we do; social practices such as the marriage ceremony. They are the means by which differences between people become produced. For Foucault, discourses are 'normative', carrying with them standards for behaviour, defining what

is proper and improper. Discourses are said to be historically variable (they vary according to context and over time) and to be tied up with power.

From a Foucauldian perspective, even scientific/biological knowledge comes to us through a filter resulting from the scientist's position as an interpreter influenced by sociological concepts, from their use of language etc. Moira Gatens writes that, "the anatomical body is itself a theoretical object, for the discourse of anatomy is produced by human beings in culture" (Gatens 1996: 70). As Simon Williams and Gillian Bendelow explain, instead of seeing sex as a biological phenomenon and gender as a cultural category, postmodern thinkers, from Irigaray to Butler, are concerned to undermine the dichotomy altogether. The pre-social body is therefore rejected in favour of a discursive body, a body that is bound up in the 'order' of desire, power and signification (Williams and Bendelow 1998: 116-117).

So in poststructuralist or postmodern models, language *constitutes* rather than reflects or expresses the meaning of society, experience and the individual's sense of self. Such theories reject notions of a coherent unified self, capable of rational reflection and agency, in favour of a model of the self which is fragmented, constantly in the process of formation, constituting itself out of its own understandings. Human beings are said to have no fixed essence; you construct who you are through discourse. There is no 'I' (and no body?) prior to (in the absence of) language and discourse. The theorizing of gender in response to these strands of thought comes to emphasise the process whereby subjects *become gendered* as a process in which subjectivities form in relation to the meanings that people have available to them. The emergence of certain discourses of sexuality are inter-dependent with social power exercised by medical, judicial and religious communities. But wherever power is exercised, a resistant discourse arises which is empowering for different groups of people. The concept of discourse gives a role to subjects in the making of themselves as gendered, via the appropriation of discourse.

Self-surveillance and performativity

Foucault's concept of 'bio-power' coalesced around two poles; the regulation of phenomena such as birth, death, sickness, disease, health, sexual relations and so on, and what he terms 'disciplinary power', which targets the human body as an object to be manipulated and trained. The central technique of disciplinary power – constant surveillance – is initially directed toward disciplining the body, but takes hold of the mind as well to induce a psychological state of conscious and permanent visibility (Foucault 1963). In other words, perpetual surveillance is internalised by individuals to produce the kind of self-awareness that defines the modern subject.

With the idea that modern power operates to produce the phenomena it targets, Foucault challenges the *juridicial* notion of power as *law*, which assumes that power is simply the constraint or repression of something that is already constituted. On Foucault's account the transition to modernity entails the replacement of the *law* by the *norm* as the primary instrument of social control. Modern individuals, moreover, become the agents of their own 'normalisation' to the extent that they are subjected to, and become invested in, the categories, classifications and norms propagated by scientific and administrative discourses which purport to reveal the 'truth' of their identities. Modern disciplinary society can, therefore, dispense with direct forms of repression and constraint because social control is achieved by means of subtler strategies of normalisation, strategies which produce self-regulating, 'normalised' individuals. So for Foucault, discourses constitute our subjectivity for us through material practices that shape bodies as much as minds and involve relations of power (Foucault 1988).

A number of poststructuralist feminist theorists, influenced to different degrees by Foucault, Lacan and Irigaray, have sought to theorise the body and its relation to difference and gendered subjectivity, resulting in concepts of subjectivity as *embodied performance*. Feminist scholar Judith Butler is one of the most influential of such theorists. She attempts to theorise the ways in which 'bodies are materialized as sexed' in the light of a critique of heterosexism, and bringing attention to a performative aspect of gender (Butler 1990). As discussed earlier, our understanding of material, anatomical differences is mediated through our cultural frame of meaning, and rather than gender following from biology, for Butler, our gender norms are seen as structuring biology. Butler posits that if gender does not follow automatically from sex, then there is no reason to assume only two genders (Butler 1990). And Butler no more accepts *sex* as a natural (given by nature) category than gender itself. Questioning the linkage between sex and gender leads to a speculation that sex may be a product of scientific discourses, and may thus be as culturally constructed as gender (the influence of Delphy is seen here). "There is no recourse to a body that has not already been interpreted by cultural meanings, hence sex could not qualify as a pre-discursive anatomical facticity" (Butler 1990: 8).

As discussed on page 39, some theorists view biological factors as having 'required' a binary division into two sexes because of a socially constructed gender, to which, Butler claims, heterosexuality is central. Heterosexuality is of course *based* on such a division. For Butler, then, it is the "epistemic regime of presumptive heterosexuality" (Butler 1990: viii) which drives our division into male and female, and which itself structures our understanding of biology. For Butler the application of theories of sexual difference institutionalises *heterosexuality* with an affirmation of a positive (heterosexual) female sexuality, and an 'othering' of *homosexuality* and lesbian desire. In focusing on performances, such as that of the drag artist, that parody aspects of

femininity and masculinity she suggests that gender cannot be thought of as having some essential basis; there is no original 'authentic' femininity or masculinity located in male or female bodies or in our inner selves.

In *Bodies That Matter* Butler shifts her focus towards the *materialisation* of sexed bodies, in answer to accusations from other scholars of having, in earlier works, denied materiality or the reality of the body. She says that although the body does not have a pre-given, essential sex, bodies become gendered (sexed) by means of a continual 'performance' of gender. This performance is not casual or ad hoc but we are *constrained* into gender. She argues that as an effect of power, sexed bodies are forcibly materialised through time. This is said to occur via a linguistic *performativity* which is citational in nature, making pronouncements (e.g. "It's a girl!") with reference to existing normative conventions.¹² So, for Butler, physical sex differences are marked and formed by discursive practices, a productive power that demarcates and differentiates bodies. Sex "is not a simple fact or static condition of the body, but a process whereby regulatory norms materialize 'sex'" (Butler 1993: 2) and "far from being chosen, femininity is an effect of the forcible citation of a norm" (Butler quoted in Lloyd 2007: 63).

Butler's account, like Foucault's, is an account of the formation of subjectivity, this being a process of submitting ourselves to socially constituted norms and practices. We become subjects from our performances and those of others towards us. The gendered performances in which we engage are in accordance with a *script* which provides us with ideals of masculinity and femininity that rendering behaviour appropriate and others not. Gendered subjectivity is thus acquired through the repeated performance by the individual of discourses of gender.

Annemarie Mol traces the interest in performativity to Goffman's 1959 book *The Social Presentation of the Self in Everyday Life* (Mol 2002). Earlier than Goffman's work, however, was that of psychoanalyst Joan Riviere, who in 1929 advanced the notion of "womanliness as a masquerade" (reproduced in Raphael-Leff and Perelberg 1997) in which she describes the case of a woman with a high degree of intellectual success (considered a masculine attribute) who would put on a mask of womanliness (flirting behaviour etc.) to avert anxiety and the retribution feared from men (p. 231).

Womanliness therefore could be assumed and worn as a mask, both to hide the possession of masculinity and to avert the reprisals expected if she was found to possess it – much as a thief will turn out his pockets and ask to be searched to prove that he has not stolen goods. The reader may now ask how I define womanliness or where I draw the line between genuine womanliness and the 'masquerade'. My suggestion is not, however, that there is any such difference: whether radical or superficial, they are the same thing.

12. See also page 313.

Mol says that as a philosopher, Butler does not talk about physical genitals (Mol 2002) but that sociologist Stefan Hirschauer takes up this task in relation to transsexuals (Hirschauer 1993), stating that transsexuality can teach the sociologist a lot about what it is to perform gender (following Garfinkel). West and Zimmerman also discuss Garfinkel's 1967 work in which he reported that Agnes "attempted to be 120% female". They also refer to the idea of "gender and accountability"; that is, actions undertaken so that they are specifically unremarkable and seen to be in accord with culturally approved standards ("how to act in society regarding things that women take for granted"), a notion that is relevant to self-surveillance, performativity and passing (West and Zimmerman 2002). But Hirschauer asserts that without physical interventions (hormones, surgery) many transsexuals have trouble performing the other gender. They need a body with the right 'sex' to be able to have a coherent identity. However Judith Halberstam explores Butler's notion of gender as performance to assert that having a penis, male hormones or XY chromosomes are not pre-requisites of being masculine or performing masculinity, nor are they barriers to the performance of femininity (Halberstam 1998).

One might expect intersexed individuals, XY-women in this instance, to be particularly tuned in to the self-surveillance and performative aspects of sex and gender. But the study of Diamond and Watson is the only one, to my knowledge, that has touched on this. They asked their sample of 39 CAIS women if they had to "work at being a woman". 17 (44%) of the participants said they had "never" had to do so. The remaining 22 (56%) however believed that at least some of the time this was something that they had to do. Twelve of the 22 believed that they must work at being female much of the time. The "working at", they suggest, might have involved dressing in a feminine way or using cosmetics or hair styles in a way to signal "female" unambiguously (Diamond and Watson 2004, also quoted by Harper 2007: 109). I hope to add further insights on this issue, with my survey question about gender performativity. I also ask participants about comparing themselves with other women (Q53), with self-surveillance in mind, but have set aside that material for future analysis.

The English abstract of a 2006 paper in Spanish by Aracelis Escabi-Montalvo and José Toro-Alfonso (title translated as 'When bodies deceive: an approach critical to the category of intersex') suggests that:

Even though we live in a postmodern society in which the traditional understanding of gender categories are questioned through acts [performativity?], particularly the lineal and deterministic views underlying gender, the position to correct the intersexual body demonstrates that there are still a discourse that reproduces and legitimize the dichotomization of gender and sex.

A rough Google translation of the paper shows that these authors view the essentialist versus social constructionist model as having limitations, since even the latter promotes a naturalisation of dichotomous notions of gender, sexuality and sex as a social product. They suggest that the poststructuralist positions of Foucault and Butler are more useful. The role of *power* in forming, maintaining, supporting and regulating bodies – requiring an exchange of speech with, and close scrutiny and questions from doctors, psychologists, the state, religion and the law – also offers spaces of *resistance*; opportunities for subjects to initiate new discourses.

The English abstract of another article in Spanish, by Araceli González Vázquez (2009), on Foucault's and Butler's relevance to intersex, states that "intersex is considered a critical, subversive and deconstructive tool for the categories of sex and gender, in particular from social constructivist theoretical positions well nurtured by poststructuralist rhetoric". The paper discusses the reception of Foucault's thought in studies of intersex and which ideas they contribute to destabilising or reifying with the current debates. A Google translation shows that the author examined the work of Anne Fausto-Sterling and of Alice Dreger, the academic theses of young researchers (such as Langlo [1999], Eckert [2003], and Gallacher [2005]), and other publications "of the few that actually exist on these issues". She outlines various concepts of the body: the *fictional body* associated with the "fictive sex" of Wittig; the *docile body* of Foucault shaped by disciplinary power; and the *deceiving body* (referencing the above mentioned paper by Escabi-Montalvo and Toro-Alfonso); and posits the *subversive body* of Butler as being central to the problematization of gender. But she concludes that Foucault's notion of biopower, whilst being complementary to Butler's theory of performativity (see page 47), holds more promise for intersex political action than does the latter; "although any such action seems far away".

The gender savant

Gregori et al hypothesise the intersexed person as either object or subject, victim or hero: [either] "hide[ing] in the shadows, mutilated and dependent on medical power and its technologies..." [or] "...the activist 'subject'... the possessor of a great theoretical experience that refers to the fluidity in bodies and identities..." (Gregori et al 2007; 10-11). Morgan Holmes challenges the extent to which intersexed women can be classed as "gender savants". In the introduction to her 2008 book she takes Sharon Preves to task for implying in her 2003 volume that intersexed bodies and persons are especially troubled, as opposed to *troubling*. She refers to Preves as follows (Holmes 2008: 13-14):

Sharon Preves has reiterated that intersexed persons are faced with an especially "uneasy choice" regarding sex assignment, embodiment, and the need to "do gender" (Preves 2003:2). Here Preves assumes that it is harder for intersexed persons than for typical males and females to do the work of performing a culturally intelligible gender, and, furthermore, that intersexed persons are de facto more aware of the process of having to do gender; the rest of us, she says,

“have never had occasion to explore our gender or sexual identities because neither has given us cause for reflection” (2). That is, while all subjects are compelled to do gender, according to Preves, intersexed persons are more self-conscious about the constructed nature of that perpetual act. I grant that the level of self-awareness of the artifice of gender appears to be more pronounced among the intersex population, and I include myself and my own awareness in that population. However, it is not necessarily the case that it is any *more* work or *harder* work for intersexed persons to do gender than it is for anyone else.

Holmes cites two reasons why gender performance is no more inherently marked for intersexed persons. First is Judith Butler’s position that *all* gender is trouble and secondly the fact that anatomy and appearance are not absolutely equal to social subject position (thus one might feel inside that one is intersexed, while still doing a traditional gender recognisable as man or woman), as Holmes claims to be the case for many of her intersexed contacts. But Preves, according to Holmes, whilst claiming that scientists and clinicians grossly exaggerate the “problem” of intersex, at the same time herself places intersexuality “at the borders of possibility” by characterising intersexed persons as being more aware of the limits and contradictions of the system around them, as “a kind of gender-savant...[...]...an ideal intersexed subject whose perceptions of embodiment and ability to detect gender dogma will lead the way to enlightenment.” (Holmes 2008: 14-15). Holmes suggests that Preves appears surprised when some of her intersexed subjects distanced themselves from identifying as intersex and appeared to uphold a two-sex system by participating in what would be outwardly perceived as heterosexual activity, and Holmes feels this “lacks compassion for those who do not maintain a critical relationship to the operation of gender norms or of heteronormativity...[who]...want simply to be like all the other girls and boys”. It appears, she says, that “Preves expects her intersexed participants to lead Western culture out of the darkness of the two-sex system”. According to Holmes, Preves “shows no recognition that even though intersexed persons *may* require more than typical effort to effect a subject position, this does not oblige the intersexed person to willingly and gladly inhabit a space of resistant unintelligibility.” (Holmes 2008: 15) None, she says, is *obliged* to act as an advocate for non-normative agendas, to “bear the burdens of social order for everyone else”.

Neither am I obligating my participants to take on any political positions. Rather I seek to determine exactly what a sample of XY-women makes of the question of sex/gender categories and performativity, and whether any particular way of looking at things is more or less salient to them in attaining an intelligible subject position. My prime aim is one of advocacy (see page 16).

‘The intersex woman’

The second part of my fourth data chapter (Chapter 7) focuses on how my participants deal with the knowledge of their male biological attributes and looks at the extent to which it might be

feasible/useful for some to adopt an identity other than that of an inferior woman, possibly as a different form of woman. This is also where the intersexed body comes back into focus, or might usefully come back into focus for some participants in a positive way.

Sexual difference theorists

In psychoanalytical terms our subjectivity is partly constituted by the social imaginaries (unconscious fantasies) and symbolic order (language conventions) in which we are placed. Simone de Beauvoir's 'making' of a woman is influenced by social conceptions of what it is to be a woman; and woman is always 'other' to the male, which forms the norm of 'the rational' and 'the human'. This difference or 'othering' is conceived negatively, echoed in a conception of the female body as lacking. So-called 'sexual difference' theorists are both indebted to, and critical of psychoanalysis, especially in its Lacanian form. Luce Irigaray criticises the phallogocentric nature of dominant symbolic/cultural influences on sexual difference and subject formation, which present women as 'lack' as compared to the plenitude of masculinity. She details how cultural theorists such as Freud have only been able to measure female sexuality as an adjunct rather than as a force in its own right, and how, in Lacanian terms, the absence of a female imaginary puts a woman in a position of experiencing herself only fragmentarily, in the little structured margins of a dominant ideology (Irigaray 1985). For Irigaray women are classified as defective men, as expressed in the section head quote on page 124.

Sexual difference theorists reject the negative conceptualisation of difference, turning it into a strength. Women, says Irigaray, should acknowledge their fundamental differences from men, and seek a more self-referential identity situated directly in their 'otherness' not only from men, but from women also (Irigaray 1985). She talks of the difference between 'real women' and the 'woman as other' (a device she refers to as double syntax).¹³ So these theorists advocate the use of differences between women in a positive sense, as a way of empowering women and allowing them to break free from a single restrictive category of 'woman'. This was a reaction against the feminist thought of the 1970s which said that men and women would be equal in all respects if social obstacles were removed; if women could transcend their female embodiment and become more like men.

Irigaray challenges the emphasis in psychoanalytic theory on the boy child, introducing her notion of the curved speculum (female) in contrast to the flat mirror (male). She calls for a re-

13. During an interview with Judith Butler (Costera Meijer and Prins 1998: p.283) Irene Costera Meijer questioned the assumed necessity of the heterosexual character of practices that generate stable identities and asked whether the heterosexual matrix might not also obscure the performative powers of sexual divisions among women, with the stability of gendered identities also depending on differences between 'proper' women and other women (Costera Meijer 1991).

valuing of the maternal body and of the mother-daughter relationship (i.e. a female genealogy) and her suggestion of a women's language has sought to theorise a positive subjectivity for women. The content of the category 'woman' is said to be fixed at the imaginary and symbolic level, and though presently defined phallogocentrically, is open to change and variation. Irigaray thus devotes much attention to the realm of the imaginary, and to a rewriting of female anatomy and sexuality that does not rest on penetration. But this task has proved difficult to advance because of patriarchy itself, which has an interest in maintaining a binary system of sexual classification and a hetero-normative pattern of sexual desire. It is not easy to leap outside the phallogocentric system. We cannot just transcend and remove ourselves from the significance attached to our bodily form, as discussed later in connection with corporeal feminism.

A view of an essential sexual difference as being unavoidable, fundamental and immutable is adopted by Irigaray, Rosi Braidotti and (corporeal feminist scholar) Elizabeth Grosz. Diana Fuss suggests that Irigaray (controversially in the 1980s, I would think) was advocating some degree of re-assessment of the role of anatomy (1989: 61). Fuss contrasts Delphy's view that social practices are more important than biology – "it is women and men that interest me, not males and females" (Delphy 1984, 24) – with the assertion by Irigaray that "no event makes us women" and "rather by our [genital] lips we are women" (Irigaray 1985, 211, 209-10). Unlike Wittig, says Fuss, who severs the classification "woman" from any anatomical determinants, there can be little doubt that, for Irigaray, a woman is classified as such on the basis of anatomy. The point, for Irigaray, of defining women from an essentialist standpoint is not to imprison women within their bodies, says Fuss, but to rescue them from enculturating definitions by men. An essentialist definition of "woman" implies that there will always remain some part of "woman" which resists masculine imprinting and socialization. To claim that "we are women from the start" has this advantage, says Fuss, a political advantage perhaps pre-eminently – that a woman will never be a woman solely in masculine terms, never be wholly and permanently annihilated in a masculine order. But Irigaray's project is not a totally essentialist one. She is not suggesting there is unmediated access to the female body. Her aims are somewhat utopian, allowing women to experience their bodies in a positive way.

All this seems highly relevant to XY-women, not least because Irigaray doesn't seem to be laying down any rules regarding women's internal anatomical arrangements, but rather is basing her assertions mainly on social role and external anatomy. Moreover, French poststructuralist feminist writers such as Irigaray and Hélène Cixous advocate a more fluid notion of female embodiment. Western culture, suggests Irigaray, is 'monosexual', characterised by the principles of identity and non-contradiction in which ambiguity/ambivalence is minimised and everything

is either one thing or another: a refusal, in other words, to think of self that is permeated by 'otherness' (Battersby 1993). As Christine Battersby explains (Battersby 1993: 38):

What I have been wanting to stress... ..is that not all talk of identity involves thinking of the self as unitary or contained; nor need boundaries be conceived in ways that make identity closed, autonomous or impermeable. We need to think individuality differently; allowing the potentiality for otherness to exist within it, as well as alongside it; we need to theorise agency in terms of patterns of potentiality and flow. Our body boundaries do not *contain* the self; they *are* the embodied self.

Irigaray and Cixous argue against spatialised (masculine) models of corporeal containment, based on 'optics', 'straight lines', 'self-contained unity' and 'solids', in favour of one modelled on a conceptualisation of feminine desire as rich and plural. Irigaray's conception is expressed as "this sex which is not one" (Irigaray 1985), that is, men having one organ (penis/phallus) and women having several (clitoris, labia, vagina). It is based also on touching (including the notion of the two vaginal lips always being in contact) rather than looking, and a self that exists not by repulsion/exclusion, but via interpenetration of self with otherness. Cixous argues for the possibility of a 'bisexuality' (not, I think, referring to orientation, but to sex) rather than a denial of sexual difference; one that involves a lived recognition of plurality and the simultaneous presence of masculinity and femininity within an individual subject (Sarup 1993).

Negotiating male body features

There is virtually nothing in the literature on how XY-women negotiate individual male elements of their biological make-up, although the genetic aspects and external genital anatomy often loom large in general discussions *about* people with intersex conditions.

The Y sex chromosome, is a powerful signifier of maleness. However, although standard biomedical wisdom says that the (SRY or "testis-determining" gene on the) Y chromosome kicks off the cascade that usually produces a male, it is hormone action that is the gatekeeper, rather than genetics (see page 5), and Judith Butler seems mistaken in reporting [Milton Diamond as saying] that the Y chromosome has primacy in determining maleness (Butler 2004).

Furthermore, the sociological significance attached to chromosomes and genes seems out of proportion to their scientific conceptualisation as tiny invisible subcellular pieces of DNA. In the mind of many though, the possession of a Y-shaped sex chromosome seems to confer some potent and continuing source of maleness, rather than representing a blueprint or initial intention of nature and one which, even in that capacity, is open to intervention or redirection by other processes and other modes of interpretation. In *Genes and Causation* (2008) Denis Noble talks of the principle of reductionism, i.e. the tendency always to look for lower-level causes such as genes, as another way in which we impose our view on the world. But genes lie a long way from their phenotypic effects, which are exerted through many levels of biological organisation and

influences (genetic buffering). Each molecule in the process, he suggests, does not know or represent such information, but the ensemble of molecules does. In this sense, molecular events are different as a consequence of the life process.

Antoinette Rouvroy adopts a Foucauldian approach in examining the ‘new human genetics’ (e.g. the Human Genome Project) and arguing that it is, above all, a “perceptual revolution”, inducing a new *perceptual* regime (Rouvroy 2007). She says:

In spite of all that is being suggested it [the new human genetics] does not transform what it is to be human as much as shifts the place we look at when trying to characterise commonalities and variations among the human species. Our scrutiny shifts from ‘visible’ superficial physiognomy and anatomy, from the layer of physical appearance and expressed behaviours, and from ‘incalculable’ social economical and environmental contexts, to the ‘invisible’ but locatable and ‘calculable’ internal molecular milieu.

According to Foucault, she explains, scientific discourses are historical practices that have their own effect or ‘veridiction’, that is, their own ways of saying what is known to be true. Referring to the Foucauldian notion of the *production* of scientific knowledge, she reminds us of the forgotten *metaphorical* nature of notions of ‘gene’, ‘genetic programme’, ‘genetic blueprint’, ‘book of life’, ‘genetic code’, and other tropes, mostly drawn from the linguistic model, that genetic scientists use to construct the object of their science. She posits that the representations of what we call our genes, those newly ‘visible’ elements of our ‘inner nature’ to which we tend to assign privileged explanatory and predictive power, are at least partly, linguistic fictions. She explains how the gene was a *theoretical concept* before being conceived as an object or thing. The *idea* of the gene had appeared long before what would later be conceived of as its material support, the double-helical structure of DNA.

Wilhelm Johannson, in 1909, had been the first to use the term ‘gene’, but used it to name “a holistically designed hereditary potential”, or “a kind of calculation unit”, that was somehow secreted by the whole organism but which was not to be considered as a piece of morphology. He also, says Rouvroy, insisted on the distinction between the phenotype (the observable characteristics of the organism) and the genotype (containing the hereditary instructions) as being *complementary realities* in the constitution of the living being, with *no hierarchy of explanatory power* between them. Rouvroy suggests that precisely what a gene really is, whether it is a *thing*, a *function*, or a combination of both, remains remarkably unclear. This realisation or shift in understanding spurs us, she says, to acknowledge the metaphorical nature of what we call our genes, and the impossibility of a pure and unmediated ontology of natural facts, citing Wald (2000):

Scientific theories and events do not exist independently of the words that scientists and journalists use to think about them, and by the time they reach the general public, they have been further transformed by the language that scientists and journalists use to report them and by the social and cultural narratives in which they are embedded.

Problems arise, Rouvroy says, not because of the use of metaphors in science, but because the metaphorical nature of scientific discourses tends to be forgotten. ‘Genes’, ‘genetic programmes’ and ‘genetic codes’ have come to be conceived as pre-discursive, empirical realities. She says that the shift from the genetic to the post-genomic era has hardly been acknowledged outside of laboratories, with the media, general public and most regulatory bodies remaining attached to the appealing scientific dogma that was initially propagated; and that the problematic privileging of genetics over the rest of biology still prevails.

However, even science is now casting doubt on the unassailable conceptual hold that the Y chromosome seems to have had on maleness. In December 2009 it was reported (Uhlenhaut et al 2009, Sinclair and Smith 2009) that a new gene called FOXL2 had been discovered which stops females from developing male physical traits, including testes. As a banner above the Sinclair and Smith paper states:

Conventional wisdom holds that the ovary and testis are terminally differentiated organs in adult mammals. However, Uhlenhaut et al. (2009) now report that deletion of a single gene, FOXL2, is sufficient to induce transdifferentiation of ovary into testis in adult mice, suggesting that testicular development is actively repressed throughout the life of females.

This gene is not situated on one of the sex chromosomes but on a non-sex chromosome (an autosome) which is *shared by male and females*. When the gene was artificially “switched off” in adult female mice their ovaries began to turn into testes and started to produce a level of testosterone found in healthy male mice. The discovery challenges the common perception that sex is determined purely by X-chromosomes and Y-chromosomes. Rather, the FOXL2 gene seems to have a “see saw” relationship with the SOX9 gene which is normally active only in males. When one is on, the other is automatically off. In the first few days of male development SOX9 is turned on, and this stops FOXL2 from becoming active for the rest of the man’s life. The reverse occurs in females, with FOXL2 being switched on first. The researchers believe that temporarily suppressing SOX9 in males would have the opposite effect by automatically triggering the ovary development gene, leading to cells in the testes turning into follicles and ceasing the production of testosterone. Apart from suggesting it might be possible in future to alter a person’s generative organs, this finding seems to deflate arguments for the pre-eminence of the X and Y chromosomes in sex development.

Where anxieties are expressed by XY-women with regard to other more concrete or corporeal body components than genes (e.g. having internal testes rather than ovaries) such discomfort

regarding the integrity of one's sense of a bodily self may have parallels in the disruptions sometimes experienced by people who have undergone organ transplantation. Feminist scholar Margrit Shildrick, who has written in the past on monsters/freaks and identity (Shildrick 1996), has a current interest in what she refers to as "the phenomenology of heart transplantation" (Shildrick 2011). She challenges the authorised narrative that says many biomedical procedures (heart transplantation, use of pigs' valves etc.) restore an originary sense of self, when in fact they disrupt modernist paradigms which say that the embodied subject is independent of others, wholly human, and unchanged over time; and they may entail the need for organ recipients to reconceptualise the question "Who am I?". She calls for changes in clinic practice to allow patients to give more open accounts of their experiencing the body as "hybrid for life", even a rethinking of the nature of embodied identity. She says that such situations "show us a destabilisation of the socio-political, legal and ethical categorisation of bodies according to normative epistemologies that create markers such as gender, sex and race" and "it demands a reimagination of the ideologies of human identity, and a reconfiguration of bioethics". This seems relevant to the view of intra-abdominal testes as 'foreign' organs, in a female body.

Corporeal feminism

There are different postmodernist ways of conceptualising the body: the body as an inscriptive surface, and the body as lived experience. Following on from the emphasis on the *social* determinants of gender, and then the turn towards *language* or *discourse* in conceptualising sexual identities, there was a return in the 1990s towards acknowledging the body, or corporeality, as having been neglected or negated. The question is whether this 'return to the body', as it is termed in the literature, is of any value to my participants in 'revisiting' the intersexed or male elements of their biology.

Certain aspects of the Foucauldian approach had treated the body as an 'inscriptive surface', a surface given meaning through discourse, but the idea that reality is a wholly cultural or discursive construction empties the body of material agency, or renders it a passive surface of inscription upon which culture writes. Corporeal feminism has emerged, in part, in response to the tenacity of this binarism. Viewing corporeality as a discursive effect, as Butler seems to suggest, fails to answer the weightiness and constraints that our bodily existence seems to provide and the role that our bodily experiences play in our subjectivities and our affective relationship to our bodies. Jody Norton presents a persuasive argument against Butler's collapsing of sex and gender into constructed categories with neither existing independently of language and leaving the sexed biological body un-theorised/un-analysed (Norton 1997). Corporeal feminist scholars such as Elizabeth Grosz also claim to distrust the representation of

bodies which disregard their materiality, thereby enabling the dominance of reason and consciousness (Grosz 1994).

These theorists align themselves with an approach originating in the ideas of Maurice Merleau-Ponty and in psychoanalysis. Merleau-Ponty was an associate of de Beauvoir and proponent of a philosophical line of thought known as phenomenology, which sees the body as *lived experience*, as a corporeal ground of subjectivity. A subject is necessarily an embodied subject, but not via a body offered to us by biological theory (Merleau-Ponty 1962, 1964). The body we experience as *ourselves* is that which makes experience of other objects possible, rather than simply being another object amongst them. Via inner sensation or proprio-receptivity we gain a *corporeal or postural schema* or *body image* which is manifest in our habitual actions and responses. We experience things *through* our body, not in a separate relationship to it. We formulate ourselves, as subjects, as *embodied* and this involves something like an image of that body, seen by Grosz as a kind of ‘psychical map’ of the body (Grosz 1994). This challenges dominant neo-Cartesian¹⁴ models of subjectivity, by highlighting the *a priori* coincidence of consciousness and the body, that is, abandoning the mind/body dualism in favour of the notion of a *body-subject*. Merleau-Ponty’s concept of *corporeal schema* or *body-image* describes the middle space between the Cartesian mind and body.

Other corporeal feminists such as Rosalyn Diprose, Moira Gatens, Vicki Kirby, Gail Weiss and Elizabeth Wilson have built on this phenomenological concept, and on psychoanalytic theories, to derive the notion of *imaginary bodies*. Psychoanalysis tells us that our body awareness is not neutral or purely cognitive but that we invest particular contours with emotional and affective salience. And the concept of the imaginary body, derived from this and reworked by Grosz and Gatens, is intended to capture the way the body is experienced as meaningful and salient, both to the subject and to others who encounter it, as a consequence of social and cultural mediation. Sexual difference, within such a framework, is constituted out of the imaginary investments in different bodily parts, and such a concept attempts to explain how the body is woven into our account of lived sexual difference. Our identities are formed as ways of giving significance to particular body forms. Gender is ‘biology-as-lived’. Performative strategies may be able to denaturalise gender, in highlighting that there is no essential link between bodily forms and certain patterns of categorisation, but this does not necessarily affect our attachments to certain bodily forms and the significance that gendered identifications play in our ways of experiencing them. The concept of the imaginary body, and Irigaray’s foregrounding of imaginary shifts as a

14. Cartesian = based on the thought of 17th century French philosopher René Descartes.

creative project, a re-imagining of ‘woman’ outside a binary structure of male and female, attempt to address these concerns.

Grosz, we are told, aims to “destabilise oppositional categories, upset binaries and install indeterminacy as a principal tactic for developing feminist theories of the body” (Howson 2005: 117), and whilst this may help to theorise ‘normally’ sexed bodies, it’s not clear how it might apply to those who *exhibit* some degree of indeterminacy. The foundation of Grosz’s thinking was that the theories of, amongst others, Freud and Lacan theorised a male body, so she turned to corporeal experiences unique to women – menstruation, pregnancy, childbirth, lactation, menopause – to lay the groundwork for new theories of sexed corporeality. I am introducing this strand of thinking into my thesis in order to explore whether a foregrounding of an intersexed or male biology in a positive way might save this from being banished by XY-women to the realms of abjection, but of course there is an uneasy fit with the presumed female corporeality of the theory’s origins. However a theory that has a phenomenological base, that stresses *lived experience*, should surely be applicable to all bodily configurations?

Grosz does, in *Volatile Bodies* (Grosz 1994: 189), ask the question:

Are sexually neutral, indeterminate or hermaphroditic bodies inscribed to produce the sexually specific forms with which we are familiar? Or do all bodies...[...]...have a specifically sexual dimension (whether it be male, female or hermaphroditic) which is psychically and culturally inscribed according to its morphology?

But she doesn’t say much more about intersex in her book other than to state (Grosz 1994: 58, note 32) that she has covered medical and popular notions of hermaphroditism elsewhere (in her 1991 “Freaks” article). However, the title of a paper by Iain Morland asks ‘Is Intersexuality Real?’ (Morland 2001) and he comments on Grosz’s proposition. His argument is that intersex represents an excess of sex difference (p. 528); that an intersexed person’s ambiguity *is* their sexual difference (p. 528, 544); that intersexuals are not actually indeterminate insofar as they “remain concrete, determinate, specific in their morphologies” (p. 528, 544, quoting Grosz); and that “there’s no such thing as half-male, half-female” (p.534, referring to a quote from the parent of an intersexed child in a paper by Weiss (Weiss 1995)).

At a late stage in my writing up (June 2011), having decided that corporeal feminism might prove useful to XY-women and having drafted the preceding material, I came across an important article by David Hester, titled ‘Intersexes and the End of Gender: Corporeal Ethics and Postgender Bodies’ (Hester 2004b). He asserts that a backgrounding of the body by theorists such as Foucault and Butler has meant that “gender and queer criticism have had a very difficult time speaking to the experiences of intersexed people” (p. 220). Intersex bodies, he asserts, are

not passive. They force certain consequences, they confront culture, they upset and undermine cherished beliefs. They are active participants in the environment of sex-gender. He asserts that “for Kessler and McKenna [in their concept of ‘cultural genitals’] there is no ‘sex’ in the sex-gender dialectic”, but he argues that intersex shows that “there is no such thing as gender, it is all *sex*... and there are *lots* of sexes”.

For gender to succeed, he asserts, it must first carve out a sex in cases where none ‘obviously’ exists. The body must be stabilised, ‘naturalised’, ‘normativised’. So, he asks, can theories of gender performance and parody ever achieve the subversive critique and disruption they seek, when gender itself requires recognisable bodies as its *sine qua non*. He advocates an exploration of the mutual impact of bodies and cultures upon each other, turning to a model that is related to the project of ‘corporeal’ feminism, a return, now informed by the insights of gender and queer theories, to the kinds of explorations begun by early Second Wave feminists, since dismissed as ‘essentialist’, and one which takes more seriously the issue of ‘sexual difference’. While people ponder, he suggests, the possibility of multiplying genders, asking what does it mean to ‘enact’ feminine/masculine/queer/straight/bi-/trans identities, very rarely do people ponder the possibility of having no clearly identifiable sex. So “sex is far more important than gender”. So important, in fact, that when sex does not fit, gender concepts will come and *make* a sex.

He proposes a new model based on the simple question: Why must we have a sex? What are the consequences of having hundreds of sexes – for research, for medical treatment and biogenetic technology, for theorising, for sexual ethics and gender constructs, for legal systems, for activism? He concludes (p. 223) that intersexed bodies “point the way out of the current stalemate set up by the dichotomy of essentialism vs. constructionism. They are beyond the sex/gender division: they are postgender“. But is this not an example of the expectation, challenged by Holmes, that intersexed individuals will lead the way to enlightenment; and where would XY-women (who are intersexed but not genitally ambiguous) fit into this?

Adopting an intersex identity

Emily Grabham examines the work of Carol Lee Bacchi and Chris Beasley in considering concepts of citizenship alongside theories of embodiment, and evaluates the extent to which this might help articulate a theory of intersex citizenship. She cites the main issue as being “the continued location of life-changing decisions about intersex embodiment and subjectivity within the medical sphere.” Concepts of intersex citizenship, she says, “should be able to address the hyper-embodiment of intersexual people through their construction as sex/gender ‘outsiders’ within the medical context”, with the work of Beasley and Bacchi enabling us “to discern a picture of intersex ‘citizen bodies’ as against a view of people whose physical characteristics

come to represent, in a hetero-normative and gendered environment, the ‘unruliness’ of corporeality over rationality” (Grabham 2007: 44).

Rosi Braidotti and Judith Butler talk of lesbians being more attuned to “cross-identifications with masculine norms and figures” (Braidotti, with Butler 1994) and Judith Halberstam has advanced the notion of ‘female masculinity’ (Halberstam 1998). However, it’s one thing to postulate such intermingling at the level of *sexuality* in a ‘normally’ sexed individual, but does it extend to a cross-identification with masculine biological elements of an intersexed body? It is not known whether those XY-women with a lesbian/bisexual sexual orientation find it easier to identify with the intersex nature of their condition, but it seems likely that having rejected social norms and patriarchy in the area of sexuality might simplify the challenge in other areas. And one might predict that people in general who have a lesbian/bisexual orientation might perhaps find intersex in others less troubling than might heterosexuals. This is borne out in a study by Canadian psychologist BJ Rye, who herself has eight AIS relatives¹⁵ and who compared people’s attitudes to a hypothetical scenario in which a woman either declares to them that she is lesbian or declares that she has AIS. Attitudes toward the intersexed seemed more negative than those toward lesbians because of lack of familiarity with AIS; and general homophobia in the listener seemed a good predictor of negative attitudes towards both situations, particularly when the AIS women were coming out to men (Rye and Hart 2000).

To adopt and display an intersex identity in practice, in a society that ‘disallows’ it, is not easy, as expressed by Morgan Holmes, who herself had childhood genital surgery. She argues that intersex subjectivity is an ascribed status, like any sex assignment made at birth, but unlike other ascribed sex statuses, intersex is placed under immediate erasure and replaced with a designated “true sex” – either male or female (Holmes 2008). Georgiann Davis’s study of intersexuals’ views on the DSD medical terminology identifies two groupings, those who adopt an intersex identity (and, as a result, experience fractured relationships with parents and medical professionals, but who are “the most emotionally comfortable with their ‘abnormality’”) and those who reject the possibility of an intersex identity, preferring the medically-oriented DSD label (and who report positive relationships with parents and medical professionals, yet “struggle with their sense of self due to their diagnosis”) (Davis in press 2013).

Holmes relates that her own response is always that whatever doctors may have declared, or may have done to her body, she remains “intersexed”. In Leslie Feinberg’s collection *Transgender Warriors* she writes of the need to form an intelligible “self” and the problem of identity

15. Has given permission for this to be mentioned here.

formation, in which she vacillates between a non-essentialist plurality of woman/women and a willingness to risk an essentialist definition of intersex: “What is even more difficult than identifying oneself as a member of the community ‘woman’ is attempting to define one’s identity as an intersex/woman. The task requires taking back an identity which has been made illegitimate by culture... ..and stolen through surgery” (Feinberg 1996: 139).

The paper by Escabi-Montalvo and Toro-Alfonso discussed on page 50 advocates (p.767) much more political work, to problematise gender labels/systems, not only in academia but also in everyday spaces, by implementing public and social policies that recognise differences, and legitimise those bodies or subjects who do not want to be defined in traditional terms. They see this as the main need, now that some of the traditional discourses have been shaken, and they target psychologists as being best placed to promote this. They say:

We understand that one of the biggest challenges of psychology in this regard is whether we want to legitimise the status quo or to promote the problematisation of a dichotomous system of gender and sex... ..Thus one might try to change the traditional conceptions of gender/sex that characterise the discourse of health professionals and therefore could create a legitimate space for the body of the intersexed... ..Similarly psychologists organisations would work with that group in the development of intersex public policies that break with the hierarchy of gender and sex, which promote the differences between bodies that are not conceptualised as normal... ..We understand that we can exploit the spaces of resistance within these relationships of power, which in turn give way to some transgressions, to begin to break at political level with the categories and labelling.

Chapter conclusions

My general stance, in conducting this study is that my topic has been well documented and discussed as a medical condition in clinical publications; it has been used by social scientists to illustrate concepts and theories related to sex and gender and to critique medical protocols for handling intersex; and it has been studied by clinical psychologists in relation to impact on gender identity, sexuality, quality of life (QoL) and the like; but has not been sufficiently researched in terms of how affected people discover their diagnosis, which elements of their unusual bodily make-up have the most impact, how they negotiate their gendered subjectivity and what resources (e.g. feminist gender theories) are available to them to assist in this. As Margriet van Heesch says at the conclusion (p.142) of a 2009 book chapter (studying how Dutch women’s narratives display lack of knowledge/understanding of their intersexed status):

Where does this leave us? How are women with XY chromosomes supposed to make sense of their bodies in a culture that prefers clearly distinguished male and female bodies and obvious heterosexuality? What does it mean exactly to incorporate XY sex chromosomes and testicular gonads in a female gender identity? What does it actually mean that XY sex chromosomes are not always forming a male body?

These are some of the questions that my thesis seeks to explore.

3 Methodology and research material

This chapter describes my methodological framework, recruitment (including ethical considerations), data collection/processing and analysis. It provides a statement regarding reflexivity, my claim to originality and an assessment of limitations of the study. It also sets out the demographic characteristics of my study sample.

Methodological overview

Data collection and processing

My study participants are adults with AIS and similar XY-female intersex conditions, recruited from the members/contacts of the UK and North American AIS Support Groups.¹ At the start of my study (January 2008) the group had an enquiry list of some 800 members of the public (just over 1000 by December 2012), with an active membership at any one time of around 100 (mostly affected adults, some parents). Participants took part in the study by filling out a questionnaire/survey (in Microsoft Word format) received by email in most cases. The survey was designed to elicit both quantitative data (demographic and other data) and qualitative data (narrative text responses).

The study employed a Computer Assisted Qualitative Data Analysis Software (CAQDAS) program, NVivo², as a tool for coding and reassembling the data; to move the data into theoretical and thematic concepts in order to extract meaning. Themes, ideas, or categories are set up as nodes to which segments of data can be coded by placing pointers or markers in the text. All the data coded to a node from different points in the data can then be inspected and manipulated so as to bring out new connections, themes and thoughts.

Mixed methods approach

As seen in the previous chapter, my study attends to the production of knowledge in various disciplines: medicine, clinical psychology, sociology and feminist philosophy. It seems appropriate that a study of bodily conditions that transgress medico-social containment might cross boundaries not only in terms of the academic disciplines that inform it but also in the methods it uses. My study employs both quantitative and qualitative analysis.

Quantitative analyses are commonplace in the medical field, including much of what has been written there about intersex. My use of NVivo enables a number of quantitative measures such as

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1. See 'AISSG' in Bibliography.
 2. QSR International Pty Ltd.

charts (column, bar, pie etc.) to be constructed using the Attributes specified in a Casebook, and from which numeric data such as frequency and percentage values can be derived (and tested for statistical significance in Microsoft Excel using the Chi-Square test). But NVivo's main strength is its use for *qualitative* data analysis. Qualitative research seeks out the 'why', not the 'how' of its topic through the analysis of unstructured information – things like interview transcripts, emails, notes, feedback forms, photos and videos. It doesn't just rely on statistics or numbers, which are the domain of quantitative researchers. Qualitative research is used to gain insight into people's attitudes, behaviours, value systems, concerns, motivations, aspirations, culture or lifestyles. The so-called "paradigm wars" of the last 20 years or so have contested the relative merits of the reliability and objectivity of quantitative research versus the "thick description" and subjectivity of qualitative studies. Qualitative studies, common in the sociological field, are becoming increasingly talked about in medical journals as being applicable to studies with a medical focus (e.g. Pope and Mays 2006, Hodges 2008).

More unusual, though, than using qualitative analysis in a study with medical leanings, is the use of *mixed* methods (quantitative and qualitative) in the same study. This type of research is being increasingly used in various fields, as an alternative to mono-methods with their exclusive reliance on either a positivist (quantitative) or a metaphysical (qualitative) orientation (Bazeley 1999, Bryman 2006, Yardley and Bishop 2008). Mixed-method researchers tend to eschew the "paradigm incompatibility" distinctions of those who assert fundamental conflicts between the two approaches (Tashakkori and Teddlie 2003). The mixed method approach is a pragmatic third way, driven by one's research questions and aiming for mutual illumination, with quantitative and qualitative data talking to each other (Sammons 2010). The pragmatic stance rejects traditional dualism and endorses methodological pluralism, because in practice most research questions cross paradigmatic boundaries. One should choose methods that are most likely to provide evidence for answering important research questions given the enquiry objectives, research context and available resources (Johnson et al 2007, Morgan 2007). Over and above the choice of method/s is the need for transparency and coherence (Yardley 2000).

The mix of qualitative and quantitative methods in my study has the intention of what Catherine Pope and Nicholas Mays, in relation to qualitative research in health care, term *complementarity* which allows the researcher to uncover different perspectives and hence more of the picture (Pope and Mays 2006). As Pat Bazeley says (Bazeley 2007: 147):

For those using survey instruments with both closed and open questions, or following up a survey with open interviews, translating the closed question responses into attributes allows you to analyse the open-ended responses, using either whole responses to a particular questions or coding derived from those responses, in relation to the choices made on the closed ones (Bazeley, 1999). Doing so can expand or complement understanding derived from the

quantitative responses (Bryman 2006, Caracelli & Greene 1997), while consideration of discrepancies between the two forms of response prompts further analysis and (possible) enlightenment (Erzberger & Kelle 2003).

In my field of interest, US-based paediatric intersex specialist William Reiner has specifically earmarked multi-dimensional and mixed-method analysis as being the way forward in understanding the psychosocial aspects of intersex (Reiner 2004), as discussed on page 80.

Qualitative analysis strategy

Langdridge tells us (Langdridge 2004: 258) that qualitative analysis can be divided into those that concentrate on *language use* (discourse analysis, Foucauldian discourse analysis), and those that emphasise *meaning* for the participants (phenomenology, ethnography/life story, and grounded theory). My study as a whole makes references to the Foucauldian concept of discourse (in particular those discourses surrounding medicine and the sexed body), and to questions of power at institutional and personal level, and the establishment of subject positions, agency etc. And it also attempts to bring out aspects of my participants' lived embodied experience, often articulated in a narrative format. So I use both of the approaches articulated by Langdridge in the overall discussion of my data, but my actual data analysis is thematic in nature, as described in more detail in "Quantitative coding" on page 76.

Deductive versus inductive approaches

Deductive data collection and analysis test specific hypotheses generated by literature review, prior empirical findings, or the investigator's expectations. In contrast, inductive data collection and analysis are guided by issues of importance, which emerge from the data themselves. I began my study with a broad set of questions, as described on page 12, but no hypotheses in the deductive sense. Instead, I allowed for an ongoing interplay between my initial questions and those that arose during the process of analysing my survey responses.

Data collection

Initial plan

The initial plan (2008) was to conduct semi-structured interviews, and to interview 20-25 people in order to obtain data for a purely *qualitative* study. For any overseas participants I was intending to use a questionnaire/survey. Focus groups were also considered as a means of data capture. These can have disadvantages in studying phenomena of a sensitive nature, where participants might be reluctant to discuss intimate issues in a group, but on the other hand they have the potential to draw people out when they hear other participants' contributions, although

this might work better with individuals who have already experienced group discussions at support group meetings than with those who have discussed their situation only, say, within their family.

Use of questionnaire/survey

A suggestion was made by one of my supervisors that I might use a questionnaire or survey document to gather some demographic data and permit some *quantitative* analysis. I was advised that data from around 100 individuals would provide sufficient material for statistical analysis. This led me to wonder if could I use a questionnaire also to gather some/all of the qualitative, textual, narrative material that I was seeking; possibly with interviews in addition. It was agreed that this strategy could lend itself well to the project, which would now become a mixed-method study.

From hereon in I will use the term ‘survey’ because ‘survey questions’ reads more easily than ‘questionnaire questions’ and because the term ‘survey’ suggests a broader scope, i.e. one not restricted to a device comprising multiple choice questions. The survey document was developed in Microsoft Word to cover all the areas that I’d planned to explore via the interview route. It was formatted using different (and consistent) typographical Word Styles for the question and the response fields. The formatting is important in terms of importing the data into NVivo. The survey document is shown in Appendix G.

Web stories

Some writings of, and dialogues between XY-women were also available to the researcher (pending any relevant permissions) from the newsletters, web site and other published resources of the support group (AISSG Web 1997 to-date). In particular, a number of personal stories had been submitted since the mid 1990s to the UK group’s website. 122 web stories were available (117 from the UK site and five from the US group’s site). The plan was that these might be used in the event of the response rate to the survey being poor, but this was not necessary. However, since some of the web stories belonged to participants in this study, it seemed that they could form the basis of a future project that matched up these pairs – a person’s structured survey responses and their more free-format, stream-of-consciousness ‘life story’ (submitted to the web site independently of the study and prior to its conception). 36 of my survey participants could be matched up with a story on the UK AISSG site, with three of these also having a story on the US group’s website.

UK/Europe recruitment

UK/Europe phase 1

In order to pilot the survey it was sent in January 2009 to five long-standing UK AIS Support Group members. As a result of their feedback some changes were made. The first batch of invitations to take part officially was sent out by email in mid-March 2009, to individual UK group members in the UK, Eire, continental Europe, Scandinavia, Israel and Africa. This took the form of a covering email giving a basic introduction to the study, with the three study documents attached. Recruitment included some current paid-up members and some on the master list who were not currently active members but were judged likely to be interested.

Two people requested the survey in hardcopy format (their returned surveys were not used in the study, for reasons outlined later) and three received it by email but returned it as hardcopy (which was then transcribed into Word for importing into NVivo). The first survey to be returned was received within four hours, whereas some participants took a number of months to complete it.

UK/Europe phase 2

In this second phase 130 exploratory hardcopy letters (sealed with tape and with a PO Box return address on the back of the envelope) were sent out to people in the UK and continental Europe (mostly UK) for whom no email address was available. It asked if they might supply an email address that could be used to send them the study documents (or asking them to pass the request on to a relevant family member). As expected, the response was lower than from the direct electronic mailings in Phase 1. Many of those who were sent letters had been on the support group's enquiry list for some years. It is likely that many people's circumstances had changed since their initial inclusion on the list. For example, they might have 'moved on' psychologically to a point where they didn't want to revisit their condition, or their affected children may have grown up, left home and been preoccupied with studying, work etc.

North American recruitment

In mid-July 2009, emails were sent to 44 people in N. America who were on the UK group's enquiry list, asking them to contact the researcher if interested in receiving the study documents. A further 76 invitations were sent out later on behalf of the researcher by officials in the US and Canadian AISSGs (making a total of 120 approaches). This, like the call for participants in UK/Europe phase 1, was a somewhat focused process, targeting people currently engaged/interested in the US and Canadian groups.

Overall response rate

Out of a total of 119 completed surveys received over the various phases, five from the UK were not used,³ leaving a total of 114 usable surveys. 12 of the survey respondents had a relative who had also taken part (6 matched up with 6). One survey question asked participants if they would prefer to be interviewed instead of filling out the in-depth second section (or would agree to a supplementary interview). A number said they'd be happy to be interviewed in addition to filling out the survey (or to talk on the phone in the case of some overseas participants). One UK participant provided answers to the quick questions electronically but requested an interview for the in-depth questions. And one said she would prefer to be interviewed in place of the entire survey, but this did not happen.

The recruitment is summarised in the table below:

Recruitment and response data

	Initial Approaches	Expressed interest	Surveys Sent Out	Orphans ^a	Declined	No Response	Will Do ^b	Completed Survey	Response Rate (1) ^c	Response Rate (2) ^d
Surveys sent out 'cold':										
Europe Phase I ^e	n/a	n/a	203 ^f	12	8	90	13	80 ^g	42%	
Exploratory approach first:										
Europe Phase II ^h	130	11	11	12	3	107	2	9		8%
North America	120	43	44 ⁱ	8	–	70	1	30		27%
Totals			258	32	11	267	16	119		

a. The invitation, whether by email or regular mail, bounced and no alternative contact method was available.

b. Promised to complete survey but failed to do so.

c. % completed, of *surveys* delivered (surveys sent, minus orphans).

d. % completed, of *approaches* delivered (approaches sent, minus orphans).

e. UK, Eire, Continental Europe, Africa.

f. Including 5 pilot surveys.

g. Includes 5 surveys not used in the study.

h. UK and Eire.

i. One person asked questions about study but didn't request survey. An AISSG US member was given permission to send survey directly to 2 women in US who'd heard about the study. Hence 43 expressions of interest but 44 surveys sent out.

3. Included one who turned out to be an XX-woman with MRKH (defined in footnote on page 22), three who were living as females but may not have spent most of their lives in that role, and one who gave inconsistent diagnostic information and may have had a condition like Mixed Gonadal Dysgenesis.

Survey questions not used

Some of the survey questions and their responses were set aside for future analysis. In general, the questions used for this thesis were those covering personal experience and identity, with those set aside broadly covering interactions with the outside world. The latter comprised questions about early suspicions (Q13 and Q32), family awareness of the condition (Q24), preferences for male/female company (Q26), sex and relationships (Q27 - Q29), disclosing information to other people and telling one's story (Q40 - Q45), acknowledging 'maleness' in an ideal society (Q52), observing other women (Q53), any personal male traits (Q55), whether others "could tell" (Q56), what forms of support had helped or might have helped (Q58 and Q59), and participants' other comments (Q62).

Ethics and politics

Reflexivity

From the 1970s the concept of a value-free position in research became no longer tenable. We go into a project with ideas and these will influence how the study is conducted and how the findings are written up. What is included/omitted? Is it an insider or an outsider view? A degree of reflexivity is required. Most of the recent non-clinical studies of intersex have been by researchers positioned in academia outside of patient advocacy groups, albeit sympathetic in many instances to their aims; although there have been some publications by 'insiders' (by intersexed people themselves, or those closely involved in running patient groups) as highlighted in "Awareness and advocacy" on page 232.

My background is in biological science and I have worked in that field in research, in the NHS and in industry. I have CAIS, and since the early 1990s have been involved in the UK AISSG; answering public enquiries, developing literature (factsheet, newsletter, web site etc.) organising group meetings, running a members' online information/discussion group, working with specialist clinicians concerning clinical services and research studies, and co-operating with the media. Having, during this time, helped various students with their dissertations/theses, I decided in 2007 to explore feminist gender theory for myself and enrolled for an MA in Gender Studies at the University of Sussex. After the first term of seminars, which made up the main taught part of the degree programme, I saw an opportunity to transfer to the doctoral programme (in January 2008) and decided that my study should be socially relevant, by combining biology/medicine and social science whilst having an advocacy purpose on behalf of AISSG members and XY-women in general (see page 16). Since I am self-funded, I do not have any political allegiances relating to a funder of the study, such as having to toe a particular line or address a specific agenda.

Care of participants

I prepared an information sheet for participants, explaining the purpose of the study and what was required of them; and gave my supervisors' contact details (see Appendix E). Participants were asked to sign a consent form which explained how the data would be stored and used, gave assurances about confidentiality and anonymity, and about leaving the study at any time (see Appendix F). The complete set of study documents comprised the information sheet, the consent form and the survey document itself. At the time my study proposal was approved there was no requirement for it to pass before an ethics committee. In cases where a family was known to have an affected daughter in their mid-teens (under 18) the parents were asked to invite their daughter to take part if they felt she was mature enough. Three such surveys were received and included in the study (P083 Denmark aged 15, P065 UK aged 16, and P114 UK aged 16).

Each participant was given an identifier in the range P001 to P114. They were told that no-one's survey document would be reproduced in its entirety in the thesis but that isolated quotes would be used. In quoting from participants' text, their location (country), sexual orientation, diagnosis and age are given. The location or orientation were omitted if either lay in one of the majority categories (the UK, and heterosexual). This was not in order to foreground minority categories, but because my analysis aims, in part, to look for differences between sub-groups defined by these various attributes – differences that could be useful in informing psychological therapy.

I needed to plan for supporting my participants through the study experience. The UK AISSG has a close relationship with clinicians at University College London Hospital (UCLH), as mentioned on page 235. Clinicians from the clinic often attend AISSG meetings and the group has direct access to them for advice and the facilitation of referrals to their care. The consultant clinical psychologist there, Dr. Lih-Mei Liao, expressed willingness to help anyone in the study who was in the early stages of adjusting to their situation and who showed distress as a result of taking part. Apart from such standard ethical governance, I was acutely aware of the sensitive nature of the issues being studied; and of wanting to act as a conduit through which my participants' experiences could be made visible, as outlined on page 16. There was thus a sense of an embedded ethical reflection throughout the study, a desire to view my participants as individuals who, in joining the study, were in some cases taking a significant personal risk, and whose detailed testimonies deserved careful and comprehensive representation.

General feedback

Only one person (a 28 year-old with CAIS) reacted negatively, when declining to take part on receipt of the survey documents. She said she found the questions/terminology leading and

upsetting, that she had struggled with her condition and didn't want to discuss it outside her own support network of family/friends, or rake up something she'd dealt with and moved on from. The others who replied to decline outright just said "thanks, but no thanks and good luck with the project" or similar; and no negative comments were received from any who returned completed surveys. A number said, at the end of their survey document or in a covering email, that they had enjoyed taking part, and that it had helped them. A 48 year-old with CAIS wrote from the US:

I really enjoyed working on your questionnaire and it wasn't too daunting if taken bit by bit. It did cause me to have to really think about how the entire experience affected me and formed me into the person I am today. I admire the sensitivity of your questions and your ability to draw information out. It was rather cathartic to take this time for myself and to really focus on the events and feelings and aftermath of the explosions that occurred at major points in my life.

I intend to keep a copy of this survey in my files to refer to as I feel this is the first time that I've put down a complete history of what happened to me. The first time that I made the effort to focus on me and how I triumphed through the horrors of lies, inept treatment, perverted physicians, a vicious husband, and so many things that should never happen just because of an anomaly on a gene.

Thank you for working on this truly worth while study. I eagerly await the results of the findings. With sincere admiration, _____

Gender theory handout

I had plans to make available a feminist gender theory handout, summarising those theories and debates that seemed particularly relevant to intersex, as a means of empowering my participants. These ideas have, I think, been well summarised in an interesting way (and mentioning both intersex and biomedical discourses) in a book chapter by Wendy Cealey Harrison (2006). The initial idea (when I was considering interviews) was that I would present the handout at the end of each interview and gather reactions later, possibly via a focus group. I drafted such a document but decided not to distribute it until the study is completed. Everyone will then receive it at the same time and I can more easily schedule a focus group meeting.

Data processing

Loading/configuring data in NVivo

As each completed survey was received, its formatting was adjusted so that it could be imported cleanly into NVivo and set up as a *Case*. The steps in the import process were as follows:

Importing surveys as Cases

Each Microsoft Word survey document was imported into NVivo (Project --> Import Document), opting to code the whole document to a Case.

Auto-coding of survey questions

NVivo expert Pat Bazeley refers to use of the software with questionnaires/surveys (Bazeley 2007: 88):

The auto code tool can be used to “code responses to standard questions, such as are generated by self-completed questionnaires, for the question to which they were a response” and “code passages for topics identified by headings in the text” and that “the resulting nodes will give immediate access to, say, all the answers to Question 3, all submissions about Eligibility Criteria” and that “critically, being able to do this depends on your having used headings to identify the relevant sections in your sources”.

Before use, the survey document had been carefully formatted with auto-coding in mind. Auto-coding by heading level was then used during the import process, to code each completed survey question to a *Node* dedicated to that question. Specifically, I auto-coded all the ‘Heading 6’ (a Microsoft Word Style) text in the document (i.e. all the questions) to a parent placeholder Node called All Questions. This node then expands out to show all the survey questions as child nodes underneath it. Once this had been done for each participant’s completed document, it then became possible to collate and display all the participants’ answers to a given question at the relevant Node.

Tree Nodes				
	Name	Sources	Refere	Created On
[-]	All questions	0	0	27/04/2009 21:24
	Name	Sources	Reference	Created On
	Q~ Please enter your name (use an initial	94	94	27/04/2009 21:24
	Q~ Please give your email address (option	94	94	27/04/2009 21:24
	Q~ What is your age~	94	94	27/04/2009 21:24
	Q~ What is your sex~	94	94	27/04/2009 21:24
	Q~ What is your gender~	94	94	27/04/2009 21:24
	Q~ Can I ask about your sexual orientatio	94	94	27/04/2009 21:24
	Q~ Partnership status (e.g. never had rela	94	94	27/04/2009 21:24
	Q~ How would you define your ethnicity~	94	94	27/04/2009 21:24
	Q~ Do you see yourself as belonging to a	94	94	27/04/2009 21:24
	Q~ Highest educational level reached (e.g	94	94	27/04/2009 21:24
	Q~ Do you have any particular religious~s	94	94	27/04/2009 21:24
	Q~ What is the medical name of your con	94	94	27/04/2009 21:24
	Q~ At what age were you were first aware	94	94	27/04/2009 21:24
	Q~ How old were you when a medical dia	94	94	27/04/2009 21:24
	Q~ Have you ever had clinical photograph	94	94	27/04/2009 21:24
	Q~ Were you ever offered psychological s	94	94	27/04/2009 21:24
	Q~ Which of these biological factors have	94	94	27/04/2009 21:24
	Q~ Have you had any of these medical pr	94	94	27/04/2009 21:24

Part of ‘All questions’ node (when contents of 94 surveys coded to it)

By clicking on a given question node the researcher can then display that particular question (‘Heading 6’ Style) and its responses (‘Normal’ Style) pulled out of all the participants’ surveys, as illustrated below (for the survey question asking if a sex/gender distinction seemed useful).

[<Internals\Questionnaires\Participant-028>](#) - § 1 reference coded [0.85% Coverage]

Reference 1 - 0.85% Coverage

Certainly. This makes it much easier to see yourself as a true woman when you understand that gender is not a chromosomally-based construct.

[<Internals\Questionnaires\Participant-037>](#) - § 1 reference coded [1.55% Coverage]

Reference 1 - 1.55% Coverage

Yes. It is helpful to remember that some people feel like they are born in the wrong body. So biology does not dictate the choice that we all have to identify with a gender. There is a difference between how you are born (no choice) and the person you become (choice).

[<Internals\Questionnaires\Participant-102>](#) - § 1 reference coded [0.89% Coverage]

Reference 1 - 0.89% Coverage

I feel that it is helpful, because many Xy woman base their gender identity on their chromosomal sex, and not on their female impulses and behaviours.

[<Internals\Questionnaires\Participant-016>](#) - § 1 reference coded [0.28% Coverage]

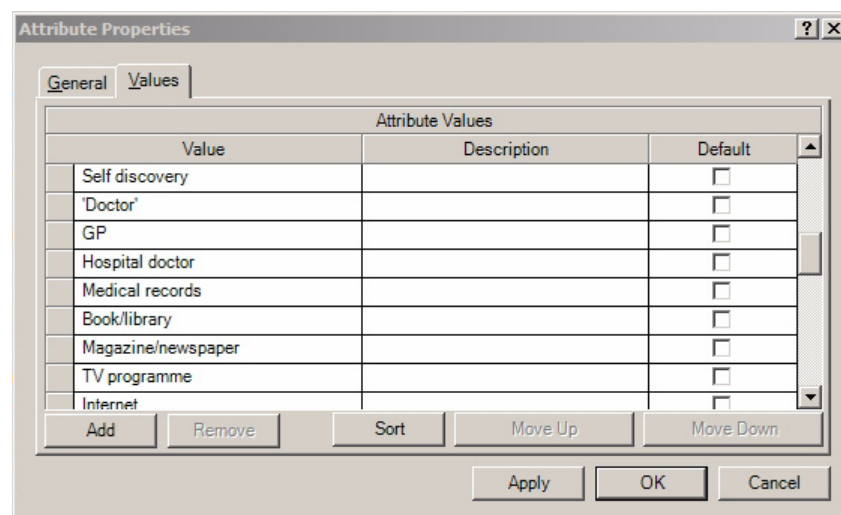
Reference 1 - 0.28% Coverage

It is to me because I think I look female.

Partial contents of a child node under 'All questions' parent node

Setting up Attributes

Much preparatory work was done to set up *Attributes* in NVivo for that part of the survey data that could be quantified.



Attribute values set up for question about 'sources of information'

For example, for each question of the type, "Where did you learn about ABC?", an Attribute was created called "Source of knowledge of ABC" with values such as 'Parent/s', 'Doctor', 'Internet', 'Book', 'No answer given' etc. And for each question asking for an age, an Attribute

was created called “Age at which...XYZ...[happened]” with values ranging from, say, 15 to 70 years, and maybe also with a “No age given” value.

Assigning Attribute values

NVivo stores Attributes within a *Casebook* (a Case is a specific type of Node that has Attributes associated with it). The next task was to open the Casebook containing all the Cases and their Attributes, and select a value for each Attribute, from a drop-down list, to reflect each participant’s response to all the quantifiable questions (demographic and other data) in their survey.

	A : 00-C... ▾	B : 01-Age... ▾	C : 02-Sex ▾	D : 03-Gender ▾	E : 04-Orientat... ▾	F : 05-Partner... ▾	G : 06-Ethnicity ▾
1 : 001-Ai...	Eire	36	Female	Female	Hetererosexual	Intermittent	Caucasian (Irish)
2 : 002-Ai...	USA	29	Female	Female	Hetererosexual	No relationships	Caucasian
3 : 003-Ak...	W. Africa	34	Female	Female	Hetererosexual	Long-term	Black African
4 : 004-Ali...	UK	46	Female	Female	Hetererosexual	Married	British (Welsh)
5 : 005-A...	USA	27	XY female	Female	Lesbian	Long-term	White (Caucasian)
6 : 006-A...	USA	41	Female	Female	Hetererosexual	Married	Caucasian (Irish)
7 : 007-An...	UK	41	XY female	Female	Hetererosexual	Married	White British
8 : 008-An...	Hungary	36	Female	Female	Hetererosexual	Married	White
9 : 009-An...	UK	51	Intersexed	Female	Bisexual	Married	White British
10 : 010-A...	USA	32	Female	Female	Hetererosexual	Long-term	Chinese America
11 : 011-A...	USA	22	XY	Female	Straight	Married	White
12 : 012-A...	USA	70	Y-chrom femal	Female	Straight	Married	White American
13 : 013-A...	Estonia	31	Female	Female	Hetererosexual	Long-term	European
14 : 014-B...	Eire	31	Female	Female XY	Hetererosexual	Intermittent	White (Irish)
15 : 015-B...	UK	52	Female	Female	Hetererosexual	Married	Caucasian
16 : 016-B...	UK	66	Female	Female	Normal	Long-term	White British
17 : 017-B...	UK	20	Female	Female	Straight	Intermittent	White
18 : 018-C...	Canada	52	Female	Female	Hetererosexual	Married	American
19 : 019-C...	UK	31	Female	Female	Straight	Intermittent	Caucasian
20 : 020-C...	UK	50	Female	Female	Hetererosexual	Divorced	White
21 : 021-C...	USA	47	46XY	F gender presen	Lesbian	Long-term	Caucasian
22 : 022-C...	USA	62	Female	Female	Hetererosexual	Married	Caucasian
23 : 023-C...	UK	56	Female	Female	Lesbian	Intermittent	English

Casebook (part of) showing some Attributes, and their values, assigned to Cases

This allows subsequent querying ‘by attribute’, and the construction of charts/graphs (and hence a degree of quantitative analysis). Bazeley refers to this role of Attributes in NVivo when using a structured survey (Bazeley 2007, p90):

Where the text for questions or topics in a structured survey has been autocoded and the data from demographic or other categorized questions have been imported as attributes, then responses to particular questions can be compared immediately for different sub-groups, using the matrix coding query tool.

Coding

NVivo allows for both quantitative coding (via Attributes) and qualitative coding (via coding of text segments to Nodes).

Lyn Richards (Richards 2009) talks of three types of coding:

Descriptive Coding – quantitative coding using attributes, e.g. age, sex

Topic Coding – qualitative labelling of text segments to record *topic* discussed

Analytical Coding – coding of the *meaning* of the text fragments.

The overall aim is to look at the meaning/s to participants of their textual responses, the subject positions they are adopting, overall discursive themes etc. Pope and Mays (2006: 108) suggest a further type or level of analysis that combines qualitative and quantitative material in a reciprocal manner:

There is also scope for the raw material from the qualitative and quantitative components to be brought together. For example, the questionnaire and interview data for an individual can be compared and patterns looked for across cases. This may involve ‘quantifying’ qualitative data, that is assigning codes to the presence or absence of themes within individual cases, or turning quantitative data into text for qualitative analysis.

Quantitative coding

Quantitative data can arise from two elements of the use of NVivo:

- a) from the use of Attributes to capture the numeric data, the ‘yes/no’ responses, and the ‘Please select one or more of the following options’ type of data (Richards’ *Descriptive Coding* above).
- b) from an evaluation of the qualitative coding (Richards’ *Topic Coding* above) to reveal, for example, that ‘n’ people talked about ‘xyz’ in their response to a particular question. This is sometimes referred to as a process of *quantifying qualitative data* (see Pope and Mays quote above).

The second is more interpretative than the first because it reflects to some extent the researcher’s decisions during the coding process but seems of value in bridging the purely quantitative and the purely qualitative, and allows some degree of quantification in those survey questions designed to elicit a narrative text response but where the overall direction of the response can be determined and coded to an NVivo Attribute, to permit charting, for example.

Qualitative coding

Once the surveys were imported into NVivo, and all the Attributes set up and values assigned to them, the next task was to carefully read the participants’ survey data and code selected segments of text to nodes representing themes or discursive structures (the *Topic Coding* and *Analytical Coding* referred to above). As already mentioned, there’s also the option of *qualitizing*

quantitative data, e.g. in the earlier quantitative part of the survey (where the responses in general were ‘yes/no’ or where the questions were of the ‘select from a list’ type) some people will have expanded on this, providing some narrative text that can be worth coding.

General approach

CAQDAS software has been criticised in some quarters for imposing a hierarchical structure on the data, and I considered a grounded theory (bottom-up) approach in which a detailed reading of the participants’ text without preconceived ideas might suggest themes for coding; with the organisation, grouping and amalgamation of the resultant nodes being done afterwards.

However, I had already taken a bird’s eye view of my research field in designing and structuring the survey, breaking the issues into broad topics with sub-topics below them (top-down), so I elected to set up some preliminary nodes based on the structure of my survey document. I then decided to take each of my survey questions in turn and examine all participants’ responses to that question (by opening and examining the child nodes in the ‘All questions’ node tree set up earlier – see figure on page 73); the alternative being to take each participant’s entire survey in turn and work through all the responses in it. The former lends itself to my chosen structured approach, the latter to a more grounded approach. My study is not primarily a grounded theory project and the survey questions asked of the participants do reflect my basic research questions, set out on page 12. Coding question by question, rather than survey by survey, also meant that participants’ demographic characteristics (age, sex, gender, orientation, location etc.) were not evident during coding (see figure on page 73) which aided objectivity.

Using the above approach, I coded the text fragments of interest to a pre-prepared basic node tree, but setting up new nodes within it as required (with the data dictating which themes and categories assumed importance). In essence then, this amounts to a little top-down activity to provide a skeleton, followed by a considerable amount of bottom-up analysis to add to the diversity and complexity of the node structure. Bazeley talks about two coding preferences: those researchers who are ‘lumpers’ and those who are ‘splitters’. The lumpers like first to code text extracts to broad categories/themes, then break those down to a more detailed level. Splitters like to code at quite a detailed level at the outset, then group together those coded extracts that are similar/related under broad categories/themes. She says (Bazeley 2007, p.67):

A common approach is to start with some general categories, then code in more detail, while those working using grounded theory, phenomenology or discourse analysis more often start with detailed analysis and work up to broader categories... ..Most end up working with some combination of the two approaches, and the software, happily, supports either or both.

I found myself operating mainly as a ‘splitter’, with some ‘lumping’ carried out as a second phase.

Phase 1 – Splitting

A first round of qualitative coding (*Topic Coding*) was carried out on all the data, having set up as many NVivo nodes for each survey question as were needed to adequately separate out the various topics being talked about. Below is an example of the nodes produced by this round of coding for one survey question (Q56, which asked if participants' had thought other people might suspect they had an intersex condition).

Name	Sources	References
Q56 - People suspect - no, or minimal answer	42	42
Q56 - People suspect - more when younger	11	12
Q56 - People suspect - self view or paranoia	9	9
Q56 - People suspect - internal features & function	6	6
Q56 - People suspect - unusual only	6	6
Q56 - People suspect - children sometimes ask	4	4
Q56 - People suspect - possibly	4	4
Q56 - People suspect - male qualities or behaviour	4	4
Q56 - People suspect - transgender, maybe	4	4
Q56 - People suspect - use of humour	4	4
Q56 - People suspect - chromosomes	3	3
Q56 - People suspect - gay maybe, not intersex	3	3
Q56 - People suspect - effect of meeting others	2	2
Q56 - People suspect - M vs F toilets	2	2
Q56 - People suspect - yes, not sure how	2	2
Q56 - People suspect - avoid relationships	2	2
Q56 - People suspect - ASD & perception	1	1
Q56 - People suspect - defending oneself	1	1
Q56 - People suspect - don't care now	1	1
Q56 - People suspect - gender in language	1	1
Q56 - People suspect - only cf Jamie Lee C	1	1
Q56 - People suspect - only re sexual activity	1	1
Q56 - People suspect - people ignorant	1	1
Q56 - People suspect - transgender, no	1	1
Q56 - People suspect - want others to know	1	1
Q56 - People suspect - media coverage increases cha	1	1
Q56 - People suspect - yes, intimate acquaintances	1	1
Q56 - People suspect - adoption helps	1	1
Q56 - People suspect - someone guessed	1	1
Q56 - People suspect - external features	0	0

Example nodes after initial coding

The numbering assigned to the qualitative nodes followed that of the questions in the survey itself, in case it proved useful to tie nodes to a particular question. The node tree for this phase rarely went down more than two levels from the holding parent node for a question.

Phase 2 – Lumping

In the next phase I assessed all the nodes for each survey question and grouped them into categories by setting up holding parent nodes and moving relevant nodes into them. Part of a typical node tree after this process, is shown below (for Q34, which asked whether or not adult carers had disclosed the full truth to them by adulthood).

Q34 - Discovering truth	0	
Q34 - Disclosure - doctors' modus operandi	0	0
Q34 - Disclosure - communication failure	10	14
Q34 - Disclosure - doctors' utterances	10	12
Q34 - Disclosure - doctors' ignorance	10	10
Q34 - Disclosure - no adult or doctor actually said	7	8
Q34 - Disclosure - false assurances	3	3
Q34 - Disclosure - treated as novelty	2	2
Q34 - Disclosure - family issues	0	0
Q34 - Disclosure - parents in the dark	11	13
Q34 - Disclosure - maternal guilt	3	3
Q34 - Disclosure - consulted relative	2	2
Q34 - Disclosure - bodily issues	0	0
Q34 - Disclosure - gonadectomy	24	28
Q34 - Disclosure - infertility	17	19
Q34 - Disclosure - hypoplasia	9	12
Q34 - Disclosure - no periods	7	8
Q34 - Disclosure - HRT	3	4
Q34 - Disclosure - breast development	2	2
Q34 - Disclosure - scarring	1	1
Q34 - Disclosure - modes of discovery	0	0
Q34 - Disclosure - own research	25	30
Q34 - Disclosure - late discovery	23	26

Example nodes after lumping

The holding parent nodes show zero for Sources and References because they do not themselves have textual content; they are just holding nodes (like folders).

Phase 3 – Analysing the common response

Coding all the survey responses, as above, generated a lot of nodes; but I saw this as a means of cataloguing all the topics/issues mentioned by my participants, so that when starting a subsequent phase I could get an overall view of what I was dealing with and decide which material to subject to further analysis and which to put on one side as ‘not so interesting’. Thus, having coded all the survey text to low-level nodes by splitting (Phase 1), and having gathered these into groups or categories by lumping (Phase 2), the next task was to look at the most densely populated nodes for each survey question and evaluate what participants were saying in these nodes. I decided to look at just the six most populated nodes for each survey question in this manner. However, the entire coding is presented in coding tables in Appendix D for reference purposes. with these six nodes indicated in *italics* for each survey question. This

process, which was conducted as part of the writing up, provided an opportunity to re-read selected coded text carefully and analyse it further by setting out representative quotes and writing about what they revealed. This goes some way towards the *Analytical Coding* phase referred to earlier, and although I would like to have done this as a ‘coding on’ exercise within NVivo, time constraints dictated that this be done ‘on paper’ as part of my writing up, i.e. this is when the ‘qualitative analysis’ took place (see also “The methodology” on page 82).

General analysis/charting

Many of the quantitative data are expressed in the form of pie or bar charts, produced in most cases in NVivo (sometimes in Microsoft Excel).⁴ Statistical significance testing (Chi-Square) was also done in Excel, with p values of <0.05 being declared as “statistically significant”, those <0.01 as “very significant”, and those <0.001 as “extremely significant”. For some of my survey questions, those responses that were quantifiable were analysed by comparing various groupings such as diagnosis, sexual orientation, educational level, geographical location etc. Diagnosis was used because those with Swyer Syndrome are likely to have a full length vagina, a cervix and a uterus of sorts (may be non-viable but can be sufficiently developed in some cases to allow IVF and pregnancy) whereas other diagnoses such as AIS do not have these female attributes. This makes diagnosis a useful way of teasing out the relative impact of various sex- or gender-related bodily issues. Sexual orientation also seemed an obvious breakdown to employ in a study of how people cope with an intersex diagnosis (to evaluate whether having rejected social norms in the area of sexuality can create more space or equanimity in dealing with other issues).

My claim to originality

In the early-mid 1990s social scientists started looking at intersex from an anecdotal/theoretical viewpoint, but there have been few studies that start from what affected people say. As far as I am aware, there are many topics in my study related to diagnosis discovery, the impact of specific biological/medical issues, views on societal norms, gendered self-view/subjectivity etc., that have not been explored before with such a population. And in the main, other qualitative studies that evaluated groups of affected people have studied smaller numbers and have not, I think, used qualitative *coding* to organise the data but have picked out quotes from interview text to illustrate general themes (often without explaining the basis on which this was done).

4. NVivo does not provide a facility to express a series of data graphically as a percentage of a group (e.g. the percentage of those with a certain diagnosis who answered A, B or C to a question). So in order to produce such charts, the data from an NVivo Matrix Query was exported to Microsoft Excel and the Excel PivotTable/PivotChart facility used to create bar charts expressing the data as a percentage.

US paediatric clinician William Reiner claims that intersex studies or articles purporting to provide overall outcomes (that is, health-related quality of life) tend to be too narrow in scope, too simplistic in their understanding of quality of life, or too indifferent to the implications of the actual measures used, to be useful in clinical practice and for helping parents (Reiner 2004). He suggests that specialties should work together to pose appropriate clinical and philosophical questions. Both reductionist and holistic analyses are necessary. He suggests that multi-dimensional and *mixed-method* analysis can be useful, as long as a large enough population sample can be assembled for qualitative or quantitative studies in conditions as rare as intersex disorders, and concludes that “mixed-method research will be the path to understanding intersex conditions and how people experience them”.

In 2009 the German Network of Disorders of Sex Development published clinical evaluation data on 439 individuals with DSD (Lux et al 2009) and Reiner suggest that quality of life information from this study sample, when published, could prove valuable. The size of my study sample falls well short of this, however my sample is larger than many to-date in this field and I also recruit from an international pool of potential participants so I have the opportunity to compare responses between geographical areas. Most previous studies have looked at a sample from within one country; or in the case of those in a clinical context, at one hospital or hospital group.

The study should help in understanding the way the medical profession, the literature, and those affected have dealt with intersex. I see it as being of interest to feminist scholars in the social sciences who are interested in questions of sex and gender, theories of performativity, embodiment and so on, or to ethicists with an interest in secrecy versus disclosure, and to clinicians who care for and advise patients with XY-female conditions, clinical psychologists in particular. The use of feminist gender concepts/theories in the psychotherapeutic field has been advocated by clinical psychologist Lih-Mei Liao (Liao 2003) but I doubt that it is standard practice amongst the very few psychologists with experience in helping intersex patients. I hope also that the study will be enlightening and empowering to XY-women themselves, perhaps broadening their horizon by offsetting a medical emphasis on biological essentialism.

Limitations of the study

My study comes at a time of changing attitudes to intersex in some areas of medicine, and to some extent in the social realm, as discussed in “Awareness and advocacy” on page 232, with the beginnings of a more holistic paradigm of medical care, an updated (if not ideal) medical nomenclature, and a dawning public awareness. Some might ask why study the effects of shifting

medical practices and terminology? However, any advances are in their infancy, are arguably focused on disclosure (and not yet backed up by professional psychological support) – with much genital surgery continuing as before – and social attitudes are still repressive in nature.

The study sample

No claim can be made for my participants being a random sample of XY-women. My study sample comprises individuals from one source, a peer support group. It does not include individuals who have never been support group members/contacts. Hospital clinic patients have been included in clinical psychology studies of intersex, but there will also be XY-women out there who are not currently in the medical system and who have never contacted a support group (and who may, or may not know their diagnosis). Also, I have not made any attempt to recruit a control group with which to compare my participants' views on general questions, such as whether there is a difference between sex and gender.

My participants represent a range of demographic characteristics, as shown on page 84, but most were Caucasian and only 13 stated themselves to be working class. They were all either native English speakers or had a good command of English. All had possessed the means to make contact at some stage with a support group, and most were well-educated, with all except five having sufficient IT skills/resources to enable them to receive and edit a Microsoft Word file, and return it by email. Some of my diagnosis-related findings need verifying using a sample containing a larger number of women with Swyer Syndrome, and my data suggesting differences related to sexual orientation could be usefully augmented.

The methodology

I might be challenged as to how 'qualitative' the use of a survey questionnaire can be. Most texts on qualitative methods refer to the use of naturally occurring talk, conversations, or interviews. But diaries, written stories, other printed texts, and even images have been subjected to discourse analysis. Kathy Charmaz discusses the use of what she calls 'elicited texts', such as personal accounts, letters, journals, or responses to open-ended questionnaires, which, she says, have advantages in fostering "frank disclosures that a person might not wish to make to an interviewer", such as revealing "secrets that risk shame, disgrace or failure" or "their genetic histories, sex lives... ..personal failures, feelings or unfulfilled hopes and dreams" (Charmaz 2006: 36). Elicited texts work best, she asserts, when the questions posed resemble interview questions, and the participants respond to them as such, rather than as bureaucratic forms, quick surveys, management ploys or trivial inquiries, and when participants (as mine do) have a stake in the addressed topics, experience in the relevant areas, and view the questions as significant.

It's possible that in studying a phenomenon such as intersex that involves stigma and secrecy, participants may *prefer* to formulate their responses in private, in their own time and in writing, and with no requirement to identify themselves. People are often more open when expressing themselves via a keyboard and with the semi-anonymity afforded by electronic communications. The personal nature of accounts on the AISSG UK web site indicate that many find it cathartic to write down their thoughts and submit them to an organisation/person that they trust to safeguard their identity. With interview data there is always the issue of inaccuracies in transcription, this being avoided when participants are typing in their own responses. A survey also enables the collection of directly comparable data from overseas participants. I believe that this data collection method gave access to a wider range of participants than interviewing would have done, with its inherent complications involving scheduling, travel, privacy, transcription etc.

I feel that my survey document successfully combines the collection of both quantitative and qualitative data by using two sections, with different types of question. Many of my in-depth questions were open-ended, with encouragement to provide as much free-flow text as participants felt able to give. Kerry Chamberlain (2000) criticises this approach as not enabling true qualitative research, but is appreciative of the difficulties encountered by students who are new to the field, in navigating the methodological complexities of qualitative health research.

There was a danger, in encouraging a high response rate (in order to gather sufficient quantitative data to satisfy statistical requirements) that I'd have too much data for a qualitative study, where 'theoretical sampling' is more often employed. Whilst 114 surveys might seem a large amount of data for the qualitative phase of the study, the overall the amount of text provided might not far exceed that generated from a much smaller number of interviews. But with hindsight, maybe I should have stuck to my original plan to interview a smaller number of participants. Or I could have confined the study to those participants where I have both a completed survey and a web story. But these would not necessarily have contained the most rich or interesting data; and by gathering a large volume of qualitative data it enabled me to "quantify the qualitative data" (via counts of participants' text extracts at a given node) and thus focus my qualitative analysis on the issues that were of importance to the greatest number of participants. I probably use more quotes from participants' text than would be usual in presenting qualitative data, but I wanted to do justice to the range of inputs.

The large amount of data also meant that I didn't have time to progress very far beyond the *Topic Coding* phase delineated by Richards (see page 75) and I am aware that my qualitative 'analysis' remains somewhat at the level of description, as opposed to interpretation, a common problem in

qualitative research according to Chamberlain (2000). I would like to have made more use of the techniques for theory building set out in the later chapters of Bazeley's and Richards' books.

Study sample characteristics

This section describes the characteristics of my study sample (general demographic data, age, sex and gender, diagnosis etc.) based on the data provided in participants' completed surveys.

Demographics

General

Data for geography (country), ethnicity, social class, educational level and religion are shown below:

Demographic data

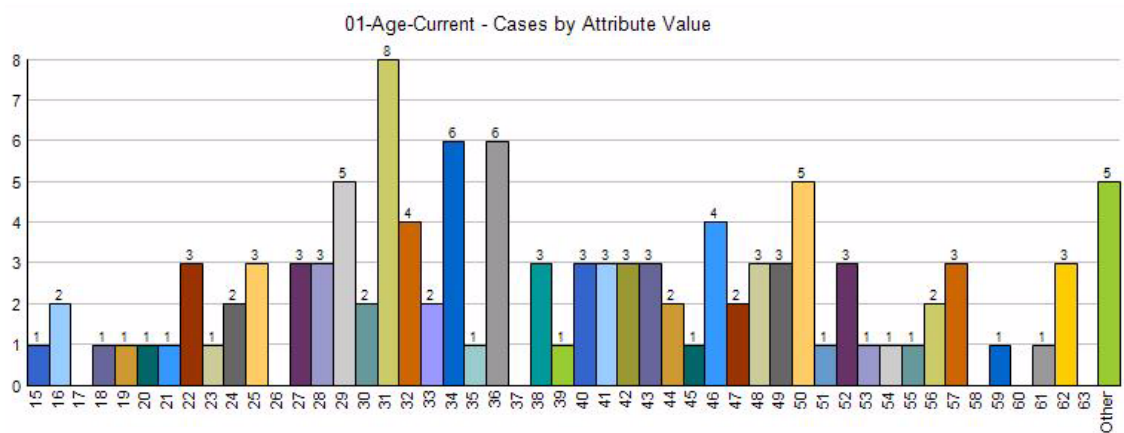
Attribute	Number of participants (out of total of 114)
Geography (Country)	UK 64, USA 25, Eire 5, Canada 6, Hungary 2, Denmark 2, Belgium 1, Finland 1, France 1, Estonia 1, Holland 1, Poland 1, S. Africa 1, W. Africa 1, Israel 1, Italy 1
Ethnicity	White British 27, Caucasian 25, White 17, White (Caucasian) 5, British 4, White European 3, Indian 3, Irish 2, Black African 2, White American 2, Caucasian (Irish) 2, Caucasian (European) 2, American 2, European 1, English 1, British (Caucasian) 1, Hungarian 1, Danish 1, Finnish 1, Dutch 1, British (Welsh) 1, Black 1, Caucasian (Afrikaans) 1, Arab Palestinian 1, Chinese American 1, Asian-Caucasian 1, White (Irish) 1, Christian 1, "I wouldn't", ^a 1, Irrelevant 1, Not given 1
Social Class	Middle 55, Non given 27, Working 13, Working --> Middle 7, Upper Middle 5, Lower Middle 2, Educated 2, Lower Middle-->Upper Middle 1, Middle Upper 1, Young professional 1
Educational Level	First degree 47, Masters degree 19, A-Levels 9, Doctorate 6, NVQs 6, Doing degree 5, Postgraduate 3, HND 3, "Some college" 3, Lawyer 3, High school 1, O-Levels 1, GCSEs 1, Teaching qualification 1, Several degrees 1, Chartered engineer 1, At school 1, College 4 Year 1, Diploma (vet nurse) 1, BTEC Diploma 1
Religion	Doesn't apply 47, Christian 17, Church of England 11, Roman Catholic 10, Atheist 8, "Spiritual" 5, Buddhist 4, Quaker 3, Methodist 1, Unitarian Universalist 1, 7th Day Adventist 1, Muslim 1, Eastern 1, Jewish 1, Baptist 1, Angels 1, Yes 1

a. Participants were asked "How would you describe your ethnicity?".

Age range

The number of participants (y axis) of different ages (x axis) is shown in the NVivo chart below. Ages ranged from 15 to 76 years. The figures above each column represent the number of

participants (y axis) sharing that age. The colours (tones in the case of a greyscale printout) are not significant: they just aid the visual separation of the columns. Five participants aged over 64 are grouped together in the 'Other' category (ages 66, 67, 68, 70 and 76).



Q3 - Ages of study participants

The age ranges for different geographies are shown below:

Geographies and age ranges

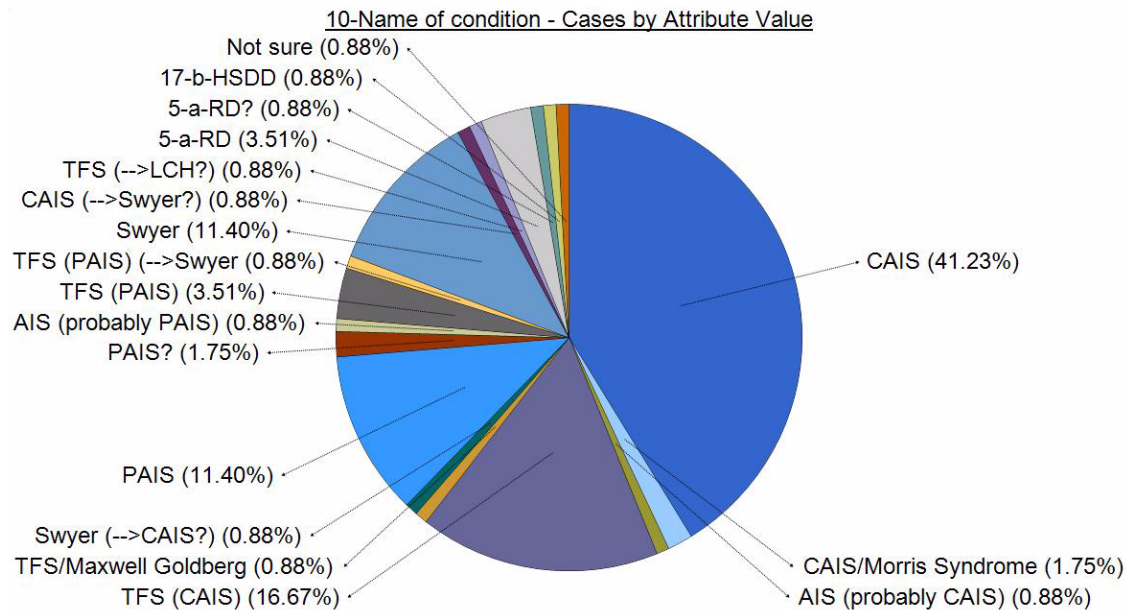
Country	Age range
UK (n=64)	16-67 (mean=37)
Eire (n=5)	30-36 (mean=33)
Continental Europe, Scandinavia, Israel and Africa (n=14)	15-41 (mean=33)
USA (n=25)	22-70 (mean=45)
Canada (n=6)	28-76 (mean=56)

Range of diagnoses

Q12 in the survey asked what participants understood to be the name of their condition. These are the diagnoses declared by the participants themselves. They have not been verified by checking any clinical documentation, although in a few cases where the stated diagnosis didn't seem to fit with other data provided, the participant was questioned further. In summary, of the 114 participants, approximate numbers with various diagnoses were: 71 with CAIS and 19 with PAIS making a total of 90 with AIS in general, 15 with Swyer Syndrome, five with 5-a-RD, one with LCH, one with 17-b-HSDD, and three who were not sure of their diagnosis.

The segments in the pie chart below move in a clockwise direction from Complete AIS (CAIS) or probable CAIS starting at 12 o'clock, to Partial AIS (PAIS) or probable PAIS starting at 7-8 o'clock, to Swyer Syndrome (pure XY gonadal dysgenesis) or probable Swyer starting at 9-10

o'clock, then the less frequent diagnoses of Leydig Cell Hypoplasia (LCH), 5-Alpha-Reductase Deficiency (5-a-RD), and 17-Beta-Hydroxy-Steroid-Dehydrogenase Deficiency (17-b-HSDD) at 11 o'clock, and finally to those who were not sure of their diagnosis.



Q12 - Range of diagnoses

The majority of the participants declared themselves to have CAIS, although in a later question (Q15) about sources of diagnostic information a number volunteered that they had initially been given the older name, Testicular Feminisation Syndrome, and had later discovered the newer name, Androgen Insensitivity Syndrome (see page 245). These are indicated as “TFS (CAIS)” in the chart. Others may well have come across the older name too at some point, because when asked about this particular term later in the survey (Q35) a considerable number of participants said it had exerted an influence on their self view (see page 125). Two participants, from Denmark and Belgium, gave “CAIS (Morris Syndrome)” as their diagnosis and another had initially been given Goldberg Maxwell Syndrome (another outdated name for CAIS). One or two just stated AIS, without differentiating between the Complete and Partial forms.

One participant with a diagnosis of Swyer Syndrome suspected she had CAIS and was obtaining clarification via the UCLH clinic. In the survey question about diagnosis she said a doctor had told her she had a short vagina and in a later question she referred to a lack of pubic/under-arm hair, both suggesting CAIS. She is indicated as “Swyer (-->CAIS?)” in the chart.

The next most common diagnosis after CAIS was PAIS, and again one of these had originally been given the name Testicular Feminisation Syndrome.

Swyer Syndrome was the next most common condition. In addition to the 13 who seemed confident that they had Swyer Syndrome two others might also have this diagnosis. One of these had originally been told she had PAIS (with her medical records stating Testicular Feminisation Syndrome) and she had genital surgery as an infant, but said she has a uterus which had grown to a good size and the UCLH clinic had advised she probably has Swyer Syndrome. She is indicated as “TFS (PAIS) (-->Swyer?)” in the chart. Another cited CAIS as her “latest diagnosis”, saying that doctors “weren’t sure”, and she confirmed that she had a small uterus discovered at gonadectomy and which, with HRT, was now of normal size, so she too may have Swyer Syndrome. She is indicated as “CAIS (-->Swyer?)” in the chart.

A few participants had the less common diagnoses of 5-a-RD, LCH and 17-b-HSDD. One said she was mis-diagnosed with Testicular Feminisation Syndrome at 17 and decided from books, at age 38, that she had LCH. She is indicated as “TFS (-->LCH?)”.

In those who were not sure of their diagnosis, or made tentative suggestions, it may be that clinicians had not reached a definitive diagnosis. Intersex conditions with PAIS-like features are quite difficult to differentiate, especially if a person presents for clarification as a mature adult and their gonadal tissue has been removed earlier in life (and their earlier medical records have mysteriously gone missing – a quite common occurrence in these patients). Or it may be that the participant cannot recall accurately what she was told, or in some cases might never have had the diagnosis communicated to her (and might merely be hazarding a guess during this study).

Sex and gender

Early in the survey document (Q4) participants were asked to state both their sex and their gender so that these ‘off the cuff’ responses could be considered when evaluating their response to later questions about differentiating (or not) between the two concepts (page 173 onwards), and about whether they considered themselves to be intersexed (page 198). The responses to Q4, recorded as NVivo Attribute values, are those offered by participants and are not options made available by the researcher, who simply asked “What is your sex?” and “What is your gender?”.

At first sight it seemed that 21% had declared their sex, and 12% their *gender*, to be other than simply unqualified “Female” (e.g. by stating female but with some qualification such as “Female XY”, or in a few cases something completely other than female) and 2% not answering the gender question. Thus there were clearly some participants who acknowledged a sex/gender non-alignment or mismatch in themselves, but it seemed strange that so many would give their *gender* as ‘XY’, ‘XY female’, ‘Male’ or the like, having given their sex as female. However, if one examines the responses given by these participants at later questions about sex/gender

differences, it seems that many were not very familiar with the definitions of these categories and almost certainly had confused the two categories at these earlier demographic questions.

Because the early demographic questions asked for participants' sex *before* asking for their gender, these participants probably entered "Female" for sex as an automatic response. Then, seeing the gender question, some possibly associated 'gender' with 'genetic'. For example, one participant responded as follows to one of the sex/gender questions later in the survey:

I wouldn't say I'm a male/female mashup, although I'm not sure I'd define the term ['intersexed'] that narrowly. Outwardly I'm very much female, just a flat chest. Also early in the questionnaire it asked what my sex and gender were and I put female for both. But technically the answers should be male sex (genetically) and female gender. It's just that I'm so used to putting F for sex that I didn't give it a moments thought! (P087 USA, Celibate, PAIS? 28)

Further enquiries were made by email and some of these participants reformulated their responses. Some just swapped their responses for sex and gender but others made it clear that they had misunderstood what gender represented. Participant P095 replied: *"In that case female for both. I thought when you asked about gender you meant chromosomes, which is xy"* and participant P047 replied: *"In my situation both Female would apply"* (her response to later survey questions about sex and gender suggested she too had been thinking of chromosomes).

A composite table, below, was produced – by applying corrections to 12 such pairings and adding them (shaded rows) to other cases where participants gave a sex other than simply 'female' – and which showed all those participants who were comfortable enough with their intersex status to give a sex other than simply "Female" up-front in the survey. One confirmed several times that her *sex* was 'Female' and her *gender* was 'Female XY' (even though she had CAIS), and one PAIS participant argued that both her gender and her sex were 'Intersexed'.

Q4 - Sex other than 'Female'

Participant	Sex	Gender
P005 USA, Lesbian, PAIS	"XY Female"	"Female"
P007 Swyer	"XY Female"	"Female"
P009 Bisexual, CAIS	"Intersex"	"Female"
P011 USA, Swyer	"XY"	"Female"
P012 USA, CAIS	"Y-chromosome female"	"Female"
P014 Eire, CAIS	"Female"	"Female XY"
P021 USA, Lesbian, 5-a-RD	"46XY"	"Female gender presentation"
P024 Swyer	"XY" ^a	"Female"
P027 USA, Lesbian, CAIS	"XY" ^b	"F"
P030 CAIS	"XY"	"Female"

Q4 - Sex other than 'Female' (continued)

Participant	Sex	Gender
P040 PAIS ^c	"Female XY"	"Female"
P043 Israel, Lesbian, PAIS	"Intersex"	"Intersex"
P045 CAIS-->Swyer?	"Female (XY)"	"Female"
P047 Belgium, CAIS	"XY" ^d	"Female"
P052 PAIS	"XY Female"	"Female"
P056 USA, Bisexual, Swyer	"XY"	"Female"
P058 CAIS	"cAIS female"	"Female"
P060, PAIS	"Female AIS"	"Female"
P063 Bisexual, 5-a-RD	"Male" ^e	"Female"
P068 USA, Lesbian, PAIS	"Intersex/female"	"Female"
P069 USA, CAIS	"46XY"	"F"
P074 CAIS	"Pseudo-hermaphrodite"	"Female"
P075 CAIS	"Female - technically XY"	"Female"
P077 Poland, PAIS	"Intersex" ^f	"Female"
P079 Eire, Swyer	"XY"	"Female"
P084 Italy, CAIS	"Female (XY)"	"Feminine"
P088 USA, Lesbian, PAIS	"Female (PAIS)"	"Female"
P095 CAIS	"Male" ^g	"Female"
P096 Canada, CAIS	"Female (with qualifications)"	"Female"
P097 USA, Bisexual, 17-b-HSDD	"M" ^h	"F"
P099 CAIS	"Intersex"	"Female"
P100 Canada, CAIS	"XY"	"Female"
P103 Lesbian/Queer, PAIS	"Female/intersex"	"Female with male rising"
P105 Finland, 75-a-RD	"Intersexual" ⁱ	"Female"
P107 USA, CAIS	"Intersexed"	"Female"
P112 Swyer	"Intersex"	"Female"

a. "XY. I don't like answer[ing] this question, but I know that this is the truth."

b. "My birth certificate says F- I identify as F, but I'm XY"

c. Had stated "Confused" for sexual orientation.

d. When questioned later by email she said: *"In my situation both Female would apply"* but I have kept her initial responses here and just switched them around since her gut reaction was that there was a difference.

e. "Male (although I have always felt female)"

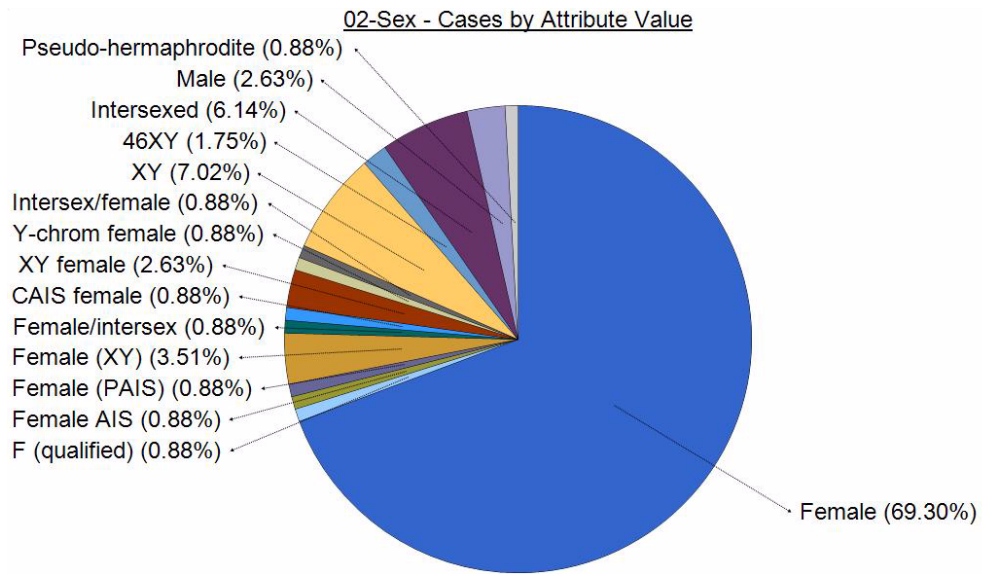
f. When questioned later by email she said: *"Oh of course I mixed those up - sorry - still after 9 years here [in UK] the language barrier is huge!"*

g. When questioned later by email she said: *"In that case female for both. I thought when you asked about gender you meant chromosomes, which is xy"* but I have kept her initial responses and just switched them around since her gut reaction was that there was a difference.

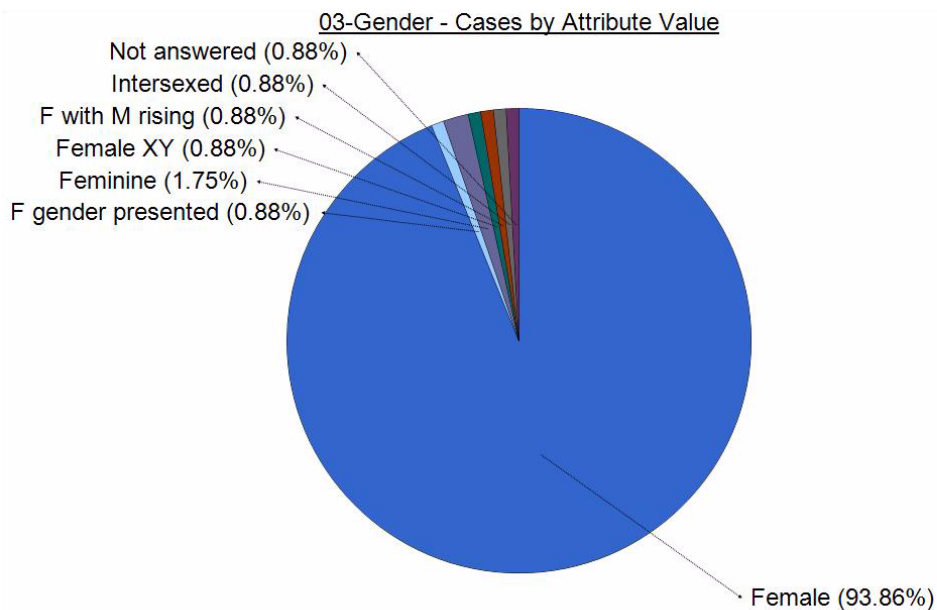
h. "M (if you mean biological/chromosomal)"

i. "Female (in fact intersexual, but I consider myself a woman)"

With these adjustments, the sex and gender for all participants are as shown below:



Q4 - Declared sex



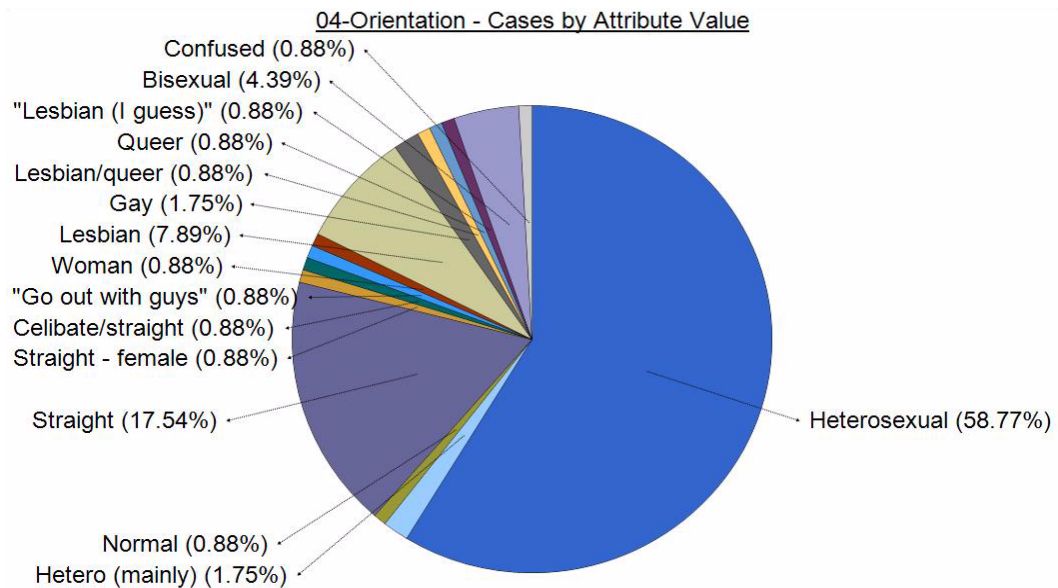
Q5 - Declared gender

Using the adjusted data, just over 69% can be said to have given their sex as simply “Female”; with just over 12% using terms that included the word “female” but qualified in some way with the inclusion of their diagnosis acronym, or their sex chromosome status, or the word “intersex”; and just over 18% giving a status that did not include the word “female” but just used terms such as “intersexed”, “pseudo-hermaphrodite”, “XY”, “46XY” or “male”. So in all, almost 31% of participants gave a sex that was other than simply “Female”. No participants used the term ‘DSD’ (see page 10) as part of a declaration of their sex.

Contrast the responses for sex with those (similarly adjusted) for *gender*, where only a few percent gave anything other than simply “Female” for their gender (and even those few stated something closely approximating this, with just one participant arguing that both her gender and her sex were “Intersexed”).

Orientation and partnership status

The participants’ declared sexual orientation is shown in below:

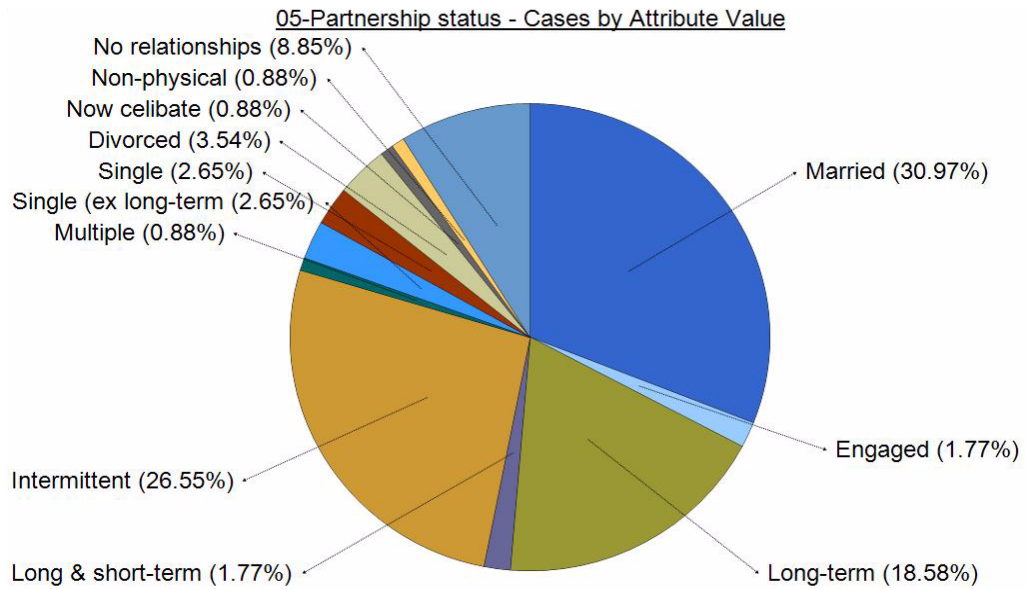


Q6 - Declared sexual orientation

Those declaring themselves to be either ‘heterosexual’, ‘hetero (mainly)’, ‘normal’ (assumed to mean heterosexual), ‘straight’, ‘straight - female’, ‘celibate/straight’ or ‘go out with guys’ made up 82% of participants. A total of 12% declared themselves to be ‘lesbian’, ‘gay’, ‘lesbian/queer’, ‘queer’, or in one case ‘lesbian (I guess)’. Presumably the latter response was questioning whether the participant’s XY sex chromosomes and (surgically removed) testes might be argued to signify a heterosexual partnership with her female partner. 4% of participants said that they were bisexual. One person specified ‘woman’ for this question and another said ‘confused’. The sexual orientation question was worded “Can I ask about your sexual orientation?”. A few participants took that literally and just answered “Yes”. Maybe politeness on the part of the researcher shouldn’t have been at the expense of clarity!

In the three main diagnostic groups the percentages giving a lesbian/bisexual orientation were 7% for CAIS (n=71), 13% for Swyer Syndrome (n=15) and 36% for PAIS (n=19).

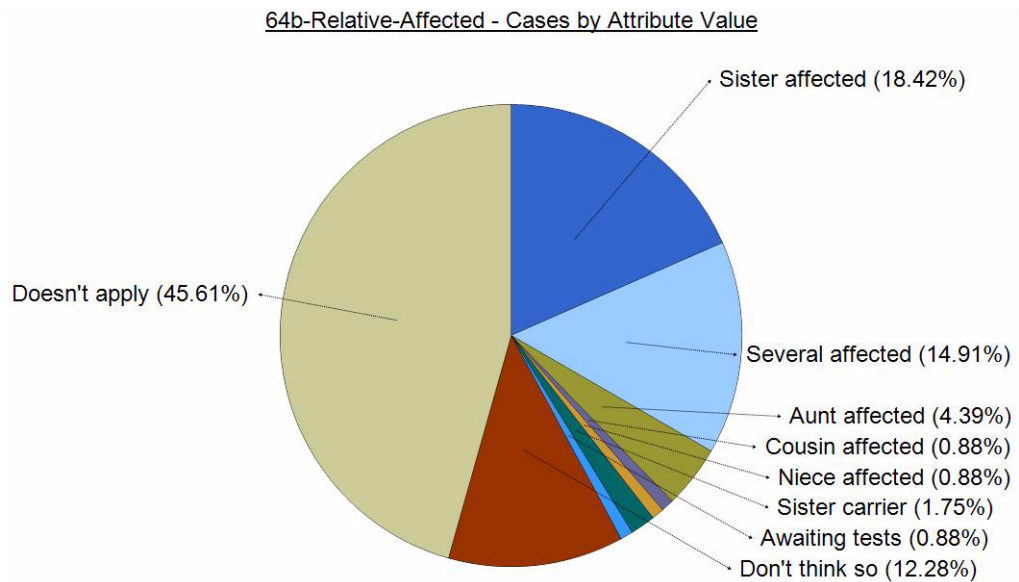
The participants' partnership status is shown in the chart below:



Q7 - Partnership status

Affected relatives?

Participants were asked in Q25 whether they had any affected relatives, and/or any relatives who were known to be carriers of the altered gene (in the case of AIS). The responses were as follows:



Q25 - Affected relatives

Met others affected?

Participants were asked in Q30 whether they had met other XY-women. 71% had met others, 23% had not, and 6% said they'd only met an affected relative.

Chapter conclusions

This chapter has set out the methodological aspects of my study and the demographic characteristics of my study participants. The next four chapters trace various stages that XY-women might go through in discovering and dealing with their unusual status, and the various identities or labels that they assume (or are imposed on them) in the process.

Chapter 4 (“The initiate and the patient”) looks at my participants’ experience in finding out about their condition, including issues of truthful disclosure or secrecy, what their understanding is of the conventional medical explanation of their condition, what medical interventions they have experienced and how they feel about these and the medicalisation of intersex in general.

Chapter 5 (“The failed male and the super female”) examines medical paradigms and terminologies that characterise XY-female conditions on the one hand as a failure to masculinise in utero and, on the other, as an example of ‘super-femaleness’. It evaluates the degree to which participants engage with these notions

Chapter 6 (“The disordered woman and the outsider”) examines how the lack, or presence of certain biological attributes may affect participants’ sense of self as women, and what their views are on the recently introduced ‘disorder’-based medical terminology. It questions their gendered position in society and their perceived authenticity as women/females.

Chapter 7 (“The gender savant and the intersex woman”) examines the relevance to XY-women of theories of sex versus gender, the social construction of gender, and the discursive production of ‘reality’, and the part that performativity may play in their gendered subjectivity. It asks whether a ‘return to the body’ might help to bring the male/intersexed aspects back into focus in a useful way.

4 The initiate and the patient

This is the first of my four main data chapters. It examines how and when my study participants became aware of various aspects of their diagnosis, what their experience was of truthful disclosure or secrecy on the part of doctors and/or parents, and what their understanding is of their condition's aetiology. It covers the clinical treatment they experienced within the medical system; what surgeries they underwent and when (and how they feel about this now), whether they have been displayed to trainee doctors or subjected to medical photography, and whether they were offered psychological support by the medical system at diagnosis. It asks what their thoughts are on intersex being viewed as a medical issue/problem which society seeks to correct. The aim is to paint a picture of what they have experienced within the medical system, to act as a background to the material in the subsequent three chapters. Whilst there have been general discussions of diagnostic secrecy in intersex medicine and its effects on those diagnosed with such conditions, there is virtually no information on how and when XY-women discover individual elements of their diagnosis (covered in this chapter) and what meanings they attach to them (covered in later chapters).

The initiate

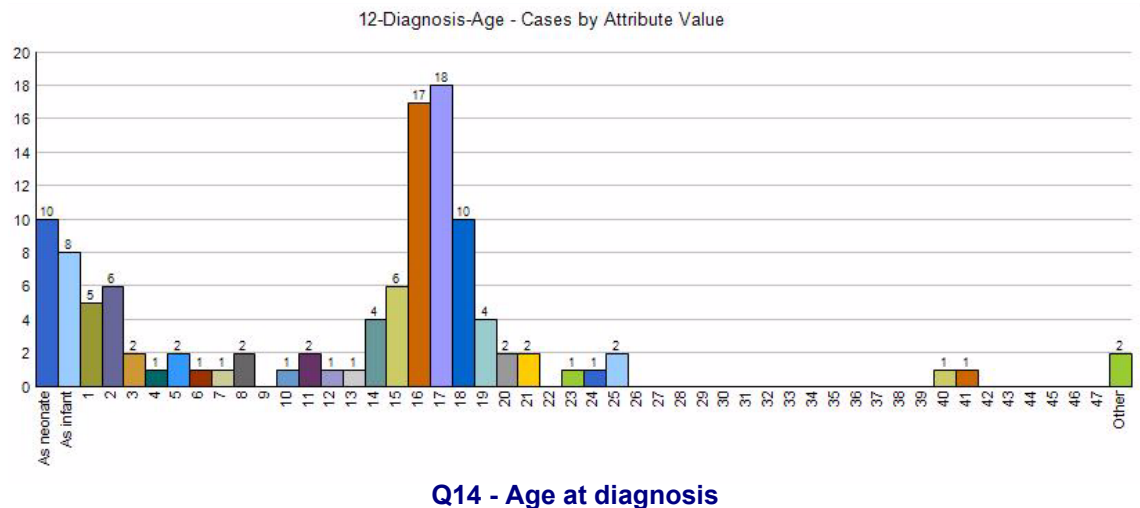
"If no one else will talk to you," she continued, "then I will. The problem, as I see it, is that you've been told and not told. You've been told, but none of you really understand, and I dare say, some people are quite happy to leave it that way. But I'm not. If you're going to have decent lives, then you've got to know and know properly... ...If you're to have decent lives, you have to know who you are and what lies ahead of you, every one of you..."

From 'Never Let Me Go' by Kazuo Ishiguro (2005: 70). Faber and Faber.

Diagnosis and discovery

Age at diagnosis

The various diagnoses reported by my participants are presented on page 85. At Q14 they gave the age at which a diagnosis was made by a doctor, irrespective of when they themselves gained any information about this. I asked about participants' earliest suspicions of 'a problem' (Q13) but have set aside that material for future analysis. Twenty-nine diagnoses were made in the neonatal/infancy period (before age 3), possibly following herniation of intra-abdominal testes into the inguinal (groin) region, or in a few cases because of an enlarged clitoris or because of an awareness of an inherited condition such as AIS in the family (see chart below). And as would be expected, a cluster also occurs in the mid-late teens as a result of investigations for delayed/absent pubertal signs. However some participants appear not to have been diagnosed until their late 20s, and even their late 30s; and early 40s in a couple of cases. The two participants charted as 'Other' were not able to say when they were diagnosed.



Age and source/s of discoveries

At Q15 participants were presented with a list of component elements of the various XY-female diagnoses and asked to state the *age* at which they learned of each, and the *source* from which this came. For the purpose of analysis these diagnostic elements were divided into:

a) ‘soft’ information (that which does not necessarily imply an intersex condition):

- Infertility
- Vague information about internal organs being ‘under-developed’ or ‘not working’
- Lack of ovaries/uterus
- Lack of menstruation (amenorrhoea)
- Short/absent vagina (vaginal hypoplasia).

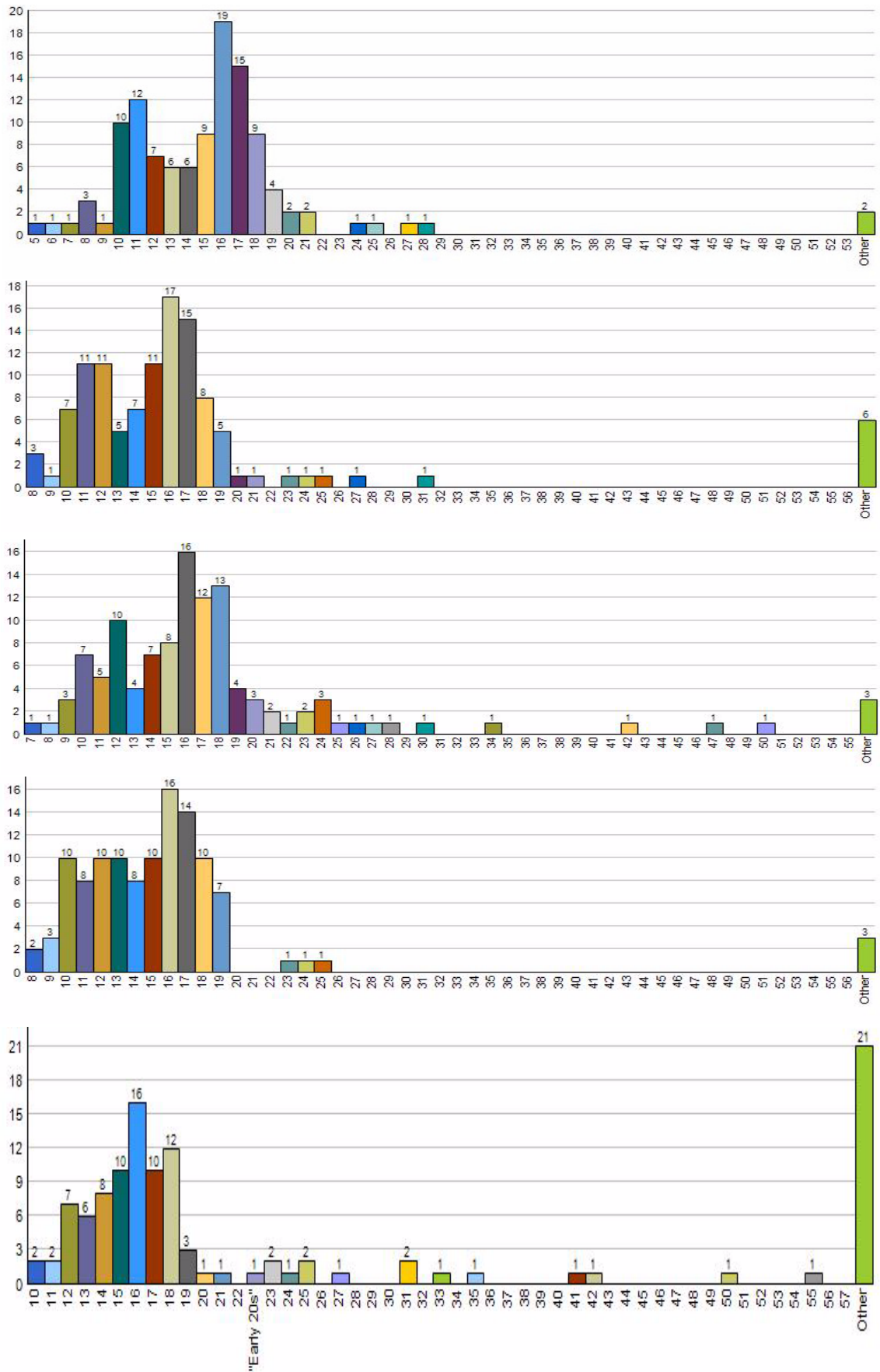
b) ‘hard’ information (which, in someone raised female, would suggest intersex):

- Presence of testes
- XY sex chromosomes
- Name of condition (the diagnosis)
- That participant is classed by medicine as intersexed.

The *ages* at which participants said they discovered these items are discussed below. The information *sources* are shown in the table on page 102 and discussed thereafter.

Age at discovery

The five figures on the next page show the ages at which participants discovered items of *soft* information.



Q15 - Ages at which participants gained 'soft' information
(from top: infertility, 'vague info', no ovaries/uterus, amenorrhoea, short vagina)

Attention is drawn to the general profile of the charts, which indicates that most of the soft information was gained by the late teens, although extending into the 20s in a few cases (and later still in some cases with regard to vaginal hypoplasia). The tendency towards a double peak in some of the charts no doubt reflects the pattern of childhood versus teenage diagnosis (and hence learning profile) seen also in the bar chart on page 95.¹

Infertility and vague information

The topmost chart shows the age at which the participants learned that they were fundamentally infertile (without necessarily being told why).² The second chart shows the age at which the participants reported being given vague information such as “Your reproductive organs just didn’t develop fully” or “Your ovaries became twisted and don’t work properly”. For some, this will have been part of a stepwise disclosure of their full diagnosis and they will have received a fuller explanation later, whilst others may have been kept in the semi-dark until they discovered the whole picture by chance, or as a result of their own enquiries.³

Lack of ovaries/uterus

The third chart shows the age at which the participants were told about their lack of ovaries/uterus.⁴ Those with Swyer Syndrome are usually born with a rudimentary uterus and are often told that they have inactive “streak gonads”. In this condition the disruption of male development (as it is viewed by conventional medical discourse) occurs at a very early stage in the cascade of changes that occur during gestation. A fault on the testis-determining gene (SRY) of the Y sex chromosome prevents the indeterminate gonadal tissue from developing towards testes, leaving undifferentiated gonadal streaks which are said to consist of “ovarian-type stroma cells without any follicles” (Minto 2004). However, most of the 15 in my study with Swyer Syndrome or suspected Swyer mirrored the responses of those with AIS, by simply giving an age and source for learning of a *lack* of both ovaries and uterus. So we could say they are giving an age when they learnt about their lack of *mature* or *working* ovaries, and might be viewing the possession of a small, possibly non-viable uterus as equivalent to not possessing one at all. A few with Swyer did add a comment/qualification about ovaries; for example, altering the question to read “lack of *functioning* ovaries” (and removing the word ‘uterus’ from the question), or stating “scar tissue ovaries seen”, or “told they were small, not absent”, or “streak gonads”, or just “gonads”.

1. NVivo sets the range of each chart’s y axis to accommodate the largest y value, so some of the charts have been stretched or shrunk vertically in order to scale them with respect to each other, and with respect to the companion set on page 100. Note also that in some cases the x axes start at slightly different ages.

2. The two in the ‘Other’ category said “biology class at school” and “guessed”, neither giving an age.

3. The six in the ‘Other’ category were either not told this or couldn’t recall.

4. The three in the ‘Other’ category were told about ovaries and uterus at different times.

Only four of those with Swyer Syndrome indicated at this question that they had a uterus. There seemed a certain lack of attention or significance given by the Swyer participants to this organ. One, who hadn't said whether or not she had one, responded thus on further questioning:

I had a uterus, it was not in good shape. I was given the option whether or not I wanted to keep it. They did an ultrasound the day before [gonadectomy] surgery and saw the tip of it. I had 5 minutes to decide. The doctor suggested I keep it because having a menstrual cycle would make me feel more feminine. I told them I didn't want it or need it. They took it out. **(P056 USA, Bisexual, Swyer 50)**

Seven others with Swyer mentioned elsewhere that they had a uterus, or confirmed this on further questioning (often referring to it as "small", "undeveloped", "hypoplastic", or "not a working one"). For example:

About the uterus, the doctors tell I have it. But a very small one. So they even think that I could carry children if I just could get a donor egg and a man to be ready for becoming father. **(P013, Estonia, Swyer 31)**

Described by the gynaecologist as 'very small' to my face and 'rudimentary' in a letter to my GP. **(P024, Swyer 44)**

Originally my doctor led me to believe that I didn't have one [uterus], however I found out that wasn't the case just before my [gonadectomy] operation. It was very small and underdeveloped and with the use of HRT it is expanding and now at a 'normal' size with good lining. **(P045, CAIS/Swyer? 23)**

In the later question (Q18) about the impact of biological issues (see page 147), the 15 with Swyer Syndrome or suspected Swyer were more forthcoming, either stating that the lack of a uterus did not apply to them, or giving it their lowest score, or (three participants) leaving the item blank.

Amenorrhoea

The fourth chart shows the age at which the participants learned that they would not menstruate. In some cases they will have been told this before puberty, by parents or doctors (i.e. if the diagnosis has been known since infancy/childhood), and in others they will have had worries or suspicions confirmed when their menarche appeared to be delayed in their teens. The two participants giving an age of 23 and 25 respectively for this discovery (current ages of 68 and 67) had been kept very much in the dark about *all* aspects of their condition.⁵

Vaginal hypoplasia

The fifth chart shows the age at which the participants learned that they had, or might have a short/absent vagina.⁶ It is probable that some of the AIS women amongst the responses recorded

5. The three in the 'Other' category were uncertain.

6. The 21 in the 'Other' category were: One stated "discovered myself" with no age given, 17 stated "not applicable", two left the item blank, and one stated "unsure".

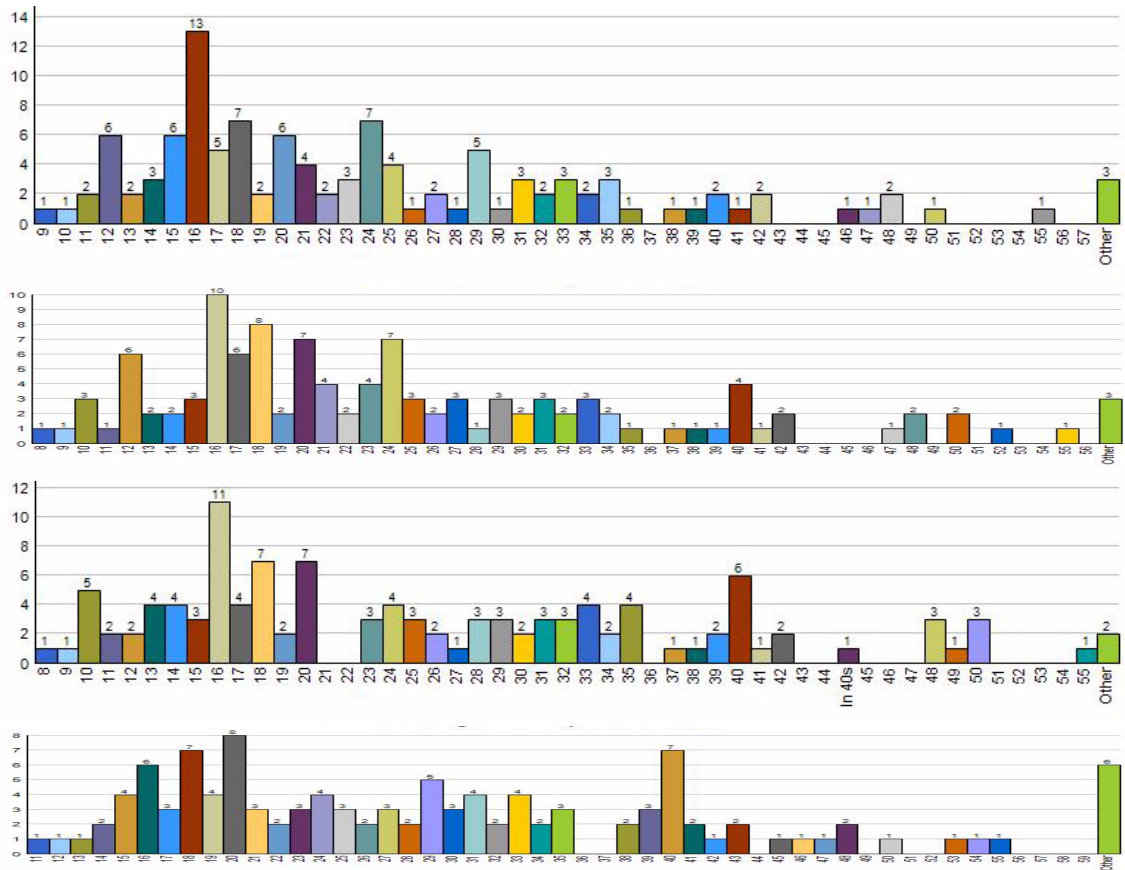
as “not applicable” here (see footnote) are those who have the maximum ‘two-thirds of normal’ length often said to be expected in AIS, and which can be extended via pressure dilation or by penetrative sex. And even though 94 (82%) of the study sample as a whole gave an age and source here for learning that a short/absent vagina was a feature of their condition, this is not to say that this necessarily proved a problem for all these participants (see page 147).

Seven with Swyer Syndrome (in which the vagina would be expected to be fully formed) actually cited sources for the belief that their vagina was short.⁷ One of these, whose talk of uterine bleeding and having had a small uterus removed seemed to support her Swyer diagnosis, had actually undergone vaginoplasty surgery and used dilators, and ranked this problem as second choice at Q18. But for the other six it is not clear whether vaginal hypoplasia is a true recollection of clinical information/status on their part, or a case of being swept along by discussions, in support group circles for example, relating to the more common diagnosis of AIS, in which vaginal hypoplasia is a frequent feature. Two others with Swyer Syndrome were, respectively, not sure, and hadn’t yet had penetrative sex (relating that at age 18 that she “was told [by doctor that sex] may be painful, would have to wait and see how I was getting on.”). However the remaining six of the 15 with Swyer did give the expected “not applicable” to short/absent vagina at the current question. And 11 of the 14 participants who, later in the survey, at Q18, wrote “doesn’t apply” or similar for vaginal hypoplasia (or left the item blank) had Swyer Syndrome or suspected Swyer. One Swyer participant, who said at the current question that a short vagina didn’t apply to her, gave a ranking at Q18 for the impact of this deficiency. She subsequently explained sexual difficulties (see page 152).

The four figures on the next page show the ages at which participants discovered items of *hard* information, i.e. that which would be indicative of an intersex condition.⁸

7. But two of them gave it a low ranking at Q18 about the impact of biological features.

8. NVivo sets the range of each chart’s y axis to accommodate the largest y value, so some of the charts have been stretched or shrunk vertically in order to scale them with respect to each other, and with respect to the companion set on page 96. Note also that in some cases the x axes start at slightly different ages.



**Q15 - Ages at which participants gained 'hard' information
(from top: testicular tissue, XY sex chromosomes, condition name, and 'intersexed')**

The distribution for the hard information has a much flatter and wider profile than that of the soft information (seen on page 96). As with the soft information, there is a peak during the mid-teens, but many participants did not discover the various items of hard information about themselves until well into adulthood.

Presence of testicular tissue

The topmost chart shows the age at which the participants learned that they had internal (intra-abdominal) testicular tissue as opposed to ovaries.⁹ Ten of those with Swyer Syndrome (in which the gonads are just so-called streaks) gave an age and a source for presence of testes, in the way that those with AIS did, implying that they became aware at that time of the intersex nature of

9. The three in the 'Other' category were: two couldn't recall and one, who had given her diagnosis as 5-Alpha-Reductase-Deficiency in which internal testes would be expected, stated "not applicable".

their condition. In the case of those with Swyer who ‘disputed’ having had testicular tissue¹⁰ I used the age at which they discovered other intersex aspects of their diagnosis.

XY, diagnosis, and intersex

The second chart shows the age at which the participants learned that they had XY sex chromosomes, as opposed to the XX pattern of a standard female.¹¹ The third chart shows the age at which the participants learned the medical name for their condition (i.e. their diagnosis).¹² Compare the profile of the chart on page 95 (which shows when the diagnosis was made by doctors) with this chart (which shows when this information reached the patients). The fourth chart shows the age at which the participants learned that medicine puts them into an ‘intersex’ category.¹³ One participant (age 21) said she hadn’t been aware until now of being classed this way and another (age 20) had stated “This survey!” for the source of this information.

Information sources

The table on page 102 shows the range of *sources* from which my participants gained information. In the case of soft information the majority were informed by doctors, with parents being the next most frequent source, except for vaginal hypoplasia which a number of participants discovered independently. Percentages of my study sample learning these soft elements of their diagnosis from non doctor/parent sources ranged from 4% for infertility to 23% for vaginal hypoplasia.

In the case of hard information doctors still played a significant part in disclosure but parents played a much lesser role. This may be because the parents themselves had not been aware of the whole picture and some of the doctors here were being consulted by these parents’ offspring *in adulthood* to find out what had been kept under the covers earlier in their life. It is evident that there was a much wider range of information sources in the case of hard information, with medical records and media sources (internet, books, magazines and so on) being cited more often, together with verbal sources outside the doctor’s surgery or the parental home.

10. Responses such as: “can’t remember”, or “streak gonads” (and stating later, at Q18, that the presence of testes was “not applicable”), or “never had any as far as I’m aware”, or “never mentioned” (and left this item blank at Q18), or “unsure” (and left blank at Q18). Another Swyer woman stated “presence of gonadal tissue” at the current question, and another left it blank at the later question (as did a number with AIS).

11. The three in the ‘Other’ category were: One said it was when she was tested at age 57, one said in her 60s, and one couldn’t recall.

12. The two in the ‘Other’ category were: One had not been diagnosed (but thought she probably had 5-a-RD) and the other couldn’t recall.

13. The six in the ‘Other’ category were: One was at age 63, one was 67, one gave no answer, and three couldn’t recall.

Q15 - Sources of diagnostic information

	‘SOFT’ INFORMATION (Number of participants):																											
	Not Answered	Doesn’t Apply	No Official Diagnosis	Not Sure/No Memory	Doctor	Parent/s	Parent & Doctor/Nurse	Self Discovery/Deduction	Medical Records	School Biology	Comment Overheard	Book/Library	Two Sources	Internet	AISSG	Person and Website	Sibling	Husband	Other Relative	TV Programme	Magazine/Newspaper	“Media”	Geneticist	Hospital Letter	This Study	Total Non-Doctor/Parent		
Infertile					65	37	7	3	1	1																5	4%	
Vague information		5	1		69	25	9	1	1		1			2												5	4%	
No ovaries/uterus ^a					77	22	7		2			2	2	2												8	7%	
No menstruation					67	30	7	10																		10	9%	
Short/absent vagina		19	1		57	5	6	13				3		7	3											26	23%	
‘HARD’ INFORMATION (Number of participants):																												
Presence of testes		1		2	56	6	6	2	14			7		5	8	2	1	1		2	1						43	38%
XY chromosomes					50	7	7	3	13			5		9	8	2	2	1	2	1	3		1				50	44%
Condition name			1	1	49	8	4	3	15			6		10	9	2	1	1	1	3							51	45%
‘Intersexed’	5				23	1	1	3	6		1	8		28	24	2	2		1	4	1	1		1	2		84	74%

a. 13 with Swyer' syndrome (15 with P026 & P045) had uterus (often small/non-viable) but are here referring to their lack of ovarian/uterine function.

Some of those citing ‘Internet’ as an information source may be referring specifically to having accessed ‘AISSG’ (via the group’s website), or to having been helped to do so in the case of those citing ‘Person and Website’; so these three columns may coalesce to some extent.

Percentages of my study sample learning these hard elements of their diagnosis from non doctor/parent sources ranged from 38% for presence of testes to 74% for the fact that medicine classes them as intersexed. One participant had even found out her diagnosis, and the fact that she had XY sex chromosomes, from her husband, whom the doctor/s had chosen to inform whilst keeping her in the dark. This, however, is not the most bizarre source known to the support group. One woman found out about the XY nature of her condition from her mortgage broker, who had obtained medical information from her GP for life assurance purposes (Personal Communication).

Q15 was structured so as to gather data specifically on age and source of information for quantitative analysis, as presented above, but some participants volunteered additional information or, for example, gave reasons why parts of the question did not seem to apply to them. This was subsequently coded to qualitative nodes, in case it could be used in conjunction with other qualitative data or might be useful in framing queries etc. The five most heavily populated NVivo qualitative nodes¹⁴ were: *Given TFS as diagnosis (17)*, *Uterus in Swyer*¹⁵ *(15)*, *Hormone treatments (2)*, *Glimpsing medical records (4)*, *TV programmes (2)*.

Some participants mentioned having been given the term Testicular Feminisation Syndrome as their diagnosis, in some cases discovering the newer term, Androgen Insensitivity Syndrome, at a later date. Some with Swyer Syndrome mentioned that they had a uterus, or remnants of such, and of having had hormone treatment to induce menstruation or to assist with IVE. A few participants mentioned having had sight of significant items of information in their medical records during medical consultations or hospitalisation. Two mentioned specific TV programmes (the BBC’s 1996 ‘Dark Secret’ documentary and the 2007 Oprah discussion) that had provided them with key information. One participant had learnt at age 23 that she’d been born with testes from seeing a medical journal article describing her family history (four sisters, each having at least one CAIS daughter). Another hadn’t heard the term ‘intersex’ until she attended an AISSG US group meeting in 2006, aged over 50. She, and another survey participant, had been two of seven CAIS cousins from their family who attended the meeting.

14. See page 245 for the complete coding for this question.

15. Includes text provided by Swyer participants when questioned later about uterus.

Summing up - Diagnosis and discovery

The profile of my age at diagnosis bar chart on page 95 closely resembles that provided by clinician Marta Berra and colleagues at UCLH (Berra et al 2010). The onset of puberty in the 19th century was 15 for girls. The international standard for normal puberty in white girls was set in the 1960s at 12.5 years for the age when periods began. But a Danish study (Aksglaede et al 2006) indicated that puberty started in girls at an average age of nine years and 10 months, an entire year earlier than when a similar cohort was examined in 1991. A decreasing age of puberty means that young people with XY-female conditions will be alerted earlier and earlier to their failure to reach physiological milestones compared to their peers. So it is appropriate that a new paradigm of truthful disclosure is evolving in the medical treatment of intersex/DSD, with a shortened period of time in the “cloud of unknowing”. But at the same time this could present a challenge in terms of these youngsters’ cognitive skills and emotional readiness to understand their condition, even if presented to them using a phased approach.

One of the most recent and useful disclosure studies is that of Lih-Mei Liao and colleagues (Liao et al 2010) who evaluated the experience of 56 XY-women in terms of receipt and sharing of diagnostic information. My survey asks about similar diagnostic components but uses a larger sample, and gathers both quantitative and qualitative data. My data accord with Liao’s findings in showing that it is the elements of the diagnosis related to infertility, rather than intersex, that had been most readily shared with patients in their formative years. Although infertility can be a major concern for XY-women, some clinicians have seemed to focus excessively on this aspect in medical consultations, and can also over-stress femaleness in XY-women with conditions like CAIS, as discussed in Chapter 5. Possibly they imagine that infertility will be the *only* issue of concern to a young patient who appears outwardly to be a regular female, and fail to acknowledge the functional and psychological impact of other female deficiencies such as vaginal hypoplasia or the ontological sequelae of being told about the male or intersex aspects of the diagnosis. Or perhaps some clinicians fear that talking of the intersex elements might somehow undermine a fundamental gender identity.

My data suggest that vaginal hypoplasia occupies a sort of halfway zone where a number of participants had to discover this on their own, and several factors could be at work here. There may have been a medico-societal prudishness or an ethical concern about investigating this in young girls, and/or a lack of clinical *concern* about the ability to engage in penetrative sex (with, again, more attention being paid to fertility/reproduction issues in phenotypic females), and/or a fear by doctors that discussions of this anatomical deficiency might arouse suspicions of an intersex status in the mind of the patient.

My finding that many participants had not discovered the intersex elements of their condition (testes, XY karyotype, condition name, ‘intersex’ label) until well into adulthood, and had gained this information from non-human sources (ranging from 4% of participants for infertility to 45% for their condition’s name and 74% for their intersexed status), chimes with the paternalistic clinical paradigm employed since the 1950s of withholding elements of the diagnosis for fear that patients would not be able to cope with the knowledge (Conn et al 2005) no doubt with the over-arching anxiety being the general societal fear of any blending within a binary sex/gender system (see also page 231).

Swyer Syndrome presents an interesting situation in terms of what clinicians do or don’t tell XY-female patients about their sexual anatomy. Whether such individuals can be said to have been born with ‘ovaries’ or ovarian tissue, as opposed to testicular tissue, seems somewhat debatable. The nature of the gonadal tissue in Swyer Syndrome (see reference to Minto 2004 on page 97) means that doctors who tell those patients that they have “small or underdeveloped ovaries” or “just gonadal tissue” are possibly being more truthful than when these phrases are used for patients with, say, AIS, where embryological development has proceeded considerably beyond the undifferentiated phase towards fully-formed intra-abdominal testes. Far enough for them to have done what testes are supposed to do with respect to the hormonal suppression¹⁶ of the development of Fallopian tubes, uterus and upper vagina; even if thwarted (by tissue insensitivity) in terms of the *masculinising* action of the androgens that they produce. However, it is evident that the use of such phrases in *all* these XY-female conditions has often been put to the service of hiding the intersex nature of the situation.

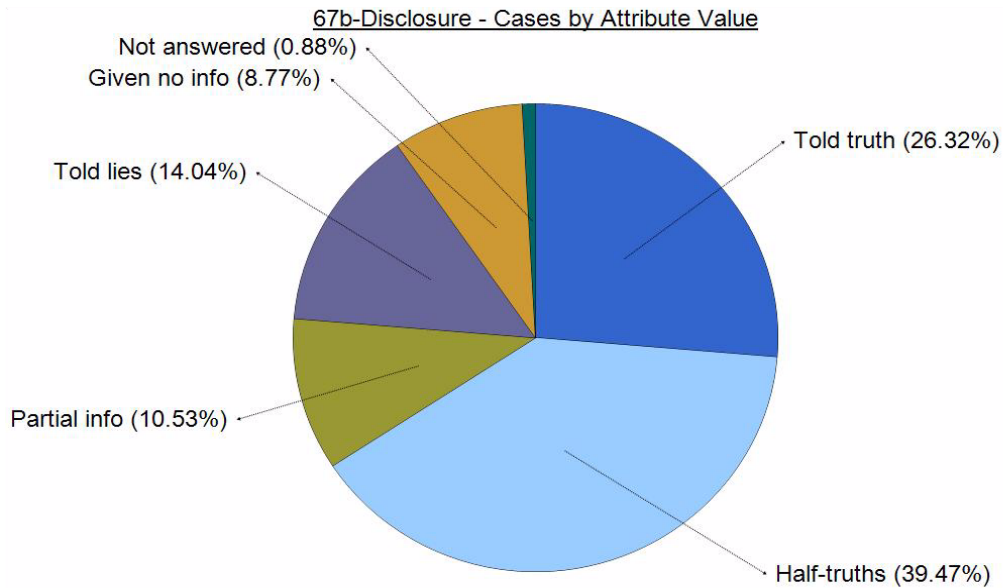
The internet has an increasingly powerful part to play in people unearthing medical information and becoming an expert in their condition (Ziebland et al 2004), and for my participants it appeared to play a significant role in the discovery of the intersex elements of their diagnosis, in conjunction with other personal research such as inspecting their medical records. The availability of online information and support has, in the last 15 or so years given patients in this most secretive and paternalistic corner of medicine more confidence in challenging medical authority and taking a more consumerist approach to their health care.

Disclosure vs secrecy

At Q34 participants described whether the adults in their life (doctors and/or parents) had ultimately given them a specific and truthful diagnosis, or had left them as an adult with lies or

16. Via Müllerian Inhibitory Factor (MIF), also known as Anti-Müllerian Hormone (AMH), another hormone (apart from testosterone) secreted by the foetal testes.

half-truths. This, and many other questions covered in my data chapters, were designed to prompt a narrative text response (for qualitative analysis) but the overall direction of the responses were coded to NVivo Attributes so as to allow quantitative analysis/charting.



Q34 - Disclosure by adulthood?

Those coded as “Told lies” in the above chart were responses that actually mentioned the word “lies”.

The table below gives data for truthful disclosure related to current age:

Q34 - Truthful disclosure vs current age

Current age (years)	Was told truth	
Youngest participant = age 15		
11 to 20 (n=6)	6	100%
21 to 30 (n=23)	11	48%
31 to 40 (n=34)	11	32%
41 to 50 (n=29)	2	7%
51 to 60 (n=13)	0	0%
61 to 70 (n=8)	0	0%
71 to 80 (n=1)	0	0%
Oldest participant = age 76		

Those over the age of 40 seemed to have been subject to considerably more secrecy than younger participants. All participants aged 21 or under (n=7) had received full disclosure. Six of these

were UK-based and one was in Denmark. However, two at the upper end of this age bracket, aged 20 and 21, said that they had not been aware of their ‘intersex’ label until participating in this survey. Whether they’d been given the newer ‘DSD’ term instead is not clear, although no-one used this term when stating their diagnosis (see page 85). Note that the number of participants in the lowermost and the upper age ranges is quite small.

The age ranges of my study sample for the various geographies are shown on page 85. The youngest participant from North America was aged 22. In order to evaluate the pattern of disclosure by geography, and to compare like with like, the seven aged 21 or under outside N. America who had received truthful disclosure were omitted. And for simplification the responses indicating either partial information or half-truths were combined, as too were those indicating either no information disclosed or lies given. Using these groupings, a relationship was found between geography and disclosure which was statistically extremely significant ($p=0.0005$):

Q17 - Truthful disclosure (age > 21) vs geography

Geography	Was told truth	Given half-truths or partial info	Given lies or no info
N. America (n=31)	3%	48%	48%
UK and Eire (n=62 ^a)	31%	58%	11%
Europe, Scandinavia, Israel and Africa (n=13)	31%	38%	31%

a. Excluding 1 who didn’t answer the question.

Only one participant (3%) in North America (P010, aged 32) had received truthful disclosure by adulthood, compared with 31% in each of the other two geographies. If the seven participants aged 21 or under are *included* in the two geographies outside N. America then the overall level of truthful disclosure rises to 36% in each of those two regions.

There appeared to be small differences (statistically not significant) between the experiences of those with different diagnoses (PAIS 32% truthful, CAIS 29%, Swyer 27%). Possibly some outward signs of slight masculinisation (e.g. clitoral enlargement) in a few with PAIS make a cover-up less feasible than in CAIS and Swyer.

To supplement the quantitative information, as set out above, the text describing participants’ experiences of disclosure or secrecy was subjected to qualitative coding. The six most heavily

populated NVivo qualitative nodes¹⁷ were: *Lies or half-truths* (62), *Truthful disclosure* (30), *Own research* (26), *Gonadectomy* (24), *Late discovery* (23), and *Infertility* (17).

The *Lies or half-truths* node was the third most heavily populated node in my entire NVivo coding exercise (see page 245). Here, participants talked of having been left with an explanation involving “ovaries” that were “only half developed”, “imperfect”, “malformed”, “small”, “twisted”, “didn’t work”, or “had behaved abnormally/strangely”, or were “‘gonads’ that were useless and could turn nasty”, with a holding back of information that would have indicated the true diagnosis and the fact that it was an intersex condition. The notion of having a “broken X chromosome” had sometimes been used to describe the genetic situation. One 42 year-old had been given a diagnosis of Maxwell Goldberg Syndrome when she’d asked what her condition was called (surely a case of obfuscation – so obscure a name for Complete AIS that she’d be unlikely to find the two terms connected anywhere, especially in the days before the internet).

One participant in her 50s related the story of her diagnosis in the context of her social situation:

I was born looking like other baby girls, and my intersexuality was not uncovered until age 17, when I visited a doctor since I did not menstruate. My doctor discovered I had male gonads and XY chromosomes, but — following standard medical practice in the 1970’s — lied to me about what they had found. They simply told me I couldn't have children due to a “birth defect”. Told me I was XX, and ovaries just didn’t work – but that I could have sex with any boy I wanted and never need any protection. Was told not to discuss with any other doctors or anyone else.

These physicians had ordered numerous medical procedures when I was 17 including a laparoscopic surgery, many x-rays, full blood workups, ultrasounds and chromosomal studies. But medical professionals apparently withheld the results. It’s possible they could have been inept, but I believe they withheld the truth. I was from a very low income, unemployed family with poorly educated parents growing up in a city of 200,000 in New England. I don’t think the doctors felt my parents and I could be told the details and understand all the ramifications of my intersexed condition. Instead, they told my family the chromosome and genetics tests they ran were all normal. I was just born without all my female reproductive organs. We were told I didn’t have a uterus but my ovaries were perfectly normal, they just weren’t uh “connected” due to the absence of a uterus – and “oh, by the way, you’ll never have a menstrual cycle and you can’t have any children...” With that news I left for college and a life in the Midwest. **(P027 USA, Lesbian, CAIS 53)**

The Y chromosome in AIS is in fact normal. The genetic mutation in the androgen receptor gene (that governs the body tissues’ sensitivity to male hormones) is sited on the X chromosome, inherited from the mother. But 33 years ago, when this participant was 17, clinicians would not have had tests to check for such mutations, so in a sense they were correct in telling the family that “the chromosome and genetics tests they ran were all normal”. They’d have been normal... for a boy. The lie would have been in not revealing a) the presence of a Y chromosome, and b) the fact that its presence was *unusual* in a girl.

17. See page 254 for the complete coding for this question.

It was not surprising to find that others, similarly now in middle age, had also received obstructive and paternalistic treatment. To accompany lies or half-truths, some had received inconclusive information. The doctor of a (now) 66 year-old CAIS woman “didn’t know” following diagnosis whether she had a uterus and advised her not to allow anyone to cut her open to check. Another (now) 55 year-old CAIS woman was given reassurance that a future husband would love for herself and not as a potential mother (possibly true, but patronising?). A 76 year-old CAIS woman thought that the exercising of a dictat that she had found in her medical records, advocating secrecy to prevent psychological problems, had in fact *caused* such problems. A woman (now 56) with Swyer Syndrome had only ever heard the words “ovaries” (at 17) and “gonads” (at 25) and was shocked, on asking some years later to see her GP records, to read the term ‘male pseudo-hermaphrodite’. Another CAIS woman responded thus:

I was given half-truths at 19, from both the gynecologist and my geneticist. At 24 I wanted to know my real diagnosis—what was the name, for heaven’s sake—and went to the geneticist along with my affected sister. (I had been stonewalled by the gynecologist.) The geneticist said that she respected our intelligence and curiosity and felt compelled to tell us we didn’t know everything about our condition, but she wasn’t at liberty to tell us the excised details. So, at 24, I saw a general practitioner in another city, and this physician sent for my records and told me the truth. He reported that the gynecologist had urged him not to tell me the truth. (P096 Canada, CAIS 57)

But even younger adults have experienced obfuscation and inventive ‘explanations’.

They only explained it to me very superficially, like my one X chromosome doesn't have a leg it should have and therefor I have little balls in my pelvis that can become cancerous, and I will not be able to have kids. (P085 S. Africa, CAIS 22)

And a 33 year-old related how a series of doctors had toed the line to keep her in the dark:

The gynaecologist who “treated” me at 15/16 told me that my mum hadn’t produced the right levels of hormone during pregnancy and subsequently my ovaries hadn’t developed properly and my womb hadn’t really formed. He said I would have to have my ovaries removed in case they developed tumours and that because they didn’t form properly it was difficult to know what “cocktail of hormones” would be produced. He said that we would need to remove them quickly in case my voice began to break or I developed facial hair.¹⁸

My eldest sister had just started to study embryology... ..so I had heard of egg donation. I asked him if my eggs would be suitable to donate, despite my ovaries not having formed properly (sorry I’m crying now because I feel such a fool). I said that just because I couldn’t have children [no uterus], perhaps someone else could because of me... he said that they couldn’t really be used. I asked if I’d need to have smear tests and that was when he said that I didn’t have a cervix, so no! So this is what I believed (and repeated to others).

Considering I had a GP at 15 who lied to me, then the gynaecologist who lied, then a doctor at university who didn’t tell me (who knew I was doing biology), then another one at the university I did my masters [degree] at who didn’t tell me, then three more as I moved around rented houses when I started my first job in _____ [UK city] who didn’t tell me... and of course my parents. All of whom knew I was capable of understanding and all of whom heard my ridiculous explanation of “why I can’t have children” so knew I hadn’t got the full details. I

18. Even though she has Complete AIS, so is totally insensitive to male hormones!

just feel such an idiot for not questioning it and I actually cringe when I think of some of the things I said to people. But would it have been easier if I'd know[n] then? I will never know. I guess not, maybe they were right not to tell me, maybe they weren't. (P058, CAIS 33)

As mentioned earlier, all seven participants currently aged 21 or under had received a truthful explanation by adulthood, leaving only 23 coded to the *Truthful disclosure* node, out of 107 participants currently aged over 21.

A number of participants talked of finding out their diagnosis through their own research, often involving seeking out their medical records and/or using the internet, the support group, or by confronting doctors. Much of this seemed to happen in participants' 30s:

My first real dive into my diagnosis was in a university medical library. I had read about the term "testicular feminisation syndrome" and made notes that I could refer to in the future. I had thought that by having a piece of paper, I could share it with future boyfriends and friends when I would find it difficult to talk about why I did not menstruate or could not have children. I seemed to close the lid then on this for a few years until I read a book by Germaine Greer - *[The] Whole Woman*. I read the chapter on Testicular Feminisation¹⁹ and can remember crying uncontrollably. I had showed the book to my sister and can remember saying to her - "this is me". My sister had no idea. It was at this stage that I decided that I needed to get some help - it was a low time in my life. (P092, CAIS, 34)

I was left with lies and half truths. I stole my medical records at age 34 and I read the truth about myself. I gave myself the truth – and it's best gift I've ever gotten. "It's the gift that keeps on giving." I had the same doctor from age 14 through age 34. He consistently lied to me over the years and contradicted himself many times about my diagnosis and the specific details. He, and the doctors I had when I was younger than that, all told me there was no one else like me. I had a random genetic mutation... ...And yet, I always KNEW I was being lied to. I now see in my medical records that my parents were lied to also. (P062 USA, CAIS, 52)

Gonadectomy was frequently mentioned in response to this survey question, usually expressed as doctors having advised that surgery was "needed" to remove "ovaries" (sometimes "gonads" or "hernias"). Terms such as "an investigative procedure" and "a hysterectomy" had sometimes been used to describe what was in fact a gonadectomy, an intervention that had been very commonly advocated on the basis of a supposed risk of cancer (a risk that may have been overestimated in some intersex conditions – see page 26). None of the participants talked of having been given a numeric estimate of the risk but many seemed to have taken on board the idea that it was significantly high:

Was told by the doctor that the bottom line was that my ovaries had not developed properly, and that they needed to be removed because there was a high risk of cancer. That I couldn't have any children but I could participate in everything else in life except professional sports. I was told not to mention it to future boyfriends until I was engaged and then tell them that I had my ovaries removed when I was 20 and I wouldn't be able to have any children. He told me that I would be dead by now and be 6ft under if the surgery was not done when it was done. But still made me none the wiser about my XY make-up. (P079 Eire, Swyer, 36)

I cannot recall exactly what I was told – what I was told though left me fearing the possibility of

19. A chapter titled 'Pantomime Dames'. See also discussion of Greer's viewpoint on page 44.

cancerous growths and that I was asexual like a eunuch. **(P025 USA, CAIS, 55)**

A number of participants talked of a late discovery of information about their condition, often resulting from a chance interaction, or by catching sight of a medical document or article:

I went to the doctor at age 21 (1991) to say I hadn't ever menstruated and after blood tests and a key hole surgery procedure (laparotomy) they said my ovaries and uterus were smaller than normal and that they should remove the ovaries as there was a high risk of cancer developing – Swyer's [Syndrome] wasn't ever mentioned nor was any explanation given other than "this happens". In August 2009 [age 38] I read Gonadal Dysgenesis on a letter my [new] Endocrinologist had copied me into, sent to my Doctor [GP] detailing our first meeting in clinic regarding my HRT. I did a web search and thought I was probably the XX variant²⁰ and then discussed it with Dr _____, my Endocrinologist at our next meeting in January 2010 and this is where I learned I had the syndrome [Swyer] and an XY karyotype. **(P044, Swyer 39)**

Learning of their infertility, sometimes in association with other pieces of information, but often with an over-emphasis on this particular deficiency, was mentioned by some participants:

I was given one short session of genetic counselling. They told me, basically, the only thing I had to concern myself with was my inability to bear children and to consider adoption. A gross over-simplification, I'd say. I lived in shame, denial and fear for the next 20 plus years. **(P053 Canada, CAIS 54)**

No one informed me of what happened, other than at my exploratory surgery at 15. I was told that they found gonads (which were removed), no ovaries, but implied there was the standard Fallopian tubes, and a short vagina. I would have to have "exercises" to enlarge my vagina to accommodate a penis. No one mentioned XY to either me or my parents. I didn't even know about the removal of gonads until way after the fact. I was told [then] that they might become cancerous thus having to be removed. Why they were there was never explained to me. Basically all they told me or my parents is that I would never have children. **(P088 USA, Lesbian, PAIS 62)**

At 15, the doctors and my parents had said that my ovaries were potentially cancerous and had to come out. The only issue for any of them seemed to be my infertility, which was a complete non-issue for me. However, they never asked what I thought, and without the truth, I don't know what I could have thought anyway. **(P097 USA, Bisexual, 17-b-HSDD 49)**

Summing up - Disclosure versus secrecy

Only 26% in my study sample as a whole said that they had received truthful disclosure of their diagnosis by adulthood. 10% had been given partial (but truthful) information. 39% had been given half-truths, i.e. misleading information. 9% said they were given no information and 14% were told outright lies, although it could be argued that those in the "half-truths" category were, in effect, also lied to about their diagnosis. As mentioned in "Disclosure vs secrecy" on page 20, several clinical studies have reported a poor awareness of basic diagnostic information on the part of intersexed individuals and a dissatisfaction with their level of knowledge (Warne 1998, Wisniewski et al 2000, Slijper et al 2000, Migeon et al 2002), and Iain Morland postulates that medicine prevents the intersex patient from knowing their own body (Morland 2001, p.537).

20. There is an XX and an XY variant of pure gonadal dysgenesis, the XY variant also being known as Swyer Syndrome.

My data indicate an apparent increase in truth disclosure from around the time those currently in their 30s would be expected to have learnt of their diagnosis (only 7% in those aged 41-50, rising to 32% in those aged 31-40). It's possible that the AIDS crisis, which was gaining momentum during the decade when the 31-40 year-olds filling out my 2009 survey would have been aged 11-20, together with an expanding openness about, and vocabulary for discussing sex in general, made it easier for clinicians at that time to start talking about intersex diagnoses with patients.

My study includes some participants young enough to have passed through a more enlightened medical system informed by 15-20 years of campaigning for change, thus enabling comparison with the 2010 study of Lih-Mei Liao and colleagues. If we take 2002 (year of the London *Intersex in the New Millennium* conference) as a 'finger in the wind' start of increased openness on the part of doctors, with this policy being recommended formally at the 2005 Chicago 'Intersex Consensus' conference (Hughes et al 2006, 2007), then we might expect those currently aged 21-23 or under to have received full, truthful disclosure (assuming they were diagnosed by say, age 14-16). As expected, all seven in my study aged 21 or under said that they had received truthful disclosure by adulthood, compared to only 23 of those over age 21 (from a total study sample of 114 participants). Liao et al divided their patients into those under age 27 and those aged 27 and above. In the younger group, 49% had known their full diagnosis by age 15 (0% in the older group). 59% of the younger participants had stumbled upon information unintentionally (70% in the older group). Using a similar age split, my data indicate that 81% (13 of 16 participants) aged under 27 had received truthful disclosure by adulthood, whereas only 17% (17 of 98 participants) aged 27 or above reported this. The higher percentages in my study may be because I asked about truth disclosure "by adulthood" (Liao et al used a cut-off age of 15) so my participants had a few more years in which to gain the information.

Overall, 31% in my study over age 21 from outside North America reported truthful disclosure by adulthood, whereas only 3% of similarly age-defined participants in North America reported this experience. It's possible that at a time before the internet provided access to global medical opinion, North American clinicians took more notice of protocols of secrecy recommended in US hardcopy journals by US-based clinicians such as John Money and John Morris. Or maybe a greater influence of religion, and anxieties over homosexuality, had some part to play. Reuters reports (2011)²¹ that gay marriage is specifically banned in 39 of the 50 US states. And although courts and state legislatures have legalized gay marriage in some US states, popular votes have consistently opposed same-sex unions.

21. <http://www.reuters.com/article/2011/06/25/us-gaymarriage-usa-idUSTRE75O0G420110625>

Understanding of condition

Previous studies of intersex patients' "understanding of their condition" seem to have focused on whether the patients had been given (or had grasped the significance of) individual 'markers' like XY karyotype, presence of testicular tissue, absent uterus, rather than soliciting a coherent explanation of how their condition arose. As far as I am aware there are no studies evaluating affected persons' understanding of the conventional medical discourse surrounding their intra-uterine development and how this influenced their sex and gender. At Q33 participants were asked what they believe happened, both before birth and after, that made them non-standard in terms of their sex development. A trick question elsewhere (see page 136) on how their body might have turned out if 'things had not gone wrong' also aims, in part, to test biological knowledge and understanding. The six most heavily populated NVivo qualitative nodes²² were: *After birth, at puberty etc. (50)*, *Accurate AIS description (46)*, *Vague account (21)*, *Omitted foetal part (21)*, *Some misconceptions (9)*/*Don't know (9)*.

Many participants talked about what happened from birth onwards, some also having talked about what happened before birth. The most popular after-birth topics were body hair, breast development, lack of menstruation, medical procedures, gonadectomy, HRT, tall stature (with many other topics being aired). The range of these responses can be seen in the coding table on page 253 but will not be analysed/discussed here, because this question was mainly to assess understandings of embryological events. Almost half of those who talked about what happened after birth talked *only* about this phase of life, omitting the foetal development part altogether.

46 (51%) of the 90 who had declared themselves to have AIS (whether CAIS or PAIS) *were* able to give a good or reasonable account of how the condition arises in a foetus and its effects on the body. The same applied to five (33%) of the 15 with Swyer Syndrome or suspected Sywer, three of the five with 5-a-RD, and the single person with 17-b-HSDD. So overall, 55 (48%) of the 114 participants displayed a good understanding. Some participants gave a short, and rather vague or sketchy account of how their condition arises, mentioning notions like starting off foetal development as a boy but this being disrupted. Some used medical terms and concepts such as mutations, genes/chromosomes, androgen receptors, insensitivity etc. but displayed misconceptions as to how these functioned or interacted, or else didn't know. The degree of understanding did not appear to correlate with level of education.

The proportion here displaying a good understanding is probably higher than in the affected population as a whole, since my participants have actively sought out information via a support

22. See page 253 for the complete coding for this question.

group and in many cases had discussed matters with others affected. The medical discourse surrounding the embryological development of sex is complex, and it is debatable whether a full medical understanding is helpful for all those affected (e.g. see quote from genetics-trained participant P001 on page 127).

The patient

She no longer wonders what is normal, whether she feels correctly. It is impossible to say. Her whole life she's known that her condition is untreatable. Now she understands that it requires no treatment. The difference is vast; you could fit a whole life in the gulf between. And so she has.

Concluding words from 'The Condition' by Jennifer Haigh. Harper Collins, 2009.²³

Participants were asked about their medical treatment. This means two things. Firstly, it refers to medical procedures such as gonadectomy, vaginoplasty and vaginal pressure dilation, and possibly genital surgery (e.g. to reduce the size of a clitoris). Secondly, it refers to the provision (or not) of professional psychological support/therapy, and to practices such as clinical photography (for publication/research purposes) and being displayed to other medical staff (for training/educational purposes). In this section I also seek my participants' views on the generalised medicalisation of intersex.

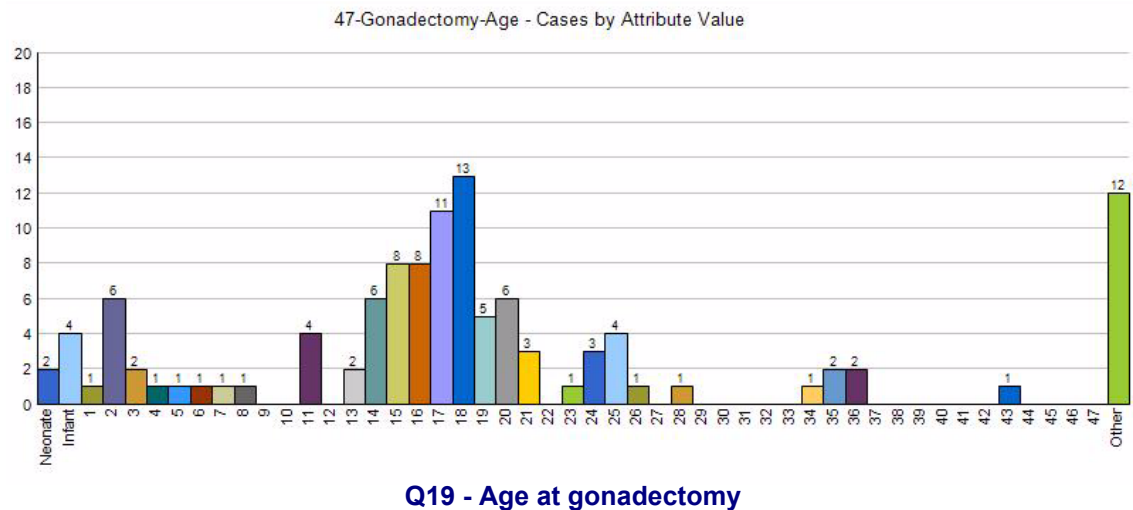
In texts based on interview studies (Preves 2003: 76, 105) or in online personal life stories (AISSG Web 1997 to-date), adult individuals often appear to be unhappy with having had gonadectomy imposed on them without informed consent. Some XY-women claim their health and well-being to have been compromised by losing their natural source of androgens (and oestrogens).²⁴ My study does not ask specifically about hormone replacement therapy, but lifelong HRT is a necessary consequence of gonadectomy and can involve problems with finding the correct preparation and dose, and with side-effects. Procedures to lengthen a short vagina are also important for some XY-women, and a few in my study may have undergone clitoral reduction surgery.

Clinical 'treatment'

At Q19 participants gave information about their medical procedures. All but six had undergone gonadectomy. A number of the gonadectomies were carried out in the neonatal or early childhood period, possibly following inguinal (groin) hernias, but the majority took place in the teenage years, with a few taking place well into adulthood.

23. Novel about the family of a girl with Turner Syndrome.

24. "It was like putting on dark glasses" observed one woman with AIS at an AISSG UK meeting (Personal Communication).



The 12 in the ‘Other’ category included two who had a gonadectomy later in life (age 48 and 57), four who’d had one or other of their testes removed at different ages, one who’d had biopsies only, four others who likewise still had their intra-abdominal testes, and one (who had given her diagnosis as 5-a-RD, in which internal testes would be expected) who left this question blank, having entered ‘not applicable’ earlier for the discovery of ‘Presence of testes’.

10 participants (9%) had undergone genital surgery such as clitoral reduction (at ages 18 months to 26 years) with one of them having had two such surgeries, in infancy and adulthood. An additional participant with PAIS (“probably middle grade”) wasn’t sure if she’d had clitoral surgery. 20 participants (18%) had undergone surgical vaginoplasty, with 18 of these having had one procedure (at ages 2 to 45 years) and two having had two procedures. 41 participants (36%) had practised vaginal pressure dilation, with 39 of these giving one age at which they had done this, in the range 9 to 45 years, and two giving two ages. Nine of those who had practised dilation had also undergone vaginoplasty surgery.

At Q38 participants described how they now felt about having undergone the various medical procedures they’d indicated at Q19. The six most heavily populated NVivo qualitative nodes²⁵ were: *Lacked info, consent, support* (38), *Happy, with reservations* (27), *Happy* (31), *Regret gonadectomy* (27), *HRT* (20), *Vaginoplasty* (13).

The most frequent complaint here was that participants had lacked information, informed consent and support in relation to gonadectomy surgery (and in one case, vaginal pressure dilation); that they hadn’t known what was being done to them or why (other than vague talk of a supposed cancer risk). One talked of how she’d been given some tissue in formaldehyde so she

25. See page 257 for the complete coding for this question.

could show her friends the results of her “appendectomy”. Those who seemed happy but with reservations again included comments on the lack of information/consent/support, on the associated scars, on the need for HRT; or they questioned the cancer risk, or expressed a *resignation* of a need for surgery. One participant with 17-b-HSDD said gonadectomy had been needed in order to preserve her female body form, but no one had asked whether that’s what she wanted. Some actually *regretted* a childhood gonadectomy, because of the lack of a natural puberty, a loss of general well-being and libido post-surgery, (and again) a lack of informed consent and/or support, or (again) doubts about the cancer risk, or trouble with HRT (which has its own health risks). One participant said that:

I hate that I had to have work done to “be” something. I wonder what [I] would be if I never had any of it. (P111 USA, Lesbian, PAIS 42)

Some said they were happy to have had gonadectomy surgery (and in a few cases vaginoplasty). Some said it “had to be done”, citing the supposed cancer risk, with a number expressing relief that it had been done as a child, when they were too young to remember it and wouldn’t have to deal with it as an adult, and some saying they were glad to have got rid of tissue that was male, or non-functioning, or which they “didn’t associate with”. One participant attached importance to genetics here:

I am glad that I had my gonads removed, I feel that I had the last bits of maleness removed. Which is daft really, since the non functioning y [chromosome] is still there in every cell of my body. (P024, Swyer 44)

In Swyer Syndrome the genetic fault lies with the SRY gene on the Y chromosome (unlike AIS, where the fault is on the X) and compromises the *formation* of testes as opposed to their gestational action ‘downstream’ in masculinising the foetal body. But the degree to which this distinction is known (or useful) to those affected is not clear.

Some talked specifically about HRT, either citing problems or concerns, or saying it had worked well for them. Regarding vaginoplasty, a common expression was regret at not having been introduced to (or in a few cases at having turned down) the non-surgical alternative of pressure dilation prior to undergoing surgical vaginoplasty:

I greatly regret the vaginoplasty procedures. The first one failed but left me with a large scar at the skin graft donor site. I now value bodily integrity more than I did at the time when surgery seemed to hold out a normalising outcome. I should have been introduced to the non-invasive, do-it-yourself pressure-dilation method (this wasn’t mentioned by gynaecologists until after 2nd surgery, in middle age). (P099, CAIS 61)

Two participants said they were too embarrassed to seek further treatment for vaginal hypoplasia. I asked my participants about sexual relationships (Q27-Q29) but have set aside this material for future analysis.

At Q16 participants stated whether they had been displayed to medical staff and/or subjected to clinical photography. 52% said that they'd had clinical photographs taken and/or been displayed to junior doctors (dressed or unclothed). 44% had *not* been subjected to these experiences. The three main diagnostic groups showed a trend but this was statistically not significant. The percentage experiencing display and/or photography in the PAIS/CAIS groups (53%/51%) appeared greater than in the Swyer group (33%), although a few with Swyer said either that they weren't sure, or that tissue samples had been taken, or they'd refused a request. Similarly, geographical location seemed to make a difference, but one that was statistically not significant. The frequency of these practices seemed similar in North America and in the UK and Eire (52% and 55%), with the area represented by Continental Europe, Scandinavia, Israel and Africa showing a lower prevalence (36%), but again not at the level of statistical significance.

The question was in the Quick Questions part of the survey document but some people gave additional information which has been coded. The six most heavily populated NVivo qualitative nodes²⁶ were: *Just no* (49), *Displayed to other docs* (33), *Just yes* (24), *Photographed* (15), *Fended off request* (3) and *Tissue samples* (2).

Some commented on other doctors having been present as onlookers at consultations/examinations, with a number of participants saying that they themselves had been too young or over-awed to object to this. Two talked of being asked to take part (clothed) in a presentation and diagnostic quiz respectively that the doctors were wanting to conduct in front of other clinicians. Of those who'd been photographed, only two participants volunteered any knowledge of what the photographs had been used for (respectively, a journal article about the genetic history of her family of four sisters each having at least one daughter with CAIS, and a conference presentation). Three told of how they, or a parent, had fended off a request to take photographs, and two participants referred to tissue samples having been taken for research, one expressing annoyance at seeing a letter in her medical records, to her consultant from another clinician, expressing thanks "for sending and sharing 'this unusual gonadal tissue'".

At Q17 participants stated whether they had been offered psychological support within the medical system. Five of the six aged 20 or under had been offered such support, but overall, a minority (39%) of my 114 survey participants had been offered this. The percentage decreased with increasing age, as might be expected.

26. See page 246 for the complete coding for this question.

Q34 - Age ranges vs psychological support

Current age (years)	Was offered support	
11 to 20 (n=6)	5	83%
21 to 30 (n=23)	13	56%
31 to 40 (n=34)	13	38%
41 to 50 (n=29)	8	28%
51 to 60 (n=13)	4	31%
61 to 70 (n=8)	1	12%
71 to 80 (n=1)	0	0%

For each age decade (except for 11 to 20 years), the percentage having been offered professional support exceeded the percentage saying they'd been given a truthful diagnosis (see page 106), suggesting that at least some of the support may have been confined to infertility counselling rather than dealing with the impact of an XY-female diagnosis.

Disregarding age, and looking at the geographical areas, 49% of those in UK and Eire had been offered support, the percentage for the area represented by Continental Europe, Scandinavia, Israel and Africa being 50%, and for North America only 10%. The lower percentage in North America may be a consequence of the lower level of truth disclosure seen there (page 107).

The question was in the Quick Questions part of the survey document but some people gave additional information that has been coded. The responses were coded to three NVivo qualitative nodes: *Not offered at diagnosis (70)*, *Yes, was offered (43)*, *Obtained later (21)*.

Most participants just answered "No" or "Never", with some explaining that they'd obtained it later by request, perhaps at a time of emotional crisis relating to their condition or when they tackled doctors for the truth about their diagnosis. This was the most heavily populated node in my entire NVivo coding exercise (see page 245). Of those who had been offered such support, some described it using phrases such as "minimal", "truly pathetic", "yes (age 23) but all he wanted to know was about my sex life!" and "more like some kind of short one-visit screening to determine my state of gender and sexual identity and maturity", or in one case talked about a psychologist having colluded with her parents to withhold diagnostic information from her. Seven had turned down the support offered. A number of those who'd obtained professional psychological support later talked of not having had access to this until they were referred to the multi-disciplinary adult intersex clinic at UCLH in London.

Summing up - Clinical ‘treatment’

Only six (5%) of my study participants had escaped gonadectomy. Most of the surgeries had been carried out by young adulthood, with a peak at age 18, but with significant numbers having lost their testicular tissue at much younger ages. Ten participants (possibly 11) had undergone some form of genital surgery such as clitoral reduction. 18 had undergone a surgical vaginoplasty procedure, with 39 having practised the non-surgical do-it-yourself method of pressure dilation to extend the vagina. Only 27% expressed unequivocal satisfaction at having undergone their medical procedure/s and 24% were happy but with reservations. 33% expressed dissatisfaction related to a lack of information about what was being done to them, and hence a lack of informed consent and psychological support, and 24% said they actually regretted the intervention.

The validity of gonadectomy in XY-female conditions is often taken for granted in the medical literature, with discussions focusing mainly on the best timing (in infancy/childhood versus post-puberty). But the cancer risk may have been exaggerated (a risk of around 5% in adulthood is often quoted for AIS type conditions – Pleskacova et al 2010) and the commonly observed push towards early gonadectomy may be motivated, at least in part, by a desire to save everyone from having to deal with truth disclosure by bringing up the issue when the child reaches adolescence. It was reported on 04 February 2010 by Cancer Research UK²⁷ that the lifetime risk of breast cancer in women in general had risen slightly to 1 in 8 (12.5%): so over twice the estimated risk of gonadal malignancy in AIS, and yet breasts are not routinely removed as a precautionary measure in young women. By 2007, some clinicians were questioning the rationale of carrying out gonadectomy (and sometimes even vaginoplasty) in childhood (Purves 2007). Certainly a case might be made in Complete AIS (with an estimated risk of 0.8%, see page 26) for ‘watchful waiting’, using imaging techniques and the monitoring of tumour markers, rather than prophylactic surgery. But whatever the exact diagnosis, it seems that any cancer risk is extremely small before adulthood, so there should be no rush to ‘get rid of the evidence’ in infancy/childhood. And the possibility of advances in assisted conception enabling some XY-women to ‘father’ a child in the future may need to be considered.

As the cancer risk is revealed to be lower in some intersex conditions than previously thought, maybe there will be more room for exploring the influence of social/cultural imperatives in seeking to rid female bodies of ‘male’ organs. Maybe a time will come when a young CAIS woman is given a chance to consider whether, as Morgan Holmes puts it, ending up with no gonads at all might make her feel more ‘ambiguous’ than she might have done without surgical intervention in the first place (Holmes 2008: 154). The 2004 Diamond and Watson study

27. See <http://www.bbc.co.uk/news/health-12356489>.

reported an 85% satisfaction with their gonadectomy amongst 39 CAIS women (data gathered from 1998, published six years later), but by the time of my survey (2009), more reliable estimates of the testicular cancer risks were available (see page 26), and patients' political awareness and self-confidence will have been higher. So it seems feasible that a greater proportion might now be questioning the validity of this surgical practice. Indeed, a recent meta-analysis by Deans et al (2012) reports on an increasing trend for women with CAIS to request the indefinite retention their testes, but suggests that the overall risk in this condition could actually be around 14% and points out that the monitoring of intra-abdominal testes is not a straightforward task.

Women with vaginal hypoplasia often regard surgical vaginoplasty as the holy grail that will solve all their problems, when in fact there is no totally trouble-free method amongst the many variant techniques. It was not my intention to study this in detail here and readers are directed to Sue Smith's 2000 study of the dilemmas faced by women in relation to such surgery, mentioned on page 27. The 2003 study of Rachel Holt and Pauline Slade on how women with MRKH (defined in footnote on page 22) deal with an incomplete vagina and womb has also been discussed there.

Diamond and Watson (2004) also highlighted the medical procedures that exacerbate rather than help the situation of intersexed patients, such as display to junior doctors and clinical photography – the latter practice being assessed in more detail by Dreger (2000) and Creighton (2000) – and which 52% of my participants had experienced. Although not statistically significant, the higher incidence of these 'guinea pig' experiences amongst my AIS participants, compared to those with Swyer Syndrome, may be because the bodily features of AIS are more dramatic or noteworthy as far as doctors are concerned, i.e. a female phenotype with (usually) good breast development (especially in CAIS), but with lack of pubic/under-arm hair, and with tall stature in many with AIS in general. In other words, how remarkable is it that someone with a Y chromosome and testes can look like this!

A minority of my study participants (39%) had been offered psychological counselling within the medical system, a deficiency highlighted by Myra Hird, as mentioned on page 28. The greater provision indicated in my study compared to that of Diamond and Watson (16%) could indicate an increasingly enlightened medical system over time (although the psychological support may not always have been based on full diagnostic awareness in my participants) or may reflect a higher proportion in my study of UK-based participants who have access to NHS services, in particular the psychology service at the multi-disciplinary intersex clinic at UCLH in London.

Medicalisation

At Q39 participants explained whether they thought it was appropriate for society to consider intersex as a medical issue/problem in need of correction, as has been the case since the late 1800s. The six most heavily populated NVivo qualitative nodes²⁸ were: *Informed consent/choice* (31), *Educate society* (30), *Not appropriate, with reason/s* (28), *Support, counselling, knowledge* (25), *Medical issue, but not problem* (20), *Appropriate, with reasons* (16).

A frequent view was that informed consent/choice on the part of the affected person, based on full information, was paramount:

I can't see an alternative to medical intervention for myself but I know that there is a wide range of experiences with AIS and related syndromes. It would be great if we could get to the stage where "patients" were able to really understand what has happened and then make an informed choice about surgery/interventions. But hey – it took me 20 years to feel that I understand what has happened to me. Can we afford to wait that long? **(P073, CAIS 42)**

A number of participants thought that society should be better educated and more accepting of intersex; and that clinicians should be more relaxed about it:

No it's not appropriate, on any level. It's a social problem in need of education. The only medical problem is that doctors think there's a problem. More specifically, it's a problem with society, and medical schools, teaching it's people to be unaccepting of differences. Society needs to get back to, and teach, some very human basics. First, differences are good. Second, the Golden Rule: Do unto others as you would have them do unto you. Third, respect everyone and don't presume that you know their reality better than they do. **(P062 USA, CAIS 52)**

One participant thought it depended to some extent on what caused conditions like hers:

Nobody seems to know why it [Swyer Syndrome] actually happens, I hear faulty SRY gene accounts for 30% but for the other 70% no reason is given, so if there is an environmental influence or another reason why this happens that can be corrected then it's definitely a medical issue that needs correction – If on the other hand it's a random biological accident then we should have detection procedures in place at birth alike other chromosomal disorders and learn as a society to embrace it by being more aware of what exactly is involved. **(P044, Swyer 39)**

The responses that gave reasons for medicalisation not being appropriate overlapped to some extent with the nodes from which the above examples are taken, with many people talking of intersex being part of a spectrum, or of being a naturally occurring phenomenon that is not usually threatening to life or health. And those who talked about the psychosocial impact of intersex conditions, advocated more emphasis on good information, support and professional psychological services:

It's both a medical AND a psychological issue, but only the medical part is treated. **(P066, USA, CAIS 49)**

28. See page 258 for the complete coding for this question.

Apart from the small risk of cancer (which is also a symptom of taking HRT for prolonged lengths of time – no?) I don't see that there was anything physical that needed to be 'fixed' in my case. All the negative issues/problems that I have experienced have been down to the psychological aspects - how it was dealt with in my family, how it affected my self esteem, my interaction with other women and men. Technology has provided patients with access to more information and support. The psychological effects of intersex conditions are just as important as the medical ones (that maybe are easier to tackle) – shouldn't these be addressed first? **(P050, CAIS 29)**

Some thought it was a medical *issue*, but not necessarily a *problem*, that it was associated with some medical concerns that required evaluation, and possibly intervention or care (e.g. hernias, HRT, osteoporosis, vaginal hypoplasia and “induced lactation for adoptive nursing”), but not a correction of the intersex state itself:

No, being intersex is a state. It brings with it medical concerns alright which may need to be addressed through surgery, therapy and/or drugs but actually being intersex is more of a situation rather than something that needs to be fixed. An alternative is to exist as intersex but show this to society as another way life can happen, and may be unusual but is not unacceptable. **(P001 Eire, CAIS 36)**

There were some participants who talked of medicalisation/correction being appropriate based on their personal experience, mainly in order to fit in with society. One participant expressed some unusual reasoning:

I do think it's preferable to see it as a medical issue, mainly because society still regards it as a sort of existential problem, i.e., intersex is bad, intersex is an inadequate form of humanity, etc. **(P096 Canada, CAIS 57)**

So this participant seems to be discounting medicine as a *contributing* factor to intersex being seen as socially unacceptable.

Summing up - Medicalisation

Only 14% of my participants thought it was appropriate for intersex to be regarded as a medical issue or problem in need of correction and giving a reason for this view. The majority of participants disagreed with the proposition. Looking at the overall coding of responses to this survey question (see page 257) there were 136 statements against medicalisation and 22 broadly in favour, with 42 indeterminate or mixed responses. The overwhelming expression was of a need for a greater degree of knowledge transfer, more informed consent and choice, increased counselling and support, and better education of society.

As discussed in Chapter 2, a number of authors have considered the manner in which medicine has assumed responsibility for the control of intersexed bodies, entailing huge psychosocial ramifications for those who exemplify what is essentially a naturally occurring and (usually) benign phenomenon. Iain Morland's concept of “trauma by design” in intersex medicine is a

particularly interesting way of framing medicine's foreclosing of patients' autonomy, their choices, and their exposure to alternative discourses (Morland 2011).

Chapter conclusions

The current chapter has discussed the way in which XY-women come to learn of two sides to their bodily and sexual make-up; their lack of certain female characteristics/functions and their possession of certain residual male features. Sometimes their inductions into these two statuses are more or less simultaneous, but in many cases the latter is discovered some time after the former, and from sources outside the clinic/home. Approximately half the study sample did not have a good understanding of their condition. Older participants (and those in N. America) had experienced a greater degree of obfuscation and secrecy, but there are signs that younger patients (21 and under) are experiencing a new paradigm of transparency and truthfulness. Most participants had undergone gonadectomy and many complained of a lack of informed consent in this regard. Approximately half had been subjected to clinical photography or displayed to other doctors for educational purposes, and less than half had been offered psychological support/counselling. Most participants disagreed with the medicalisation of intersex, as a problem in need of correction.

The next chapter continues the focus on medical discourse and covers two medical 'identities' based on genetic, embryological or hormonal principles, and the accompanying terminology to which participants will have been exposed.

5 The failed male and the super female

This chapter is concerned with two identities that, like that of ‘the patient’, arise out of my participants’ interaction with the medical system. It focuses on the medical paradigms and accompanying terminology that inform two notional identities based on genetic, embryological and hormonal principles. I qualify these as ‘notional’ because they are not necessarily willingly adopted, but rather are labels *assigned to* XY-women (covertly in the first case, overtly in the latter) by intersex medicine.

The androcentric emphasis displayed by the medical discourse surrounding AIS and similar conditions, and the problematic nature of the accompanying medical terminology have been introduced in “‘The failed male’” on page 28 and in Appendix A. The under-masculinisation paradigm is unfortunate for those who emerge as XY-women because the preoccupation of some paediatric endocrinology/urology specialists with this ‘failure’ or ‘breakdown’ seems at odds with most adult individuals’ view of themselves as women who are under-*feminised* (ALIAS Newsletter 2002). Basic medical theory, education and terminology focus on the aetiology of these conditions and on what is going on internally during gestation, whereas XY-female patients are, on a day-to-day basis, more aware of their female external bodily appearance and their (usually matching) gender identity.

However, whilst specialist clinicians might use male-oriented concepts and terminology in patient records, research papers and textbooks, some can go to the other extreme during patient consultations, suggesting to CAIS girls/woman that they consider themselves *more female* than XX-women (whose body tissues, unlike those of CAIS women, can respond to male hormones). This chapter gives voice to XY-women’s views of the ‘failed male’ paradigm by exploring their experience of medical terminology and asking what they imagine the alternative biological outcome might have been, had their development taken a different path in utero. And it seeks their opinion on the over-emphasis of some clinicians on CAIS patients’ femaleness.

The failed male

[Luce] Irigaray aims to show that Western philosophical and psychoanalytic discourse sees sexual differentiation as though there were only one sex, and that sex were male (that is to say, women are defective men)... ..Western culture, identity, logic and rationality are symbolically male, and the female is either on the outside, the hole or the unsymbolizable residue. The feminine always finds itself defined as deficiency, imitation or lack.

Madan Sarup (1993: 117-119)

Archaic and stigmatising male-oriented medical terminology, and the way this is used to sensationalise intersex in the media, has had a significant effect XY-women’s self-view (AISSG

Web 1997b). At one moment a teenager may have no reason to doubt that she is a regular girl whose periods are late starting, and half an hour later can have received an account that completely overturns her fundamental beliefs, often in the past conveyed by a middle-aged man in a white coat, sometimes behind a large desk, and possibly using terms like ‘Testicular Feminisation’ (the old term for what is now referred to as Androgen Insensitivity). However, such terms, and even more disturbing labels such as ‘Male Pseudo-hermaphrodite’ (an umbrella term for this group of XY-female conditions), are more usually reserved for *written* material that patients are not supposed to see. However, many who were not given a diagnosis in their teens will, during later GP visits, read these terms upside down in their medical notes, see them displayed on the doctor’s computer screen, or come across them in medical publications. As discussed in “Spreading the word” on page 235, in the late 1990s members of emerging support/advocacy groups started to discuss and challenge the medical terminology, but it wasn’t until 2006 that a (somewhat controversial) revision was made to the nomenclature.

Medical terminology

At Q35 participants selected, from a list, any medical terms that had exerted an impact on their self-view when they were finding out about their diagnosis. The responses were as follows:¹

Q35 - Which terms had an impact?

Term	Yes (had impact)	
Testes	78	68%
XY (sex chromosomes)	78	68%
Testicular feminisation	72	63%
Genetic male	68	60%
Gonads	64	56%
Intersex	64	56%
Male pseudo-hermaphrodite	50	44%
Hairless pseudo-female	18	16%

At Q36 some participants elaborated on *how* their selected terms had affected them. Not all participants elected to give a response to this question, having already indicated at the previous question which terms had exerted an effect on them.

1. Suggestions for additional terms having had an impact (given under ‘Other’) included: “Hermaphrodite”, “Infertile”, “Female by default only – hate this one!”, “A most fascinating subject” and “She looks just like a girl” (the latter two given by the same participant), “Sterile”, and “Referring [to] me as a boy, and phallus as penis in my medical notes”.

The six most heavily populated NVivo qualitative nodes² were: *General: negative (62)*, *Testicular feminisation: negative (32)*, *XY (sex chromosomes): negative (23)*, *Testes: negative (21)*, *Male pseudo-hermaphrodite: negative (19)*, *Genetic male: negative (19)*, *Gonads: negative (16)*.

In general talk about the terminology, the majority expressed negative feelings. This was the fourth most heavily populated node in my entire NVivo coding exercise (see page 245). Here, people talked in strong terms of feeling “shocked“, “devastated“, “angry“, “anxious“, “confused“, “sick“, “stigmatised“, “freakish“, “alien“, “excluded“, “unlovable“, “disgusted“, “grossed out“, “dirty“ and “ashamed“ on coming across the terms:

The truth behind these terms weren’t really what affected me so much. I think it was more that since it was hidden from me and that it wasn’t something that could be told to my parents or to me, either as a 16 year old or a 23 year old, it must be something that is so horrific to the world that no one should ever know and no one could deal with this. This is a shameful existence. Something evil and dirty that if my parents would know they might not even be able to continue to love me as their daughter, their little girl. The world would never see me the same way. **(P028 USA, CAIS 48)**

Another participant, however, hinted that the ‘truth’ is better than lies, no matter how devastating, but again drew attention to issues of secrecy and deception:

Utter and total SHOCK. The “penny dropped”, “the scales fell from my eyes”. Suddenly all my previous history made sense. I felt so angry and so sad. How could all those medics have kept this from me ? **(P048, Swyer 56)**

One participant speculated that a name for her condition could have reassured her that there were others affected, but:

Instead, all those freaky names simply made it worse: my condition is not a specific kind of womanhood but a genre of fraud. A hairless pseudo-female sounds like a desperate and disgusting satyr who wants to enter the ladies’ changing room with a very cunning trick. **(P041 Hungary, PAIS 40)**

The terms were said to be very male-oriented and at odds with participants’ view of themselves as female up to that point:

These terms make you doubt yourself, your identity and even your sexuality. They all relate to a ‘failure of masculinity’ type of approach, focussing on the failure of our bodies to become male or female, and don’t allow us to have an identity of our own and that we can be proud of. **(P049, CAIS 29)**

However, some participants made neutral comments about the terms (coded to a subsidiary node) and revealing an interesting alternative view of the embryological process or mechanism that these terms implied, and the meaning attached to it:

2. See page 255 for the complete coding for this question.

That was when it hit me that I was technically a male that hadn't turned into a female not as I'd always be led to believe a deformed female. It made a lot more sense and in fact I preferred it... like I'd just developed as my genetics had meant me to develop not that I was a freak (as I'd felt before) but that there was nothing else that could have happened and I was actually just a normal variant and that there were even other people like me and that what I had even had a name!!! I was suddenly... normal... well sort of. **(P058, CAIS 33)**

In the preceding survey question (Q35) 'Testicular feminisation' had come third (after 'Testes' and 'XY sex chromosomes') in the list of terms that had influenced their self-view, but when asked to elaborate on their choices in the current question it received the most attention from participants. Views expressed about this term were similar to those summarised above in relation to the terms in general:

Testicular feminisation: This produced intense anger, as I saw it as a quasi-medical way to try to invalidate my self perception of being a woman. The focus of that term was on testes, as if that were the sine qua non of gender definition. It seemed to imply something that I definitely didn't feel. It seemed to say "you're a boy who is effeminate". Or "you had internal testes therefore you're a boy who's been feminized". How wrong I knew that to be! **(P062 USA, CAIS 52)**

I felt sick in the stomach and very angry when I read the terms 'testicular feminisation' and 'male pseudo-hermaphrodite' in medical books during my teens. How dare these guys use these horrible terms to refer to me behind my back (in publications they thought I and other patients would never read) but never to my face. **(P099, CAIS 61)**

Another participant had half-doubted the term's veracity after she'd first heard 'testicular feminisation' when spat out during a marital argument (her doctor had disclosed the diagnosis to her husband but not to her). Another hated the way the term "appears larger than life" on her GP's computer screen during surgery appointments. However a few participants made neutral or positive comments. One said that the term "was at last the 'truth' but quite shocking - although affirming what I thought to be the likely scenario" and another said, unusually, that she had not associated the word 'testicular' with 'testicles' (but had still "been left feeling like a freak of nature").

Some participants elaborated on the effects of being told they had a male (XY) karyotype. They found this hard to understand and accept, and began to examine their gendered self; whether, for example, they were "supposed to be gay" or even questioning their right to use the female toilets. And it seems that genetics can be threatening both to those with scientific knowledge:

I have a huge problem with knowing I have Y chromosomes, being trained in genetics. I feel shame and worry that others who find out will judge me and will see me as being not female. To this day, this has the biggest impact on me, regarding my AIS. **(P001 Eire, CAIS 36)**

and to those without:

Although I was in my fifties [when I found out], I had never thought of myself as male. The chromosomes worry me because I cannot see them (whatever they are) and I just have to take someone else's word for it. **(P016, CAIS 66)**

One participant, however, commented that although the terms XY, gonads, and testes were confronting at first, “they are just medical facts” and she “learned to deal/live with them relatively fast”. Several others (coded to another subsidiary node) thought ‘XY’ was good because it was a useful scientific, clinical, or biological way of labelling the condition (as in ‘XY-female’ or ‘XY-woman’) which didn’t imply freakishness or sensationalism in the way that ‘testes’ or ‘genetic male’ could do. One commented that understanding the genetic mechanism involved in AIS had given her a sense of “knowledge is power”.

In talking about negative associations of the word ‘testes’ participants expressed difficulties similar to those outlined above relating to ‘maleness’. A couple said they found ‘gonads’ more acceptable than ‘testes’, but others tarred both terms with the same brush.

Whereas terms like ‘testes’ seem to instil doubts and confusion regarding sex/gender, the term ‘male pseudo-hermaphrodite’ elicited talk of abjection, freakishness, weirdness and anger. Several participants didn’t see why it should even be applied to them because they had no outward signs of maleness or ambiguity. Several commented on the ‘pseudo’ prefix:

Male pseudo-hermaphrodite: Anger, fear and sadness – all at the same time. What does it mean to be a hermaphrodite? That’s so stigmatizing in our society. But to be a PSEUDO hermaphrodite – a FAKE hermaphrodite – that smacked of wilful fraudulence and further invalidation of my integrity as a person per se, and as a sexual person in particular. I became so sad to think that I could never be understood for who I am – that I could never be seen as a valid sexual being who had the right to be with other sexual beings. **(P062 USA, CAIS 52)**

However, a few participants made neutral comments about the term (coded to another subsidiary node), dismissing the term as being either “silly” or “ridiculous”, or not relevant to them, or explaining:

Male pseudohermaphrodite appeared in books and also didn’t make sense, but in general the overly medical texts I consulted didn’t make too much of a negative impact as they were from a different, impersonal world, it seemed. Not much bearing on me. **(P104, LCH 46)**

The ‘pseudo-hermaphrodite’, well I kind of know what a hermaphrodite is, and I know that I’m not.. a hermaphrodite, so that one doesn’t really affect me. **(P113, CAIS 44)**

One participant was unusual in expressing a positive view of the term:

To support that possibility [that she’d not registered having heard the term ‘intersex’] let me say that the term ‘pseudo-hermaphrodite’ was one with which I was comfortable. I suppose I assumed hermaphrodite had the same meaning as ‘intersex’- - so ‘pseudo’ meant to me ‘not real’. That was a comfortable way to deal with concept of intersex or hermaphrodite. And, to this day I do not call up any feeling of discontent with the term. And if science would choose to classify me as intersex -- - that’s their issue and not one that bothers me in any way. **(P032 Canada, Lesbian, CAIS 76)**

Some of the negative comments about the term ‘genetic male’ centered on the way this term seemed to label their whole being as male, not just parts of their body, in addition to the usual anxieties about challenges to their sex:

Genetic male: The affect was anger. Even if I was “genetically” a male, seeing that as the summation of my being was so misleading and unfair to me. After all, I KNEW I was a woman. So the Y chromosome was the anomaly, not the rest of my body and my being! In other words, it was the Y chromosome that was out of whack with the rest of my being. (Most doctors and people think it’s the other way around. Meaning, you have a Y chromosome, therefore you are really male. In my mind that’s then followed by the unspoken assumption that “... so you’re really fooling yourself and everyone else, so you better hide it...”). **(P062 USA, CAIS 52)**

Again, a few participants made neutral comments about the term (coded to another subsidiary node) registering views such as:

Genetic Male- Hard to believe I am really a male genetically, but this term is at least straight forward. **(P069 USA, CAIS 43)**

Genetic male only affects me in the shock value sense, while pseudo-hermaphrodite I find offensive. While they may be applicable, I do not find them of much use or applicability in my life. **(P076 USA, CAIS 57)**

Being genetically male makes me slightly uncomfortable, but as I look outwardly female this isn’t really a big deal. **(P087 USA, Celibate, PAIS 28)**

Most participants who talked about the term ‘gonads’ had made a connection with testes, or with something “out of science fiction, [an] alien creature” or “that made me feel less than human for some reason”, or at best as a something vague that was being used as a euphemism:

I have never liked the way doctors have used the term ‘gonads’ in talking about AIS to obscure the fact that they are really testes (since they have in truth gone somewhat further than the undifferentiated stage). It’s as if they think that someone is going to be happier if told that they, or their body organs, are somewhere in-between rather than one thing or the other. How naïve. **(P099, CAIS 61)**

Gonads: When I had my “ovaries” removed at age 18 (“because they were underdeveloped and would never work”), the consultant used the term Gonads in conversation with me. From Biology classes, I understood this to mean the sexual organs, thinking it was just a term that he used to talk about the ovaries. Years later when I challenged him about his deception, he insisted he never told me he was taking out my ovaries, saying he said he was removing gonads. Way to cover yourself, Doctor! **(P001 Eire, CAIS 36)**

A couple of participants made neutral comments about the term (coded to another subsidiary node) saying they preferred hearing the term ‘gonads’ to ‘testes’, or would use that term themselves by preference.

Summing up - Medical terminology

With hindsight, Q35 could have been better worded. It should possibly have comprised two sections, asking: a) which terms had been encountered, and b) which had an impact. It’s possible that ‘male pseudo-hermaphrodite’, a generally hated term based on anecdotal evidence, was

rather low down the list because not many people had come across it at the time they were dealing with their diagnosis (although more may have come across it later). Conversely, some participants possibly chose terms that they hadn't actually come across when finding out but which seemed at the time of completing the survey to be stigmatizing, offensive and so on. However, the inclusion of the term 'hairless pseudo-female'³ – which participants are extremely unlikely to have come across (the researcher has only seen it once, in a very old text) – provided a 'decoy question' that gives an indication of how many participants are making selections in the second way.

However, each of the male-associated terms – 'testes', 'XY', 'testicular feminisation' and 'genetic male' – attracted the votes of 60% or more of my participants as having had a particularly strong impact on their integrity as girls/women. The terms 'gonads' and 'intersex' were selected by 56% of my participants, with 'male pseudo-hermaphrodite' having apparently reached the eyes/ears, and affected the self-view of 44%. Although most of those with AIS had, earlier in the survey, stated CAIS, PAIS, AIS or Androgen Insensitivity Syndrome as their diagnosis, a number were probably initially given the older term Testicular Feminisation Syndrome, or had at least come across this term at some point, either from a doctor, or from reading their own medical records or other written material. The term was mentioned by some at Q15 where participants were asked about source and age for various items of medical information (see page 94). An NVivo text-search query on the responses to Q15, Q32 and Q34 indicated that 25 of the 90 (i.e. 28%) recorded as having AIS mentioned having been given this term, or having read about it and assumed it applied to them.

Those who chose to explain their terminology selections focused on negative aspects of these terms as a whole; or on specific terms, with 'testicular feminisation' receiving the most attention here, and 'intersex' the least (apart from 'hairless pseudo-female' which, as already mentioned, was somewhat of a decoy option). Only a small minority of participants made dismissive (not assigning any significance), neutral, or positive comments about any of the terms, but amongst these responses were some interesting ways of interpreting the medical discourse behind the terminology, such as the preference of one participant for the 'failed male' over a 'failed female' paradigm and the participant who had no problem with 'male pseudo-hermaphrodite' because she felt the 'pseudo' prefix negated the intersexuality implied by 'hermaphrodite'.

3. A similarly stigmatising term might be discovered by anyone who digs deeply enough to locate a 1969 book that gives the term "Testicular Feminization – Simulant Female" in a chapter titled 'Sex Reassignment as Related to Hermaphroditism and Transsexualism' (Green and Money 1969).

‘Genetic male’ is a term that is often used in medical writing (patient records, textbooks, research papers etc.) in the sense of “this outwardly female patient is in fact *a genetic male*”, i.e. with male used as a noun. Some XY-women find this quite irritating and inaccurate, with its implication that their whole person is being labelled as male. Participants also talk about the significance of their XY karyotype in other parts of the survey: in terms of what society expects of a women, as an item of diagnostic information, as contributing to a sense of being an outsider, as a defining component of sex in the sex/gender dichotomy, and in relation to their gendered identity.

The word ‘gonads’ can describe the undifferentiated foetal structures that usually will become either ovaries or testes and is also used as a generic term for the fully formed organs. However, it would be more usual once a child has arrived in the world (and certainly in the case of an adult) simply to use the term ovaries or testes. But some clinicians in this field of medicine seem to think that if they use the term ‘gonads’ when talking with parents and patients then no-one will suspect that they are covering up the fact that an XY-female child/adult may have quite fully formed testes inside their abdomen. Does not the use of such a word, that is alien or obscure to many lay people, immediately flag up that “something is being covered up here”. I would argue that where the word ‘gonad/s’ reaches public consciousness it is usually as something on the outer surface of the male body, and often sniggered at, as exemplified by the *Viz* comic character “Buster Gonad and his unfeasibly large testicles” (which he has to carry around in a wheelbarrow). In parallel to this, doctors will often use the term gonadectomy (if they are not using hysterectomy, a common euphemism in the past) when in fact the removal of testicular, as opposed to ovarian tissue is more accurately termed an orchidectomy or an orchiectomy. But these ‘male’ terms are unlikely to be used when addressing XY-female patients or their parents – even though the medical literature (including case notes, textbooks and research papers) abounds in such terms –with their authors having until quite recently enjoyed the assurance that patients’ eyes would not be alighting on these texts.⁴

‘Intersex’ is a somewhat contested term. It has been adopted by some as a political identity (possibly in most cases, by individuals born with so-called ambiguous genitalia, rather than XY-women with conditions such as CAIS) whereas others would not want to be associated with it in any shape or form. There were 12 expressions of negativity towards this term here, but with 13 saying at Q37 that they *preferred* ‘intersex’ to the new DSD terminology (see page 160), so this term doesn’t appear to attract such strong views as the mythological and male-oriented terms.

4. That is, until say the early 2000s, when 5 years or so of campaigning for more openness by intersex patient groups (and the growth of the Internet) had empowered patients to start seeking out information in such materials.

As discussed in “‘The failed male’” on page 28, Iain Morland has framed the term ‘pseudo-hermaphrodite’ as a *defining negation* which confines the patient’s subjectivity within medical discourse and constructs the patient as one who cannot know their own body: it may only be known by medicine (Morland 2001).

Sometimes women with these conditions appear surprisingly forgiving of clinicians’ use of archaic and stigmatising language. In response to the survey question about ‘truthful disclosure or lies’ (Q34) one participant explained:

I was given a specific and truthful diagnosis by a specialist gynaecologist in Oxford, following a whole series of blood tests. My local G.P. had carried out an internal inspection of my vagina and confirmed that I did not have a cervix, which coupled with my lack of pubic hair, resulted in the blood tests being carried out to determine chromosomes/fertility/testosterone levels/etc. The only difference was that the specialist gynaecologist called me a “male pseudo-hermaphrodite” but then my diagnosis was in 1991 before the “intersex” terminology was widely used. (P106, CAIS 34)

Even though in 1991 the term ‘intersex’ might not have been familiar outside medicine, it had in fact been in clinical usage, e.g. in journal articles, for some 74 years! Margriet van Heesch talks of XY-women patients almost colluding with clinicians in using medical terminology to obfuscate (Van Heesch 2009). It would be interesting to explore the relevance of sociologist Pierre Bourdieu’s theories of dispositions/habitus and symbolic violence to the manner in which XY-women incorporate diagnostic information into their subjectivity, and the role of complicity in taking on the subject position of patient in a unquestioning way⁵ (Bourdieu 2001).

It is unfortunate that my participants lie at the furthest extreme of a spectrum of genital appearances and phenotypes which in the eyes of paediatric medicine, with its proximity to genetics and embryology, represents varying degrees of a failure of *masculinisation*. Much of intersex medicine, including the terminology, is controlled/influenced by such clinician (e.g. the 2005 Chicago conference and its subsequent ‘Consensus Statement’ – Hughes et al 2006), who usually don’t see the outcome of their care in adult patients or necessarily have an appreciation of the psychosocial ramifications of the conditions they treat. In 2002 the AISSG UK newsletter published a discussion (*Talking Terminology*) following a support group meeting at which a senior paediatric specialist in these conditions had used terms such as ‘genetic males’ to describe AIS women, and had referred to their hypothetical CAIS women relatives on a schematic inheritance chart as their “brothers”, “uncles” and “nephews” (ALIAS Newsletter 2002). Several teenagers/young women had left the room in tears. When asked about this afterwards, he said that this was the way geneticists had always interpreted inheritance charts, “a square means male, and a circle means female”. He had frequently been challenged by AISSG during the 1990s for

5. See quote from Suzanne Kessler on page 233.

perpetuating the use of the term ‘male pseudo-hermaphrodite’ in his research papers and for an overemphasis on the ‘failure of masculinisation’ paradigm in AIS (constant reference to an inadequate penis, and so-called ‘locker room’ anxieties, in PAIS boys) with no mention of short/absent vagina in CAIS girls.

At a meeting of the British Society for Paediatric Endocrinology in September 1996, this well-intentioned clinician/researcher suggested replacing the terms ‘female pseudo-hermaphrodite’ and ‘male pseudo-hermaphrodite’ with ‘virilized female’ and ‘undervirilized male’. He claimed that this proposal came out of patient support groups having told him they didn’t like/understand the older terms and he thought the alternative terms were less offensive and easier for patients to understand (ALIAS Newsletter 1997, ALIAS Newsletter 2002). When his suggested terms received a frosty reception from AISSG members he explained that he was open to other ideas but would only favour a nomenclature that served the same classifying and differentiating purpose as did the hermaphrodite-based terms. The support group’s favoured umbrella term, ‘XY-female’, was deemed not suitable as a substitute for ‘male pseudo-hermaphrodite’ because, for example, some patients who have the Partial form of AIS might assume a male gender identity/role. This is understandable from a classification point of view; however he and other clinicians had been happy to refer to girls with CAIS as male pseudo-hermaphrodites based on certain male internal characteristics (chromosomes and gonads) that are shared across the range of clinical presentations, but not so happy, it seemed, to use a term that suggested feminisation for boys, even though it made some concession to maleness by including the prefix ‘XY’.

His suggested replacement umbrella terms illustrate a) the tenacity with which some in the medical profession cling to terms based on genetics and embryology and b) a misunderstanding of adult CAIS patients’ view of themselves as women who might not take kindly to a new term (‘undervirilized male’) which didn’t seem much different to the old one in terms of labelling them as ‘failed males’. Whilst a PAIS individual towards the male end of the male-female continuum of AIS genital appearances might possibly be tolerant of such a term, those who are women at the CAIS end are not likely to be excited by this suggestion. In fact, these individuals more closely represent the notion of ‘*sex reversal*’ that is sometimes referred to in the older medical literature.

In October 2005, a few weeks before the Chicago conference at which the new ‘Disorder of Sex Development (DSD)’ terminology was introduced and ratified, the clinician emailed AISSG, in all likelihood not knowing that ‘DSD’ would be squeezed onto the programme during the course of the conference, saying that:

We have been proposing the terminology ‘undermasculinised male’ (and conversely ‘masculinised female’)⁶ to get away from the pseudohermaphroditism terms but I guess CAIS should not really be in the former category if I have learned anything from my educational visits to AISSG meetings.

And in June 2006, around the time of the publication of the post-Chicago ‘Consensus Statement’, he again emailed AISSG concerning the newly introduced DSD-based terminology:

I think the sea change in nomenclature is a giant step forward and I am encouraged by the fact that clinicians are already embracing the new terminology. I accept the concern about using the word ‘disorder’ particularly in the context of CAIS individuals being normal females. Indeed, we have previously discussed many times that CAIS is clearly not an intersex disorder.

It seemed though, in the eyes of AISSG, that he had missed the point. The support group wasn’t claiming that CAIS women weren’t intersexed... that they were “normal females”... just that the archaic terminology was too much focused on masculinisation. Surely CAIS *has* to be an intersex condition in biological/medical terms (XY, with testes, but female phenotype: how much more of a divergence in these sex attributes can you get?). Ambiguous genitalia per se have never been a *requirement* for intersex, surely. But being intersexed doesn’t mean that CAIS patients aren’t women, in most functional... and all social terms... and most can, with appropriate support, acknowledge the biological intersex concept, come to accept it, and move on to focus on their lives as women.

All this illustrates the difficulty that some clinicians, especially those in paediatric disciplines, have in getting to grips with the psychosocial aspects of these conditions; in this case veering from suggesting ‘undermasculinised male’ as an umbrella term for conditions that include women with CAIS to stating that CAIS is not even an intersex condition (seeming to regard ‘intersex’ and ‘woman’ as incompatible).

AISSG saw some benefits in the new terminology, but not because of any particular desire to get rid of the term ‘intersex’ (which some people had come to accept and assign value to). Its main benefit seemed that it gets rid of the male-focused hermaphrodite-based terms. It does also, however, dispel an unhelpful *use* of the term ‘intersex’; that is, the frequent equating of ‘intersex’ with ambiguous genitalia (and with possible gender dysphoria) which has caused problems for the group in relation to the press/media. Some clinicians, particularly in the paediatric field, might state, for example, that “genital surgery is a consideration in intersexed babies”, when this is not the case in CAIS and Swyer; and causing journalists to assume that all AIS/Swyer patients have ambiguous genitalia (by virtue of being intersexed) and extending this to imply gender identity issues in all cases. Conversely, in discussions about *non-genital* issues such as

6. Here he is using ‘masculinisation’, which usually describes foetal development. His earlier (1996) suggested terms used the word ‘virilisation’, which is usually applied to pubertal changes.

psychological support/therapy, this automatic associating of the two things can exclude, in the mind of the ambiguity-focused reader, some conditions that actually belong in this category (and with some doctors saying, as exemplified here, “CAIS, oh that’s not really an intersex condition is it”).

So is a privileging of male anatomy now disappearing from intersex medicine? AISSG was asked in July 2009 by the lead clinician (a paediatric endocrinologist) in the Scottish DSD Network (SDSD⁷), to comment on a proposal for the development of a UK-located EuroDSD Registry⁸ based on a database of (mostly paediatric) intersex patient data. A basic patient dataset (anonymised) was to be presented as an online ‘shop window’ to Europe-wide research clinicians, to enable them to select cases whose detailed clinical data they could then request for study purposes. AISSG critiqued aspects of the proposal to do with the content of the dataset and the ethics of the scheme. The lead clinician concerned is a one-time protégé of the above mentioned AIS specialist who had clung to the ‘failed male’ model of AIS, and seemed to have inherited some of this way of thinking. The basic patient dataset⁹ seemed heavily angled towards phallus size and an associated measure termed the ‘external masculinisation score’ (EMS), with no data items such as an estimate of vaginal development that might encourage prospective researchers to research, and develop improved treatments for ‘under-feminisation’ rather than ‘under-masculinisation’.

A recently published DSD clinical guidelines document edited by the SDSD lead clinician gives the following explanation (Ahmed et al 2011):

Besides those whose genitalia are truly ambiguous, in the clinical situation, infants can often be divided into those who are apparently a boy with atypical genitalia and those who are apparently a girl with atypical genitalia. However, it is very important to bear in mind that the same girl with congenital adrenal hyperplasia (CAH) may present as an apparent girl with clitoromegaly or an apparent boy with bilateral undescended testes. When evaluating these infants, the clinical features of the external genitalia that require examination include the presence of gonads in the labioscrotal folds, the fusion of the labioscrotal folds, the size of the phallus and the site of the urinary meatus on the phallus, although the real site of the urinary meatus may, sometimes, only become clear on surgical exploration. These external features can be individually scored to provide an aggregate score, the external masculinization score (EMS).

So still an emphasis on male external genital appearance.

Although the hermaphrodite terms (and to some extent the term ‘intersex’) are, since 2006, disappearing from the medical literature, the notion of ‘failed masculinisation’ will probably

7. See ‘SDSD’ in Bibliography.

8. See <http://www.eurodsd.eu/en/registry.php>. It has now been developed further into the *International DSD (I-DSD)* database open to access by all clinicians and researchers involved in DSD research.

9. See <https://tethys.nesc.gla.ac.uk/EuroDSD/docs/eurodsdregisterdataset.pdf>. Copy also on page 240 of thesis.

persist in medical discourse and need to be dealt with on a personal level by XY-women in coming to terms with their situation. Any XY-woman who conducts some basic research in the medical literature will realise that this ‘problem’, and what to do about it, is alive and well in paediatric medical circles, and she can uncover the use of the external masculinisation score (EMS) in the clinical assessment of intersex in infants/children (Ahmed et al 2000). In 2010, for example, a journal special issue on DSD (which included papers on psychosocial aspects and on the holistic management of the conditions) carried an article covering AIS, *including girls/women with CAIS*, under the title ‘46,XY disorders of sex development – the undermasculinised male with disorders of androgen action’ (Werner et al 2010). Clinicians insist on having umbrella terms to circumscribe conditions that manifest in a wide spectrum of phenotypes but then seem to forget about those at one end of the spectrum, and slip back into privileging or emphasising concerns about those at the other. In a recent BBC TV documentary (BBC 2011) Dr. Tom Kolon (urologist, Philadelphia) explained (my italics, to reflect his emphasis):

DSD is a broad range. We’re looking at a spectrum ranging from girls who may appear much *more* masculine initially, to boys who are *under*-masculinised, so it’s really anywhere along that spectrum.

Just interesting, the way that it’s still, in 2011, all framed in terms of masculinisation. He doesn’t, for example, say “....girls who are under-*feminised*....”. But there again, he is a urologist!

And in spite of the advent of the newer DSD-based nomenclature, the current (Version 2010) online World Health Organization ICD-10 (International Classification of Diseases) still shows liberal use of the terms ‘male-pseudohermaphroditism’ and ‘female-pseudohermaphroditism’ (in section Q56 - Indeterminate sex and pseudohermaphroditism¹⁰), and ‘male-pseudohermaphroditism’ and ‘testicular feminization syndrome’ (in section E34.5 - Androgen resistance syndrome¹¹).

Patients with say, CAIS, are currently conceptualised in medical terms as the most under-masculinised, rather than the ‘most-feminised-but-not-quite-feminised-enough’ of this group of patients; and the medical terminology that has been used to classify and describe them reinforces this paradigm.

Alternative outcome?

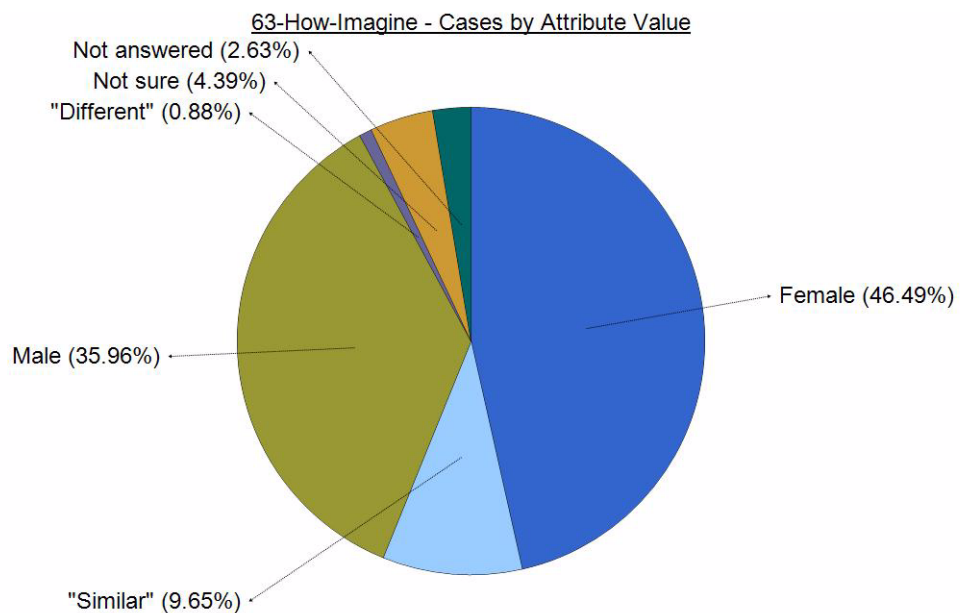
Having discussed the way in which some influential specialist clinicians frame the aetiology and presentation of these conditions, I now evaluate the extent to which my study participants are

10. See <http://apps.who.int/classifications/icd10/browse/2010/en#/Q50-Q56>.

11. See <http://apps.who.int/classifications/icd10/browse/2010/en#/E20-E35>.

conscious of this way of thinking in talking of their own bodily manifestation, and in imagining how it might have been different. One's gender may go a long way towards affirming, or even constructing one's sex in these conditions but in a momentary crisis of subjectivity, biology (or the cultural meaning assigned to it) can bite back to destabilise one's identity. A woman with CAIS, for example, must ponder from time to time "what would I have been like if things had not 'gone wrong' with my development and I'd had ovaries, uterus and so on", but might then experience a sudden moment of collapse when recalling that if things had 'gone right' her Y chromosome would have dictated a *male* reproductive system and bodily appearance.

How do XY-women accommodate... or do they even consciously recognise... the notion that "if things had developed normally" when they were in the womb they would have emerged as a member of the "opposite" sex? At Q23 participants were asked about this. In some respects this is a trick question because it is the development after conception (the point at which the sex chromosomes are fixed) that is being asked about, so the theoretically correct answer is that they would have had a male phenotype. However, one might expect many XY-females to imagine their 'normal' alternative development to have been that of a regular (XX) female. So this question evaluates a) the degree to which subjects mis/understand or de-emphasise the embryology of their condition and/or b) the strength of their self-identification as female.



Q23 - Imagined alternative outcome

There was a trend between the three main diagnostic groups but it was not statistically significant. Participants with Swyer Syndrome seemed the most likely (73%) to say they would have had a *female* outcome or "a similar outcome" to their current phenotype (meaning female appearance), with the percentages for CAIS and PAIS being 63% and 44% respectively. There

was also a trend between the two main sexual orientation groups but it was not statistically significant. More of those in the heterosexual group (65%) imagined a *female* outcome, or “a similar outcome”, compared to the lesbian and bisexual group (44%).

Responses were coded to five NVivo qualitative nodes: *Assumed female* (64), *Assumed male* (40), *Unclear answer* (5), *Didn't know* (4), *Humour* (6).

Those stating an assumed female alternative outcome gave descriptions such as “shorter, with pubic hair and female internal organs”, or phrases using the word “similar”, e.g. “similar but with smaller hands and feet”. This was the second most heavily populated node in my entire NVivo coding exercise (see page 245). However 36% of participants understood the catch and indicated that they would have had a male body form, with some participants outlining both scenarios (and in a few cases appearing to realise the trick in the course of considering and answering the question). Some gave what has been coded as an unclear (‘Not sure’) response such as “Different” or “Normal” (not necessarily unclear perhaps, but unexpansive) or didn’t know. Others used some degree of humour with responses such as “Oh. Good one. I look at my male cousins (and study photos of my father as a young man) and try to imagine how I might have turned out. It’s a real brain teaser because I cannot really imagine being a man. Poor things.“, or “It doesn’t bear thinking about, not with XY chromosomes!“, or “The same. With stretch marks from my multiple pregnancies.“, or “Oh my god I would have been male!“ or “Sensitive man with big penis“. ¹²

Summing up - Alternative outcome?

It is clear that the majority of my study participants think of themselves as women, with many having no reason to imagine otherwise until they failed to menstruate at puberty, and most of them having stated up-front in the survey that not only their gender but also their sex was female (see page 85). This is problematised to some extent at a later question (Q48) which asks directly whether they view themselves as being intersexed (see page 198) but in the current survey question 56% of the study sample imagined that they would have been born as a regular female (46% female, plus 10% “similar”) had they not, as an embryo, been affected by the mutation or other bio-molecular event that caused their condition, whereas in fact they would have been born as a regular baby boy. Those with PAIS (who perhaps have more reminders of some degree of masculinisation than those with CAIS or Swyer Syndrome) and those with lesbian/bisexual sexual orientation appeared to be more aware of the underlying embryological principles

12. It’s not clear whether this last comment is a reference to being sensitive to androgens or to the man retaining some traditional or archetypal female *psychological* qualities, maybe both?

involved in medicine's explanation of their condition (or more willing to entertain the implications?) but this was not statistically significant.

Overall, over half of my participants felt their destiny to be female at a fundamental level, whether that be through a misunderstanding the embryological principles involved in intersex or having forgotten or simply backgrounded "how it's all supposed to work". And this is not because they are *unaware* of the intersex nature of their condition, since all have given details in this survey of learning about XY sex chromosomes, testes etc. and all were members of a support group that provided un-censored information about these things. And even the 36% who showed awareness that a male alternative path would have applied are no doubt settled in their female identity. So the conventional medical terminology that focuses on failed masculinity seems rather unhelpful for these individuals.

The super female

What I meant when talking about 'mythologizing' etc. was just that there does seem to be this idea going around that AIS women are more attractive, and behave in a more feminine way than other women. Whether true or not, I think that these ideas are popular because a) they make the syndrome seem more remarkable and b) they reassure those people who are uncomfortable with the idea of an XY woman.

PAIS woman (AISSG Web 1997b)¹³

I was initially planning to use the term "Superwoman" in the title of this chapter/section, but then decided that this comic/cinematographic reference conveyed too much of an idea of power and strength, which is almost certainly not what doctors have in mind in this particular discourse (more Barbie than Barbarella?). As is seen from the Caster Semenya case, there are problems when women appear to show too much prowess at physical activities; and what is more often being promoted by the way in which CAIS women are sometimes portrayed in medicine and in the media (when they are not being framed as hermaphrodites and freaks) is the idea of women with exaggerated stereotypical feminine features.

CAIS more female?

At Q49 participants stated what they thought of the "CAIS women are *more* female than XX-women" clinical pronouncement employed by some doctors. The six most heavily populated NVivo qualitative nodes¹⁴ were: *Doctors misguided* (37), *No, disagree (or minimal negative response)* (27), *Sugar solution* (21), *Yes, agree* (19), *Yes and no* (17), *No, due infertility* (16).

13. Part of an exchange discussed on page 30.

14. See page 267 for the complete coding for this question.

Many participants expressed the view that such clinicians were misguided, some just giving short responses like “Rubbish“, or “Crap“, or “Sounds like spin to me“, or “Ridiculous“, or “Bizarre“, or “It’s just an excuse“, with some making a connection to ideals of femaleness based on external appearance (“I can only think that male doctors only consider appearance of the female body, ignoring other characteristics. The concept of “more female” is more or less ridiculous anyway.“) or to the urban myths about XY-women:

It’s on par with telling CAIS women things such as: Many Super Models have AIS. There are many beauty queens that have had AIS. There is a certain Hollywood movie star with AIS. If a man just had a double mastectomy due to breast cancer, would his doctor feel it appropriate to say, “Mr. Jones, we got all the lesions. Good news, too. Now you’re more male now! You don’t have any breast tissue left! Aren’t you happy to know that you are more of a man?” We don’t need these platitudes. We need to be treated with dignity and respect. Given factual information. Provide opportunities for mental support in coming to terms with this news. **(P028 USA, CAIS 48)**

As we say in Canada, horse hockey. That statement is terribly offensive to women with PAIS, 5-ARDS, 17-Beta, etc.¹⁵ Women with CAIS sometimes seek comfort in that statement but it betrays a profound lack of awareness. Everything in nature is on a continuum. Who is more female than who. Was Sophia Loren more female than Jayne Mansfield or vice versa? Doctors repeat that to patients in hope that it will offer some comfort. These are the same doctors that repeat the Jamie Lee Curtis drivell and the super model drivell. **(P053 Canada, CAIS 54)**

Some at this node thought that it was more important, in fostering a sense of femaleness, to have the appropriate female *internal* organs and functionality (“The less there is the *less* woman you are, so in that way of thinking CAIS women are *less* female since they are missing things.“) and to have the wherewithal to bond/connect with XX-women:

I disagree with this statement. An XY woman doesn’t experience any of the “normal” physiological aspects of being a woman (menstruation, pregnancy, childbirth, menopause). In my opinion, this takes away from the experience of being a woman. I feel like I have less in common with my female friends/co-workers because I can’t sympathise/empathise with them on such matters. I feel like an outsider. **(P090 Canada, CAIS 28)**

And some suggested that doctors should focus more on improving *functional* opportunities for XY-women:

Nice try... Doctors can do much better than that :-). For example, they can help you have a normal size vagina so that you feel more female when having sex with a male partner, or they can help you induce lactation and feel more female when you adopt and nurse a newborn baby. [Platitudes about] Hormone-responding tissues are too thin of consolation when you are depressed with your sex life or when you are down for infertility... **(P041 Hungary, CAIS/PAIS? 40)**

or on explaining how the signs and symptoms of their androgen insensitivity form a standard, well-documented pattern, rather than trying to deflect attention from this:

15. That is, to those who *are* sensitive to androgens to varying degrees.

[The proposition is] A bit silly really. [What] I wish [I'd been told], as one doctor female friend explained to me when I was 24, was about the outside physical differences between us and normal women in terms of how a normal woman responds to her own testosterone eg: [in CAIS] lack of facial acne, lack of pubic hair, lack of underarm hair. Understanding that the lack of these was normal for AIS women made me feel alot better – I thought I was just peculiar, but then knew I was just normal - for AIS! I felt limited benefit from being told I was more female than XX women because of total immunity to testosterone. I benefitted far more from being told that I had the usual symptoms shown by most AIS women. **(P093, CAIS 48)**

Some thought such 'reassurances' were more about helping the *doctor* to feel better ("Do I really need to be assured that I [am] "more female", or does the doctor himself need that reassurance? I wonder", and "Well, it was said to me as a way to comfort me and spare *his* stress at telling me such potentially devastating news, so I don't lay much credence on it."), or that it even exacerbated a sense of being different ("Do CAIS women want to be more female? Don't we just want 'to be'? No more no less. By doctors saying this it is again stigmatising differences."). Another echoed the benefits of facing, and acknowledging one's differences:

It sounds as daft and patronising as saying a diabetic has a sweeter nature than a non-diabetic because they can't get rid of sugars from their blood. It sounds ill conceived and completely contradictory... "you're more like something because you're nothing like it"??? plus it seems to encourage a denial type attitude of both the intersexed individual and those around them. Personally, both before and after I knew the cAIS part, I felt people who made comments like that really didn't understand how I felt and were merely trying to dismiss my perfectly valid confusion about how I fit in with others around me. That sort of comment only left me feeling I couldn't "get what I needed" from that person which I guess was acceptance that YES I'm different but that's OK, so is everyone else!! Actually, the more I think about that statement the more I see that it is again more about the "explainer/doctor" coping than a genuine wish to help the intersexed person. It's not a competition to be more female, it's about the fact that life is still worth living even though you aren't able to follow the same path as most other people. "More female" still leaves you as not like other women!!! **(P058, CAIS 33)**

Others used a knowledge of endocrinology, and an understanding of sociological concepts, to argue against the validity of the statement:

Well the doctors are wrong - sure I can't respond to male hormones - but equally [having had gonadectomy aged 3] I have no female hormones to which I can respond (until I began taking Premarin [HRT] at 35). **(P032 Canada, Lesbian, CAIS 76)**

In my opinion, the statement is insensitive and condescending, because they are not thinking about the bigger picture and who this statement may offend, degrade or socially exclude¹⁶ – I know fundamentally, male and female are very much the same 'entity' bar the influence of androgens and how they develop a foetus. But the cultural differences of being a woman is more than just having xx karyotype and being at the mercy of or indicative to oestrogen, it's a culture, a perception of one's self, both of which are intrinsically linked to a physical appearance, social conditioning and being a member of a wider organised social group experience 'womanhood'. **(P044, Swyer 39)**

16. Thinking possibly of women with the Partial form of AIS who may exhibit some 'male' features.

It's true, but only at the hormonal and cellular levels, and only insofar as we know hormones today. Therefore, it's misleading. For me, it depends on their MOTIVE for saying that. If a doctor is trying to describe the action of hormones, and that's all, then I'm ok with it. I think it's factually correct, based on my understanding of the medical facts, as they are known today. If a doctor is using sex and gender interchangeably, and/or is trying to reassure his patient, then I object to the statement. "More female than XX women" is actually demeaning and misogynistic. It's like saying a Barbie doll is more female than a less buxom representation of a woman. Likewise, it's pejorative to try to soothe, or smooth over, a CAIS woman's emotions about her medical status. **(P062 USA, CAIS 52)**

Some participants gave a short response disagreeing with the notion, but without necessarily criticising doctors in particular:

I pay no heed to this. I am what I am and I don't need people (doctors or not) to tell me that I'm more or less of a woman than the next woman. **(P045, CAIS/Swyer? 23)**

I'm sure this makes sense in a bloody laboratory but it makes no sense in the world today. **(P073, CAIS 42)**

As a lawyer, I think this is nice rhetoric but it doesn't matter. They are all females. It's like you can't be sort of pregnant. You are or you aren't. **(P111 USA, Lesbian, PAIS 42)**

and sometimes deferring to biology in order to suggest that a narrative or discursive construction of identity on the part of XY-women has been taken too far:

I've never heard this from doctors, but I have heard it from a number of CAIS women. I think they are trying to fool themselves. They are denying their intersexuality and trying to convince themselves of their normality based on greater societal terms. **(P097 USA, Bisexual, 17-b-HSDD 49)**

This is a comforting, if weak theory. Although hormones play a part, if your chromosomes are mixed up, it's still ambiguous; you can't ignore a number of aspects of the condition to legitimate your own existence. **(P098, CAIS 24)**

The statement was likened to sugaring the pill by some participants, with talk of doctors being "patriarchal to women", or "patronizing", or "giving out consolation prizes", or of it being a "romanticised" view of the condition. One response in this vein was particularly interesting in deploying the classical medical paradigm in order to cast doubt on the validity of the statement:

I think it is a cute notion to try and make CAIS people feel better about themselves. However, CAIS in reality is the most severe case of AIS. **(P005 USA, Lesbian, PAIS 27)**

This participant is pointing out that the Complete form of AIS is seen by medical science as the most severe form of tissue insensitivity to androgens, and hence manifesting the greatest degree of under-masculinisation of an XY foetus. So she is privileging male genetic and embryological imperatives, but possibly her aim here is to play clinicians at their own game (as in... you can't have it both ways).

Some participants agreed with the proposition, giving a short response such as "I LOVE putting it that way!", or "I like that analogy", or "Fine", or "I think in some respects that is true", or

“This is good”, or “Yippee finally a doctor on our side”, or “I think it’s okay. It’s another way of taking the sting out, I guess”, or “I love that idea! Because in my mind I *naturally* feel very feminine”. Others at this node amplified their views, sometimes airing their knowledge of hormonal physiology:

Well, all XX women use some small amount of male hormones (androgens) and they [their effects] become more visible post-menopause as estrogens levels drop. We CAIS’ers can’t use ANY androgens, so in some ways I’m the most perfect form of female as I am wholly insensitive to any and all androgens despite my body being filled with them [before gonadectomy]. **(P027 USA, Lesbian, CAIS 53)**

and sometimes pointing out tangible physiological and psychological benefits of being androgen-insensitive:

I think I would agree. Even if you pumped me full of the same amount of testosterone as a body builder I would still have no reaction. I am more feminine looking and probably closer to the feminine ideal, hairless, soft skin, no spots, thick shiny hair etc. than most women. I always think that I am quite docile and not aggressive, I guess this could be down to lack of testosterone [action] though I’ve never asked a consultant about this. **(P050, CAIS 29)**

I find it quit[e] true for some reason, because looking at myself I am much more feminine looking than other girls, because I don’t respond to testosterone, I am very tall, slim, have a smooth skin and I am a typical “pink girly girl”. **(P085 S. Africa, CAIS 22)**

One participant felt the statement was a valid attempt to help the patient feel less stigmatised or confused:

I think it is a clever medical insight that has developed in order to try and counteract some of the incredibly insensitive ways in which CAIS has sometimes been described. I think it is recognised that it is quite easy to feel confused about yourself and your identity with a condition such as this, and this type of description is clearly aware of this fact. **(P086, CAIS 27)**

A few participants talked about irony; and the notion of ‘fooling people’:

I think there is a certain truth and also an irony to that statement which I can definitely appreciate. I also don’t mind them saying that because it points out to the uneducated that gender is not a binary and is actually a complex combination of items. **(P091 USA, CAIS 32)**

I agree! I consider myself an Uber-Female! And that’s what I tell people when I disclose. It really disconcerts them; they start looking at their arm hair, for example! **(P076 USA, CAIS 57)**

I have never heard this, but can understand it and in terms of image I believe this could be the case. Reminds me of the episode of House where a patient has CAIS and House describes her as the perfect woman (breasts, skin and height being the attributes he describes). The joke of this was that he followed [with] the sentence that she is a man. **(P030, CAIS 29)**¹⁷

Some hedged their bets and didn’t come down either in favour or against the proposition:

An interesting point to be pondered - makes a thought provoking statement about rigid definitions of male and female. **(P010 USA, Swyer/CAIS? 32)**

17. US hospital drama series, screened in UK on 13 April 2006 on Channel 5 (‘House’ Series 2, Episode 13, titled *Skin Deep*). For a short transcript of the relevant part of the script see www.aissg.org/articles/house.htm.

It is a rather quaint view. More than a grain of truth. I have seen ‘real women’ with moustaches, which AIS individuals don’t get. **(P060, PAIS 24)**

Some at this node could see a degree of truth in the statement, pointing out, for example, that “Any normal woman can be masculinised [by hormones], but CAIS women, never”, but thought that other aspects of XY-female conditions (e.g. lack of monthly cycles, hormonal swings, periods and pregnancy, and having a Y chromosome and needing to take female hormones) detracted from the notion:

I like it. I’ve heard it called being a super-woman which makes me smile. It’s easy to be XX and be a woman, but we’re women in spite of our chromosomes. Maybe that’s why I’m so attracted to doing things that are difficult! Although it is still somewhat hollow. What is more female than being pregnant? I’ll never get to do that – unless they perfect the womb transplant! **(P049, CAIS 29)**

I didn’t get it at first. In fact I balked at it and said how can that be, I am XY?! I just thought the doctor was trying to make me feel better. But I am starting to get it a little bit. Since normal XX women have some testosterone and CAIS women like me don’t have any reaction to it, in that one way yes it makes more sense but I think it begs the question, what is being “female”...and to me that means more than estrogen but also having a period, being fertile, etc. and those things just aren’t possible for XY CAIS women. **(P069 USA, CAIS 43)**

Infertility was singled out by some participants as a potent reason for not accepting the statement:

Garbage. Well-meaning maybe, but possibly says more about their own difficulties in being honest and in communicating diagnostic information to patients. Is rather insulting and condescending actually, if one has also just been told that one has no uterus and is infertile. **(P099, CAIS 61)**

Their habitus really is more female, but I would not say them more female, as in biology the mammalian female is the one who produces the egg cells and carries the foetus. **(P105 Finland, 5-a-RD? 32)**

I’ve never heard this statement! I don’t think that a CAIS woman is more female than an XX woman as CAIS women cannot procreate, and that’s a women’s role in life. **(P106, CAIS 34)**

Summing up - CAIS more female?

The “more female than XX-women” discourse seems to be assigned more or less validity or salience by XY-women depending on what stage they are at in relation to their diagnosis. On the whole my participants appeared to disagree with the proposition, possibly seeing this as yet another way in which medicine/society endeavours to manipulate their self-perception and negate their existence as intersexed women. First there are the lies and half-truths about the diagnosis, then there’s the behind-the-scenes use of stigmatizing terminology and concepts of ‘failed masculinsation’, and now it’s a somewhat tortuous compensatory notion of ‘super femaleness’.

Chapter conclusions

Participants revealed a general dislike of the older medical terminology that reflected a paradigm of failed masculinisation and it seems that even though this nomenclature is now fading out, paediatric clinicians still make this concept the basis of their research interests, which in turn inform diagnostic procedures. Of course there are many clinicians in disciplines that diagnose and treat people with such conditions who do not have a special clinical or research interest in intersex (e.g. endocrinologists and gynaecologists who deal with a broad range of medical issues); but all will have been trained in the ‘failure of masculinisation’ paradigm, and will look to the (usually paediatric) specialists currently engaged in research and the setting of clinical protocols for guidance in diagnosing/treating these rare conditions.

Although participants’ responses to a question about a hypothetical alternative developmental outcome indicated strong identifications with being female, most participants did not have any sympathy for the discourse that says CAIS women are *more* female than XX-women. Of course, accusations of wanting it both ways can be levelled. Some might say that advocacy groups complain when male diagnostic labels are hidden from patients and their femaleness is overstressed, but then object to the male nature of such terms once they are out in the open. But perhaps it’s the polarised nature of these stances that’s at issue, and the motivation of those involved in hiding or promoting these alternative world views? To initiate a change in such medical discourse is likely to be a Herculean, if not impossible task, although patient advocacy groups are doing what they can to feed micro-resistance into the system in a Foucauldian sense, on behalf of those at the female end of the spectrum who are unwillingly included in a patriarchal medical paradigm designed primarily to eradicate defective masculinity.

Having considered several medically-influenced phases or identities in these two chapters, the next chapter looks at two early phases or identities that my participants might go through or adopt in the wider social sphere. It focuses mainly on participants’ self-view as women, but women with a ‘disorder’, and discusses how this, together with knowledge of the intersex nature of their condition, affects their sense of inclusion in, or abjection from society.

6 The disordered woman and the outsider

In contrast to the previous chapter, which focused mainly on medical discourses that construct these bodily manifestations as failures of androgenisation, this chapter focuses mainly on my participants' view of themselves as women who are deficient in characteristics traditionally thought of as female. This, and the chapter that follows, move my participants into their post diagnosis/discovery/treatment phases, to consider identities they might pass through or adopt... or identifications they might make... outside the clinical sphere.

I am not interested here in gender identity conflicts (gender dysphoria) – which will possibly not have affected any of my participants – but rather in how diagnostic knowledge upsets the psychosocial status quo in individuals with an established female identity, and in how these individuals incorporate diagnostic information into their subjectivity. There is very virtually nothing in the literature about how such individuals negotiate the unusual aspects of their bodily parts and function.

We might usefully divide the bodily aspects of one's gendered self-view into significances attached to a) genetics and embryology, b) anatomy, organs and physiology, c) capacities for doing things (e.g. sex and relationships, fertility), and c) embodied experience. There is significant overlap between these, and they are likely to assume greater or lesser significance at different life stages, but may serve as a loose framework for discussion. Other parts of this thesis focus more on genetics and embryology, and on embodied experience; and take into account the male elements of these diagnoses. Here I am concerned more with female anatomy, organs, physiology and functionality and the ways in which these are considered as disordered by XY-women.

This chapter is informed by the concept of sexual dimorphism, the separation of bodies into male and female, based on biology. It asks which physical aspects of their condition have had the most impact on their self-view as women and returns briefly to the medical sphere to examine views on the recently introduced 'DSD' terminology, with its focus on "disorder". XY-female conditions highlight the question of what it means to say one is female, or a woman; so I ask my participants what they believe 'makes a woman' in society, I explore whether they feel authentic in their (female) sex/gender, and discuss abjection and an outsider status as possible issues for some.

The disordered woman

What constitutes femaleness? It is my considered position that femaleness is conferred by the final pair of XX chromosomes. Otherwise I don't know what is... I would not agree with you therefore that CAIS individuals are women, i.e. female.

Germaine Greer – Letter to father of CAIS daughter (1999)¹

If it looks like a duck, and quacks like a duck, we have at least to consider the possibility that we have a small aquatic bird of the family anatidae on our hands.

Douglas Adams – Dirk Gently's Holistic Detective Agency (1987)

Julie Alderson's concept of "compromised womanhood" in AIS (Alderson 2000, 2004) was introduced in "Psychosocial issues" on page 32. This appears to be a similar concept to that of "gender role insecurity" put forward by Bean et al (2009) to describe the concerns of XX-women with MRKH (defined in footnote on page 22) about their (in)ability to perform adequately the roles that biology typically equips them to fulfil and that society historically has expected them to perform.

Biological influences

The presence or absence of certain biological features and functions (organs and physiology) seems likely to influence XY-women's *self*-view in several ways. Issues such as primary infertility, often discovered at an early age, can have a major impact on one's prospects for a normal life trajectory as well as affecting one's identity as a woman, as can the underdevelopment of anatomical features such as the vagina. The absence of certain organs (ovaries, uterus) or signs (menstruation) can represent a lack of functional opportunities (fertility, normal hormonal function) but can also compromise the individual's sense of womanhood. But these effects can be hugely compounded by discovering that one also possesses certain biological characteristics usually associated with male bodies (XY sex chromosomes, testes, and possibly some degree of genital masculinisation).

At Q18 participants assigned numeric choices to any of 11 biological features (or lack of) that had exerted a strong impact on their sense of self, with 1 being the most influential and 11 the least. The results for the 114 participants in the study are shown in the table on page 148. The table divides the features into a) those that are relevant to the vast majority of the diagnoses under study, and b) those that are relevant to some but not all the diagnoses. The three selections most frequently assigned to each feature are highlighted in bold and shaded.

1. See www.aissg.org/43_debates.htm#prejudices.

Q18 - Impact of biological features

	High impact<----->Low impact															
Rankings: 1(st), 2(nd), 3(rd) etc.	1	2	3	4	5	6	7	8	9	10	11	Not chosen	“Doesn't apply” ^a	Composite score	Overall ranking	
	Below = number of participants who assigned rankings to each biological feature. Bold/shaded = the three most popular rankings for each feature.															
<i>Features relevant to most diagnoses:</i>																
Infertility	36	23	20	11	10	3	4	3	0	0	0	4	0	1010	1st	
Lack of menstruation	23	17	19	11	10	7	2	3	3	3	1	14	1	817	2nd	
Lack of ovaries	13	15	10	9	16	19	5	1	2	0	0	24	0	692	3rd	
Presence of Y chromosome	22	13	12	4	5	8	13	5	5	2	0	25	0	674	4th	
Presence of testicular tissue	15	17	11	13	5	7	10	3	1	2	0	28 ^b	2 ^c	654	5th	
<i>Features relevant only to certain diagnoses:</i>																
Lack of uterus (womb) ^d	13	14	9	12	20	4	1	6	0	1	0	25	9	621	6th	
Short vagina ^e	19	20	7	8	8	1	8	2	2	0	0	25	14	613	7th	
Absent/sparse body hair ^f	14	11	16	8	5	8	6	7	6	3	2	23	5	611	8th	
Tall height ^g	8	5	7	7	4	3	1	5	6	8	4	48	8	310	9th	
Flat chestedness ^h	12	8	7	1	4	2	1	2	3	3	2	50	19	284	10th	
Larger than average clitoris ⁱ	8	5	5	4	3	1	1	3	4	1	1	50	28	196	11th	
Other features:	23 participants suggested additional features											91				

a. Where participants actually entered "n/a" or "doesn't apply" or equivalent.

b. Including one participant with 5-a-RD who said she never had testicular tissue.

c. Two participants with Swyer Syndrome who said "n/a".

d. Uterus (often under-developed) usually present in Swyer Syndrome.

e. Vaginal length usually normal in Swyer Syndrome.

f. Generally only applies to CAIS.

g. More likely to apply to AIS than Swyer Syndrome.

h. More likely to apply to Swyer Syndrome than AIS.

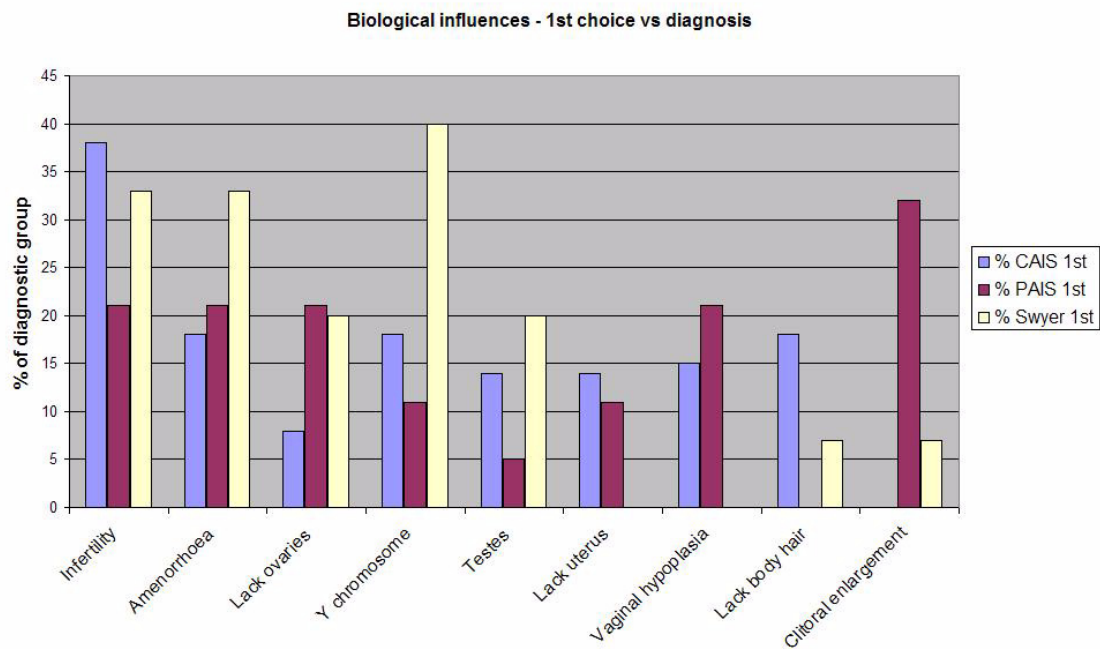
i. Not applicable to CAIS or (usually) to Swyer Syndrome. Can occur in PAIS.

Some participants gave each of the 11 items a unique score (1-11) whereas others stopped at, say, their 4th or 6th choice. Others chose, say, 3 items and assigned them all a score of 1. If they didn't consider a feature as having an impact, or if it didn't apply, most left that feature blank ('Not chosen' column). Others made a comment such as 'n/a' under these circumstances, i.e. impact not applicable or feature not applicable ("Doesn't apply" column). With hindsight the survey question could probably have been better expressed, e.g. by asking participants to rank, say, the *six* most influential features, and by having a specific option labelled 'Doesn't apply', but the results still provide useful information, with a further level of processing having been carried out, to develop a more accurate interpretation of the data. This resulted in the figures in the last two columns.²

Infertility seemed to have had the greatest impact on participants, with only four leaving it blank ('Not chosen'). Lack of menstruation (amenorrhoea) also attracted a high number of hits with only 15 participants not giving this item any ranking. These two features did not attract any 4th - 11th rankings. In spite of the fact that the lack of ovaries, and the presence of a Y chromosome and testicular tissue were significant influences for a number of participants, 24-28 people left these items blank. Vaginal hypoplasia was highly significant for a considerable proportion of participants although, again, 25 passed over this feature, with 14 stating explicitly that it didn't apply to them. A similar pattern is observed for absent/sparse body hair, lack of a uterus, and an enlarged clitoris, but with the latter showing much higher 'Not chosen' and "Doesn't apply" scores. This trend continues for flat chestedness and tall stature, however these two attributes are not necessarily diagnosis-related and can be greatly influenced by other factors. Women with CAIS are often tall with well-developed breasts for chromosomal and hormonal reasons (the Y chromosome may influence height, and a puberty more aligned with the male chronology means a later closing of the epiphyses of the long bones than in XX-females) but people can exhibit these bodily features because of familial trends. Women with Swyer Syndrome may have under-developed breasts due to a lack of hormone production by their 'streak' gonads, but again this can also be seen in XX-women for hereditary reasons.

The choices made by participants with different diagnoses were evaluated. The chart below shows participants' *first choices* for all nine biological influences examined, broken down into the three commonest diagnoses:

2. Each first choice was assigned a score of 11 points, each second choice 10 points etc., down to 11th choice, assigned one point. All the points were added up for each biological feature. A figure was subtracted from each sum, as a negative weighting, to represent the number of 'Not chosen's plus the number of "Doesn't apply"s. This gave an overall composite score for each feature (penultimate column) which was then ranked in the final column.



Q18 - Biological influences - 1st choices vs diagnosis

Evaluating the five biological issues that are common to all the diagnoses (i.e. infertility, amenorrhoea, lack of ovaries, presence of Y chromosome, and testicular tissue³), the differences in first choices appeared to be statistically significant ($p=0.036$). However, some of the Excel cell counts during Chi-Square testing were low, because the overall number of participants with Swyer Syndrome and PAIS was low ($n=15$ and $n=19$) and I was looking at a subset of these (only five of the biological issues and only first choices) thus casting some doubt on reliability.

With that proviso, infertility seems of greatest concern to those with CAIS, whilst those with Swyer seemed more affected by amenorrhoea than those with AIS. The PAIS and Swyer subgroups seemed the most troubled by the lack of ovaries. Those with Swyer seemed to assign considerably more significance to the possession of a Y chromosome than did those with CAIS or PAIS and a similar profile was apparent for the possession of testicular tissue. As might be expected, lack of a uterus seemed not to be a major concern for the Swyer participants (no first choices). PAIS attracted the greatest percentage of first choices for an absent/short vagina – expected since this is the group in which some may have a more masculinised genital anatomy – whilst none of the Swyer women did so (again expected). At Q29⁴ (about sex and relationships) only 41% of those with PAIS stated that they felt equipped for sex, compared to 63% of those with CAIS, and 85% of those with Swyer (statistically significant, $p=0.040$).

3. But accepting that amenorrhoea and presence of testes is not totally clear cut in the case of Swyer Syndrome.

4. Details of the responses to Q29 were set aside for future analysis, due to lack of space in this thesis, but it seemed useful to mention these percentages from that question here.

It is expected that a lack of body hair might be of concern in CAIS but would not usually be an issue in those with PAIS. A Swyer woman assigning this a first choice thought that a lack of natural hormones prevented hair growth. And as expected, an enlarged clitoris was seen not to affect those with CAIS. A first and a second ranking for Swyer represent two participants who said that gonadal tumours had been found and which probably caused raised testosterone levels.⁵

The first choices arranged by sexual orientation did not show any statistically significant pattern, although the heterosexual group seemed more troubled by infertility and the lesbian/bisexual group more troubled by most of the other features.

Summing up - Biological influences

My data suggest that of the various biological or bodily aspects of intersex, it is infertility, and the lack of menstruation and ovaries that are ahead of the field in terms of influence on XY-women's self-view. So certain missing female attributes top the list, with the presence of male features (XY sex chromosomes and testicular tissue) following on, albeit quite closely behind the lack of ovaries. It seems that this question mainly brought out participants' feelings about their lack of female functionality.

Whether the impact of a lack of menstruation is one of having missed out on a rite of passage or of it being a reminder of one's infertility is not clear but I suspect it is mainly the former, compounded by the social problem of explaining or covering up this deficiency in the course of interactions with female friends and with sexual partners of either sex. XY-women frequently talk of problems in conversing with women about periods and babies, and it's possible that such anxieties contributed to these three issues (infertility, amenorrhoea, lack of ovaries) being at the top of the list. The implication of having a Y chromosome and testes isn't likely to come up as a casual topic of conversation with other women, or with men!

Participants talk about the significance of their XY karyotype in other parts of the survey: in relation to medical terminology, in terms of what society expects of a women, as an item of diagnostic information, as contributing to a sense of being an outsider, as a defining component of sex in the sex/gender dichotomy, and in relation to their gendered identity. From a rational viewpoint one might ask whether a vestigial maleness in the form of XY sex chromosomes *needs* to be of much practical concern. And indeed, for some, these intangible genetic 'entities' may be

5. Dr. Gerard Conway, consultant endocrinologist at UCLH, confirmed (personal communication) that there is a group of patients who may not have a diagnosis of Pure Gonadal Dysgenesis (Swyer Syndrome) but appear to have a virilising form, either resulting from a gonadal tumour or because of some degree of Mixed Gonadal Dysgenesis.

just that – nebulous and unimportant, or even irrelevant – compared to absent functionality (such as menstruation) which may provide more concrete reminders of difference. Yet for others their genetics can be extremely disturbing and stigmatising. Similarly, intra-abdominal testes in CAIS do not have any adverse functional effects (apart from a small risk of cancerous changes in adulthood) and in fact do something useful. They produce androgens, which are converted in the body tissues to oestrogens via the process of aromatisation, thus enabling women with AIS for example to develop breasts spontaneously at puberty, and contributing to the maintenance of bone density. Yet their presence, or the knowledge of having possessed them prior to gonadectomy, can have a significant negative impact on self-view.

The lack of a uterus seems to have been assigned a lower priority than the attributes mentioned to-date, even though the majority of participants will have been born without one (or with only a primitive one in the case of those with Swyer Syndrome). At this question around 60% (nine participants) of those with Swyer marked a lack of a uterus (or impact of) as not applying to them and the remaining six either assigned it their lowest ranking or left the item blank. Perhaps the availability of surrogacy makes this seem not so essential in fertility terms to my participants in general, or maybe the knowledge that one doesn't have the wherewithal to produce eggs makes a uterus seem of secondary importance.

Many participants will be seen later in this chapter to regard the presence of a vagina as an important requirement of womanhood in the eyes of society, but not all participants will themselves have had problems with this, either because it was of normal length (in most cases of with Swyer Syndrome) or because it was long enough to be stretched by pressure dilation or penetrative sex (or because it was not important for some). At the current question 11 of the 15 with Swyer Syndrome either left the vaginal hypoplasia item blank or said that it (or its impact) didn't apply (and at Q29 this diagnostic group expressed the highest degree of preparedness for sexual relationships). Two with Swyer gave vaginal hypoplasia a very low ranking and two others ranked it second. One of the latter appeared to have undergone vaginoplasty surgery and used dilators, even though she had Swyer Syndrome. The other had entered "not applicable" for a short vagina at Q15 about finding out things but gave it a ranking at the current question. When questioned about this, she explained:

Good question. When I was younger (17/18) one of my doctors noted that I had hypoplastic uterus. While I was told my vagina was normal it was impossible for me to have intercourse at a young age. Later, about twenty years later, I am more comfortable with this kind of sex. So, do I have a short vagina? I don't know. I don't think so technically. But, I was nonetheless physically unable to experience intercourse. Things got better as I got older -- maybe twenty years of hormones changes that part of my body too. I don't know. **(P070 USA, Bisexual, 50)**

This illustrates the multi-faceted nature of what, for want of a better term, I'll call vaginal adequacy, and the possible role of factors other than a straightforward anatomical dimension, as discussed on page 27. Holt and Slade are probably the only authors to have looked at the feelings of women (with MRKH, defined in footnote on page 22) about having an incomplete vagina and womb as discussed on page 32 (Holt and Slade 2003). I asked my participants about sexual relationships (Q27, Q28 and Q29) but have set aside that material for future analysis.

Absence of pubic/axillary hair is generally a CAIS-specific phenomenon, and the low score for a larger than average sized clitoris reflects the fact that the study recruited participants who were well towards the female end of the spectrum. None of those with PAIS marked lack of body hair as their first choice and none with CAIS marked clitoral enlargement thus.

It is relevant to ask whether the Swyer sub-group of XY-women have fewer biology-related concerns and an easier path to womanhood than those with AIS, because of the presence of uterine tissue (even if hypoplastic, that is, underdeveloped, primitive or the like; but which, with HRT can allow menstruation and, with IVF, may be able to gestate a donor egg), together with the fact that their gonads are said to be 'streaks' of inactive cells rather than testes per se, and the fact that they usually have a normal length vagina and normal pubic/axillary hair? In spite of some doubt on the statistical reliability of my first-choice data, some of the observed findings confirm expected patterns, suggesting some validity in the data. The finding that infertility has somewhat more of an impact on CAIS women than on those with Swyer seems understandable in view of the latter's potential for child-bearing. And the apparent low impact of this deficiency on those with PAIS could be because some participants in that sub-group may be focusing more on their possession of a larger than average clitoris.

The Swyer group showed the highest proportion of first choices for amenorrhoea, and for the possession of a Y chromosome and testes. These findings are unexpected. But if valid, maybe it's worse to be told you have an underdeveloped uterus and may not menstruate than to be told outright (as in AIS) that there's no uterine tissue at all and therefore no chance of menstruation? Those with AIS perhaps have more certainty; they will never menstruate, so there's no point dwelling on it? And maybe eventual menstruation in Swyer women is a regular reminder of the fact that they are not able to menstruate *naturally*, without the assistance of exogenous hormones? And it's also possible that those with Swyer perceive a sharper discrepancy between their male sex chromosomes and their otherwise female biology than do women with AIS, who have additional anomalies to occupy their attention (no uterus, possibly some degree of vaginal hypoplasia and/or clitoral enlargement, and gonads that are truly testicular in nature)? I suggest that the apparent impact of 'testes' in the Swyer group could be a secondary association which

mirrors, in a less pronounced way, the significance they appear to assign to the Y chromosome (i.e. they come to associate their 'streak' gonads with testicular tissue when learning of their male karyotype)?

Much of this is speculation of course, and it would be interesting to evaluate a larger group of Swyer participants. However later, at Q46, the Swyer group did seem more aware of performative aspects of gender. And there was another oblique suggestion that a greater complement of female biological attributes may not necessarily correlate with a more secure path to womanhood. An XX-woman with MRKH (in which there are ovaries, and none of the intersex or male elements present in XY-women, but an absent/under-developed uterus and vagina) who was sent the survey in error seemed very disappointed to learn that the study could only include XY-women and said:

I understand... Sure, it must be different when your body tells you two things [female and male] as opposed to one thing, and that [it is] not 100% [one or the other]... ...still again, so many similarities [with MRKH], I think, discovering that you are not female in the way you and everyone else thought you were... it comes down to the similar question of 'if I am not really female then what am I?'.

Sexual orientation might also be expected to have some relevance. Infertility seemed of more significance to the heterosexual group (possibly because they were more likely to have envisaged a conventional male-female partnership with their own biological children) with many of the other features appearing more troublesome to the lesbian/bisexual group (but not at the level of statistical significance). One participant with PAIS who at age 17 had realised she was lesbian or bisexual, made the general comment that "[it] depends on age", and that the absence of body hair had been "horrific aged 13/14", and vaginal hypoplasia had been "v important as teen, when wanting to start sex with boys, [but] not now" and that for enlarged clitoris "[it] depends: quite positive with women (not men)". So the degree to which any of the factors have an influence must also, to some extent, relate to when the information was gained and/or at what stage of life individual features come to the fore. To learn at say, 35, that your 'ovaries' had really been testes might make you very angry that no one had told you this before, but it might not be as devastating in terms of self-image as if you were learning this at age 16. This is another survey question that probably could have been better expressed, to make it clear whether I was asking about a particular stage of life, or about the point of discovery (whenever that was).

In conclusion, in terms of personal experience it is infertility that is the disorder carrying the most weight although, as we will see later, in societal terms my participants view a disordered woman primarily as one who is not equipped to engage in penetrative sex (with fertility coming some way down the list of requirements).

The DSD terminology

Although participants talked in this part of the survey about bodily deficiencies that compromise their own and society's concept of womanhood, they do not generally frame these as disorders, a term more often used in medicine than in everyday speech. The identity of "disordered woman" is a notional one that I set up as counterpart to the identity of "failed male" in the preceding chapter and because it ties in with the recently introduced DSD (Disorders of Sex Development) terminology. The latter, whilst replacing generally despised umbrella terms like 'male pseudo-hermaphrodite', is seen by some as substituting another stigmatising medical concept, that of a disorder(ed person).

At Q37 participants gave their views on the DSD terminology. This is another question that, with hindsight, could have been better worded because it wasn't made clear that I was asking whether participants approved of DSD replacing *intersex*, as well as whether they preferred DSD to the older hermaphrodite-based terms. In fact, the former substitution is probably the more controversial. However, some participants picked up and commented on this issue anyway.

The six most heavily populated NVivo qualitative nodes⁶ were: *Dislike 'disorders' (20)*, *Just use diagnosis (17)*, *Just 'OK', or minimal answer (13)*, *[DSD] Less freakish/stigmatising (13)*, *[DSD] Better than 'herm' terms (12)*, *OK with 'intersex' (13)*, *M vs F and spectrum issues (12)*, *[DSD] More scientific, factual (11)*, *Why lump together (11)*, *Don't really care (11)*.

Some strong feelings were expressed against the word 'disorder' in the new terminology, with many associating it with pathology, medicalisation, birth defects, disability, disease, abnormality, an inability to function correctly, or something that needs to be cured or fixed etc:

What I do not like about this term is that it is not descriptive but it suggests a value judgement (order – disorder). I guess this opinion has been said several time before. A good terminology, in my view, would be purely descriptive and would refer to the technical feature that makes the condition different from others. **(P041 Hungary, PAIS 40)**

To me DSD suggests there is something wrong with me and from my point of view it was the lies and deception which was wrong! I "developed" exactly how I was supposed to develop ok I am an infrequent variant but it feels like an excuse to "treat" me if it is a disorder... there is something wrong that needs to be fixed, and quickly before everyone around you realises you're a freak. I guess that stems directly from the gynaecologist suggesting my voice might break, I have a lot of anger still in me towards that man unfortunately. **(P058, CAIS 33)**

A number of participants asked why not just use the patient's diagnosis, e.g. Androgen Insensitivity Syndrome or AIS. Of course, clinicians *do* use specific diagnostic labels but they also like to use umbrella terms, especially in medical books and articles, as a way to group

6. See page 256 for the complete coding for this question.

conditions together based on certain similarities. It is understandable, though, that those affected should feel they have no interest or stake in this.

A number gave a minimal positive response, merely saying the new terminology was “fine”, “OK”, “better”, “preferable”, or “better but it’s all jargon” or “I like the new terminology but still find myself using the word intersex to define myself”.

Some responses specifically mentioned the ‘hermaphrodite’ terms when favouring DSD:

I love the new terminology. The term hermaphrodite is inaccurate medically speaking, and is also too loaded with feelings of negativity, strangeness, “other”ness, and sickness. It also makes me think of pornography usually involving a pre-op male to female transsexual, who has breasts and a penis – often termed “chicks with dicks”. Though the term is inaccurate for this type of individual, I think that this idea would come to mind for many men. **(P091 USA, CAIS 32)**

Others elaborated on ways in which the new terminology seemed less freakish or stigmatising than “the older terminology”. Whilst not specifically mentioning the ‘hermaphrodite’ terms in making their favourable appraisal of DSD these participants used language suggesting they *were* probably focusing on this archaic nomenclature, rather than on the term ‘intersex’, in making their comparison; for example:

I like the new term. It is specific and gives a more clarity. The other terms almost refer to us as beasts. In my mind, when I hear the old terms, I think of a centaur. **(P003, W. Africa, CAIS 34)**

A number of participants said that they preferred the term ‘intersex’ rather than DSD.

Some referred to a perpetuation of a male/female binary system in medical terminology in the face of the obvious spectral nature of sex and gender. Some liked the DSD terminology because it didn’t foreground any gender specific words like ‘male’, ‘female’, or “bring to mind any specific preconceived notions”. However others thought the new terminology didn’t go far enough (presumably by pathologising variations via use of the term ‘disorder’, and using ‘XX’ and ‘XY’ in its sub-categories) and advocated more recognition of the spectral, or sliding-scale nature of sex and gender in medical terminology:

The real issue is acceptance of the SPECTRUM of sex, and getting away from the bigoted sense of a rigid male/female dichotomy. I agree that for the non-medical people, it is helpful and destigmatizing to avoid the words hermaphrodite and intersexual. But that only takes it so far - it’s like defining something by saying what it’s not, instead of what it is. And as long as the dichotomy is worshipped, doctors will keep thinking it’s ok to “fix” us toward that standard of “if you are woman, you must look exactly like this, with a clitoris that’s N inches and no more, and a blah blah blah...”. I often despair that no name will be found for this that does justice to both the medical and personal/human realities. **(P062 USA, CAIS 52)**

Another participant thought that DSD was:

Quite derogatory really. I think gender is naturally more of a continuous spectrum of variation. I would prefer it if they called it something more like: ‘Special Genders/Sexes’. (P074, CAIS 29)

Others, however, seemed to cling to the male/female dichotomy:

I don’t feel this terminology really indicates accurately what a person may be. E.g. I have CAIS so I am 46,XY DSD. How will this distinguish me from a male with infertility problems, [who is] also 46,XY DSD? I believe there can be better terminology used to describe such conditions; even 46,XY DSD Female is relatively better. For now, I can accept XY Female and will never publicly admit to being Intersex. (P001 Eire, CAIS 36)

I am not really worried too much about the terms medics use as long as they think I am a female! (P016, CAIS 66)

A number of participants felt that the DSD terminology was *more* “scientific”, “factual”, “generic”, “descriptive”, “clear”, “accurate”, “neutral” or “straightforward”; and *less* “vague”, “stigmatising”, “euphemistic”, “ambiguous” and “baggage-laden”. But there was some negative reaction to the whole concept of lumping conditions together under an umbrella term which couldn’t do justice to the differences between the various diagnoses within its compass. One participant said that DSD was:

Better. However, it is still an umbrella term covering a number of conditions – a number of them which are still extremely different to AIS. It puts me in the same category as conditions that are far more extreme and – to me – frightening. (P050, CAIS 29)

Presumably she is thinking of related intersex conditions such as Partial AIS in which there could be some degree of external genital masculinisation. Even amongst those who are different from the norm, there are anxieties about degrees of difference and of crossing boundaries into ‘forbidden’ territories that are recognised as being alarmingly close.

One participant liked the idea that DSD might “give us a certain solidarity or community a bit like a ‘gay community’ might be perceived”. Another didn’t want to be lumped together into an overall category, saying that although she was lesbian she had no “brotherhood” with gays or bisexuals or trans-sexuals and had been “quite put off” by a doctor who had thought she could be helpful to a transsexual patient of his. Some participants said they didn’t really care what terms clinicians used as it didn’t really affect their daily life. One responded:

Spare us! – just find out how this happens and how to stop it – does it really really matter what you call it? (P033, CAIS 49)

Summing up - The DSD terminology

This survey question met with a mixed response. The most populated node under this question was one in which participants expressed a dislike of the word ‘disorders’ in DSD, with its

underlying message of pathology, and with a number questioning the need for an umbrella term, saying for example: “why lump together” or “why not use the diagnosis”, or saying they were happy with ‘intersex’ as an umbrella term, or that DSD perpetuated a binary, dimorphic view of sex (with its 46,XY DSD and 46,XX DSD). However a number of participants thought the new scheme was “OK”, or was “less freakish/stigmatising”, or “better than the hermaphrodite terms”, or “more scientific/factual”. Some said they didn’t really care one way or the other. It is worth noting that none of the participants had used the term ‘DSD’ when stating their sex up-front in the survey (e.g. ‘female with a DSD’), or as part of their stated diagnosis, whereas a number had on the other hand used terms such as ‘XY’, ‘XY Female’, ‘CAIS Female’ and ‘Intersex’ (see page 88) but this may in part be due to the newer terminology not yet having filtered through to the affected population as a whole. However, at Q48 47% of my study participants showed a degree of comfort with the ‘intersex’ term, by agreeing with the proposition that this label applied to them, and with a further 19% accepting this with reservations (see page 198).

Looking at the qualitative coding as a whole for this question (page 256), to gain a very rough idea of the spread of views, it seems that there were 74 expressions against DSD, 64 in favour, 39 mixed views, 21 saying that no terms worked, and 13 don’t know/care. However, some of the nodes overlapped, so these figures cannot be interpreted as numbers of people with discrete views, just numbers of instances where the particular views were expressed.

As already explained, the survey question didn’t mention ‘intersex’, but some participants brought it into their response. One might surmise that those saying they were happy with ‘intersex’ might be those who had a more outward manifestation of their intersexed status, such as a larger than average clitoris, but in fact six of the 13 participants expressing this view had CAIS and two had Swyer (in which there would be no such feature), leaving only three with PAIS and two with 5-a-RD who could have had this anatomical status (both the 5-a-RD and one of the three PAIS women had undergone genital surgery). However, eight of the 13 favouring ‘intersex’ had given their sexual orientation as lesbian (6), bisexual (1) or queer (1), all of these except one having PAIS, 5-a-RD or Swyer, so although the numbers here are small, this may suggest that it is a non-heterosexual orientation that fosters a greater acceptance of, or identification with an ‘inter-sex’ status. This is born out as a statistically significant finding at a later question (Q48) about acknowledging an intersexed status (see page 198).

As discussed in “DSD terminology” on page 36, it is suggested by Davis (2011) that the displacement of the term ‘intersex’ by ‘DSD’ within medicine has allowed doctors to regain control over a label and a bodily/identity status that was being successfully framed by activists as a social rather than a medical issue. The recently published DSD clinical guidelines document

initiated by the Scottish DSD Network (SDSD) has been mentioned on page 135. In a clinician-contributed section on psychological support for patients and families within the medical system, the document gave the following advice to doctors (Ahmed et al 2011):

Parents' and adolescents' initial recollections of conversations with professionals may have a long-lasting effect on them and their relationship with their affected child and health professionals. The use of phrases such as 'differences' or 'variations' in sex development may help to introduce the concept of the range of variation that may occur in sex development.

The SDSD lead clinician, who was editor of the document, attended the Chicago 'Intersex Consensus' conference and supports the new terminology. And yet already, just a few years after the introduction of a new nomenclature that is supposed to be more acceptable to parents and patients, we have clinical specialists implying that their colleagues should not use the official terminology in front of parents and adolescents, and that instead of using 'disorders' they should deploy some of the very words ('differences' or 'variations') that opponents of the DSD scheme had been saying should have been considered when drawing it up (DSD Letters 2006, Diamond and Beh 2006). This carries echoes of what Cheryl Chase, founder of ISNA, referred to (Chase, quoted in AISSG Web 1997b) in the late 1990s as:

... the pattern in which no individual who is able to talk back to you can be labelled a hermaphrodite. Hermaphrodites are allowed to exist only in the abstract, as objects, not as subjects.

The point being that the infant is an object of interest and perhaps of intervention rather than a subject. But when a doctor is confronted by an older individual (or a parent) who is able to talk back as a subject, there is a propensity to deny that the individual (or their child) is a hermaphrodite or intersexed, even if the patient's medical records have employed these terms from infancy.

The new terminology goes a long way towards banishing the dreaded hermaphrodite-based terms, but may risk throwing out the baby with the bath-water and getting rid of the 'intersex' term – which some adults had adopted as an identity – in favour of a clinician- and parent-friendly taxonomy based on the pathologising term 'disorder'.

The outsider

I honestly thought I was the only one. I didn't even know there was a medical term for it. I have always felt like a freak, and now at age 37 because of a TV program⁷ that introduced me to the word [AIS], I realize I am not alone. I feel numb with the realization that there are others like me!... I spent many years attending appointments - surrounded by doctors, interns, students - it seemed like "the more the merrier". That is the most distressing thing... now that I look back.

Jay's story⁸ on AISSG website (February 2000)

Most females probably do not question their right to womanhood, but if learning that one is 'disordered' in a fundamental way, from birth, with a developmental deficit, a lack of certain reproductive organs and accompanying physiology, it is easy to start questioning one's authenticity as a woman; a feeling of not being a 'real' or a 'proper' women. Affected individuals may identify as women, yet feel excluded from the female club and its discussions about biological *functions* such as menstruation, sexual activity, pregnancy and childbirth; with these inadequacies being on top of certain perceived female *anatomical* deficiencies (e.g. uterine and vaginal) in some cases. This is further complicated or exacerbated when the question of male biological elements comes into the picture, with these exerting an additional pull towards the hinterland of abjection.

What makes a woman?

At Q21 participants selected which of a number of body-related features they thought society says that nature must provide before someone can be a girl/woman. They were not asked to rank the features, just to place a cross against any they thought applied. The results are shown below:

Q21 - What does society say a woman should have?

Attribute	Yes (required)	
Vagina	104	91%
Breasts	84	74%
XX sex chromosomes	82	72%
Uterus	81	71%
Ovaries	80	70%
Menstruation	76	67%
Female body shape	71	62%
Ability to become pregnant	49	54%
Standard sized clitoris	38	33%
Natural menopause	29	25%

7. Probably the 15 February 2000 screening of the BBC documentary *Hormonally Yours* (in the *Body Chemistry* series). See http://www.aissg.org/12_history.htm#body_chemistry.

8. <http://www.aissg.org/stories/jay.htm>

Some participants added extra text to stress their choice of XX chromosomes as being particularly important, saying:

XX chromosomes – X

I put a capital X on “XX [chromosomes]” and a small x on the rest because I think society makes some allowances occasionally for some of the other features but no allowance and generally complete ignorance that you can even be female without XX chromosomes. (P022 USA, CAIS 62)

XX chromosomes – X

Very generally this is what the general public would say, all the others below vary so greatly even in XX women who are “completely” women so it does not really mean anything to define [them] as being specific “women” features. (P026, ?PAIS/Swyer 31)

However, another commented:

XX chromosomes – x

Although if you have the rest of these, I don’t think anyone cares so long as you don’t say anything – not having XX has been the problem in my head. (P100 Canada, CAIS 68)

One participant said:

Society expects us to have them all. The fact that we don’t does not make us non women, but it does show that society is rather ignorant of our existence. (P024, Swyer 44)

At Q22 participants stated whether their own views differed from those they had specified in Q21 as society’s requirements. The six most heavily populated NVivo qualitative nodes⁹ were: *Inner sense or feeling [more important]* (37), *Just ‘No’ (agree with society) or minimal answer* (20), *XX and/or reproduction not important* (12)/*Pragmatic, insightful view*¹⁰ (12), *External features or expression [more important]* (10), *One’s view changes* (9)/*Yes & no* (9).

Many participants reported that an inner sense or feeling of being a woman, and/or classifying oneself as such, was as important as having a full set of biological attributes, but with a few expressing a clouding of this conviction as a result of their condition:

On a bad day, I can fall victim to the trap of society’s measures. But on a reasonable day, I think womanhood is a state of mind. (P010 USA, Swyer/CAIS? 32)

Psychological aspects are very powerful; personally I know and feel I am female through and through but knowing that I have a Y chromosome in my cells challenges that faith. Aside from the previous list [presented at Q21], having a female brain should constitute female-ness but with conditions such as mine, this assertion is confounded. (P001 Eire, CAIS 36)

Yes. Since I identify as female, and have never questioned my gender, yet have XY chromosomes, I have no choice but to differ from the rest of society on what constitutes a woman. While I struggle with feeling like I’m not a “real” woman sometimes, I know in my heart that I am. (P002 USA, CAIS 29)

9. See page 247 for the complete coding for this question.

10. A node used to store text samples where the participant seemed to have weighed up the question quite carefully and presented a reasoned argument that appeared particularly informative.

Participants P001 and P002 above focus on genetic normality as a prime expectation of society, whereas the following participant talks of a general feeling of shame/secretcy as setting her apart.

It does [differ] now somewhat because I believe that being a woman involves a certain mind set. When the doctor told me at age 36 that I was “really a boy” I somehow knew that he was wrong. However, I guess the fact that I am unwilling [willing] to tell only a few vary [very] selective people of my true situation and that I am intersexed, I guess my honest view is that in some ways I agree with society’s perceptions. **(P012 USA, CAIS 70)**

A number put forward the view that having XX sex chromosomes and being able to reproduce were not important components of womanhood:

Well, I don’t believe you have to have XX, or ovaries or ability to reproduce. I have always been and felt like a girl. From the time of my early childhood, I was girly (played with dolls, wore dresses, liked girl things). Even before the vaginal reconstruction, aside from lack of pubic hair, you would never have known anything was awry. **(P006 USA, CAIS 41)**

Yes – I see myself as a woman, but do not have XX chromosomes, ovaries etc. I understand that you can still be a woman without these things, but I don’t think society agrees. **(P036, Swyer 19)**

An XY woman is little different from an XX woman who has had full hysterectomy that includes removal of top end of vagina, and has never had children. So I don’t think that XX, ovaries, uterus or full vagina are mandatory. **(P099, CAIS 61)**

Some responses emphasised functional aspects (being physically equipped to experience womanhood):

I would say the three traits [that I] selected above (XX, Uterus, Vagina) would be basic female traits to most people. In pure biological terms, being a woman to me involves XX chromosomes. However, to me, womanhood is mostly a construct... I would say that only a vagina is necessary, along with corresponding levels of female hormones, to fit my picture of womanhood. I would say that function/usage (having a vagina and using it; or a penis and using it) creates the identity (though there is much to say about that). **(P039 France, PAIS 38)**

Womanhood is the experience of being a woman, which may be a very different experience for some woman to others, but it does involve having particular physical traits to fully experience and embrace womanhood, I think!– Being a biological woman is a different concept to womanhood. **(P044, Swyer 39)**

However, some hinted at a narrative or discursive interpretation:

Yes, because I didn’t become a woman in the societal norms, I redefined womanhood for myself to make it fit my experience. **(P056 USA, Bisexual, Swyer 50)**

Sometimes mixing this with a privileging of genetic and hormonal determinants:

Yes and no. I believe a normal woman does menstruate and have a uterus and vagina, and has XX chromosomes. I also believe it’s possible to be a “normal” woman and to be born without [these], but XX chromosomes must be present, as well as the ability to respond to female hormones. Consequently, I do not believe I am a “normal” woman, but the way I describe myself, in terms of my sex and gender, is that I’m a woman who came to this sex/gender through an unusual route. Key to my sense of my own gender is the fact that I respond to female hormones and do not respond, or respond only a tiny bit, to male hormones. **(P096 Canada, CAIS 57)**

The above participant values a responsiveness to *female* hormones; although of course regular males can also respond in that way (oestrogens are prescribed for male-to-female transsexuals), just as XX-women can respond to *androgens*.

It is probably quite common for XY-women to engage in a level of self-surveillance and self-judgement that uses higher standards than they themselves apply to others:

For myself no it doesn't differ [from society's view] but strangely when I think of other people I think that all that is required is for them to consider themselves as female and I accept that... I am probably harder on myself. **(P058, CAIS 33)**

I think society makes very superficial judgements about individuals in order to class them as a woman, and therefore if you 'look' and 'act' like a woman, then you will be considered as one. **(P086, CAIS 27)**

Some thought that external features or expression were particularly important:

Not really [view doesn't differ from society's]... I think I appear womanly on the outside, I have large breasts and I suppose am quite curvy, it's just what people can't see that I feel is unwomanly. **(P089, CAIS 34)**

Yes - I feel that I have always been female whether society has defined me that way or not. I am physically female on the outside, breast[s], vagina and other female characteristics, etc. What you see is much more significant than what you can't (chromosomes). **(P098, CAIS 24)**

My gut feeling is that external genitalia are important, i.e. a very large clitoris, or a [pre-op] transsexual man would not qualify. So it's external appearance (gender?) that is more important. **(P099, CAIS 61)**

Participants P089 and P098, whilst both privileging external appearance, seem to differ on the significance of internal/hidden features, with participant P089 finding them a barrier to full womanhood and participant P098 demoting them to a lower level of importance.

Some participants described how their view had changed:

Yes, it does [differ] now, since I was in my 30's. However, until I discovered my diagnosis at age 34, the list above DID define what I thought was womanhood. More importantly, until age 34, the list above defined how [I believed] I would never achieve womanhood. **(P062 USA, CAIS 52)**

Yes. With growth, knowledge and understanding of AIS and other connected conditions, I believe my view has changed [compared] to that of society. 10/15 years ago, I would have defined my womanhood as the ability to conceive. As a 34 year old woman, that definition has shifted to one where my outward body, the shape, the curves, the breast size all define me as a woman. The one body feature that I still have insecurities in defining my womanhood is the shortness of the vagina. **(P092, CAIS 34)**

I feel comfortable with appearing as a woman to society, as it makes society feel more comfortable about me being part of it. However, as I mature in age and confidence I feel more at ease displaying all facets of my character even if they may appear to some a more male type characteristics. Gender roles in our society are now sufficiently blurred so as to make me feel much more comfortable in myself knowing that I am intersexed. **(P093, CAIS 48)**

Summing up - What makes a woman?

Ovaries, uterus, and XX sex chromosomes (components that are missing in most XY-women) were thought by 70-72% of my participants to be required in members of society that are classed as girls/women. These elements were given a slightly higher priority than menstruation (67%) and a female body shape (62%) but were not deemed as important as the possession of female breasts (74%) and a vagina (91%).

Contrast the table in this section (page 160) with the ranking that participants assigned to biological features of their own bodies in terms of influence on their sense of self (page 148) where infertility headed the list, with vaginal hypoplasia coming some way down. Of course all my participants will be personally affected by infertility, whereas only some will have had a problem with vaginal hypoplasia. Menstruation was higher up the list of personal influences than it was in the societal requirement list, probably due to its personal significance as a rite of passage to adulthood.

Women in general have been shown by Braun and Wilkinson (2005) to attach high significance to the vagina as a signifier of femaleness, as described in “Biophysical issues” on page 32, and it seems reasonable that people might attach particular societal importance to a gendered attribute that they don’t possess but would like to have. At Q15 (about discovering diagnostic information) 82% of my participants gave an age and source for learning of a short/absent vagina being part of their condition (see page 94). But at Q18, (about the impact of various biological features, or their lack, on their self-view) only 69% participants assigned a score of some degree to ‘short vagina’ (see page 147). And at Q29¹¹ (about sex and relationships) only 15% of the participants stated that they currently did not feel equipped to have sex (although 23% gave a ‘yes and no’ type response to this question). Overall, 18% had undergone vaginoplasty surgery and 36% had practised vaginal pressure dilation (see page 114). So it seems that even if a number of participants had eventually overcome a deficiency in vaginal length (whether that be via surgery, via pressure dilation, or just via penetrative sex) or viewed it as unimportant to them, most still hold it higher than other female attributes as an expectation of society.

Q21 simply referred to the societal importance of the presence or absence, or the dimensions of certain features. It did not ask about their relative role or importance in sexuality. But the position of the vagina at the top of the list seemed to be related to its role in penetrative sex rather than childbirth since the ability to become pregnant was significantly lower down the list. The importance assigned to female breasts possibly also reflects thoughts of a role in sexual

11. Details of the responses to Q29 were set aside for future analysis, due to lack of space in this thesis, but it seemed useful to mention these percentages from that question here.

attraction/activity. However, female body shape/proportions was lower down the list, even below attributes that are not visible under normal circumstances (XX chromosomes, uterus, ovaries, menstruation). I would suggest that my participants are reflecting the societal discourse that privileges heterosexual penetrative sex and the need for a vagina in this respect, and citing this as an important requirement for womanhood. It seems that they are to some extent channelling the conservative view of women needing to have the wherewithal to attract and satisfy men.

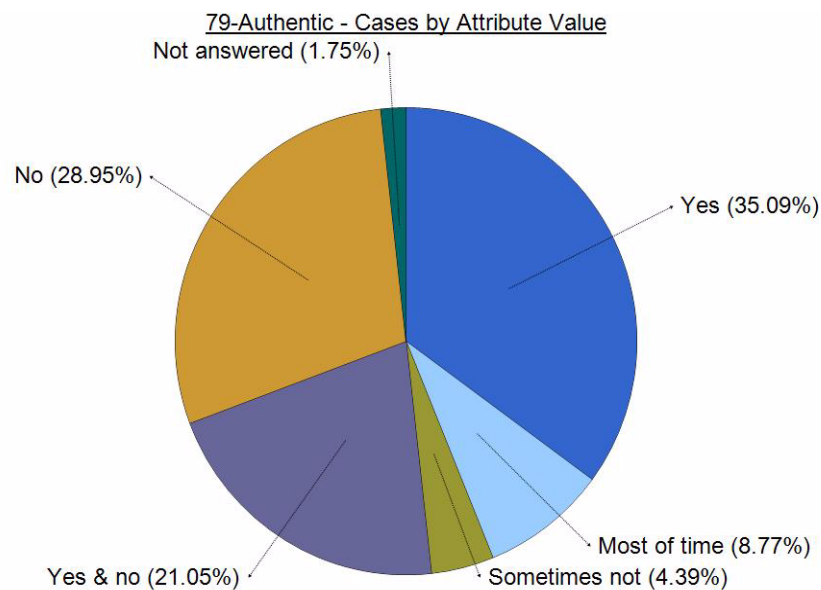
The common textual pairing of the vagina and penis echoes the way in which, in pre-modern times, the vagina was thought of as a homologue of the penis, an inverted form of the male organ. But of course it is the clitoris that is the female counterpart of the male penis, not the vagina, and Gayatri Spivak suggested that there is an erasure of the clitoris in the representation of female sexuality via a 'uterine social organisation', with woman conceived as reproductive objects (Spivak 1987: 50), as also discussed by Stevi Jackson (Jackson and Jones 1998: 195). The privileging of male genital anatomy in paediatric intersex medicine has been discussed in various parts of this thesis. This is an attitude that doesn't respect the integrity of female genitals, in which it is assumed that a vagina of suitable proportions to accept a penis is all that's required (and that it is easy to create such a receptacle if absent). The vagina there has a lesser significance than the penis, but the clitoris is given even less attention, in medicine and in society as a whole. Arguably, the clitoris merits a higher profile; as indeed is the aim of many intersex activists in challenging gender-reinforcement surgery that removes defective phalluses but at the risk of impairing the individual's sexual response as a female. Apart from the clitoris, it is the labial area and the lower third of the vagina that is the most sexually sensitive part of the female genital anatomy, so it can be argued that the inner two thirds is possibly not so important anyway in pleasure terms. After all, minor surgical procedures can be carried out on the cervix without any anaesthetic. Even though, of course, many women do enjoy penetrative sex, my participants could in theory have adopted the view that women (including most XY-women) are born with a phallus (clitoris) and perineal tissue (labia etc.) that provide them with a full sexual response, and might therefore have questioned the absolute need for a full-length vagina in that respect?

Abjection and authenticity

My study participants have to (re)negotiate the path to subjecthood with a bodily make-up that seriously challenges society's... and their own... expectations. If XX-women are defined in negative terms in a patriarchal system, it would seem understandable that the discovery of one's intersex status as an XY-woman might, in many cases, cast one into a well of shame, stigma and freakishness, with a feeling of being a fraud in some cases, especially if accompanied by an awareness that parents and/or doctors have done their best to hide the situation, and if one has

had no opportunity to share one's fears with a counsellor and/or to realise that there are others affected. The sense of being a fraud, or a freak, can even adversely affect one's perceived authenticity as a *human subject*; what Herman E. Stark, in his analysis of authenticity in intersex, terms a sense of "self-estrangement", a feeling of having "failed at existence", or what R.D. Laing describes as "ontological insecurity", as discussed on page 25.

At Q50 participants stated whether they felt themselves to be an authentic member of their sex and gender. The question deliberately didn't specify a particular sex or gender, in order to see if anyone questioned or commented on this.



Q50 - Authentic in sex/gender?

The difference between 'Most of the time' and 'Sometimes not' is somewhat subtle and perhaps unimportant, merely differentiating between those who stress a general *inclusion* in the authentic category and those who highlight an occasional *exclusion*.

Combining the 'Yes' and the 'Most of time' responses, the three main diagnostic and the two sexual orientation groupings showed some differences, but were not statistically significant (CAIS 50%, Swyer 46%, PAIS 47% feeling authentic; and heterosexual 46%, lesbian/bisexual 37%).

The six most heavily populated NVivo qualitative nodes¹² were: *Just yes (not confirming female /woman)* (26), *Yes, as different sort of woman* (18)/*Feel a fraud, freak or outsider* (18), *Yes & no, or it varies* (14), *Yes, authentic female or woman* (13), *Just 'No', or minimal response* (10).

12. See page 268 for the complete coding for this question.

Some confirmed a feeling of authenticity; and seemed to assume a standard female identity was being asked about. Others talked of feeling authentic, but as a different sort of women:

No. I only felt I truly belonged when I found other women with AIS. (P009, Bisexual, CAIS 51)

I'm an authentic XY woman. I don't feel like an authentic standard female. (P049, CAIS 29)

I can't imagine identifying as a male, but I also can't imagine being a "typical female" any more either. I wouldn't want to be. I don't think I'm an authentic woman, but that doesn't make me feel bad – nor does it make me feel like I am hiding myself either. Society insists on sex and gender split and I'm probably more like typical females than I am like typical males (although its close in some cases!), but the people who know me [know this] and [that] the way I relate to myself is outside of these boxes anyway. I think I would probably feel inauthentic if I was trying to fit in more than I am. I don't fit in, I don't try to fit in... so I am authentic to who I am and that's it. (P068 USA, Lesbian, PAIS 38)

No. Obviously not a 'proper' woman (whatever that is) but feel comfortable identifying as a different sort of woman ! (P071, Lesbian, 5-a-RD 45)

So-so. Deep down I know that I am a "different" woman, mainly because of my sterility and the fact that I do not have menstruations. (P084 Italy, CAIS 41)

Some here suggested that their sex might be intersexed or male:

Yes, I am an intersexed person who most closely fits in the female box... to help those around me cope with a grey (or multicoloured) world which needs to be fit into a binary system??? So am I a woman – NO but I'm also NOT a man! I call myself woman. (P058, CAIS 33)

I am an authentic member of my sex in that, as I stated earlier, my sex is Intersexed, but I wouldn't say that I am an authentic member of the Female sex. Regarding gender, yes, I consider myself to be more or less authentic when operating as a Woman in society. (P099, CAIS 62)

I am an authentic intersex person, and I feel quite comfortable in my female gender identity but I am definitely not authentically of a female sex (or a male sex, but I guess if I had to choose one I would regard my sex as being closer to male than female). (P107 USA, CAIS 50)

All three above have Complete AIS so have a totally female phenotype, but even so, they are classing themselves as intersexed in terms of their sex, supporting the view that one doesn't need to have any degree of external genital masculinisation or ambiguity to be intersexed.

Some participants, however, talked of feeling themselves to be an outsider:

No, it feels like a borrowed label. I identify myself as female because I appear to be by appearances a female but I know that I have no reproductive capacity and therefore am excluded. (P073, CAIS 42)

Yes, but at the same time I often feel there is a gap between me and "real women" and that the gap is unbridgeable – almost that they are fully grown up and I am not. (P075, CAIS 34)

No I have never felt an authentic member of my adopted sex as a female. I have lived my life as a fraud in fact. I function successfully as female, and feel comfortable with that. I feel comfortable with the subset of normal women who, for one reason or another, are unable to bear children. I feel most uncomfortable when there are discussion surrounding menstruation, PMT and menopause. (P093, CAIS 48)

Or a fraud:

The sex I adhere to (XY Female), yes [authentic]. The gender I adhere to, yes (most of the time). However, when I have to check the “F” on applications, I have a feeling that I am somewhat not being completely honest. **(P005 USA, Lesbian, PAIS 27)**

No I feel a fraud and that one day someone is going to find out and shout it from the roof tops. And maybe they’ll get all confused and not let me work with children anymore. **(P024, Swyer 44)**

No, sometimes I feel like a pretender. Sometimes I feel that people can see through me what I really am. **(P105 Finland, 5-a-RD? 32)**

Or even a freak:

Sometimes, and then sometimes I just feel like a complete freak. It largely depends where I am psychologically at the time. Although I’m almost 42 I am not particularly well adjusted to the condition. **(P007, Swyer 41)**

It is very painful for me to have to say no to that question because, although there is no *good* reason why I shouldn’t say yes, my early experience with the medical profession has in-grained in me the feeling that I am somehow freakish. **(P031, CAIS 59)**

Or all three (an outsider, a fraud, and an alien)

No I feel like a lie, a fraud, neither one thing nor another – an outsider – always displaced from real people, an alien – walking around trying to pass off as human. **(P072, CAIS 30)**

Participant P073 above cites a lack of reproductive capacity as her main reason for exclusion from the female ‘club’, yet many XX-women are unable to have babies for various reasons. It must be more than infertility, rather a case of being stigmatised by knowing the rather unusual *reason* for lacking this functionality, with a fear of this coming out in discussions with other women, as articulated here by participant P093. Participant P075’s response highlights the impact of a lack of the usual rites of passage (e.g. menstruation) on one’s sense of attaining womanhood. Participants also referred to freakishness when talking about medical terminology (see page 126) and about performativity (see page 190 and page 194).

Some were a little more ambivalent (‘Yes & no’) in their response:

Not totally. I think my feelings is somewhat ambivalent. Phenotypical I am a woman like everyone else, but on the other hand I know that I am not like any other woman. It is that knowledge that separates me from being an authentic member. If I didn’t know I would answer yes. **(P046 Denmark, CAIS 27)**

Sexually I cannot be considered female in the strictest sense; I have no ovaries, no uterus, a very short vagina, and most importantly XY chromosomes. Outwardly I appear and identify psychologically/socially for convenience sake as female. **(P087 USA, Celibate, PAIS? 28)**

Yes and no. Yes, because I don’t feel that I am someone trying to “pass” as female. But no, because I think that technically speaking I am either not female (but also not male) and am technically intersex, or maybe just an XY-female. **(P091 USA, CAIS 32)**

To say yes or no would be too simplistic. I do consider myself female; however I do feel like I am an inferior female. **(P108, CAIS? 25)**

One might pose to participant P087 above the question of whether a regular woman who has had a total hysterectomy for cancer is not a woman, but then the matter of what body parts one is *born with* might come into the picture, and there is always the Y chromosome, which assumes great significance for some, as it does for her.

Two responses showed up the somewhat nonsensical nature of this survey question, as follows:

We do a very poor job of reassuring women with AIS. We forget to remind them that this is the way God/Nature made them. The medical establishment treats AIS as if it were a mistake. All the medical focus on “do your genitals look right?” and using sex and gender interchangeably, reinforces that. If you were born that way, it IS authentic, by definition.... AIS is authentic – it occurs in Nature, therefore it’s natural. **(P062 USA, CAIS 52)**

If I'm truthful I don't think of myself as a member [of the female sex/gender] but I certainly don't think the opposite apart, separate and therefore not female - don't like the word authentic as it implies I could be fake. Is there such a thing as an “authentic” woman? **(P052, PAIS 46)**

However, the question was essentially posed in order to stir up thoughts in the minds of study participants rather than to draw any specific inferences on ‘authenticity’.

Some participants, in giving a positive response, stressed that they were referring to a *female* label or identity. Most here seemed to be focusing on their inner gender identity and ignoring the issue of biological sex (or assuming they were one and the same thing), saying things like: “YES, I was meant to be a woman, I am a woman“, or “Yes, I do. I’ve always felt like a woman and never doubted it”, or “Yes. Inside I feel that I am a true woman, no question about it. My problem comes when I worry about what others think of me.”, or “Yes Im a girl”, or “I am Female”, or “No to male and Yes female”, or “Yes, I am a female, and a very special one!“. A few here provided more expansive answers:

Hmmmm. I do feel authentically female gendered. My interests, my sensibility, are very much in the female gender camp (though I’m a feminist, and I feel the rise of feminism and improved rights for women have enhanced and freed up my life hugely, and that those freedoms have allowed me to experience a broader repertoire of appropriate female behaviours). My heterosexuality, and my pretty good sexual response, reinforce my sense of female authenticity. **(P096 Canada, CAIS 57)**

But only a few participants at this node appeared to overtly acknowledge biological sex and social gender as separate entities:

My sex is Female. My Gender is Female. **(P003 W. Africa, CAIS 34)**

Yes, there is so much more to womanhood than menstruation and giving birth. There are so many women who could have babies but end up without any. Being a woman is also a state of mind, an attitude, a spiritual status. In many aspects of both sex and gender I feel myself an authentic woman. **(P041 Hungary, CAIS/PAIS? 40)**

Yes. I consider myself to be female but would not be uncomfortable if described scientifically as genetically male. I am definitely a woman as regards my gender identity. **(P081, CAIS 31)**

Some participants just entered “No”, with one saying:

No, unless you define my sex as male and my gender as intersexed. (P021 USA, Lesbian, 5-a-RD 47)

Summing up - Abjection and authenticity

Most participants seemed to assume (as I would have expected) that the question was asking about sex/gender authenticity as a *female/woman*, although a few did make it clear that they felt their sex to be authentic as ‘intersex’. 36% of participants claimed to feel authentic in their sex/gender, with another 13% saying they did so ‘most of the time’ or that they ‘sometimes did not’. 21% gave a ‘Yes and no’ type of response, whilst 29% said they did not feel authentic.

The qualitative coding revealed some expressions of authenticity as a different sort of woman, but matched by an equal number of declarations of a fraud, freak or outsider status. It seems feasible that some of my participants might not have achieved the separation from “the constitutive outside” or the abject, required in feminist gender theory for subject formation – thus identifying *themselves* as abject beings – *freaks* – as a result of the circumstances in which they found out about their condition and of having been exposed to archaic and stigmatising medical terminology or degrading practices such as exhibition to junior doctors or medical photography. The other status claimed by some participants is that of being a *fraud*, often in relation to specifying ‘Sex’ on official forms or when discussing what they have in common with XX-women.

Chapter conclusions

In terms of their own biology XY-women appear most troubled by their lack of certain female functions (infertility, amenorrhoea, absent ovaries), but with their male biological attributes (Y chromosome, testicular tissue) lurking not far behind. The CAIS women seemed more troubled by infertility than did participants with other diagnoses, but the women with Swyer Syndrome seemed more troubled by amenorrhoea and the presence of Y chromosome and testicular tissue than did those with AIS diagnoses. I argue that the male attributes may stand out in higher relief for the Swyer women because of their greater complement of female characteristics compared to the AIS sub-group. Views on the new DSD-based medical terminology were mixed, with some disliking the ‘disorder’ element but some preferring it to the archaic hermaphrodite-based terms.

In terms of societal expectations, my participants placed the vagina at the top of the list of requirements for womanhood, followed by breasts. I argue that they are reproducing the standard discourse of privileging heterosexual penetrative sex and the need to attract/satisfy a man.

Unsurprisingly, many participants' own view of womanhood puts more emphasis on one's inner feeling or sense of being a woman, or on how one presents oneself in society.

Approximately a third of my participants claimed not to feel authentic in their (female) sex/gender and I argue that this is not unexpected in view of the way people with non-standard sexual configurations have been characterised as outsiders and freaks, both by medicine (via secrecy and surgery) and sociologists (via theories of abjection).

Ultimately, many individuals with AIS-like conditions probably do come to view themselves just as women who, like some with XX sex chromosomes, have a few extra challenges in life, such as infertility. And some in my study claimed an authenticity as a different sort of woman or as an intersexed person. But it's not a matter of just putting on a different coat as they walk away from the medical consultation. Most need to arrive at that point via their own journey, over a period of time; a journey that ideally involves talking with counsellors/therapists and with other affected women, and deciding for themselves what aspects of their unusual make-up are of lasting significance to them. It does not happen in an instant, as a result of a doctor's exhortations at diagnosis. The individual may have to re-invent herself to a large extent over many years, an evolution that is reflected in a number of participants' responses throughout the study. The challenge for an XY-women may be how to (re)form her subjectivity in a way that recognises her particular corporeality.

The next chapter turns more towards the societal recognition of intersex and how my participants might reach a more holistic relationship to their medical history/status. It looks at how participants view the sex versus gender distinction and asks whether their gender comes naturally or involves some degree of self-consciousness or performance. It looks at how participants deal with the male aspects of their make-up, and whether they consider themselves to be intersexed.

7 The gender savant and the intersex woman

Previous chapters have looked at how my survey participants were initiated into awareness of their XY/intersex status and an associated medicalisation, at how they reacted to discourses of ‘failed masculinisation’ and ‘super femaleness’, and how they navigated a self-view or identity involving compromised womanhood and a possible ‘outsider’ status. This chapter looks at two further phases or identities that participants might explore or adopt, possibly at a later stage in living with the knowledge of their unusual situation, and approached following some reflection on the implications of their condition. Firstly, I am asking to what extent XY-women are ‘gender savants’, a term borrowed from Morgan Holmes (2008); in other words, how aware are they of sociological debates and theorising about sex and gender? Secondly, to what extent is it feasible, and useful, for XY-women to face an intersexed status head-on and incorporate it more directly and openly into their identity? Does this hold out opportunities for greater autonomy and agency, as compared to a scenario in which a totally *female* sex is constructed; and in which significant effort is expended, by some at least, in hiding or denying their biological heritage?

I am questioning whether a more positive or integrated acceptance by XY-women of their status would place more, or less emphasis on biology? Would it entail a greater acknowledgement/revaluing of a male/intersexed internal bodily status? Or can we conceptualise maleness out of the picture? To what extent can embryological tissue that’s programmed to become testes, but hasn’t fully differentiated, be said to be male? Maybe a positive identity is the one already adopted by many in my study, one that concedes that these individuals invariably function as women in terms of appearance, gender identity and social role, albeit with some ontological complexities and stigma attached to their knowledge of a non-standard genetic status and internal anatomy. So an identity that places less emphasis on biological sex (with, after all, no awareness in many cases of anything unusual until puberty) and more on the social and discursive production of gender (and sex)? What, for example, differentiates a hysterectomised XX-woman from a CAIS woman, other than a slight difference in the configuration of a piece of sub-cellular DNA and in the amount of body hair? In the spirit of those feminist questions that employ a pun on materiality or corporeality, one might ask “Need biological sex *matter* (to XY-women)?”

To a large extent this chapter traces the evolution of feminist gender theory, from the introduction of a sex/gender distinction, through social constructionism and performativity, to a return to ‘the body’. It looks first at how participants view the sex versus gender distinction and asks whether my participants’ gender comes naturally or involves some degree of performance. I then ask how participants negotiate the male aspects of their corporeal make-up, leading to the question of whether they consider themselves to be intersexed at a biological level.

The gender savant

But man is defined as a being who is not given, who makes himself what he is. As Merleau-Ponty puts it, man is not a natural species; he is a historical idea. Woman is not a fixed reality, but rather a becoming, and it is in her becoming that she should be compared with man; that is to say her possibilities should be defined.... [A]s viewed in the perspectives that I am adopting – that of Heidegger, Sartre and Merleau-Ponty –...the body is not a thing, it is a situation: it is our grasp on the world and a sketch [esquisse] of our projects.

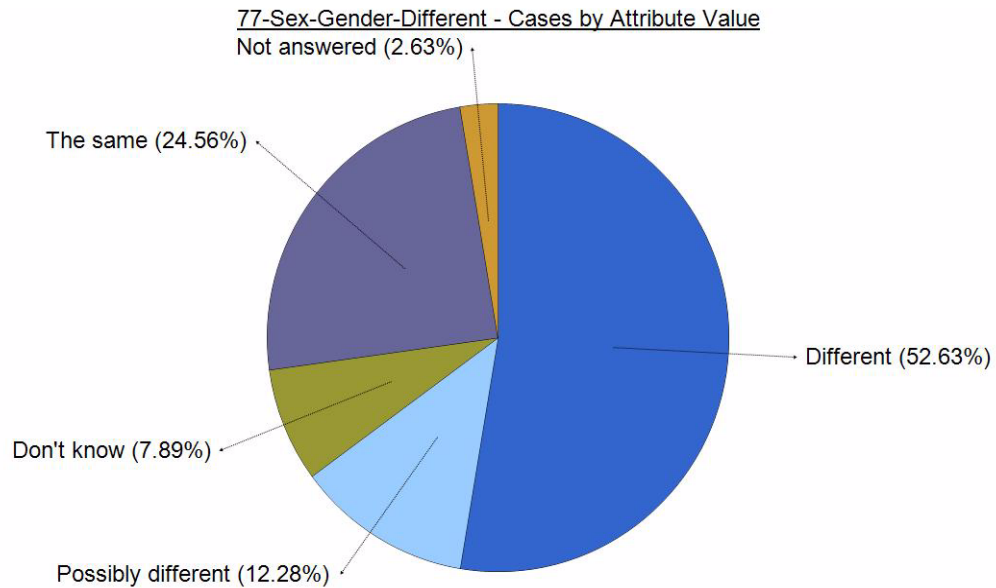
Simone de Beauvoir, 'Le Deuxième Sexe' (1949: 33)

As discussed on page 46, some scholars have questioned the extent to which intersexed persons can assume roles such as that of “the gender savant” (in whom “the level of self-awareness of the artifice of gender appears to be more pronounced“ Holmes 2008: 13-14) and “the activist ‘subject’” (“the possessor of a great theoretical experience that refers to the fluidity in bodies and identities...” Gregori et al 2007; 10-11). Gregori et al, in contrasting their “activist subject” with an alternative role as a “victim” of medicalisation, appear to promote the former as a *positive* status, whereas Holmes expresses the view that intersexed persons should not be “obliged to act as an advocate for non-normative agendas, to bear the burdens of social order for everyone else” (Holmes 2008: 15).

Sex versus gender

Because the concepts of sex and gender evolved from observations made by clinicians working in intersex medicine, as outlined on page 39, it would be appropriate if this categorisation was of particular salience or usefulness to intersexed persons themselves. One might expect this distinction to be particularly acknowledged by, and useful to XY-females in forming/supporting an identity that de-emphasises biological essentialism. I suggest that this could be a necessary first step towards an acceptance of an intersexed status; to be able to declare that “yes my bodily sex is intersexed (or male) but I am a woman”. Simone de Beauvoir’s original feminist ideas could be particularly apposite for XY-women, who might be said to fulfil her paradigm of not being born a woman (sex, in this context), but becoming one (gender), in a somewhat more concrete sense than most women (de Beauvoir 1949).

Q46 asked whether participants thought sex and gender were the same or different. The responses given by the study sample as a whole are summarised in the following pie chart:



Q46 - Sex vs gender - same or different?

Examining the responses from different geographies gave the following data:

Q46 - Views on sex vs gender by geography

Geography	Different	Possibly different	Don't know	The same
North America (n=31)	81%	6%	6%	6%
Europe, Scandinavia, Israel, Africa (n=14)	50%	7%	21%	21%
UK and Eire (n=66 ^a)	41%	16%	6%	33%

a. Excludes 3 who didn't answer question.

Participants in North America appeared the most certain of a difference. The lower figure for Continental Europe, Scandinavia, Israel and Africa (and the higher "Don't Know" percentage there) may reflect a language issue (some appear not to provide separate words for the two concepts). Those in the UK and Eire sub-group seemed more ambivalent about the question. Combining the "Possibly different" and the "Don't know" responses, the differences between the three geographies were statistically very significant ($p=0.007$).

A breakdown by diagnosis showed some trends but they were not statistically significant. The profiles for CAIS and PAIS were similar (54% and 53% respectively saying there was a difference). Those with Swyer Syndrome seemed somewhat less inclined (47%) to recognise a difference. However, those in the AIS groupings seemed more likely to be indecisive about the question, with more responses coded as "Possibly different" (CAIS 14%, PAIS 11%) than for

those with Swyer Syndrome (7%). There were differences between the two main sexual orientation groups, but again these were not statistically significant. Those with a lesbian or bisexual orientation seemed more inclined to recognise a sex/gender difference (74%) compared to the heterosexual participants (49%). The heterosexual group seemed more indecisive (14% “Possibly different”) than the lesbian/bisexual group (5% “Possibly different”). In terms of educational level, those with a higher degree seemed the most likely to recognise a difference (close to 70%) and those at school the most likely to say they were the same (40%), but this too was not statistically significant.

The six most heavily populated NVivo qualitative nodes¹ were: *Just yes, different* (46), *Yes with comment* (23), *Just no, the same* (17), *Insightful comments* (10), *May have misunderstood* (10), *Don't know* (8).

Some of those who recognised a difference between the two categories made a direct reference to their condition:

I was going to say I don't know but as I had male gonads and yet feel and have always felt a girl or woman who is attracted to the opposite sex, I guess there is. (P055, ?PAIS 46)

I guess that anyone with AIS would know that there is. The challenge is reconciling what you know about the condition with what you feel about yourself and who you are. (P073, CAIS 42)

Yes, most people with CAIS are living proof that there is a definite difference. (P100 Canada, CAIS 68)²

But there was a certain amount of ambivalence or uncertainty about the question from some participants:

I think society has caused the differences between sex and gender, but in actuality they are the same. (P011 USA, Swyer 22)³

I believe it because they tell me there is [a difference]. (P012 USA, CAIS 70)⁴

Until I started reading about it I would have said no they are the same but now I realise different. (P033, CAIS 49)

Both terms are confusing to me. I never know which is which. I consider my chromosomes just like my blood type. It doesn't matter. (P047 Belgium, CAIS 36)⁵

The comment of participant P047 above is in contrast to many others in my survey who attached great significance to chromosomes as a key determinant of sexual identity or classification.

1. See page 264 for the complete coding at this node.

2. Had given differing values for own sex and gender up-front in survey.

3. Had given differing values for own sex and gender up-front in survey.

4. Had given differing values for own sex and gender up-front in survey.

5. Had given differing values for own sex and gender up-front in survey.

Some showed an awareness of the role of a linguistic or discursive construction, but often revealing some scepticism of the classification, or of the role of language in setting it up:

Have never thought about it. It's an interesting division – all these categories to make people feel more comfortable. I don't think there is a difference – I could never use wordplay to make myself feel more acceptable. **(P072, CAIS 30)**

Sex=biological classification, gender=language game. **(P087, USA, Celibate, PAIS 28)**

I am not certain. I know that language and definitions change all the time. I feel that it's only been in recent years that these two have diverged in meaning – at least in popular use. **(P091 USA, CAIS 32)**

A number of participants, however, appeared to have misunderstood the question, apparently thinking they were being asked whether or not their own sex and gender were in accord or in conflict (and that they were being prompted to consider their sex as male?) rather than the theoretical question of whether the two terms represented different things/concepts:

I have no such personal experience. But I can image and accept that there are people who feel their biological sex just does not match the gender they have in their personality. **(P041 Hungary, PAIS 40)**

Yes I suppose so, although I did answer 'female' for both questions at the start [of the survey] because I can't see myself any other way. **(P059, CAIS 31)**

No I think of my self as being female for both, and have never felt male. **(P063, Bisexual, 5-ARD 48)⁶**

No. I am female and that's how I view myself. **(P106, CAIS 34)**

At the follow-up question below some continued to misinterpret the proposition, whereas some revealed that they *were* in fact aware of a difference between the two concepts (but didn't necessarily go back to change their response to the current question).

At Q47 participants explained what they thought the terms sex and gender stood for. The six most heavily populated NVivo qualitative nodes⁷ were: *Biol-phys vs psychosocial* (55), *Are same 'cos no conflict* (14), *Gender constructed* (13), *Chromosomes vs identity* (12), *Both are spectrum* (7), *Gender is spectrum (sex more limited)* (6).

Almost half the participants gave some variation of the “sex is biological/physical and gender is psychological/social” view of the two terms. This was the fifth most heavily populated node in my entire NVivo coding exercise (see page 245). However, I had presented a definition of this form later in the survey document (when asking whether a sex/gender distinction appeared *useful* to XY-women) so it's possible that some participants had used this to inform their response at the earlier question (although the two questions were placed in different parts of the document to try

6. Had given differing values for own sex and gender up-front in survey.

7. See page 265 for the complete coding at this node.

and minimise such an influence). And of more interest are the responses expressing the view that sex and gender were the same thing, although usually based on there being no conflict between their own sex and gender. As with some at the previous question, those responses appeared to focus on the male/female binary rather than on a differentiation between the concept of sex and the concept of gender, and again seemed to indicate a misunderstanding of the question, or possibly that these participants did not have a clear view of what constituted the categories of sex and gender:

To me sex and gender are interchangeable and cover what you *feel* and what you *are*. Very few intersex people will remain completely in the middle but will align themselves with either male or female and will assert their gender consequently. [In previous Q, asking is there a difference, she said “No. It boils down to the same thing.”] **(P001 Eire, CAIS 36)**

I have no idea – for me they sound exactly the same. [In previous Q, asking is there a difference, she said “Not in my case, I am female outside, I feel female, I am aroused by male and the only non-female part is this chromosome part.”] **(P013 Estonia, Swyer 31)**

Sex: a genetic construct. Gender: a descriptive term. [In previous Q, asking is there a difference, she said: “I can’t answer this question, it is too difficult for me. My initial reaction is that no there is no difference, but there obviously is a difference for some people.”] **(P024, Swyer 44)**⁸

Participant P001 above has a career in genetics research⁹ and yet doesn’t seem to subscribe to the standard separation of sex and gender based on biology/genetics versus social presentation/role. Participant P013 subsequently communicated to the researcher that there was no separate word for gender in the Estonian language. Participant P024 seemed conflicted about the question, even though she had assigned different values to her own sex and gender up-front in the survey.

Another participant opens up the possibility that her sex may represent something different from her gender but quickly closes the door to focus on a general ‘femaleness’:

To be perfectly honest I’ve never really given much thought to the differentiation between sex and gender, having always considered myself to be a girl/woman. I now appreciate that medically I’d be termed as intersex but, apart from the sexual relationship & reproduction issues associated with CAIS, I consider my life as a woman to be as complete as any other’s. So in my case yes, I still consider my sex and gender to be the same. I do appreciate though that with others it’s likely that gender assignment issues have led to conclusions that they are separate and distinct. In conclusion, whereas medically I’m intersex, in my head I’m completely of the female gender. (Don’t know if that helps at all?!) **(P004, CAIS 46)**

Some participants showed awareness of the concept of social construction in terms of gender:

Gender is what you ask to be identified as. It’s also about what you put on or take off your body. For example, the length of your hair, nails with polish or not, do you wear makeup, jewelry, your clothing and how you say you wish to be identified are all great examples of gender, which is a social construct! **(P027 USA, Lesbian, CAIS 53)**¹⁰

8. Had given differing values for own sex and gender up-front in survey.

9. Has given permission to mention this here.

10. Had given differing values for own sex and gender up-front in survey.

As a physiologist and anthropologist, I have thought about these terms. Of course gender is widely accepted as a social construct and sex is biological. However, sex is tricky to define. It is biological, but what are its defining characteristics? Gender also gets a little sticky when I think about ones conception of self with regard to gender versus societies conception of you with regard to gender... ..So, for me I realize that my sex is mostly male, except of course with regards to all outward signs. My gender is and always has been female. As stated above [at Q46], its about inherent biological properties versus ones, or societies, conceptions. **(P097 USA, Bisexual, 17-b-HSDD 49)**¹¹

Participant P027 above works in a university gender studies department,¹² so her investment in a distinction is no surprise. The response of participant P097 throws up the issue of whether sex is defined by invisible chromosomes and internal reproductive organs or by visible external genital structures and phenotype, or by both; a question that is arguably not of significance to normally sexed individuals, but is highly relevant to the situation of the XY-woman.

The notion that sex is determined specifically by one's genetic make-up, with gender being more of an identity issue, was highlighted by some:

Sex= chromosomal makeup. Y is biologically male, X is biologically female. Gender= how you personally identify (male or female) may not correspond with your biological sex. Gender is partly a social construct. **(P002 USA, CAIS 29)**

One refers to your chromosomes, the other refers to who you are. **(P047 Belgium, CAIS 36)**¹³

To me, sex is your genetic makeup (which would be male) however my gender is without question, female as that is how I feel and what my genetalia says. I suppose it is how I present myself. [In previous Q, asking is there a difference, she said "Now I do."] **(P112, Swyer 36)**¹⁴

It seems that amongst those XY-women who, as above, assign primacy to chromosomes in defining sex, some will echo this when declaring their own sex, whereas others will background it. For example, participant P112 above had given her sex and gender as 'Intersex' and 'Female' respectively up-front in the survey, whereas the other participants above had given 'Female' for both (even though at the current question they are implying that their sex would be male based on their sex chromosomes).¹⁵ Some here appealed directly to science in relation to chromosomes:

Sex refers to the scientific/genetic explanation and gender is the socialised (and to some degree) choice we make as to whether we're male or female. I do agree with the concept of nature and nurture, I agree with the socialisation process that suggests that a child 'labelled' female, will learn how to be female in society... ..[but] I think eventually, you would realise you were physically different, albeit superficially. [In previous Q, asking is there a difference, she said "Yes and no."] **(P098, CAIS 24)**

11. Had given differing values for own sex and gender up-front in survey.

12. Has given permission to mention this here.

13. Had given differing values for own sex and gender up-front in survey.

14. Had given differing values for own sex and gender up-front in survey.

15. Participant P047 had originally given 'Female' and 'XY' up-front (i.e. gave 'XY' for gender), but as seen at Q46, she admitted to being confused about the two categories, so probably intended to state 'XY' for her sex, although she claimed not to attach much significance to chromosomes. (and on later questioning she replied: "In my situation both Female would apply").

For purposes of scientific accuracy, I guess we have to speak in terms of chromosomes, but chromosomes do not define a person. I am a woman. I do not know how to be anything else except a woman. I have no desire to be anything but a woman. I am one of those people who is more female than normal females since my body (and brain?) are totally insensitive to male hormones! **(P100 Canada, CAIS 68)**¹⁶

Participant P100 above appears to give credence to the notion discussed in “The super female” on page 139, of androgen insensitivity equating to heightened ‘femaleness’. One or two, in privileging genetics in relation to sex, also mentioned other biological components/aspects:

I now believe that sex is what your chromosomes or body internally is and gender is how you identify/feel. **(P069 USA, CAIS 43)**¹⁷

Sex refers to one’s biological characteristics (nature of sex chromosomes, gonadal tissue and other reproductive organs, and external genitalia). Gender refers to one’s presentation in society (general body form, hair, clothes, voice, attitude and ways of behaving). **(P099, CAIS 61)**¹⁸

A view that both sex and gender represent a spectrum was expressed by some:

Sex is the biological description of oneself. I am XY female; however, there are many many other classifications (xx female, xy male, xx male, xo, xxy, xxxy etc). Gender is how one lives. Typically gender is a binary mould of male and female; however, we are evolving into more social labels such as androgenous, intersex, transgender etc. **(P005, Lesbian, PAIS 27)**¹⁹

I think sex refers to the physical continuum between the sexes and gender refers to one’s expression and presentation. I have come to believe that there is not a digital comparison between the sexes, but a spectrum between ideals that no individual actual[ly] meets (like Plato’s forms). Everyone is somewhere on that continuum, but most people are close enough to one end or another that they don’t see it for what it is and think there are two boxes to choose from... ..Gender is even more fluid and it seems to me that society is starting to accept that more and more, which I think is good... ..We have a long way to go but I am very hopeful for our society as things go forward and I’m excited about the future. **(P068 USA, Lesbian, PAIS 38)**²⁰

I think sex is not as fixed as people think. Sex is the poles. Gender is the tent. **(P103, Lesbian/Queer, PAIS 40)**²¹

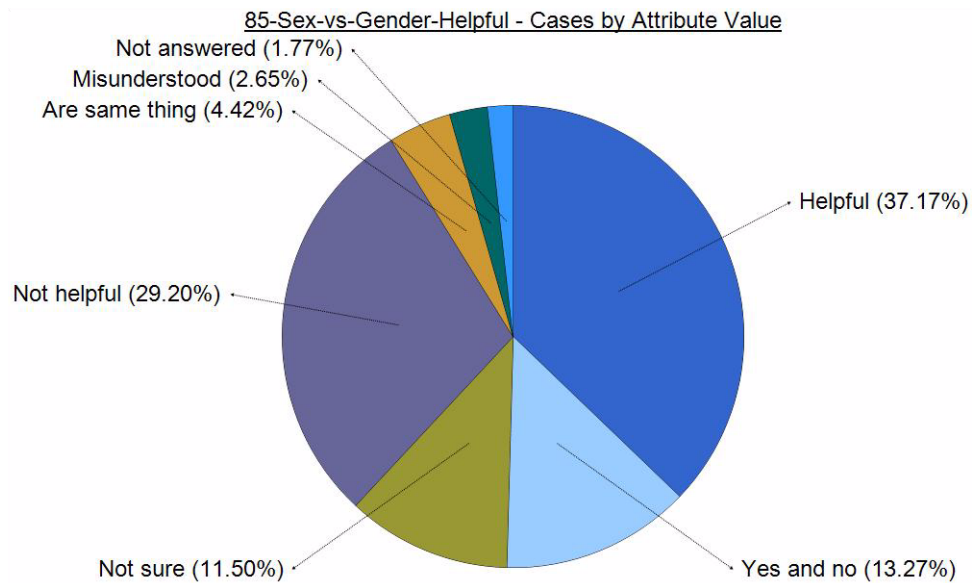
And some thought there could be a spectrum of genders, but stating or implying that sex was more fixed or limited:

Sex refers to reproductive activity and in my mind is quite specific, gender refers to a more general set of points which includes a host of different traits... e.g. this feature of my personality slots in with a “female” identity and this part “male”, so therefore people would inherently have a blend of gender-type characteristics. Sex seems specific, gender seems more vague and changeable. **(P058, CAIS 33)**²²

16. Had given differing values for own sex and gender up-front in survey.
 17. Had given differing values for own sex and gender up-front in survey.
 18. Had given differing values for own sex and gender up-front in survey.
 19. Had given differing values for own sex and gender up-front in survey.
 20. Had given differing values for own sex and gender up-front in survey.
 21. Had given differing values for own sex and gender up-front in survey.
 22. Had given differing values for own sex and gender up-front in survey.

Sex is the scientific distinction between the male and female of a species. Gender is the human construct of ‘man’ and ‘woman’ that society operates on. I do think that people considered male by the medical profession are entitled to consider themselves to be a woman and vice versa. I also feel that society is becoming more open to gender being less fixed. (P081, CAIS 31)

Later in the survey, at Q57, participants stated whether they thought the conventional distinction between sex (given as the biological features of male/female) and gender (given as the social aspects of men/women) was helpful to XY-women. The responses given by the study sample as a whole are summarised in the following pie chart:



Q57 - Sex vs gender helpful?

There were geographical differences but they were not statistically significant. A greater proportion of those in North America viewed a sex vs gender distinction as being helpful to XY-women (52%) than did those in the other two geographies (35% in UK and Eire, 14% in Continental Europe, Scandinavia, Israel and Africa). This may reflect the greater recognition of a difference seen earlier in the North American participants.

The six most heavily populated NVivo qualitative nodes²³ were: *Yes, with reason/s* (39), *No, with reason/s* (24), *Yes and no* (18), *Insightful comments* (16), *Chromosomes* (12), *Just 'No' or minimal response* (10), *Don't know or confused* (10).

23. See page 273 for the complete coding at this node.

A considerable number of participants explained why they thought a separation *was* helpful. Several thoughtful examples are quoted here:

Yes, clearly it is helpful to ALL humans, but it is woefully absent from the general population. The reason is simple: biology is NOT destiny. Let's play devil's advocate here with this question. (1) If sex and gender were the same, then many AIS women would have no place in the human realm. Specifically, the AIS women who know their gender is female would have no place in the human realm. That is both abhorrent and false. AIS women were born this way. (2) Similarly, if XY really did predetermine that you are male, then every male-gender-identified AIS individual with either a female phenotype, or an ambiguous phenotype, would also have no place in the human realm. AIS folks, indeed all DSD folks, were born this way. **(P062 USA, CAIS 52)**

Yes, to some degree. Frankly I think it relates to the issue of homosexuality too. If you think globally of everyone having a biological sex, that may or may not align with their gender ID, then it sort of normalizes the spectrum males and females and sexual orientation across the board. At a minimum, separating sex and gender in this way has helped me to realize internally with some sense of peace, that I can in fact be biologically male but socially female ...so yes, it helps. **(P069 USA, CAIS 43)²⁴**

Yes I think that this distinction is justified and helpful. I consider my sex to be female although I am now comfortable as having some male biological features. I consider this quite a separate part of my identity from my gender identity as a woman. I might have had testes but I don't hesitate about which public toilets to use! Considering the biological aspects of myself analytically and to an extent dispassionately has allowed me to come to terms with my condition without overly questioning my gender role in society. **(P081, CAIS 31)**

Participant P069 above seems to problematise the norms/assumptions of society by questioning what exactly defines a hetero- or homosexual relationship in the situation where sex and gender are fluid, and one or both partners may have an intersexed biology. Participant P081 displays a pragmatic view of the personal usefulness of the distinction, one that I imagined more of my study participants might have adopted.

Others thought a sex/gender separation was *not* helpful, and gave their reasons. Again, there was a range of different viewpoints that seemed worth representing here:

I see no difference in it. Physical appearance and biology and acting like woman go together. The difference is only in chromosomes in my case. **(P013 Estonia, Swyer 31)**

No – my sex is female and my gender woman – can you honestly say that you could put me into a male prison with my body and call me a man!!!! **(P033, CAIS 49)**

This separation is helpful only for a society that is still insisting on two sex. If there are a third or fourth or fifth sex this means that there will be a rainbow of Gender identities like the queer world we are living in. What makes my life difficult as an intersexed person is that two very hard categories so what would make life easier for Xy women is a more open society for more sexes and Gender identities and not necessarily the separation between these two. **(P043 Israel, Lesbian, 5-a-RD 36)²⁵**

No not really. At the end of the day we can't have children and I think that is the main way that people identify women as women. **(P064, CAIS 32)**

24. Had given differing values for own sex and gender up-front in survey.

25. Had given differing values for own sex and gender up-front in survey.

Not to me, it isn't. I don't think the definition works: in it, gender is partly based on sex, implying that gender cannot exist separately from sex, implying that gender is like clothes upon the sex of our bodies, implying sex is some underlying truth. (P082, *Queer*, PAIS 28)

I don't know that it makes any difference. All that really matters to an XY woman is how well she can adjust in her own mind and not lose track of who she thought she was before she knew the truth. (P097 USA, *Bisexual*, 17-b-HSDD 49)²⁶

No I do not feel this is helpful. If we are told that the above is the absolute truth then it makes XY women feel that they are frauds, because we do not fit neatly into those categories therefore we do not have a right to refer to ourselves as women. (P108, CAIS? 25)

For those with Swyer Syndrome, such as participant P013 above, there is perhaps more truth than in other diagnoses in saying that their *only* male attribute is their Y chromosome since they can have a uterus, cervix and full-length vagina, and gonads that are less differentiated in the male direction than in AIS, even referred to sometimes as ovarian-type stroma cells (see page 105).

Participant P033 shows some emotion in stating that the distinction is not helpful, and in doing so identifies explicitly as being of the female *sex*, but seemingly based on the external form of the body, disregarding internal structures, and in particular disregarding the Y chromosome that seems an important marker of sex for some. But are people really segregated into male and female prisons on the basis of sex (are their bodies examined and their sex chromosomes tested?) or on the basis of gender? Is it not the “cultural genitals” described by Suzanne Kessler that are checked here? In contrast to any physiognomy argument, participant P064 seems to invoke the lack of a biological *function* or *capacity* (infertility) as overriding any cultural case for gender taking precedence over sex, whilst participant P082 presents a rehearsal of an academic critique of the argument against a separation of the two categories.

The comment of participant P097 is also interesting in that she foregrounds the *pre-discovery* self-view or identity as an ideal, to be clung onto, yet at the same time refers to the gaining of diagnostic knowledge as knowing “the truth”, although seemingly not a truth that sets you free but one that imprisons you in falsehood. The reasoning behind the survey question was that an XY-woman might perhaps attain some conflict resolution by coming to recognise or accept her sex (genetic/gonadal) as being male and yet of no real consequence compared to her gender as a woman. Participant P108, however, seems to have turned this around, implying that the two categories have to be conflated, and termed ‘female’ (even in the presence of internal testes and XY chromosomes), in order to operate as a woman in society.

Amongst those who seemed somewhat ambivalent about the value of a sex/gender separation, one participant argued for broad definitions to be applied within the two categories:

26. Had given differing values for own sex and gender up-front in survey.

Yes because sexual features can often be allotted²⁷... although for people with some intersex traits it might be important to keep the definitions broad e.g. when would you define a large clitoris as being more like a penis? Are they actually different structures entirely and so should be named differently. For instance, did I have testicles or did I have gonadal structures that were more closely resembled testicles than ovaries but that would never actually have become either. I'm not trying to give an answer... I really don't know? Ummm like when you're classifying plant or animal species... when do you say that a pansy is no longer a violet or a courgette is not a marrow?? Gender also seems ok in this sense because you can call yourself whatever you want, of course the harder part is getting everyone around you to agree. **(P058, CAIS 33)**²⁸

Some here reasoned, as did others elsewhere, that both their sex and their gender, or those of XY-women in general, are female:

Now that you mention it, it might be helpful. But to be honest I believe it will only confuse people and cause more issues, because the way I describe myself is genetically male, but morphologically, mentally and emotionally female!!!! Thus I see my gender and sex as being female. But those are just terms because I see myself and CAIS as totally female! **(P085 S. Africa, CAIS 22)**

It could be. However, I still think that most XY-women would believe themselves to be female in sex and gender both. **(P091 USA, CAIS 32)**

So participant P085 above detaches sex from genetics, saying she is genetically male but is of the female sex.

Some made the point that any usefulness of the proposition depended on one's level of understanding, or the stage one is at, in learning about and dealing with one's condition:

In some ways yes, but I think this is more complex than that. It would take a lot of time to help and make XY-women understand these distinctions and the feelings they have inside. **(P008 Hungary, CAIS 36)**

I think it depends on the XY woman's sense of herself. If you have a strong sense of your own identity then you can rationalise gender/sex labels and descriptions. However if you are coming to terms with the implications of a diagnosis of AIS or related syndrome then there is no easily recognised/accepted third way that can make the realities of AIS less painful to understand. **(P073, CAIS 42)**

These responses highlight the difficulties in challenging an entrenched *medical* system of induction into these bodily states, one that doesn't allow for much thinking outside the 'realities' of biology. And some said they found it difficult to deploy the distinction in times of doubt:

It is a helpful way of looking at it. However, I find it difficult to hold on to this way of thinking when I am finding things harder than normal. Seeing myself as female is something I really struggle with - I often find myself worrying if am I dealing /thinking/ behaving with a particular issue in a male-like way. **(P102, CAIS/PAIS? 42)**

27. She possibly means labelled, fixed, or catalogued.... in a narrow or restrictive way?

28. Had given differing values for own sex and gender up-front in survey.

Or felt that the distinction wasn't appreciated in society at large:

Perhaps. But unless this is a common[ly held?] distinction then it doesn't help in being more open about the condition. **(P038, CAIS 18)**

I feel this would help XY women understand themselves but feel society would stigmatise said individuals. **(P061 Eire, ?Swyer 30)**

And some were rather dismissive of the proposition:

Yes/ no. Depends on how we perceive the information. Personally I'm unaffected by abstract intellectual constructs - life's too short. **(P052, PAIS 46)**

I think it is as useful to XY women as it is to XX women. I don't think the distinction is any more or less useful to XY females. **(P101, Lesbian, CAIS 31)**

Participant P101 above seems to reject the idea of XY-women being a special case.

Genetics was the focus for some participants. Here, some seemed accepting of the view that 'XY equals male sex' in chromosomal/genetic terms, but implying that once acknowledged this could be disregarded in practice in order to focus on gender, thus making the sex/gender separation helpful:

Yes, I think it probably is helpful to me, since it makes the whole thing less "black and white". The distinction allows for more flexibility. Biologically, in some ways which seem increasingly irrelevant, I am not a woman, (I'm thinking of those little chromosomes), but in terms of gender, without being particularly feminine, I feel very much that I am a woman. I've been reading the books of Richard Dawkins – The Selfish Gene....[etc.]. I've really enjoyed this and am still working at it. I might be genetically close to a male, but I'm also genetically very close to a chimpanzee. **(P054, CAIS 57)**

Yes, absolutely. I think I kind of explained above, but in my view, in the realm of sex, we aren't truly women.²⁹ I realize there are infertile XX women or XX women born without uteruses and vaginas,³⁰ I still consider them more female on the sex level than I am, because of the chromosomes, etc. On the sex level, they're thwarted women, while I'm a completely and utterly thwarted male. But in terms of gender (and I don't think that's just a social phenomenon but also has a great deal to do with hormones and response to hormones), I feel quite confident about my femininity. **(P096 Canada, CAIS 57)³¹**

I think that this distinction can help because it means that you can choose or be your own person no matter what biology or genetics say etc. In my opinion to XY women I think that sex does not matter but it is just gender that matters because it is what you believe you are that matters. **(P114, PAIS 16)**

Participant P096 above seems to acknowledge the failure to masculinise concept that was discussed in "The failed male" on page 124, and yet she's confident enough in her female gender to view that dispassionately. And maybe the response of the 16 year-old (P114) is an example of

29. She'd talked about her lack of body hair (e.g. in changing rooms at the gym) broadcasting the fact that she is "not a complete woman in terms of sex".

30. E.g. women with MRKH (defined in footnote on page 22).

31. Had given differing values for own sex and gender up-front in survey.

a new confidence in these matters in a generation that is benefiting from a new regime of truth disclosure and general openness.

Others here saw a problem with accepting a ‘male-sex-but-female-gender’ paradigm:

I don’t know that I would find it helpful. I would have a serious problem if that meant that someone would classify my sex as male just because I have a Y chromosome. **(P029 USA, Lesbian, CAIS 34)**

Helpful how? - No, as doesn’t that suggest we are only socially female but still genetically male? – The issue is the classification of sex via chromosomes alone in my opinion! **(P044, Swyer 39)**

I don’t find it helpful. I think XY women are female in both biological and in social terms. The biological features are more female than male because they include body form (female), secondary sex features (female breasts, female external genitalia, no male facial hair) and primary sex features (missing uterus and ovaries, undescended testes, short vagina, XY chromosomes). Altogether, it takes half a clinic to tell that she is not an XX woman. So in normal social context it is absolutely correct to identify her as a female in both sex and gender terms. The only terms of reference under which XY women are not female are the genetic aspects. **(P041 Hungary, PAIS 40)**

Participants P029 and P044 find a problem with the ‘genetically male’ idea, without involving other biological components, whereas participant P041 seeks to paint it out of the picture by foregrounding what she sees as the many female elements of her biological make-up. These three responses present an opposing view to that of the preceding set of quotes, which saw no problem with being “socially female but still genetically male”; and with participants P105 (in preceding set) and P044 (here) seeming to set out very similar scenarios and yet reaching polarised conclusions.

Summing up - Sex versus gender

Just over half (53%) of my participants thought that there was a difference between sex and gender, with another 12% saying they were possibly different. 24% felt that sex and gender were the same, with 11% saying they didn’t know or not giving a response. Some who said they were the same seemed to have misunderstood these questions about sex and gender as abstract *categories* and spoke of whether or not their own sex and gender were in alignment. As mentioned in “Sex and gender” on page 87 some 11% (12 participants) had also confused the meanings of the two terms when answering the up-front survey questions about their sex and gender. And some who had given differing values for their own sex and gender at the up-front questions, stated at the current question that the two concepts were the same thing.

There were statistically significant differences between the three geographical regions in terms of those saying the terms were different or the same, with North America showing the highest percentage (81%) acknowledging a difference, possibly reflecting the continent’s longer history

of feminist scholarship and/or more emphasis on sociology/feminism in educational curricula. The first women's studies courses were developed in the late 1960s in the USA, and although some courses were present in adult and higher education in the UK, it wasn't until 1980 that the first MA in Women's Studies was offered at the University of Kent, followed by other masters and undergraduate degrees elsewhere (Robinson and Richardson 1997: 4). Comments from one or two participants from Continental Europe indicate that some languages (e.g. Estonian) do not provide separate words for the sex and gender. And reference has already been made to issues in the French language relating to the term 'gender' (page 39) and to the use of the term 'sex development' in the new 'DSD' medical terminology (page 36).

Participants' definitions of the category 'sex' varied between those who focused on the sex chromosome designation (karyotype) and those who focused on external bodily appearance, in both general and genital terms. Participants also talk about the significance of their XY karyotype in other parts of the survey: in relation to medical terminology, in terms of what society expects of a women, as an item of diagnostic information, as contributing to a sense of being an outsider, and in relation to their gendered identity. What seemed absent at these survey questions, other than in a few cases, was much awareness of, or comments about internal anatomy (reproductive organs, including gonads). Maybe this is because the majority of participants had undergone gonadectomy so were no longer conscious of having (had) internal testes. However, these aspects were talked about to some extent at later questions (see, for example, "Acknowledging an intersex identity" on page 198).

37% of the study sample viewed the sex/gender distinction as being helpful to XY-women and 13% thought it was helpful with some qualifications ('Yes and no'). Some weren't sure (12%) and 29% thought it was not helpful, with some of these saying or implying that this was based on a view that both their sex and gender were female.

Whilst I do not have a control sample for comparison, I was surprised that a greater proportion of my study sample did not interpret the two categories as being different and view such a separation as useful in accepting or reconceptualising their situation. But such a position possibly pre-supposes that XY-women might accept a intersexed or male status in terms of their sex (their female gender not being in doubt in most cases) and this might be a step too far for many. A number of my participants seemed to take up a position of resistance towards the implications of these sex/gender questions, possibly indicating a reluctance to adopt the role of 'gender savant' discussed by Holmes.

As discussed in “Sex versus gender” on page 39, over the past 20-30 years a number of scholars in the feminist theory field (Butler 1990, Hood-Williams 1996, Delphy 1993, Hird 2000, Hird and Germon 2001) and social biology circles (Fausto-Sterling 1999, Diamond 2000) have questioned the validity of the sex versus gender distinction, with Butler and Delphy, for instance, positioning sex as a discursive product of gender. Ann Oakley, however, as one of the original proponents of the distinction, has robustly defended its usefulness. As feminism matures, she says, “gender slips uneasily between being merely another word for sex and being a contested political term” (Oakley, in Oakley and Mitchell 1997: 30), and she points out that now people are generally asked to declare their ‘gender’ instead of their sex on an application form (p.51). Whilst a distinction between sex and gender will be a familiar concept to sociologists – albeit one that is perhaps considered outdated in poststructuralist/postmodern terms – I am not sure of the level of awareness in society at large. The two terms are often confused or used interchangeably. The TV listings for a recent BBC documentary on intersex announced that in the broadcast “people born with ambiguous genders tell their stories” (BBC 2011). Surely one’s gender does not emerge until some while after birth? As intersex(ed) scholar Iain Morland quipped, one would hardly expect a midwife to declare: “Congratulations.... it’s a.... Conservative!” (Morland 2011).

It seems, in some senses, that those XY-women who insist that their sex, like their gender, is female are discursively producing or constructing their sex in the way proposed by Judith Butler. They are *proclaiming* their sex, based on their female gender and external morphology, and ‘writing off’ the internal reproductive anatomy (and genetics) that they were born with. However, it doesn’t seem likely that people in general who equate sex with gender as abstract concepts, or even the alleged ‘gender savants’ in my study who express this view, are reflecting knowledge of a particular brand of feminist gender theory (none of my participants referred to such theories) but more likely a ‘common sense’ or phenomenological view that if one’s bodily form/appearance, brain-sex, mindset, mannerisms, voice, upbringing, and social role are aligned to a particular gender, then one’s inner biology doesn’t seem quite so relevant in identity terms. The fact that the heterosexual and the Swyer Syndrome sub-groups appeared less likely to recognise a sex/gender difference than did the lesbian/bisexual and AIS sub-groups (although not statistically significant) may support this. Those are the two sub-groups that have the least reason to question what might be termed, respectively, a standard female sexuality and bodily status.

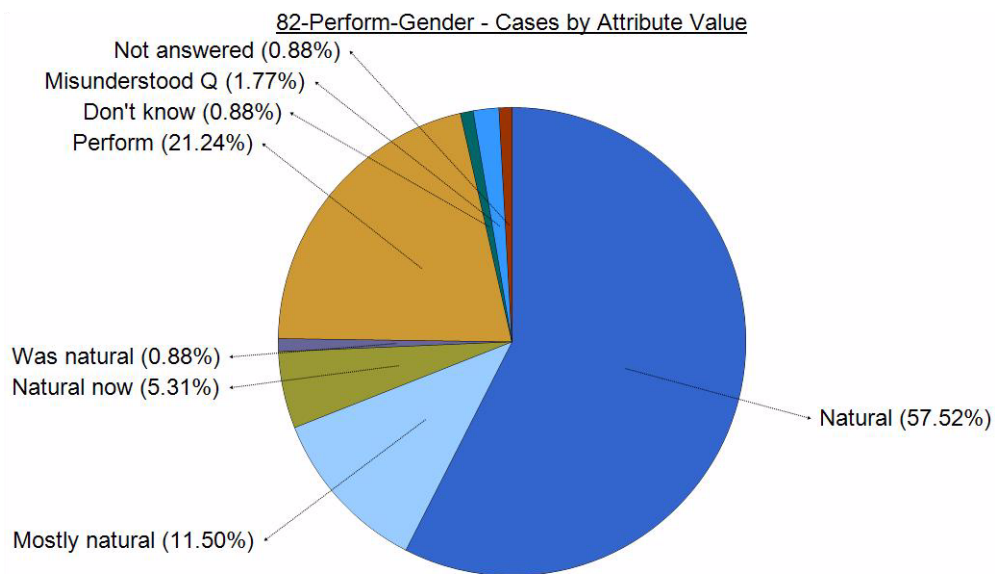
In conclusion, whilst some of my participants display an awareness of the sex versus gender split, there was considerable lack of recognition or knowledge of this, and less than half my sample claimed to find such a distinction useful. If one assumes that an understanding and acceptance of such a division is a necessary precondition to identifying as an intersexed woman,

then it doesn't seem likely that a majority of my study participants will be inclined to self-identify in that way. But that's a topic for later in this chapter. First, I want to examine whether XY-women construct their subjectivity at a more conscious level, with more reflexivity, than women in general. What role is played by self-surveillance and performativity in the formation of XY-women's gendered subjectivity. Do they discipline themselves and perform gender more consciously or vigorously than do XX-women?

Performativity

Probably very few of my participants will be familiar with Butler's somewhat subtle and complex use of the concept of gender performance, so they are likely, if at all, to talk of a more overt and conscious expression of gendered attitudes/behaviour, but it still seemed useful to identify those who may have felt sufficiently unsettled in their gendered sense of self at some point to warrant a degree of comparison with a perceived norm and of conscious performance.

At Q54 participants stated whether their gender came naturally to them or involved a degree of work, play-acting or self-consciousness. The responses given by the study sample as a whole are summarised in the following pie chart:



Q54 - Perform gender?

The table below shows that combining the 'Natural' and 'Mostly natural' data, there was a relationship to diagnostic group. Those with Swyer Syndrome appeared more likely to report some degree of gender performance than those with AIS, with the CAIS group showing the lowest awareness of this. This was statistically very significant ($p=0.003$).

Q46 - Performativity vs diagnosis

Diagnosis	Perform	Natural or mostly natural
Swyer (n=15)	47%	53%
PAIS (n=18 ^a)	39%	61%
CAIS (n=60 ^b)	12%	88%

a. Excludes 1 who misunderstood Q.

b. Excludes 6 who said “natural now”, 1 who said “was natural”, 1 who said “don’t know”, 1 who misunderstood Q, and 1 who didn’t answer Q.

A relationship to sexual orientation was also statistically very significant ($p=0.007$). The lesbian or bisexual group seemed more aware of performative elements than the heterosexual group.

Q46 - Performativity vs orientation

Orientation	Perform	Natural or mostly natural
Lesbian/bisexual (n=16 ^a)	50%	50%
Heterosexual (n=85 ^b)	19%	81%

a. Excludes 2 who said “natural now”, and 1 who misunderstood Q.

b. Excludes 4 who said “natural now”, 1 who said “was natural”, 1 who said “don’t know”, 1 who misunderstood Q, and 1 who didn’t answer Q.

The six most heavily populated NVivo qualitative nodes³² were: *Natural* (58), *Some performing* (23), *Mostly, or fairly natural* (17), *Natural with time* (11), *Avoid being feminine* (8) and *Non-standard genders* (7).

Many participants gave short responses stating that their sex/gender came naturally to them:

No, it comes naturally to me, I feel and act female. Ironically, I was called a “Goddess of Strength” by a male stranger in a pub a few nights ago. He was pleasantly drunk :-) (P001 Eire, CAIS 36)

Yes. I just see myself as having taken a rather roundabout route to becoming a woman. (P015 Germany, PAIS 52)

There was talk of a degree of performance, sometimes in a short response such as “I have never been self-conscious, but I always feel to be “acting” to some extent“, or “No it doesn’t [come naturally]. All three things [work, play-acting, self-consciousness] apply.“ or “Takes a lot of work trying to fit in“ or “It does not come to me as easily as I ‘perceive it would be’ if I’d had a

32. See page 272 for the complete coding at this node.

monthly period, and all the ‘normal’ aspects of being a women.“. Some gave a more expansive response, focusing, for example, on clothing:

As a gay woman, I tend to dress a more softer feminine style often. But I gravitate a bit more to the “middle” – a soft butch when hanging out with my friends. Yet, I won’t go all the way butch, because my AIS brain says stop, don’t give into my XY status, I’m not a boy! So I back up in my dress, my clothes, my style and soften back into a more female girly look at work and school! **(P027 USA, Lesbian, CAIS 53)**

If I have to act very feminine, which is rare these days, I feel a bit like I am in drag. So, yes, it involves work if I have to wear a skirt. **(P070 USA, Bisexual, Swyer 50)**

Or talked in more general terms:

To be fair no it doesn’t come naturally, I always over think everything and go over everything analytically to think of what I should of said or could of done. I often feel uncomfortable around other people and self conscious. I feel I stick out like a sore thumb and yet sink into insignificance at the same time... that I don’t matter but that everyone is staring at me. **(P058, CAIS 33)**

It doesn’t come totally naturally. Ever since finding out in my early teens that something was amiss ‘in that area’ I suspected an intersex condition, so I’ve always tried hard to appear feminine. I think this has held me back, in career etc., in that I have always been afraid to push myself forwards (a male feature?) and have tried to stay invisible, in the background, and to concentrate on academic things. **(P099, CAIS 61)**

The comment of participant P099 has echoes of ‘masquerade’, as discussed on page 49.

Those coded as mostly, or fairly natural tended to mention things that took the gloss off feeling totally natural, such as lacking confidence in their female appearance to others, or not fitting in with other women, or not knowing how to flirt, or having a competitive/ambitious streak at work. Some talked of their mode of operation seeming more natural with the passing of time:

When I was younger, in my late teens and early twenties I put on an act a bit, but now I am just myself (although perhaps that ‘act’ became natural and incorporated into who I am). **(P009, Bisexual, CAIS 51)**

Who I am comes to me naturally. When I was younger (11-16 or so) I was very paranoid and did a lot of acting and over-compensating, frightened that I was a freak. As I have accepted myself, I have become comfortable. **(P075, CAIS 34)**

It mostly comes normally, but I do playact some aspects - not as much as I did when I was young. In my 20s and 30s I did study and use how women talk about sex, fertility and menstruation among themselves. **(P097 USA, Bisexual, 17-b-HSDD 49)**

Some said that they did not take active steps towards being more feminine, such as wearing make-up or girly clothes. And there was some talk of feeling sometimes or somewhat “asexual” or “androgynous”, or of not having a standard gender:

Gender is very difficult for me. I don’t identify as either female or male and choose to think of myself as intersexed. Having said that, I do not try to make waves and keep my gender presentation just to the female side as to reduce the number of stares and sirs I get. **(P021 USA, Lesbian, 5-a-RD 47)**

I have just had a break: I started to write that maybe I have no gender. This isn't true I am a wife and mother, I play the female role all the time. I chose to do that. I want to do it. But I do find it hard and I do feel a fraud at times. (P024, Swyer 44)

My gender is female, only because I let it be female...but it could as easily be male if I had a penis. In a sense, I feel above genders...and my female gender comes with a little bit of play-acting only in rare selected situations (when I am among an all-female group, which is rare since I am not into female conversations). I am aware of how much of a construct gender is; but I don't make much effort trying to fit a particular gender. I am rather confident about my look and who I am as a person. (P039 France, PAIS 38)

Summing up - Performativity

Most of my participants (58%) said that their gender came naturally to them or was mostly natural (12%). A further 5% said that this had been more the case as they got older, having 'performed' more at the time immediately following their diagnosis. In cases where there seemed to be any doubt expressed, the person's response was coded as 'Perform' (21%). The statistically significant tendency for those with a lesbian/bisexual orientation to be more aware of a performative element may be a reflection of a greater sensitivity to sex/gender norms in that group. It is not quite clear why those with Swyer Syndrome should feel that their gender comes less naturally than those with PAIS and CAIS, unless it is related to the greater significance that they seemed to assign in this survey to biological attributes such as XY sex chromosomes (see page 150).

An appreciation of performative aspects of gender amongst my participants could represent a useful liberatory awareness that helps to decouple identity/behaviour from biology, but it could also signify 'work' involving excessive self-surveillance. As discussed in "Self-surveillance and performativity" on page 47, theories of gender performativity, such as that of Butler, refer to performing in accordance with a *script* which provides us with ideals of masculinity and femininity that render certain behaviours appropriate and others not. As also discussed there, the early work of Garfinkel in relation to transsexuality is often quoted by scholars studying gender performativity. However, XY-women, unlike male to female transsexuals, already have the appropriate female body form, general habitus; and social upbringing; it's just their internal anatomy (and perhaps a larger than average clitoris in some) that's out of alignment. Nevertheless, they may still try to be, in Garfinkel's words, "120% female", and to undertake actions so that they are "specifically unremarkable and seen to be in accord with culturally approved standards" (West and Zimmerman 2002), a self imposed regulation of behaviour reported also by Diamond and Watson (2004) specifically in relation to CAIS women. There, 22 out of 39 CAIS women said they had to "work at being a woman" at least some of the time, with 12 of those saying it was something they had to do most of the time, by arranging details of their appearance/behaviour to signal "female" unambiguously.

The intersex woman

Increasingly, women with Complete AIS are wanting to keep their testes. So testes... the presence of testes... is now compatible with womanhood, with femininity. Fifteen years ago, when I came into this field, that was... inconceivable. I think that the fact that women feel that having testes is actually compatible with their femininity is really, really exciting.

Lih-Mei Liao (Consultant Clinical Psychologist, UCLH)³³

It could be argued that the ultimate goal of a personal recognition of one's intersexed nature might be a status of 'intersex citizen', in which an individual is totally open and 'out there' with a declared intersexed identity and perhaps expecting, claiming, or fighting for certain associated rights. However, this could be a step too far for most of my participants. Whilst there will be some PAIS individuals in the XY-female population as a whole who were assigned as male at birth and could experience problems in getting their birth certificate changed to female (it's easier to achieve this, in the UK at least, if one is transsexual than if one has an intersex condition), such 'rights' are not something that affect my participants, unless one talks of a right to be given full diagnostic information and a related right to be offered informed consent in the case of gonadectomy. I am more interested in a part-way stage where XY-women might merely be supported or sanctioned by society in giving a greater acknowledgement to, or developing a less problematic relationship with their intersexed biology.

Negotiating male biology

Before questioning participants on a possible intersexed status I asked them to focus on the male elements of their make-up and talk about the challenge of reconciling these with their female phenomenology. At Q51 participants explained how they thought XY-women incorporated the biologically male aspects of their make-up – specifically their XY sex chromosomes and internal testes – into their sense of self, either in a positive or negative way. The six most heavily populated NVivo qualitative nodes³⁴ were: *Ignore or deny it* (24), *Difficulties* (22), *Identity issues* (16), *Deeper insights* (15), *Support group* (12), *Time or age helps* (12).

There appeared to be several ways in which some participants distanced themselves from their hidden male attributes. Two particular strategies seemed to involve either an *ignoring* or a *denial* of such features. For some, the male aspects of their foetal origins appear potentially troublesome, so they actively *deny* them:

I don't know. I think it is so difficult that what has worked for me the best this far, is simply some state of denial. You can't combine that knowledge with feeling like a woman, I would say it is impossible, since the above mentioned things are so typical for man. (P046 Demark, CAIS 27)

33. Speaking in US version of BBC documentary. See 'BBC (2011)' in Bibliography.

34. See page 269 for the complete coding at this node.

I think that most XY women only think about it at AIS annual [support group] conferences and choose to not think about it during the rest of their lives. I think it is second nature for most XY women to push this part of themselves into the corners of their mind as a defense mechanism. I am constantly aware of it and have been since I learned the truth 11 years ago. **(P002 USA, CAIS 29)**

One participant, who up-front in the survey had given her sexual orientation as: “Lesbian/queer - married to a woman - have had relationships with both sexes”, said:

I think there is a degree of denial and DSD³⁵ feeds this. As a queer AIS [person] I feel a bit like the wicked witch at the ball - reminding the straight [XY] girls and their husbands that midnight is approaching. **(P103, Lesbian/Queer, PAIS 40)**

So she seems to be saying that her openness, as an XY-woman, about her sexuality may be perceived by others as an unwelcome reminder of their intersex status.

For some participants, the male aspects – particularly the Y chromosome – were claimed to be of no real relevance; so for them it was perhaps a case of *ignoring* rather than denying:

I personally do not incorporate this into my sense of self. This is an aspect of my anatomy, but it's not superficial, and I can't see it, so as far as I am concerned, this is not an important part of my condition, or my life. However; I have met a number of women through the support groups etc, who find this information a conflicting force, creating a lot of confusion about who they are, and who they could (or perhaps should) have been. I can understand this reaction on the surface, but I can-not relate to it, maybe because I have never felt remotely male, and have always felt wholly female. **(P098, CAIS 24)**

Personally I don't connect it in terms of my sense of self - I see it as a waste of time to get hung up on the xy thing - out of my hands. My sense of self comes from being around my partner, friends and family. I guess I ignore it. **(P052, PAIS 46)**

Others rationalise the male aspects as having been rendered ineffective by the very nature of their condition:

Well, it depends on the XY woman. For me I regard them [male aspects] as being, not irrelevant, but definitely shut off or made inactive by other factors, by my androgen insensitivity. **(P096 Canada, CAIS 57)**

So here we have another challenge to the significance of the Y chromosome in governing maleness, with an understanding that ultimately it is hormone action that governs what path the reproductive system follows, in foetal life and thereafter.

Some articulated difficulties or conflicts with the knowledge of ‘maleness’ within, either in general terms:

I have married CAIS cousins who have not disclosed their condition to their husbands which leads me to think their view of themselves is unresolved and laced with shame. **(P025 USA, CAIS 55)**

35. Disorders of Sex Development, the new term put forward in 2005 to replace the archaic hermaphrodite-based medical terms, and used by some also to replace the term ‘intersex’.

Or referring specifically to male genetics and/or gonads as being problematic:

Even though the chromosomes and testicular tissue are not visible or obvious to anyone else, and they would never know about it unless I told them, I still feel that everywhere I go, everyone who lays eyes on me knows I'm different somehow. **(P090 Canada, CAIS 28)**

It's hard to know that society refers to humans [as] men or women concerning their Gonads or chromosomes since if it's like this I don't fit anywhere. **(P043 Israel, Lesbian, 5-a-RD 36)**

I can only really talk about myself, but I think having a clear definition of sex and gender is fundamental in identity and self as a whole. To be told that you are not normal and that something so key as sex on a genetic level is wrong is very hard to take in and assimilate in a positive way. So, yes, I think it would definitely be part of who you were though probably in a negative way. **(P050, CAIS 29)**

Some focused on the attitudes of other people; such as the media, sexual partners or doctors:

I don't think many of us incorporate that knowledge in a positive way. We struggle with viewing ourselves as freaks, which is definitely supported by sensationalism in the popular press. Many also struggle with self-esteem with regard to sexual partners, fearing they will be rejected or humiliated if their partner knows. **(P097 USA, Bisexual, 17-b-HSDD 49)**

We are survivors and although sometimes thru low self esteem get involved with totally unsuitable partners i.e. men who are perhaps drawn to us for some unexplained maleness and usually turn out to be nasty (or is that us just seeking love and affection from any quarter? I'm not going to dwell on it). **(P055, ?PAIS 46)**

With difficulty. And this can be complicated by the response of professionals – my G.P. casually remarked, “I expect you thought you were a girl when you were growing up”. I was astonished but not ready to respond. He spoke as if I were some kind of specimen. I can remember [him] casually continuing: “Ah yes, genotype male, phenotype female”, which is accurate, but not, I felt, very appropriate at the time. **(P054, CAIS 57)**

Some focused on problems with *identity* in relation to the male aspects of their make-up:

If CAIS is to be described as a condition/disorder then I believe that, more than any physical development issues, it is a condition/disorder of ‘identity crisis’. **(P031, CAIS 59)**

I know that in my case, it has caused me to see myself as an outsider of sorts... ..I have a very twisted view of my self. I have little or no self-esteem, I am to some degree anti-social. I am a very unhappy, unfulfilled person. I don't necessarily think that it is entirely because of my diagnosis, but I can't help but feel that it has something to do with me feeling this way. I have no sense of purpose, direction, ambition... I really feel like I don't know who I am entirely. **(P090 Canada, CAIS 28)**

I think it usually has a significant effect on XY women's self-view, by de-stabilising their identity, setting them apart from much of humanity etc. They may feel a bit special (angels, supposedly androgynous, are sometimes mentioned as coming to mind at diagnosis) but the negative effects of society's taboos on sex/gender categories outweigh any positive psychological factors. **(P099, CAIS 61)**

However, there were expressions of equanimity or resignation concerning the effects on identity.

It's just a matter of acceptance and then learning to live with the new you as who you really are. **(P057, CAIS 40)**

We tend to cobble our identities together like a patchwork quilt. We take a little of what works and fake the rest. **(P066 USA, CAIS 49)**

Since I truly never found it an issue, it's only been a minor part of my makeup... ..Being a feminist in the 70s made more of an impact on me than this did, but it also helped me become more open about the condition... ..But my sense of self has never been dictated by my chromosomal mutation. **(P076 USA, CAIS 57)**

Some of the above participants, e.g. P057 and P066, touch on the postmodern notion of a narrative or discursive construction of subjectivity, a fragmentary as opposed to a unitary concept of identity, whereas others show a more passive or 'determined' view. Participant P057 talks of the post-disclosure subject as being "who you really are", in contrast to the advice given at Q57 by participant P097 who said that an XY-woman should not "not lose track of who she thought she was before she knew the truth". Participant P076 provides a rare (possibly the only) instance in this survey of feminism being cited as having had an influence.

Some expressed a *positive* view, and talked about this in some detail. One participant, who elsewhere in the survey expressed relief at having escaped genital surgery, has a lesbian sexual orientation, and is 'out there' (on the web etc.) as an intersex woman, described her confident attitude. She liked being "outside those boring old boxes" and didn't go out of her way either to conform to, or to buck the system of female tendencies/behaviour that society often forces her into. XY chromosomes and testicular tissue just didn't affect day-to-day life for the most part, but she added:

It's lonely a lot of the time because no one gets you (hell, even other intersex people may not get you), but it is what it is. I like being outside of things and living on my own terms. At this late age, I wouldn't trade it for normallacy under any circumstances. **(P068 USA, Lesbian, PAIS 38)**

Another participant described a more tentative yet positive approach. She'd gradually realised she had been in denial for most of her life, but the blurring of societal gender roles had given her more freedom to experiment with thoughts and behaviour without fearing they might appear too masculine/feminine. She now enjoyed thinking about things such as whether or not she'd have thought differently had she been "a normal XX" or "a normal XY", and added:

I feel a much happier mixture of gender roles now, and can now simply be myself, and don't have to try to appear more one thing or another, and don't have to try to appear normal – many people aren't - for lots of different reasons – not just AIS! **(P093, CAIS 48)**

One participant had come to accept and be proud of her XY status, partly through an interest in genetics and evolution, and felt her condition to be a blessing. To have been born male was an alien idea, but she couldn't say if she'd have been happier as an XX-woman. She was an XY-woman who felt 'different' because of her chromosomes, but not always unhappily. She added:

I feel that as a result of my gonadectomy I never got the chance to really incorporate my testicular tissue into my sense of self, but I do feel that my testes did the best they could! **(P081, CAIS 31)**

Some further responses were noted that seemed to provide deeper insights. Yoga and meditation was cited by one participant as having (unintentionally) been useful. She'd come to distance herself somewhat from her body, which was "not independent of my-self but not identical with my-self either... ..my-self is not equal to the sum of all my body parts... ..[it] is the mother of my body, so I love it along with all its imperfections". She was one of the five participants who still had their internal testes, and commented:

This [yoga/meditation effects] proved to be therapeutic after I was diagnosed with testes and XY chromosomes. Moreover, I started to respect my testes: they cooperate with the rest of my body, produce useful hormones of which a small part is absolutely accessible and essential for other body parts. **(P041 Hungary, PAIS/CAIS 40)**

Some turned to medical discourses to deflect the impact of male attributions, challenging the supremacy of genetics by finding positivity in the notion of a lack of male hormone action allowing femaleness to manifest:

Initially, I found the fact that all fetuses start out "female" very reassuring. I also tried to imagine that I lived 100 years ago before we even contemplated chromosomes. I'd just be the barren lady down the road in the purple cottage. **(P053 Canada, CAIS 54)**

I didn't want to believe it at first, but that was because I had been educated at school that females are XX with ovaries and males are XY with testes. They hadn't taught us about all the other varieties of sex at school... ..A few months later when I learned that my body can't respond to male hormones, though most normal XX women do respond to male hormones, and they are therefore more masculinized than me, and some people said I'm the most feminine person it's possible to get, I felt OK.. ..My only regret was that the testes had been taken out without my informed consent. I wish I had my testes for longer! **(P074, CAIS 29)**

Some adopted a stoical approach. One participant talked of it not being the worst thing that could be, that she had to remember to "get over myself", that "I am still just me", and that people cared more about her actions than whether or not she has a womb, or had working testicles or ovaries ("who cares, they didn't work either way??"):

In other words it's ok for people to have an understanding of what makes me tick but I can't "use it as an excuse". I still have to have a rounded life and personality whatever is different about me. **(P058, CAIS 33)**

Work with a professional counsellor was also advocated, to work through the knowledge and the emotions, together with meeting other AIS women, which was described by one participant as "fundamental and foundational" and which forces the person to "get out of your own head for a while to help others cope". She commented on others affected as follows:

For others, I think that they either increase their acceptance, or they choose not to incorporate it and they fight it. I see many AIS women try to "intellectualize" their way through it with reading on the topic, and discussing details of the syndrome, etc. I also see other women trying to self-soothe with increased secrecy and denial. What I mean is they treat the support group like a bubble. Now they're hiding behind a group of AIS women, instead of hiding behind themselves. **(P062 USA, CAIS 52)**

Others too mentioned a support group³⁶ as playing a part in their dealing with their condition:

The other XY women I met when I went to the AISSG meeting... at least the more mature ones (quite a few had just found out about their condition recently), seemed very confident, self assured, and secure in their lives, though I understood that it was only after a great deal of personal struggle they came to feel that way. They struck me as very well-adjusted, happy people. **(P090 Canada, CAIS 28)**

I struggled at the AISSG meetings as I found them too depressing. I think that XY women that I've met fail to see that they can be "normal" women and have huge issues about their own sense of self. **(P106, CAIS 34)**

An increasing acceptance with time, or with age was also mentioned:

Today, my having AIS is no longer the big big thing it once was. My job, my health, my happiness all those are more important life factors than having this rare genetic syndrome. For me, having AIS is no longer the elephant in my living room when dealing with friends and family. It's not going to kill me, and after years of therapy and counselling, I'm truly okay with being intersexed and infertile now. **(P027 USA, Lesbian, CAIS 53)**

This syndrome made me self reliant and strong willed and independent. It has taken 40 years however. We are unique, strong and quite often self assured. **(P055, ?PAIS 46)**

I have a feeling that when you are first diagnosed, are [and?] first become aware of the differences, you find it very difficult to understand who you are, and it is only with time and self awareness that you discover who you really are, and maybe come to terms with your condition, however I suspect there are many who never do. **(P063, Bisexual, 5-a-RD 48)**

Summing up - Negotiating male biology

A number of participants expressed difficulties here with knowledge of their XY status, and had made negative comments earlier in the survey about being labelled as 'genetic males' by medical terminology and had mentioned their karyotype as being an issue in other places; e.g. as biological diagnostic information, and in terms of what society expects of a women. Many had, with time, reached a more easy relationship with the knowledge, but for many, as for society as a whole, the Y chromosome holds considerable power as a signifier of maleness; a small and nebulous 'entity', and yet one that carries so much symbolic potency. Feminist writer Germaine Greer has expressed the view that its presence in CAIS individuals precludes any entitlement to womanhood (Greer 1999). But as discussed on page 55, Denis Noble has pointed out the fallacy of adhering to a reductionist principle that ascribes supremacy to lower-level causes such as genes (Noble 2008). And Antoinette Rouvroy describes in Foucauldian terms how the 'new human genetics' is, above all, a *perceptual* revolution, by tracing the gene's original conception as being more of an idea or a metaphor than a thing or an entity (Rouvroy 2007). She talks of a problematic privileging of genetics over the rest of biology. And there is recent biological research that challenges the primacy of X and Y chromosomes in directing sex development at

36. The issue of support was aired at Q58 but this is one of the questions set aside for future analysis (see page 70).

all (Uhlenhaut et al 2009, Sinclair and Smith 2009). And even under the traditional scheme, those with AIS often forget, or are unaware of the fact that it is actually their X chromosome (specifically a mutation on its androgen receptor gene) that has had a much greater effect on their biology than their Y chromosome.

XY-women often appear to find awareness of their karyotype more threatening than that of intra-abdominal testes, in terms of what they are prepared to divulge to others, for example, although for some it's the reverse. But whilst the presence of a Y chromosome can be hugely significant for many XY-women, this is probably rarely accompanied by any degree of understanding of the complexities of chromosome/gene structure/operation at a molecular level. Intra-abdominal testes, on the other hand, perhaps have a more clear-cut psychic presence in the minds of these individuals. Most people probably have a more acutely defined mental picture of the form, function, and usual location of ovaries and testes than they do of genetic elements.

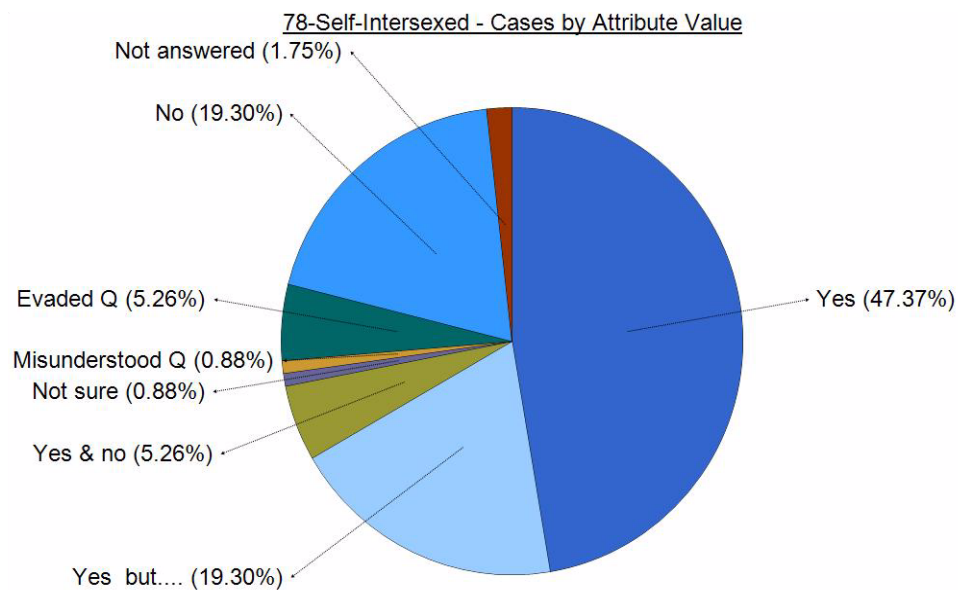
With regard to testicular gonads, it is probably the case for some XY-women that these represent unwelcome 'foreign' organs which don't belong in a woman's body. And this is certainly a likely subtext to the cancer-scare rhetoric (if that's not too strong a phrase) of doctors when recommending gonadectomy surgery. Some XY-women do express relief at 'getting rid' of their testes at gonadectomy, and in doing so may be referring to the banishing of the small cancer risk or to an expurgation of the maleness they represent, or both. The parallels with Margrit Shildrick's observations of organ transplant patients, discussed in page 57, are not exact in as much as in XY-women the organ in question (testis) is only foreign by *embryological* or *gestational* 'transplantation', and the attempted restoration of an originary sense of self is a reason (sometimes advanced) for *removal* of the organ. But the issues of identity in relation to a hybrid embodiment would at least seem directly transferable to the intersex situation. One could even say that the 'transplant' takes place in the mind of the XY-woman, at the time of discovering her diagnosis; and we could use Shildrick's arguments in reverse, and ask to what degree can the *removal* of a naturally acquired ('congenital') organ that is viewed as foreign be considered to restore an originary sense of self?

Acknowledging an intersex identity

Most individuals with conditions such as CAIS or Swyer would probably say that their gender is female, but some might have problems defining their sex. Is this female on the basis of external morphology? ...or intersexed on the basis of the mismatch of this with certain internal organs and subcellular components? ... or even male on the basis of genes and gonads, and disregarding phenotype? It is likely that most XY-women, especially those who are heterosexual in

orientation, might actively distance themselves from any idea of masculinity in their make-up and might not be very interested in political identifications/agency. But it's possible that some degree of acknowledgement of their male biology might help them to reach a more satisfactory acceptance of their status? Whilst the social construction of gender can in many ways be seen as a useful strategy in their lives, they nevertheless have to come to terms with their unusual biology and in many cases this is not achieved in an entirely satisfactory way, resulting rather in a dismissal, denial, or abjection of their intersexed 'nature'. Arguably, an *intersex* identity which de-stabilises the male/female binary, and challenges Freud's notion of lack, might prove more positive and/or authentic for those affected.

At Q48 participants stated whether they considered themselves to be intersexed, based on a definition involving a male/female cross-over of any of the three things (sex chromosomes, gonads, external genitalia) said to determine sex (and not necessarily meaning ambiguous external genitals). The responses given by the study sample as a whole are summarised in the following pie chart:



Q48 - 'Are you Intersexed?'

Those coded as 'Yes but....' had stressed that they were also female or felt female, or that they would never publicly acknowledge that they were intersexed, when filling in official forms etc.

The table below shows that those in N. America seemed more likely than those in the other two geographies to agree outright ('Yes') that they are intersexed, as opposed to denying it ('No'). This was statistically significant ($p=0.032$).

Q46 - Are you intersexed? vs geography

Geography	Yes	Yes but...	Indecisive^a	No
N. America (n=31)	58%	26%	6%	10%
UK & Eire (n=67 ^b)	46%	16%	17%	19%
Europe, Scandinavia, Israel, Africa (n=14)	29%	21%	7%	43%

a. Sum of the 'Yes and no', 'Not sure', and 'Misunderstood Q' and 'Evaded Q' responses.

b. Excludes 2 who did not answer the Q.

If the 'Yes but...' responses are included with the 'Yes' responses, the differences remain statistically significant ($p=0.034$).

Those with a lesbian or bisexual orientation seemed more likely than the heterosexual group to agree outright ('Yes') that they are intersexed, as opposed to denying it ('No'). This was statistically significant ($p=0.021$).

Q46 - Are you intersexed? vs orientation

Orientation	Yes	Yes but...	Indecisive^a	No
Lesbian/bisexual (n=19)	84%	0%	11%	5%
Heterosexual (n=92 ^b)	40%	23%	13%	21%

a. Sum of the 'Yes and no', 'Not sure', and 'Misunderstood Q' and 'Evaded Q' responses.

b. Excludes 2 who did not answer the Q.

The heterosexual women seemed more likely than the lesbian/bisexual group to give a 'Yes, but....' type of response, and if the 22 heterosexual women who responded thus are included in the 'Yes' group, then the differences become statistically non-significant ($p=0.082$).

Those with PAIS seemed slightly more likely to agree outright (statistically not significant) that they were intersexed (58%) than did those with Swyer (47%) or CAIS (45%). CAIS showed the greatest proportion responding with "Yes, but...." (27% compared to 11% for PAIS and 7% for Swyer). 20% of those with Swyer evaded the question (3% for CAIS and 5% for PAIS).

The six most heavily populated NVivo qualitative nodes³⁷ were: *Just 'Yes' or minimal response (32)*, *Yes, with reasons (28)*, *Yes, but also female (17)*, *Reluctant yes (13)*, *Just 'No' or minimal response (12)*, *Yes, but not in public (7)*, *Feel female (not intersexed) (7)*.

37. See page 266 for the complete coding at this node.

In those who gave reasons for agreeing that they were intersexed, emphasis was placed by many on outward appearance (phenotype) contrasting with chromosomes (karyotype), often disregarding internal genital anatomy (testes):

Yes, I am intersexed in the aspect that I live as a female, but I have XY chromosomes (AIS). **(P005 USA, Lesbian, PAIS 27)**³⁸

Yes. I do not have ambiguous [external] genitals, but my phenotype and genotype are opposite. I am a conundrum. I am between sexes because I do not fit into a particular box that society has been taught to provide. **(P024, Swyer 44)**³⁹

Because of a genetic failure I turned out as a woman, except for the fact that I am infertile I consider myself as a woman. The combination of chromosomes and of what I look like and feel who I am does however make me intersexed in a medical sense. **(P047 Belgium, CAIS 36)**⁴⁰

Intersex can refer to chromosomes, so yes I feel intersex. Even though my body is supposedly externally female it is such because of hormones. Take those away and my true nature is intersex. **(P070 USA, Bisexual, Swyer 50)**

Others gave more acknowledgement to internal structures:

My genitals were not ambiguous, I had a very shortened vagina and enlarged clitoris, no ovaries, and rudimentary testes. Yes I fit the terminology and diagnosis for intersex. **(P020, PAIS 50)**

Huh???? Yes, I'm intersexed. My indoor plumbing doesn't match the outdoor plumbing. My sex and my birth certificate do not match my chromosomes. But hey, chromosomes weren't even discovered until 50 years ago, and I'm pretty sure that for the past hundreds of years, people weren't confused on who was the girl or the boy.... **(P027 USA, Lesbian, CAIS 53)**⁴¹

I definitely consider my[self] intersexed. Internally, all physical characteristic were stereotypically male: XY chromosomes, testes and vas [deferens], and androgen production (minus of course enough testosterone for complete development). Externally, I was female looking at birth, developed breasts at puberty, and did not have an excessively large clitoris (I didn't think so). However, the endocrinologists described my labia as partially fused and scrotalized, and my clitoris as enlarged. **(P097 USA, Bisexual, 17-b-HSDD 49)**⁴²

Some accepted the proposition but commented on the term 'intersex':

I am growing to hate the word intersex. It suggests "between", or both, or indeterminate. And since both doctors and the general population use "sex" and "gender" interchangeably, that's a big problem. At the most literal, physical level, I guess I am intersexed. My phenotype (completely woman) and genotype (XY) are different. I had internal testes, but have fully functioning female bits (vagina, clitoris). So, "intersexed" is a factoid about my physical body. I am female. That's my self-reality. For me, gender trumps sex – in this semantical exercise. I know that I'm a woman, and I always did. Full stop. **(P062 USA, CAIS 52)**

Yes, I am intersexed because although I (had) testes, and am XY, my body doesn't respond to androgens and externally I look more female. I really like the term "intersexed" because it describes not only who I am, but what I am. **(P107 USA, CAIS 50)**⁴³

38. Had given differing values for own sex and gender up-front in survey.

39. Had given differing values for own sex and gender up-front in survey.

40. Had given differing values for own sex and gender up-front in survey.

41. Had given differing values for own sex and gender up-front in survey.

42. Had given differing values for own sex and gender up-front in survey.

43. Had given differing values for own sex and gender up-front in survey.

XY-women in my study seemed willing, as does participant P062 above, to list separately the various individual conflicting attributes that make up an intersexed biology but recoil at categorising them as a whole under a term suggesting a position between two poles. This seems similar to the way in which XY-women might talk about individual aspects of their female constitution, such as infertility or vaginal hypoplasia, in terms of deficiencies, yet be unwilling to adopt an overall identity as a ‘disordered woman’.

One participant used the ‘female as default’ medical discourse in her response:

I consider myself intersexed. I was designed to be male but not destined to be. I am female because anyone who fails to become male is female by definition and default. **(P111 USA, Lesbian, PAIS 42)**

Some agreed that they could be defined as intersexed but made a point of stressing an accompanying femaleness:

I guess yes if you put it as simply as that, I have ‘male’ sex chromosomes and had internal gonads, although externally am female. **(P064, CAIS 32)**

According to society and its need to provide definitions, I am intersexed. I know there are conditions that are controversial [not so clear cut, i.e. with ambiguous genitals?], but in my case I am what I feel I am. I look, I feel, I live, I love like a woman and I am attracted to men, therefore I am a woman, despite my chromosomes. **(P084 Italy, CAIS 41)**

A number of participants seemed to concede that they could be classed as intersexed, but with some reluctance:

That’s what they tell me—but I still don’t like saying it. **(P012 USA, CAIS 70)**

I suppose in theory yes, but its not a term I like or would ever use. **(P036, Swyer 19)**

I assume so but I am not intersex if that makes sense. **(P055, ?PAIS 46)**

Technically yes. But I do not identify that way. I simply feel that I am me, and female. **(P075, CAIS 34)**

Yes if that is the definition. **(P081, CAIS 31)**

Some conceded that they fitted the definition but would never make a public stand on that basis:

Yes, by the definition of the word, but I am also female and will never tick the intersex box should it ever be presented to me on an application form! **(P001 Eire, CAIS 36)**

Before joining the support group, had I known the term, I would have been unable to consider myself intersexed. But following a lot of discussion within the group I’m now comfortable *in that environment* about being considered intersexed. However I have not used that term outside the group other than in one scenario. I attended group therapy for a few years in order to practice ‘telling people’. When I used the term intersex the other participants were shocked/appalled on my behalf to such an extent that I felt I couldn’t use it again. **(P031, CAIS 59)**

I would say that I am intersexed purely because I was born with gonads and XY chromosomes but I’m so clearly a woman, however I would never make a big deal of it (like I’m sure some would) when completing forms, etc where I’m asked if I’m Male or Female. **(P106, CAIS 34)**

Some of the above responses back up the observation that a greater number of survey participants are prepared to concede to being intersexed at this question than gave a ‘non-female’ response for sex at the earlier demographic question asking for their sex and gender (see page 85). It is also interesting to note the way in which some (e.g. P064 earlier and P106 above) use the single word “gonads”, unqualified, to refer to their internal testes (as opposed to saying “male gonads”, which I think is what they mean). They, and others who use the term in this way, seem to have absorbed from doctors the use of what is in fact a *generic* term for ovaries and testes, as a somewhat oblique way of referring to *male* organs.

Some used the fact that they *felt* female to imply they could not rationalise being biologically intersexed yet socially female (without in many cases actually giving an opinion on the ‘intersexed’ proposition):

I am unique female, a little different than other females, but a complete female nevertheless. (P011 USA, Swyer 22)⁴⁴

Im female, with issues..? lol (P040, PAIS 25)⁴⁵

I am female. That’s what I feel inside. Its how I think and its who I am. (P042, CAIS 22)

Personally, I do not feel intersexed. I know what my sex chromosomes say and that I once had gonads, but as I said before, I feel totally female. (P100 Canada, CAIS 68)⁴⁶

No – in my mind I am female – I try not to think about my Y chromosome. (P102, CAIS/PAIS? 42)

In focusing on feelings, these participants seemed either to have misread the question or to have been unable or unwilling to consider the proposition on a conceptual level, even though two participants above were amongst those who, in the demographic sex and gender questions early in the survey, had given a sex that did not match their stated gender.

Summing up - Acknowledging an intersex identity

A higher proportion of my participants appeared willing to accept an ‘intersex’ label at this question than when volunteering their sex and gender up-front in the survey. As discussed in “Sex and gender” on page 87, the vast majority did view their gender as female at the up-front questions, but about a third of those who gave different responses for their sex and gender appeared to have switched the two terms in their mind, in some cases equating the term ‘gender’ with genetics and hence chromosomes. So even a proportion of this supposedly ‘aware’ segment of the general population seemed to have confused the two categories. However, when this was allowed for, almost 31% of participants did appear to regard their own sex as being something

44. Had given differing values for own sex and gender up-front in survey.

45. Had stated “Confused” for sexual orientation.

46. Had given differing values for own sex and gender up-front in survey.

other than simply “Female”. But when asked in the current question to consider an intersexed status in a more focused way, 47% appeared willing to accept this bodily identity without qualification, and 19% with some proviso (coded as ‘Yes but....’). Some said no (19%), and as in the ‘Yes but....’ sub-group, a fairly common qualification here was an emphasis again on *feelings*, e.g. “No, I have never felt intersexed, I feel female”. It is interesting to compare the pie chart on page 90 (which shows the up-front responses) with the chart on page 199 in the current section.

So when these individuals are presented with a definition of intersex in a confidential survey form, and are encouraged to ponder their biology, more will concede that the intersex label applies to them than would regard themselves in this way under normal day-to-day circumstances. I suspect that a mere handful of individuals would declare an intersex status on documents such as application forms in the public domain, even if such forms offered an “I” alternative.⁴⁷

The greater tendency for those in N. America to concede to an intersex status (statistically significant) seemed to reflect the greater recognition of a sex/gender separation seen in this group, one that allows their biology to be delegated to a category that needn’t necessarily compromise their day-to-day social identity as women. All except one of the 18 N. American participants who agreed outright (‘Yes’) that they were intersexed (and three of the eight responding ‘Yes but...’) had recognised a sex/gender difference. It is also noteworthy that this awareness of the two categories, and acknowledgement of an intersexed label, was in spite of the significantly lower level of diagnostic truth disclosure seen in this geographical group (see page 105).

In “Adopting an intersex identity” on page 61 was mentioned the notion of lesbian women being more attuned to masculinity, as proposed by scholars such as Braidotti, Butler and Halberstam; and the question arises as to whether this, if true, might equip XY-women thus orientated to deal with their intersexuality more easily than heterosexual XY-women. 84% of those in my study with a lesbian or bisexual orientation appeared to accept an intersex status without qualification, compared to 41% of the heterosexual participants (statistically significant). This, together with the increased awareness of performative aspects seen at Q54 in this sub-group (see page 188), may reflect a greater engagement with alternative discourses of sex and gender (and possibly a closer association with activism). That being said, it seems reasonable to predict that even the heterosexual XY-women in my study might be more accepting of an intersexed status claimed by

47. In Sept 2011 it was announced that Australia will introduce a third option for gender on passports (<http://www.guardian.co.uk/world/2011/sep/15/australian-passports-third-gender-option>).

others than the heterosexual population in general, even if they don't fully embrace that identity themselves (see BJ Rye's study discussed on page 61). Those with a diagnosis in which there is a higher chance of some degree of masculinisation (e.g. PAIS) also seemed more likely to accept the "Are you intersexed?" proposition than did those in the other two diagnostic groups, but this was not statistically significant.

As discussed in "Sexual difference theorists" on page 53, French poststructuralist feminist writers such as Luce Irigaray and Hélène Cixous have advocated a more fluid notion of female embodiment, based on a self that exists not by repulsion/exclusion, but via interpenetration of self with otherness, a simultaneous presence of masculinity and femininity within an individual subject. However, also discussed there is Emily Grabham's articulation of the difficulties experienced by intersexed persons in gaining a more seamless integration into society as intersex citizens, due to the continuing influence of medicine in determining embodiment and subjectivity, and in construing them as outsiders (Grabham 2007). Morgan Holmes also talks of the difficulty in identifying as an intersex woman (as opposed to a woman in general terms) because it involves taking back an identity that has been made illegitimate by culture and (in her case) stolen in childhood through (genital) surgery (Holmes, in Feinberg 1996, Holmes 2008). One could argue that even XY-women with CAIS or Swyer Syndrome (who have not 'needed' genital surgery) still have their intersex identity stolen to some extent, by gonadectomy.

Chapter conclusions

Just over half of my participants seemed confident that there was a difference between sex and gender, with a quarter saying they thought the two amounted to the same thing (and smaller proportion giving indeterminate responses such as the two categories possibly being different). Those in North America seemed much more confident of a difference than those in other geographies, a finding that I attribute to a greater/longer heritage of gender studies. Just over a third thought the distinction to be *useful* to XY-women, with just under a third saying it was not useful (and a smaller proportion giving a Yes and No type response). In terms of participants' own sex/gender, almost a third had given a non-female response for their *sex* up-front in the survey, with the vast majority stating a female *gender*. Genetics (sex chromosomes) and external bodily appearance were commonly cited as important factors when defining what the two terms represented. Some participants showed resistance to separating the two categories, possibly fearing the implications for their own status.

Around a fifth of participants expressed awareness of a performative element to their gender, with most of the remainder saying their gender came naturally or mostly naturally. I argue that

this could be seen as a liberatory awareness, as it could in any individual, but in people with personal knowledge of a non-standard sexual make-up it could equally form an aspect of their self-disciplinary practice. The lesbian/bisexual participants seemed more aware of performativity (statistically very significant), with similarly significant differences being seen between the diagnoses, with the Swyer participants being the most aware and the CAIS participants the least aware of this. This awareness seemed to lessen with time in some participants.

There were many expressions of difficulties in coming to terms with the male elements of their constitution, although some participants talked of them having no impact, or of various ways in which they had reduced their threatening nature or even incorporated them in a positive way. Again, there was a degree of reverence expressed towards genetics. The intersexed elements of their biology are clearly a major unresolved challenge for many XY-women, as indicated elsewhere in this study, and in others, with just under half here agreeing outright with the proposition that they are intersexed (although around a fifth agreed but with reservations). Those in N. America and those with a lesbian or bisexual orientation found the idea easier to accept than did those in the other geographies or those who are heterosexual (statistically significant in both cases).

A fruitful way forward may be for XY-women, and those responsible for their psychosocial care, to move outside of society's rigid categorisations of male and female and, with the help of feminist gender theory, to reframe what it means to be a woman with certain 'male' biological characteristics. The possibilities for this are explored in the next chapter which presents my overall discussion and conclusions.

8 Discussion and conclusions

I am filled with spirit and hope. Women have broken down barriers, overcome obstacles and are now destroying stereotypes that have restricted and enclosed them in brackets. I am confident that one day women will completely do away with these brackets. (p.xv) ... Women know what their worth is. They refuse to be kept in brackets much longer. Not by husbands, bishops, popes, or presidents. Women have just concluded that the age of brackets has ended (208).

Marilen J. Dañguilan MD (1997) - see footnote on page 4 of this thesis

My study has set out to explore how medicine and society as a whole ‘treat’ XY-women with AIS and related intersex conditions, by examining clinical practice, and psychosocial discourses within clinical psychology and sociology, against a background of feminist gender theory.

The patient experience

XY-women constitute a minority group whose female gender is often over-emphasised (by doctors, by the media), but who in terms of their (inter)sex have not been ‘allowed’ to exist, and whose voice has rarely been heard hitherto. My study paints a picture of a group of women in which many have been kept uninformed about significant aspects of their medical condition, with almost half finding out their diagnosis from sources outside the home or hospital, and often not until late in life. There were many complaints about lies, half-truths and obfuscations on the part of doctors. Less than half displayed a good understanding of how their condition arose. All but six had undergone gonadectomy, with frequent comments about lack of informed consent. Just over half had been displayed to other doctors as educational ‘specimens’ or had been subjected to clinical photography, and a minority had been offered psychological support within the medical system. Although some had adapted well to their situation, many expressed difficulty in assimilating the knowledge of their XY sex chromosomes, ascribing much (usually negative) significance to genetics, and some expressed feelings of freakishness and outsider status. Most participants did not agree with medicine’s view of intersex as an aberration, to be corrected by surgery and secrecy, and instead advocated treatment that involves more information, psychological support, and choice; together with better education of society.

However, the last 18 years or so has seen the start of changes in the awareness and management of these conditions (see “Awareness and advocacy” on page 232). Many specialist clinicians have now taken on board the message that patients do better if all the cards are put on the table, and some of today’s teenagers can be expected to have a more open and truthful diagnostic experience. The number of cathartic accounts submitted to the AISSG UK ‘Personal Stories’ web page appears to have dropped off in the last few years and some young people are now open and ‘out there’ about their status online (Blogs 2012, YouTube 2012). There is talk at international medical conferences of a multi-disciplinary approach to clinical practice; and a

need to smooth the transition of adolescent patients from the paediatric to the adult medical system is starting to be articulated. However, specialised clinical psychology resources are needed to support increasing levels of disclosure to young patients and – as society becomes more open and aware of intersex – to answer an increasing demand for psychological help from older individuals who are unearthing hidden diagnostic information about themselves. But thus far the NHS has not committed funds to implementing these proposals. One only has to examine the list of references at the foot of medical web pages devoted to AIS provided by national medical organisations¹ to see how pathology-oriented the general clinical viewpoint still is; and the project and publications pages on the EuroDSD web site,² for example, reveal the overwhelmingly medical/biomolecular focus of this recently formed organisation.

Doctors may no longer be quite so quick to reach for the scalpel when confronted with a moderately/slightly enlarged clitoris, but in terms of sex (re)assignment surgery in general it's not clear how much has changed. Susannah Cornwall gives an appraisal of the situation (Cornwall 2010: 58):

Thanks in large part to pressure from intersex groups, since the mid-1990s there has been accelerated coverage of intersex/DSD outcomes in clinical and psychological journals, with [clinicians] Sarah Creighton, Catherine Minto, Lih-Mei Liao and colleagues being particularly outspoken in their claims that intersex/DSD treatment needs thorough review and excellent follow-up, and that many surgeries should at least be deferred... ..However, unfortunately, claims Katrina Roen [Roen 2008: 49], even where newer protocols are acknowledged, certain clinicians merely 'gesture towards the fact that some challenges have arisen, and then they dismiss those challenges within a sentence or two, going on to reiterate and reinforce the dominant clinical practice'.

There was disquiet in European patient advocacy/activism circles in 2011 over the *IV World Congress on Hypospadias and Disorders of Sex Development* to be held in London on 17-19 September, especially about the fact that "live genital surgery" via video link was being advertised, to draw delegates in; and during the event a small group of peaceful protesters from a group in continental Europe stood patiently outside for hours with placards. One specialist clinician attendee, who has conducted surgery outcome studies and advocated restraint, commented afterwards to the researcher (Personal Communication):

The live surgery was so much worse than I had thought it would be.....I am very despondent about the paediatric surgeons, most of whom have no intention of giving up routine genital surgery. At the end of the day I felt like going and picking up a banner and joining the protesters myself!!!

1. For example, AIS page provided by the US National Library of Medicine <http://omim.org/entry/300068>.

2. <http://www.eurodsd.eu/en/the-project.php> and <http://www.eurodsd.eu/en/publications-1.php>.

The area of language and representation is gradually changing, but there is a huge residual effect from unhelpful terminology. Every time Jeffrey Eugenides' publishes a new novel, his unfortunate (and incorrect³) use of the word 'hermaphrodite' is re-aired in the media in connection with his earlier novel 'Middlesex' about a character with 5-Alpha-Reductase Deficiency (Holmes 2006). And at the level of regional hospitals and community medicine (e.g. in gynaecology and general practice) there are still many old-school clinicians, steeped in the terminology of a bygone era, and seemingly intent on preserving it. One XY-woman, herself employed in the NHS, told the researcher in February 2010 of how her GP had recently referred her for evaluation (an x-ray, or the like; for a problem unrelated to her AIS) in the hospital department where she used to work. She'd been horrified to find that he had stated her diagnosis as "Fake Hermaphrodite" at the top of the referral letter, and moreover seemed not to understand why this was inappropriate⁴ (Personal Communication). And in a summer school at the University of Cape Town in January 2012, Prof. Ian Aaronson, an old-school US paediatric urologist, focused heavily on the classical hermaphrodite idea in a lecture series billed as a cultural and biological exploration of intersexuality. But more enlightened clinicians also have trouble shaking off old linguistic conventions. Adam Balen (consultant gynaecologist and head of a multi-disciplinary team in Leeds) opened a recent BBC documentary (BBC 2011) with: "Some babies are born with ambiguity. We don't actually know whether they are male or female" (immediately perpetuating the old idea that medical investigation/treatment will uncover and establish a 'true' male or female sex); when he could have used the spotlight as an opportunity to start changing perceptions, with something like: "Nature provides other forms of sex".

The case of South African athlete, Caster Semenya, whilst being badly handled by the sporting authorities, and by the press in many instances, has at least brought intersex to international public attention and gathered huge sympathy and support for the beleaguered runner. But in general, the imperatives of society and medicine to police non-standard sexes and genders are likely to continue, and probably many of the doctor/patient disconnects identified by the AISSG parent member in 1999 (see page 237) are still in operation.

Inverted commas and 'reality'

I will now draw together some theoretical/academic insights arising from my empirical findings and explore some policy issues impacting on the treatment of a set of conditions that are calling out for a psychosocial therapeutic approach, whilst being firmly embedded in a medical milieu.

3. Strictly speaking, in medical parlance someone with 5-a-RD is a 'male pseudo-hermaphrodite' rather than a true hermaphrodite (see page 8) but why did he have to use *any* of these archaic terms?

4. See also quote on page 128.

There seems no doubt that a female *gender* comes easily to most of those in my study, in spite of various deficiencies in their female biology and a degree of self-surveillance and performative awareness; and in spite of reminders from exposure to medical discourse/terminology of a failure to masculinise, contributing to feelings of inauthenticity in some. They are clearly girls/women so, as with Marilen J. Dañguilan's brackets, there has never been any justification for (some doctors) enclosing them in the inverted commas suggested by my study's title. But what is the 'reality' (also in my title) of their *sex*? Are we justified in using inverted commas here? It seems that in terms of their biological sex, there are several basic positions available, which I will characterise using the following statements:

Biological essentialism – "I have a Y chromosome and have/once had internal testes, this must make me male. How can this be, because I look and feel like a woman? *I must be a one-off freak.*"

Discursive production – "I have a Y chromosome and have/once had internal testes, but these male elements are abjected/irrelevant. My female gender precedes, and determines my sex. *My sex is female.*"

Corpo-real(ity) acceptance – "I have a Y chromosome and have/once had internal testes, I embrace the language of intersex. *My sex is intersex (or male).* My female gender thus makes me an intersexed woman."

Different 'sexual difference' – "I have a Y chromosome and have/once had internal testes. *I am a different sort of woman/female*, which may not be defined in standard male/female terms."

Some will traverse through these stages, as they assimilate and refine the meaning/s of their diagnosis, possibly in a similar way to Elisabeth Kübler-Ross's five stages of grief (Kübler-Ross 2005), and others will stay with the first or second position. If we assume that it's a good thing to leave biological essentialism behind and to travel towards at least the second position, then what resources are available to XY-women to help them on this journey, and what stands in their way?

Opportunities

Gender theory

I started this study with the naive assumption that the general population would have a basic awareness of the sex versus gender dichotomy used since the 1970s to argue against biological essentialism; and that my study participants might view this as a particularly useful split; so that in a sense they might compartmentalise their internal biology (and call it what you/they will...

intersexed?... male?...) in order to focus on the social, i.e. gender. By these means, the male and female elements of their constitution might not be seen as incongruous or incompatible; and they might appreciate that it is 'in order' for someone to claim 'male' or 'intersex' as their sex, but 'female' as their gender. But I found that whilst some did acknowledge a difference and some found it useful, many did not (although I have no way of knowing how this compares to people in general). I also asked my participants whether they were familiar with feminist gender theory (Q60) and only 13% said Yes. A small proportion (17%) said they were vaguely or somewhat familiar, in some cases citing school/college courses from the past. The majority (66%) had no familiarity, with just a few saying it sounded interesting and that they'd like to know more (or that it didn't interest them), suggesting that many probably did not see it as being relevant.

As the study progressed, I became more familiar with my participant's views, and with postmodern and poststructuralist theories. These are theories that place emphasis on the reversal of the sex – gender axis so that gender becomes the precursor to sex, on cultural mediation, on the idea of the body as an inscriptive surface, on theories of sexual difference, and on corporeal feminism's return to materiality. I came to appreciate that it's not as simple as pigeonhole-ing ('abjecting' even) an unusual biology to focus on gender, and that there might be opportunities for XY-women to be freer and more creative in the way they conceptualise their situation. This they might accomplish via an understanding of historical discontinuities in the way in which (what we refer to as) sex and gender have been framed, of the role of cultural mediation in science and medicine, of concepts of discourse and bio-power, of notions concerning performative aspects of gender (and sex), and so on.

Constructing a female sex?

There seems an obvious tension in many of my participants between an *intersex* status that is culturally imposed on them by medicine as an agent of society, and a perceived/claimed *female* sex, comprising a female external anatomy (that is mandated by biology) and a female internal anatomy (that they seem to discursively produce). Although some will defer to medicine/embryology and concede, or in some cases embrace, an in-between (inter-)... or even a male... sex, the majority will not do so, and will construct for themselves a totally female sex to match their gender.

Are those who responded to the question about acknowledging an intersex identity by saying: "I'm female, full stop", or similar, exhibiting a denial of an intersexed status? Or is this an example of a female gender creating or constructing a female sex (Delphy and Butler's brand of feminist gender theory realised in practice)? The latter is an attractive notion. Recognising a sex/gender difference would arguably be a first step on the part of an XY-woman in understanding on

a theoretical level how gender could come to be the point of departure rather than the point of arrival, but is one that most such individuals probably put into play without any reference to academic deliberations. In some ways the diagnosis-aware XY-woman has, of necessity, to employ a separation between sex and gender, even if reluctantly (i.e. not ultimately accepting an intersexed or male bodily sex) before they discursively produce a female sex. And of course biology is on the side of XY-women in this endeavour, by virtue of their female phenotype and lack of androgenic hormone effects (brain androgenisation, deep voice etc.). It might not be so straightforward for an intersexed individual towards the centre or in the male region of the bodily sex continuum, or, of course, for a male-to-female transsexual. And the obvious question is “What actually changes, in terms of sex, between going into the diagnostic consultation as a[n apparent] girl/woman and coming out?”. The patient’s body hasn’t changed, only some language used to describe it. In most cases they, and everyone around them, believed they were female before coming to medical attention. Has that now changed? However, it’s possible that those who do acknowledge an intersexed status, in addition to having some appreciation of non-standard discourses, could reach a more holistic relationship to the new information about their biology.

Acknowledging an inter-sex?

During much of the evolution of feminist gender theory/scholarship, emphasis has been placed on a backgrounding of the body, as a reaction against biological essentialism. Whilst this may be a good fit with conventionally constructed (in both senses) female and male bodies, in which biology might be sidelined as having been acknowledged but shelved for the sake of argument, this is somewhat problematised by intersex, in which it’s difficult to dismiss a non-standard morphology into standard dimorphic pending trays.

So the move of corporeal feminist theory towards giving significance to particular body forms is a potentially useful turn as far as XY-women are concerned, because it is all too easy for an over-emphasis on *gender* to mask a banishing of the intersexed *body* to the realms of shame and stigma. As discussed in “Corporeal feminism” on page 58 Elizabeth Grosz (Grosz 1991:22) is one of the main advocates of corporeality...

...the internalised, lived or imaginary representation of the body, the psychical mapping of the body in which the subject’s phenomenal sense of the body is the combined effect of perceptual and sensori-motor lived experiences, as well as the social inscription of the body’s external surface...

... as a key influence on identity, or more simply put, ‘biology as lived’. However, whether corporeal feminism’s ‘return to the body’ is a help or a hindrance to XY-women is, I think, unexplored, especially as it seems to focus on issues to do with the conventional female body.

Feminist gender theory hasn't yet taken account of women who are externally female and internally 'male'. The challenge is to enable XY-women somehow to integrate the male aspects of their bodily make-up into their sense of self in a more satisfactory way than has hitherto been the case.

Do XY-women necessarily have to face a stark choice between identifying as female or male in terms of biological sex, or is there any scope for acknowledging an intermediate sex as a valid and acceptable state in its own right? To what extent does an acceptance or a claim for oneself of an intersex identity involve a recognition of a specific intersex morphology (perhaps something akin to the so-called 'third sex')? Iain Morland's paper 'Is Intersexuality Real?' seems, in considering this question from Grosz, to come down on the side of intersexed bodies as being "concrete, determinate and specific in their morphologies", with their ambiguity *being* their sexual difference (Morland 2001: 528, 544).

Grosz talks of an inability of the sexes to "bridge the gap, the interval, between the sexes" and to grasp or experience life as the opposing sex (Grosz 1994: 207) and asks whether the hermaphroditic (as she calls it) body is culturally inscribed in one of the two standard forms, or in a form specific to its morphology. Maybe XY-women are somewhat more able than most to "bridge the gap", at least in fleeting moments of ontological instability; when caught off-guard by reminders of their status. Such moments can arise when they connect to how things might have turned out differently but for an embryological glitch (see "Alternative outcome?" on page 136). Then there's anecdotal evidence that some XY-female patients may, on first hearing their diagnosis explained, experience a feeling of being "some kind of angel". Whether this is a genuine experience of insubstantiality or a mental association with androgyny is not clear. Luce Irigaray discusses angels as "the figurative version of a sexual being not yet incarnate" and suggests that "the neuter might signify an alchemical form of the sublimation of genitality..." (Irigaray 1991, quoted in Whitford 1991: 173 and 172).⁵ Many XY-women also report a feeling that "everyone can tell" (that they have an intersex condition), that it is "written on their foreheads", and which may also relate to a feeling of transparency. I asked my participants about any feelings that other people could 'tell' (Q56) but set aside that material for future analysis.

As mentioned on page 60, an article by David Hester (Hester 2004b) that I discovered at a late stage of my writing up, seemed to have pre-empted much of my argument that corporeal feminism's 'return to the body' might prove useful to intersexed individuals. There, Hester advocates an almost essentialist return to bodily sex; but as a multiplicity of sexes rather than just

5. Elizabeth Grosz examines Irigaray's interest in the divine (Grosz 1986).

the two common categories, and with a backgrounding or dismissal of gender and its performative leanings. He seeks to reject the nature/culture, or sex/gender dualism at the heart of gender theorizing of the last decade by fusing together sex and gender, and proposing a 'postgender' alternative that explores the mutual impact of bodies and cultures, of physiology and environment, upon each other; and which takes issues of 'sexual difference' more seriously. "Why must we have a sex?" he asks (a male, female... or even an inter-sex... one assumes he means); "What are the consequences of having *hundreds* of sexes (my italics), for research, for medical treatment and biogenetic technology, for theorising, for sexual ethics and gender constructs, for legal systems, for activism?" Intersex bodies, he says, "point the way out of the current stalemate set up by the dichotomy of essentialism vs. constructionism. They are beyond the sex/gender division: they are postgender." (p.223). But most XY-women probably don't feel any different to regular XX-women, even if compromised physiologically and psychically in some respects, so why would they want to "act as an advocate for non-normative agendas, to bear the burdens of social order for everyone else"? (Holmes 2008: 15).

An-other form of woman?

Maybe there is a mid-way position between the discursive construction of a female sex and the acknowledgement of an intersexed or male sex. This would be a position that recognises, and gives positive value to an XY-woman's differences from XX-women. As mentioned in "Sexual difference theorists" on page 53, scholars such as Luce Irigaray actively promote acknowledgement of women's differences or 'otherness' from each other (to break free from the single category of 'woman') as well as from men (Irigaray 1985). And Irene Costera Meijer has questioned Butler's notion of the heterosexual matrix as the sole reference point for generating gendered subjectivity and speculated that comparisons between women could play a role (Costera Meijer 1991).

Certainly, the way XY-women experience their bodies appears to be more labile and discursive than women in general. They are probably more acutely aware of the differences between women, whether that be between XX- and XY-women, or between XY-women. They may not on the whole be 'gender savants' in terms of sex versus gender debates, but they must be more cognisant than most of the fluid and spectral (in both senses perhaps) way in which anatomical sex expresses itself in nature. After all, a variation in the genetic anomaly that resulted in their particular biological configuration could have significantly altered their bodily make-up; the difference between, say, having a uterus and full length vagina or not (e.g. Swyer versus AIS), or between having a standard female clitoris or having a micro-penis – what Morgan Holmes (1994) has termed a 'phallo-clit' – (e.g. CAIS versus PAIS). And many with CAIS will be aware that

some of their PAIS ‘sisters’ (having just a slightly different gene mutation which gives them some sensitivity to the masculinising effects of androgens) may come dangerously close to the traditionally perilous areas of genital ambiguity.

Alex Hughes and Anne Witz discuss the extent to which Judith Butler’s theories can overcome the heritage of Simone de Beauvoir’s residual ‘troubled female body’, dogged by crises of puberty, menstruation, pregnancy, childbirth, lactation, menopause, and so on (Hughes and Witz 1997). But in some ways XY-women have, by their very nature, already overcome the ‘troubled female body’ in the way framed by de Beauvoir; and without needing to employ Butler’s efforts to obscure gender behind the discursively produced matter of bodies. But ‘trouble’ depends on one’s viewpoint. My participants’ sense of subjectivity or identity is arguably compromised more by the fact that they do *not* experience these ‘troubling’ female bodily events. They may well experience crises related to these female biological functions, but not in the same way that regular, XX-women do. XY-women do often express relief at not having to deal on a practical level with PMT, periods, etc. but, as discussed in Chapter 6, many would give anything to have had the reassurance of femaleness that menstruation provides, not to mention the natural female capabilities of fertility, pregnancy etc. And their crises are coloured by the fact that these deficiencies in female corporeality take on an additional dimension or overlay; that of ‘maleness’, or intersex.

One could argue that, following Irigaray’s lead, some of my study participants might seek a more self-referential identity situated directly in their ‘otherness’ from *both* of the ‘other’ sexes; possibly in a more authentic form of the androgyny favoured in different ways in the 1970s by Gayle Rubin, by Shulamith Firestone and by Kate Millet (Lloyd 2007: 30, note 18) who were seeking at that time to break down gender categories as a socially subversive act. Firestone argued that equality between men and women might be achieved by an elimination of differences in reproductive function (with the use of in vitro fertilisation and artificial wombs) and arguing that women’s bodies have to become more like men’s (Firestone 1979). Some XY-women, if they have any familiarity with feminist gender theories, might take solace in the notion that they have in effect attained this idealised status (even if artificial wombs are not yet with us). At worst, if they are not inclined to claim a theoretical advantage over XX-women via such notions, then they might at least feel a sense of sisterhood with XX-women as runners up in terms of Irigaray’s postulate that *all* women are viewed as defective men! But Irigaray’s vision for women, with her assertion that “we are women from the start” and that “by our [genital] lips we are women”, expressed by Diana Fuss as “a woman will never be a woman solely in masculine terms”, seems like an early (1980s) nod towards corporeal feminism (or at least a revaluing of anatomy) and one which focuses on women’s genitals rather than her internal structures and physiology. And

after all, XX-women with MRKH (defined in footnote on page 22) have no vagina or uterus. So this could be a useful identification for XY-women. However, Alison Stone critiques Irigaray's later philosophy of sexual difference as overlooking what she calls "the natural multiplicity within each of our bodies", and as being problematic for intersex (Stone 2006) and this requires further investigation.

Obstacles

What are the problems or obstacles in the way of those XY-women who might aspire to at least some way towards a greater integration of the unusual elements of their biology? Firstly, there's the question of whether XY-women are prepared to risk 'intersexuality' (perhaps in the way some feminist scholars are said to risk biological essentialism?). And then there's terminology and representation that can cause feelings of stigmatisation, freakishness or abjection.

Not sufficiently hermaphroditic?

It can be argued that in (re)valuing an intersexed or male biology my participants might be exchanging the un-troubled female body discussed earlier for the "troubling" intersex body hypothesised by Morgan Holmes. Claiming to be female, even if "disordered", may be safer than straddling or jumping the fence that divides off dangerous territory. Probably many XY-women might ultimately not see any need to draw attention to what they might come to see as some non-problematic differences compared to regular XX-women.

However, it's possible that some XY-women see themselves as outsiders in *two* senses. They can see themselves as being outside the circle of regular (XX) women, and at the same time may not feel themselves to be sufficiently intersexed to aspire to membership of the politically inclined group that mainly comprises those born with so-called genital ambiguity. Their outwardly female form and their female gender appear, in many cases, to outweigh any identifications with an intersexed status based on their male internal components. This is the viewpoint expressed by the clinician quoted on page 134, who said (disingenuously I think, whilst trying to appease AISSG over some challenges about his use of terminology⁶):

I accept the concern about using the word 'disorder' particularly in the context of CAIS individuals being *normal females*. Indeed, we have previously discussed many times that CAIS is clearly *not an intersex disorder*.“ (my italics)

6. He has been one of the main promoters of the 'failed male' discourse with respect to conditions such as AIS.

So maybe most of the XY-women in my study are not sufficiently “sexually neutral, indeterminate or hermaphroditic” (Grosz 1994: 189) to consider themselves intersexed. In many ways this makes their situation easier than those born with genital ambiguity, yet in other ways presents them with a greater ontological conflict. In a sense, and because of the significance attached to genetics, they are *more* intersexed than the latter group by virtue of the polarisation between their sex chromosomes and their phenotype; those with Swyer Syndrome arguably being the most extreme example of that polarity, in view of an internal anatomy that is essentially female (even if not fully developed). Perhaps in the age of molecular biology/genetics and medical imaging a CAIS woman’s ambiguity is merely unmasked, by technology, as having relocated to the body’s external/internal boundary, an observation made by Iain Morland (Morland 2008).

Individuals might well gain a useful perspective on their situation by becoming conversant with gender theories – with the sexual difference stance of theorists such as Irigaray seeming particularly relevant and worth aiming for – but I doubt that for most the adoption of an overtly intersex identity is likely to provide a greater degree of personal integrity or agency. In a sense, compared to those with genital ambiguity, XY-women represent a halfway house in which they can ‘get away’ with being (and being seen as) female in society, albeit with certain internal forbidden aspects of their bodies. So social constructionism is probably as far as many are likely to extend their reach. On the whole, they do not seem particularly motivated to challenge traditional sex and gender categories.

Abjection

Sociological theories of abjection and their use in the literature with reference to intersex have been discussed in “Subjectivity/abjection” on page 42. It was noted there that Grosz, in her 1991 article titled ‘Freaks’, referred to the circus side-show type of voyeurism in the past tense (“They occupied the impossible middle ground between binary pairs”). However this sort of fascination seems alive and well, in 21st century Sussex for example, and can represent everyday reminders to XY-women of their outsider status. The 2011 Brighton Festival hosted an entertainment by a Spanish ensemble (Teatro de Ciertos Habitantes⁷) called *Monsters and Prodigies*, described in the festival brochure thus:

Baroque opera meets history of ideas in this elaborate and witty musical take on the castrati enigma. The castrati – boys castrated before puberty in the service of art – were the superstars of the 18th century. Operas were written for them and many commanded vast fees, though their origins often lay in poverty. This delirious mix of circus lampoon and academic treatise, sublime music and extreme physical comedy, stars a hoof-stomping centaur, Siamese twins and even Napoleon Bonaparte!. Each plays their part in revealing the inherent contradictions and

7. <http://www.ciertoshabitantes.com/>

peculiar whims of these ‘monstrous angels’ – at once artistic prodigies and beautiful freaks. A wild ride from the opulent extremes of the Baroque to 20th-century reason – from ‘bel canto’ to techno – *Monsters and Prodigies* is an off-the-wall satire on our doomed pursuit of perfection.

Tropes such as that of the ‘freaks’ described by Grosz focus a lot of attention on external visible ambiguity or ‘doubling’, the morphology that is at the heart of the classical notion of the hermaphrodite. One could argue that XY-women with conditions like CAIS or Swyer Syndrome do not come within the orbit of such ambiguity, because of their outwardly female phenotype; but many become aware of parallels between their ‘XY-status-with-early-gonadectomy’ and the idea of the pre-pubertally castrated male. And they may well shudder on encountering sensationalism exemplified by the above, notwithstanding its academic gloss in claiming to show how an 18th century focus on the beauty of the voice became transformed into a 19th and 20th century preoccupation with the freakishness of the emasculated body (Freitas 2003).

Feminist-oriented theories of abjection and corporeality attach significance to the material surfacing, from the visceral depths, of bodily fluids such as menstrual blood, as well as to signs of sexual difference (Gross⁸ 1990). Whilst being female in phenotype, and in gender, most XY-women do not experience female corporeal processes (even menopause is usually offset by hormone replacement therapy throughout most of their life, post-gonadectomy). It could be said that they thus have more in common with a masculine embodiment where the viscera are more easily ‘negotiated’ or overlooked. But they still have to acknowledge the internal reproductive anatomy they were born with as being non-standard, or at odds with their female phenotype, without having the means of integrating that knowledge into their subjectivity in a satisfactory way. Although not outwardly hermaphroditic, XY-women are certainly caught in the slipstream of culture’s anxiety about unusually sexed body surfaces.

As with *medical* discourses that employ terminology and paradigms that objectify individuals with intersex conditions and assign stigmatising labels to them in absentia, *feminist scholarship* too generates concepts such as abjection which – whilst claiming to explain how normal subjects circumscribe their gendered identity, and how society comes to banish intersex beyond the margins of acceptability – also, like medicine, fail to consider how such individuals can orientate *themselves* in these schemes. How many theorists, developing notions that employ intersex as a deconstructive tool, imagine that such an individual might actually read their published work and try to apply it to their own situation? XY-women emerge from the medical system with labels of ‘under-masculinisation’ (if not ‘male pseudo-hermaphrodite’) and at best, ‘disorder’, and may then have to negotiate a sociological minefield, dodging identifications with monsters and freaks.

8. It was given as Gross in the original article but is probably a mis-spelling of Grosz?

The way forward?

Agency

As discussed on page 51, Aracelis Escabi-Montalvo and José Toro-Alfonso suggest that the poststructuralist positions of Foucault and Butler are more useful in intersex than the essentialist versus constructionist model, with the Foucauldian concept of power in particular offering “spaces of resistance; opportunities for subjects to initiate new discourses”. Araceli González Vázquez also concludes that “Foucault’s notion of biopower, whilst being complementary to Butler’s theory of performativity, holds more promise for political action in relation to intersex than does the latter; but that any such action seems far away.” (Vázquez 2009).

The question arises as to whether it is more realistic to work towards changing the medical discourse surrounding sex development, or to empower patients and parents to use alternative discourses to reframe what medical information means to them; to encourage greater degree of agency? It is not easy for a minority group, such as that comprising XY-women, to combat the hegemony of medical science and discourse; to challenge medicine to re-formulate, say, the way in which it views embryological development, although patient groups have made significant headway in getting issues such as truthful disclosure and multi-disciplinary approaches to care put on the table. And it may be that the Spanish authors primarily have in mind, as do many, those intersexed people who have ambiguous genitalia, and for whom gender identity and genital surgery may be personal issues. My interest is in how the use of intersex as “a critical, subversive and deconstructive tool” (Vázquez 2009) can be offered to XY-women (whose issues have a somewhat different focus) to enable an exploration of alternative conceptualisations. I would consider this as relevant to agency, enabling a wider choice of possibilities for subjectivity, if falling short of Vázquez’s “political action”.

Affected women might usefully expand their horizons by exposure to sociological theories that either question the primacy of biology or allow a reinterpretation of its cultural meaning. It’s probably more realistic to accept the onward march of medical science but to use feminist gender theory to help XY-women understand the arbitrary nature of some of medicine’s formulations,⁹ and to reframe social sex and gender labels. A significant factor, however, is the young age at which most XY-women are diagnosed. How well equipped is a teenager to receive and make use of alternative discourses? It may be sufficient, though, for those affected merely to gain a

9. Progesterone, for example, is generally thought of as a female hormone (and a constituent of the contraceptive pill) when in fact it is a neuro-steroid produced in the brain of both females and males. It is even being researched by emergency medicine expert Prof. David W. Wright (Atlanta) as an agent for general and military clinical use to help protect against brain damage in stroke and traumatic brain injury (<http://whsc.emory.edu/home/news/experts/emergency/david-wright.html>).

superficial understanding of ‘medicine as discourse’, and of the fact that alternative discourses exist. Merely to gain an awareness of the Foucauldian concept of all forms of knowledge, including scientific knowledge, being constructed or mediated through culture and discourse might demystify medicine and open some doors. If those given an XY-female diagnosis were offered a chance to understand, even in broad terms, that such things are under active discussion, albeit in academic circles, it might possibly help them to reach a more nuanced and empowering viewpoint on their situation.

By this means, they might increase their social capital and agency, and might even be able to effect small disruptions in medical thought which might eventually achieve some purchase on dominant discourses. One example of this might be the way that some CAIS women are now asking their clinicians for testosterone as HRT, either on its own or in combination with oestrogen. Even though they are supposedly insensitive to androgens such as testosterone, it has been suggested by at least one leading endocrinology specialist that the brain may have different receptors to the body tissues and may, in CAIS for example, have some sensitivity to androgens (in terms of effects on mood, libido etc.); and there’s also speculation that androgens may play a part in maintaining bone density in both sexes (Soule et al 1995). This clinician has also been known to suggest to women with Swyer Syndrome (who have a generalised sensitivity to androgens) that they could use testosterone “for the weekend”, to increase libido (but not on a continual basis, in order to avoid its virilising effects). Some XY-women have reported a degree of satisfaction in “running rings” around uninformed, traditionalist GPs (or even consultants) by asking for such medication (Personal Communication). And as attitudes change, and more control over their bodies is handed back to patients in this way, there may come a time when XY-women (those with CAIS at least) will consider bodily integrity more important than conforming to social pressures and will seek to retain their intra-abdominal testes for the useful physiological functions they provide (electing to *use* medical technology to monitor them for any adverse changes). Similarly, they may come to eschew invasive, problem-laden vaginoplasty surgeries for the more effective non-surgical do-it-yourself method of pressure dilation, and again assume more independence from medicine’s ‘Mr Fix-It’ mode of operation.

Policy issues

As discussed on page 63, Aracelis Escabi-Montalvo and José Toro-Alfonso advocate much more political work, to problematise gender labels/systems, not only in academia but also in everyday spaces, and target psychologists as being best placed to promote this (Escabi-Montalvo and Toro-Alfonso 2006). They regard the issue of intersex as a fertile field for research, particularly

for those psychologists and gender researchers who promote a society that breaks the dichotomous system of gender/sex, but conclude that (p769):

The taboo surrounding this issue makes it difficult to study and address. It is important that health professionals, including psychologists, consider undertaking further studies with this population, which validates its social reality and its needs, and to facilitate a process to review the limitations of a dichotomous sex and gender approach to the issue of intersex. This way you could have a conclusions fairer to the body of these people.

It is true that alternative discourses relating to sex and gender, and the part that intersex plays in challenging certain assumptions and categories, are still largely confined to academia. And there is a tendency for academics to talk *about* those who are intersexed, as do doctors in the medical context, but there is no easy way for intersexed individuals themselves to gain access to these discussions, other than by gaining some proficiency in navigating the academic literature. So patients, especially younger ones at the point of receiving their diagnosis, could benefit from professional psychological support that is *informed* by this wider world view, as suggested by Lih-Mei Liao (2003), and which will ease them into alternative ways of looking at things, allowing some degree of re-conceptualisation of their situation. I suggest that feminist theories of sexual difference (and to a lesser degree, corporeality) with their emphasis on differences between women (and on ‘the lived body’) may provide a framework for XY-women, at least to explore, and possibly revalue their biological status.

However, it’s one thing to nominate psychologists to spearhead the way forward,¹⁰ but the UK provision of clinical psychology in this area is severely underfunded. The fact that a significant number of intersex cases manifest in babies and young children means that *paediatric* clinicians are often involved in the front line of diagnosis, treatment, research and, importantly, the setting of protocols/guidelines that will be consulted not only by clinicians, but also by funding bodies when specifying the allocation of financial resources. Paediatric clinicians tend not to put emphasis on psychology services (although, of course, this should be an important service for parents) or on the transition from paediatric to adult care. The recently published DSD clinical guidelines document (Ahmed et al 2011) mentioned in various parts of this thesis (and which covers adolescents and parents, as well as babies/children) was criticised by outside reviewers at final draft stage for merely paying lip service to the involvement of clinical psychology. One of the few specialist clinical psychologists in the adult intersex field reviewed the document and commented to the researcher that the lack of emphasis on psychology would make it difficult for lead clinicians in teams to justify funding applications for psychology. Any amount, however inadequate, would satisfy the guidelines. The purchase of just one (or half a) psychology session

10. The authors of the two Spanish papers appear to be writing from university departments, even though one of the two papers was published in a clinical psychology journal.

per patient would meet the guidelines as drafted, whereas clients need an extended period of help in order to explore and process diagnostic information, and to make informed choices regarding elective investigations and procedures. Within current payment structures in acute NHS trusts, surgery is income, whereas psychology is an expense. In her hospital it is easier to create one whole surgeon post than 0.1 of a psychologist post. The user throughput at her clinic had grown an estimated 16-fold, but there had only been a 5-fold increase in psychology resources. Thus for several years now she had not been able to spend time with, and follow up patients as she had done with the ‘first wave’ of clients in the late 1990s. Such paralysis of psychology services ultimately means that surgery becomes a proxy for psychological care (which is perceived “not to work”), even though the psychosocial resources required would be at a fraction of the cost of surgery and have the potential to reduce the demand for elective medical interventions. This, she says, remains a disadvantage of the prevailing surgery-led service model (Personal Communication).

So to restore the balance would require a much greater commitment by doctors to... and investment by funding agencies in... specialised clinical psychology services. Whilst it’s never too late to broaden one’s outlook by seeking additional information and support outside the medical system (and many in the past have had no choice but to unearth *all* relevant information about their condition in that way), it would be more effective to open doors to alternative discourses while individuals are in the early stages of medicalisation and first negotiating their socio-somatic disposition or habitus in relation to diagnostic information. But since there are very few clinical psychologists with experience of helping these patients in *any* shape or form, it doesn’t seem likely that the holders of the purse strings will suddenly start funding therapies that privilege social discourses over those backed up by medical science. Maybe there is a role for university sociology departments that run gender courses, in assisting with the training of doctors and clinical psychologists?

I fear that it may be some time before intersexed persons can escape from the victim mode proposed by Gregori et al (Gregori et al 2007; 10-11), because for these individuals to be inducted into their intersex status solely via the medical system, especially when this is done by doctors alone, with no access to professional psychology input (“the continued location of life-changing decisions about intersex embodiment and subjectivity within the medical sphere – Grabham 2007: 44)” is to provide them with only half the story, and to deny them potentially useful tools in formulating alternative versions of what their ‘disorder’ could mean.

Historically, the clinical specialties that deal with these conditions (in particular paediatric endocrinology/urology, and gynaecology) have been overwhelmingly staffed by male doctors,

who possibly find it more difficult than do their female colleagues to understand that the concept of ‘male development gone wrong’ does not have to be life-shattering news to a female-identified patient if handled properly?

In January 2011 the researcher attended a two-day conference staged by the British Society for Paediatric and Adolescent Gynaecology (BritSPAG); and the vast majority of attendees were women. And the proposal for the pan-European quality of life study (DSD-Life) in which AISSG UK is to be the patient group contributor (see page 238) states (in a section on complying with European policy on equal opportunities for women) that the majority of the consortium members are women. Both BritSPAG and DSD-Life have a strong female presence at the top of their management structure. Contrast this with the international *Working Party on DSD Evaluation* conference held near Annecy, France, in March 2012, and controlled by male paediatric endocrinologists and urologists, where it was (the many) male speakers who talked about biomolecular, morphological and surgical aspects (largely framed in terms deficient masculinisation) and (the few) female participants who addressed psychological and gender-related outcome issues, or else ‘neutral’ methodological aspects such as medical imaging. The citations in this thesis also make it clear that it is mainly women who take an interest in the psychosocial side of these conditions, whether within psychology or sociology.

In the early-mid 1990s, 90% of doctors were men, but in 2008, for the first time, 55% of newly qualified doctors were women and in 2009 it was predicted that over the next five years it would rise to 70%.¹¹ This, together with the fact that today’s medical students probably receive better training in the psychosocial side of medicine, bodes well for the future. So I, like Marilen J. Dañguilan, am “filled with spirit and hope”. The *spirit* is that shown by my study participants, to which this thesis bears testimony, and the *hope* is that the future will be bright because of the role that women in clinical medicine will play in “breaking down barriers, overcoming obstacles and destroying stereotypes” that have enclosed XY-women in brackets... inverted commas... and other restraints.

The contribution of my study

Some of the originality claimed for my study has been covered on page 80. My project has added to the few existing studies that evaluate a sample of XY-women, and is unique in having employed a mixed methods approach that enabled quantitative, positivist data to be collected,

11. Kate Bleasdale, founder and vice-chair of Healthcare Locums, quoted in the *Sunday Times* 14 Nov 2009. Another *Sunday Times* article (09 May 2010) reported that 57% of medical graduates are now women, who make up 40% of all doctors, and that they will form the majority by 2017.

together with qualitative, subjective material allowing the women's voices to be heard. My study has achieved greater granularity than previous work in this field, by having enquired about detailed elements of participants' diagnosis and bodily attributes, and by exploring a greater range of psycho-social factors that are not just confined to gender identity (which has been a pre-occupation of many medical studies). My sample has been large enough to make some inferences based on age, diagnosis, sexual orientation and geographical location, which has not previously been accomplished. My project is also unusual in having combined medical aspects with feminist gender theory, enabling me to make some conceptual observations as to how the latter can illuminate the former and which may be useful in clinical psychology service development.

A Appendix - Patriarchy and intersex

Although it is an issue that has been under the spotlight over the last 15-18 years as a result of campaigning by patient groups, gender (*re*)assignment surgery will not have formed part of my participants' treatment, since they have been selected for the possession of a female phenotype and having grown up as women. However, a few with conditions like PAIS may have undergone surgery to reduce a larger than average clitoris (which may be thought of as 'gender reinforcement' surgery); and they are all directly impacted by the social discourses and medical attitudes on which such surgical protocols are founded (a patriarchal safeguarding of heterosexuality based on a male/female binary and a phallocentric preoccupation with male genital morphology/performance). These principles colour the general 'treatment' of all manifestations of intersex by medicine, including the terminology used. I therefore wanted to say something about how patriarchy and phallocentrism have been theorised as an over-arching influence in intersex medicine, but didn't want to foreground this in the main body of my thesis.

Within psychoanalytical discourse patriarchy refers to the Oedipal structure of human subjectivity (Sigmund Freud) and the internalised Law of the (Symbolic) Father (Jacques Lacan). Freud's theory that Oedipal mechanisms and a castration complex govern the development of the gendered subject during early childhood, with an associated 'penis envy' in girls, has had a strong influence on theories of the patriarchal nature of society; a society in which only men can be true subjects, with women defined as subordinate or 'other'. Reworkings of Freud by Lacan promoted *language* as the structuring agent for the social subject, with the 'mirror phase' replacing penis envy as the source of female identity, and women being seen as constituted outside of society or culture, the latter conceptualised as the Symbolic Order (society's communicative/language rules) grounded in masculine terms (the Law of the Father).

Moya Lloyd asserts that patriarchal society has been said to take certain features of male and female biology and turn them into a set of gendered characteristics that serve to empower men and disempower women, and which are then presented as natural attributes of males and females, and that sex is said to be a *regulative ideal*, operating to exclude or pathologise those whose anatomy does not fit its normative parameters (Lloyd 2007). The medical treatment of intersex is said to reflect the patriarchal mechanisms operating in society as a whole (Holmes 1994). Gender reinforcement surgery in intersexed infants/children has been theorised, via psychoanalytical discourse, as being closely linked to patriarchy because intersex challenges the predominant heterosexual norm that operates in society and which is supported by a binary sex system. Genital surgery, to maintain a clear separation between the sexes, is said to act in support of this; so that 'penis in vagina' (PIV) sexual activity is safeguarded as the officially sanctioned norm.

Uni-causal models of patriarchy (women's oppression, for example) fell from favour in the 1980s and were given a more multi-causal analysis by writers such as Sylvia Walby (Walby 1990). And it has been argued that being based largely on analyses of the ideas of Freud and Lacan, the concept of patriarchy does not sit well with postmodern theories of Foucauldian discourse and localised power operations. However, medicine has until recently largely been the preserve of men, and in the intersex field it does appear to concern itself disproportionately with safeguarding the integrity of male anatomy. As Simon Williams and Gillian Bendelow put it: "It is male minds, bodies and life experiences that, implicitly or explicitly, have been taken as the 'norm' against which 'all else' is judged" (Williams and Bendelow 1998).

If patriarchy is a somewhat problematic concept, then *paternalism* has been widespread in intersex medicine, particularly evident in the protective way in which XY-women are treated with regard to the disclosure of diagnostic information; and *androcentrism* and *phallocentrism* are certainly of relevance in this field. This distils into a clinical preoccupation with male genital size and performance, and on what the Americans call 'the locker room factor', that is, concerns about young intersexed boys suffering stigmatisation when undressing in the presence of others. Preserving fertility has more often influenced decision-making in intersexed babies with functional ovaries/uterus. Phallocentrism certainly seems to be at work in the rush to feminise those infants whose phallus doesn't measure up to required male standards, with any notion of informed consent on the part of the patient appearing to be set aside. Hence the vast majority of surgical sex assignments have been to a female genital anatomy (effectively involving castration) but without any evidence-base on the part of paediatric clinicians as to how well these children will function sexually as adult females, or any empirical knowledge as to whether brain androgenisation in utero might have predisposed them to a male gender identity as they mature (see Creighton 2006 for an overview). Long-term follow-up studies do not exist (although prospective studies are now being set up) because until recently the attendant secrecy has prevented the follow-up of fully informed adult patients.

Socio-cultural anthropologist Nuria Gregori and colleagues discuss the higher standards required in intersex medicine for a penis compared to a clitoris, due to the former's greater degree of sociological significance (Gregori et al 2007). This thinking is also evident in the famous (and much regretted) words of Dr John Gearhart, "It's easier to make a hole than to build a pole" (Hendricks 1993), and in Suzanne Kessler's comment that in paediatric intersex medicine "there is a striking lack of attention to the size and shape requirements of the female genitals, other than that the vagina be able to receive a penis" (Kessler 1990), belying the fact that surgery to create/extend a vagina is, in fact, no less problematic than phalloplasty. It would seem that the female sex is seen doubly as 'other' in intersex medicine. It is seen as subordinate in the conventional

Freudian sense, and is also used as a surgical bucket category or fallback position in cases where a child's genitals do not measure up to the required male standard.

B Appendix - Genealogy of intersex conditions

This appendix summarises the historical background to the phenomenon under study and traces significant changes in the way intersex conditions have been viewed since the early/mid 1990s. It discusses how patients found their voice and started calling for revisions to medical practice and taking ownership of, and challenging the terminology used by doctors to label them.

Historical medical context

Medicalisation of intersex

Gender historian Christina Annalena Eckert traces the history of the intersexed body through various eras: from the age of pre-medicalisation (ancient Greece, the Middle Ages, the Early Modern period) to the development of biological determinism, the age of surgery, and the dawning of post-medicalisation (feminist and queer theories, the “inter(net)sex” movement) (Eckert 2003). The hermaphrodite, in the classical sense of a human being with a dual set of fully functioning reproductive organs (such as even to allow self-impregnation) is a mythological concept which cannot exist in practice, and Elizabeth Reis, a researcher in women’s and gender studies, explores the changing definitions and perceptions of “impossible hermaphrodites” from the colonial period to the early 20th century (Reis 2005, 2009).

Over the period studied by Reis medical observers postulated that patients with confused/ambiguous external or internal genital organs were in fact cases of mistaken sex, not hermaphrodites, and that a ‘true’ male or female sex could be uncovered and, from the mid 20th century onwards, enforced by surgery (Reis 2005). As Michel Foucault points out in relation to the famous nineteenth century case of Herculine Barbin, it is the moment in history when ‘hermaphrodites’ stop being people in whom a combination of sexual characteristics can be found (and who might therefore be allowed to *choose* what *they* wanted to be) and become those whose bodies deceptively hide their real identities, their true sex, which the expertise of *doctors* can uncover (Foucault 1980b). Canadian intersex(ed) academic Morgan Holmes also asserts that it has not always been bodily issues that were the main focus of medicine in the case of such individuals. She argues that in the nineteenth century a person would be led to a physician for diagnosis in adulthood by a combination of desires and sexual practices, or by political interests (request for sex reassignment in order to marry, avoidance of conscription, access to property through inheritance, and so on) rather than their biology per se (Holmes 2008). She also comments that as recently as 50 years ago the size of infant genitals was not a primary identifier

of intersexuality because there were no surgical means of ‘correcting’ them until the advent of wartime plastic surgery and postwar transsexual surgery (Holmes 2008).

In the early 20th century many alleged hermaphrodites were re-categorised as women with a large clitoris. But arguably the notion of *androgyny*, implying an equal mix of male and female, as depicted in ancient representations of the hermaphrodite (which at one time was revered as a representation of spiritual perfection), is more acceptable in society than the notion of a ‘phallic female’, a woman with a large clitoris, which raises great anxiety over the possibility that they might penetrate other women. History of Science scholar Christine Matta gives 1852 as the date of the first published report of gender corrective surgery in the US and draws attention to an increase in gender reinforcement surgery after homosexuality became a matter of discussion in American medical journals (Matta 2005). So even if hermaphrodites did not exist, the idea of one body exhibiting characteristics of two sexes raised a host of anxieties about sex and gender, and it didn’t stop medicine perpetuating the use of hermaphrodite-related terms for labelling those people not fitting the norm until just a few years ago.

In her book *Hermaphrodites and the Medical Invention of Sex* medical historian Alice Dorumat Dreger traces evolutionary thought through the late 19th and early 20th centuries about what makes a person male or female. At the time, a person’s ‘true sex’ was assigned by the sole criterion of whether a testis or an ovary was present. Partly because of the simultaneous increase in access to gynaecological care, the reported number of intersexed people grew, leading to a perceived need to establish diagnostic criteria for ‘maleness’ and ‘femaleness’ in a period during which gender, sexuality and sex were indistinct notions (Dreger 1998b). By the mid 20th century, says Reis, physicians understood the scientific importance of chromosomes and hormones but elevated external genital morphology as the single most important criterion, with ‘corrective’ surgery becoming routine in enforcing a bipolar system. Deborah Findlay focuses on obstetric and gynaecologic definitions of intersexuality in the 1950s, exploring the role of medical science in producing and reflecting taken-for-granted categories of biological sex. She examines how biomedical science used cultural and social concepts of biological sex and gender as resources in dichotomizing sex, and creating diagnoses of ‘true’ biological sex (Findlay 1995). This model, assuming a need to assign a sex and stressing surgical convenience over all other considerations has, Reis asserts, had lasting negative consequences (Reis 2005). Intersex was largely confined to the medical sphere until the mid-1990s, there being very little knowledge until then of its existence on the part of society as a whole.

Knowledge of AIS

What is now known as Androgen Insensitivity Syndrome may have been reported as early as 1817, when Steglehner described the case of an apparently normal woman who had undescended testes (Steglehner 1817). AIS has been of relatively long interest to geneticists. Dieffenbach, an American geneticist, first pointed out in 1906 that there is a hereditary pattern to the occurrence of the condition (Dieffenbach 1912). Petterson and Bonnier (1937) concluded that the affected persons are genetically male.

The condition has several synonyms as various clinicians claimed discovery of some new aspect or other of the phenomenon. As mentioned in the previous chapter, what is now known as Complete AIS (CAIS) was first reported as a clinical syndrome by Morris, in 1953, assigning it the name Testicular Feminization Syndrome. Wilkins first demonstrated that the basic defect is tissue unresponsiveness to androgens or male hormones (Wilkins 1957), hence the newer (and as far as most patients and clinicians are concerned) more appropriate and less stigmatising name of Androgen Insensitivity Syndrome (or sometimes Androgen Resistance Syndrome). However, the term Testicular Feminization Syndrome has persisted in the medical literature, along with the newer term, until very recent times. It is only with activism from patient support/advocacy groups in the last 18 years or so, and as older clinicians left the arena, that this term started disappearing. Occasionally the condition is referred to as Goldberg-Maxwell Syndrome (Goldberg and Maxwell 1948). In 1963 Morris and Mahesh described the clinical features of the partial form (PAIS) of the condition (Morris and Mahesh 1963). The complete form of AIS (CAIS) has often been referred to as ‘classic testicular feminization’ or Morris’s Syndrome, in the sense that it was the first form reported by Morris, and is more common than PAIS.

Netter and colleagues reported what is now known as AIS in a famous photographic model (Netter et al 1958) and Marshall and Harder reported affected twins who worked as airline stewardesses (Marshall and Harder 1958). Subsequent medical papers often referred reverentially to such reports, although many AIS women view these paternalistic attempts to give their condition a gloss (almost always by male clinicians) as unnecessary and patronising. Much is made also on the internet of urban myths about certain movie actresses supposedly having AIS.

In 1974 Migeon showed that in AIS the tissue resistance to male hormones lies in a fault with the androgen receptor (Keenan et al 1974, Migeon 1981). The androgen receptor gene, which is located on one of the mother’s two X sex chromosomes, was cloned and sequenced in 1988.

Non-disclosure of diagnostic information

Intersex medicine has sought to erase ‘failed masculinity’ at all costs, not only via *surgery* to maintain a clear gap between the size of a clitoris and that of a penis but also via *secrecy* (Holmes 1994) and events in the 1950s have played a key part in the way medicine has handled intersex for almost 60 years. It was then that John Money (Johns Hopkins, Baltimore, MA) expounded his (now discredited¹) ‘gender neutrality’ or ‘optimal gender’ theory (claiming that babies can be moulded into either gender if ambiguous genitalia are normalised early enough) based on his famous ‘John’/‘Joan’ study (Money et al 1955a, 1955b). He also proposed that doctors and parents should withhold their sex-(re)assigned child’s medical history from them, so as to reinforce the gender of rearing. This established a paradigm of early genital surgery in cases where morphology was deemed abnormal, a lack of disclosure in clinical interactions, secrecy within families, leading to isolation and stigmatisation amongst patients as they grew up.

Until the late 1990s medical texts often referred to the birth of a baby with ambiguous genitals as “a medico-social emergency” and although many individuals with AIS (those with the complete form, that is) show no outward signs of ambiguity, their XY chromosomes and their internal testes mean that they have been swept along in the general tide of taboo and secrecy about intersex. Morris’s 1953 paper had argued against diagnostic truth disclosure to patients with ‘testicular feminization’, stating:

It goes without saying that it would be unwise to inform the patient of the true state of affairs...
It seems only necessary to state that child-bearing is impossible.

He expressed concern about the apparent high prevalence of psychiatric morbidity among such patients, suggesting that this often resulted from “overzealous medical attention”:

What ever the legal, moral, or religious view of this unusual circumstance may be, where a male is married to a female with male gonads, the obvious humane attitude is not to interfere and by such meddling produce a psychiatric casualty and perhaps a suicide.

Morris’s paper arguably established the tenor of the psychosocial management of Complete AIS for decades. Until the mid-late 1990s the accepted paradigm was that CAIS patients (and sometimes parents of affected babies) were to be told half-truths: for example, that their ‘ovaries/uterus’ had not developed properly and that they needed a ‘hysterectomy’ (in reality a

1. In 1997 Milton Diamond and Keith Sigmundson revealed that Money’s recommended raising of a young (non-intersexed) boy as a girl, after the loss of his penis through a botched circumcision (the famous ‘John’/‘Joan’ case) had, contrary to Money’s claims, not been a success, with ‘Joan’ having reverted to the male role (Diamond and Sigmundson 1997). They thus challenged 50 years or so of surgical practice in cases of ambiguous genitalia, which had been based largely on this single supposed demonstration of the malleability of gender identity.

gonadectomy, or more correctly an orchidectomy). They would not be told about their XY sex chromosomes or their internal testes.

Just over 30 years ago, two influential UK clinicians and textbook authors in this field gave the following appraisal of those with intersex conditions (Dewhurst and Gordon 1969: vii):

To visualise individuals who properly belong neither to one sex nor to the other is to imagine freaks, misfits, curiosities, rejected by society and condemned to a solitary existence of neglect and frustration. Few of these unfortunate people meet with tolerance and understanding from their fellows, and fewer still will find even a limited acceptance in a small section of society: all are constantly confronted with reminders of their unhappy situation. The tragedy of their lives is the greater since it may be remediable; with suitable management and treatment, especially if this is begun soon after birth, many of these people can be helped to live happy well-adjusted lives, and some may even be fertile and be enabled to enjoy a normal family life.

This text is typical of its time, with doctors adopting a pitying and condescending tone towards patients, and implying that medicine, especially surgery (“suitable management and treatment, especially if this is begun soon after birth”) will solve all their problems, but neglecting the treatment that would probably be of most benefit: i.e., to be told the truth about one’s diagnosis, to know that one is not a “freak” of nature, and that others are affected, and to be able to talk about one’s differences. In the mid-1990s, Dewhurst’s successor tried to discourage attempts by the newly formalised UK-based AIS Support Group and the BBC to increase patient and public awareness of AIS and other intersex conditions,² and it emerged that his department was clinging to a policy, inherited from Dewhurst, of withholding diagnostic information from its XY-female patients, and probably didn’t want a queue of angry patients at their door demanding why they’d been kept in the dark (AISSG Web 2001).

Awareness and advocacy

This section outlines how, in the 1990s, discussions about intersex moved out of the closed medical community and became a topic of debate for non-clinical professionals such as sociologists and, importantly, for patients themselves. Since my study has a advocacy aspect to it, the sections below are framed in relation to the emerging advocacy movement, because patient groups have played an important role in bringing these conditions into the open and encouraging clinicians to change the way they treat patients.

2. Tried to discourage AISSG from distributing their newly created factsheet on AIS and the BBC from making a documentary on the subject (both went ahead and the film was screened in August 1996 under the title ‘XY Women’, as part of a BBC ‘Dark Secrets’ series).

Out of the clinical closet

The start of discussions about intersex beyond the conventional medical aspects can be traced to the late 1980s. At that time US medical publications showed the first signs of a debate on truth disclosure in AIS (Minogue et al 1988, Green and Horowitz 1989). In 1991 UK-based Janet Goodall's paper 'Helping a Child to Understand her Own Testicular Feminisation' appeared in the respected UK medical journal *The Lancet* (Goodall 1991). The child whose case was discussed in the article, by now in her early 30s, made herself known to AISSG in late 2010, and participated in this study (participant P026). It is clear, often from their title, that patients were not intended to see some of these articles. Elizabeth Scott's reflection on a case history, published in a popular magazine for General Practitioners, used the title 'Does She Need to Know She is a He?' (Scott 1993). These articles from the 1980s and early 1990s related to cases of Complete AIS, where the absence of ambiguous genitalia makes it somewhat easier to keep diagnostic data from the patient.

In the early 1990s, social scientists started to investigate intersex and report on it for the first time from the viewpoint of those affected. In 1990 US social psychologist Suzanne Kessler (who in 1978, with social anthropologist Wendy McKenna, had co-authored 'Gender: An Ethnomethodological Approach') published a milestone article which probably marked the point when discussions of intersex moved outside of the medical arena. 'The Medical Construction of Gender: Case Management of Intersexual Infants' was based on interviews with paediatric surgeons and endocrinologists, as well as parents of intersexed children, and with adults who had been treated in childhood (Kessler 1990). She showed that clinicians, whilst claiming to reveal, through surgery, a true biological sex, were in fact applying social principles in their decision-making. She also reported (p.23) that:

There are no published studies on how these [intersexed] adolescents experience their condition and their treatment by doctors. An endocrinologist interviewed mentioned that her adolescent patients rarely ask specifically what is wrong with them, suggesting that they are accomplices in this evasion.

In 1993 the article 'The Five Sexes: Why Male and Female are Not Enough', by US biologist and feminist historian of science Anne Fausto-Sterling, appeared in the March/April issue of *The Sciences*. In an accompanying editorial she wrote (Fausto-Sterling 1993):

As it happens, the physiological reality [that a vast range of external sexual characteristics can occur] is almost unknown outside medicine - and that fact alone is symptomatic of a society unwilling to accept the truth about its members.

The July/August issue of the journal published a response to the article from intersexed woman Cheryl Chase (Chase 1993). It invited other intersexed people to contact her with the view to

forming an Intersex Society of North America (ISNA). Children who had been subjected to John Money's surgical gender reinforcement protocol were now, like Chase, reaching an age where they were inclined to protest about what had been done to them without their consent. 1993 was also the year that I helped to formalise the UK AIS Support Group (AISSG), which had existed in a small informal way since 1988, without any knowledge at that time of similar initiatives in the USA. The arrival of the internet, and of an increased openness about sex as a result of the HIV/AIDS crisis, helped these and other emergent intersex advocacy groups to establish themselves.

In 1994 Chase sent AISSG a draft she was preparing titled 'Affronting Reason', telling of her painful reading of her medical notes at the age of 21 and her discovery of her 'hermaphrodite' status and childhood clitorrectomy; and how she was channelling her anger by working to build up ISNA. The article was published a few years later, and in it she observed that "Intersex is a humanly possible but (in our culture) socially unthinkable phenomenon" (Chase 1998a: 208). The first appearance of an AIS patient's words in a professional UK publication, talking from personal experience, was probably the *British Medical Journal* article 'Once a Dark Secret' (Anonymous 1994). The identity of this writer is still not known to those in patient support/advocacy circles.

Morgan Holmes has identified herself in print as being intersexed, and for a while ran a Canadian chapter of ISNA, but most of her work has been published in her role as an academic. In 1994 she published an important article, 'Re-membering a Queer Body', about the social attitudes that underpin the treatment of intersexed infants (Holmes 1994). This might claim to be the first feminist-oriented analysis of infant gender-reinforcement surgery, focusing on patriarchal attitudes to inadequate male genitals (see also Appendix A). Her 1995 paper 'Queer Cut Bodies: Intersexuality and Homophobia in Medical Practice' draws parallels between gender reinforcement surgery and female genital mutilation and cites homophobia as a motivating factor in the management of intersexed bodies (Holmes 1995, 2000).

In Spring 1995 AISSG introduced its newsletter, A^LI^AS (*Looking At AIS*), which sought to empower group members and report on their personal experiences (ALIAS Newsletter 1995a). These revolved around the half-truths and secrecy to which they'd been subjected and difficulties encountered in clinical and family interactions. ISNA's newsletter, *Hermaphrodites with Attitude* (first issue Winter 1994, later to become *ISNA News*), focused more on campaigning against genital surgery (HWA Newsletter 1994).

AISSG forged collaborative links with specialist UK clinicians from the start. In 1995 the group was invited by Richard Stanhope, a paediatric endocrinologist at the Institute of Child Health, part of the University College London Hospital (UCLH) NHS Trust, to make a presentation at a Royal Society of Medicine symposium (*Management of Intersex into Adult Life – Especially Androgen Insensitivity/Testicular Feminisation Syndrome*). In 1997 clinicians in adult intersex medicine at UCLH's Middlesex Hospital (Gerard Conway, Sarah Creighton, Lih-Mei Liao and colleagues) consulted AISSG on the setting up of what was to become the first interdisciplinary intersex clinic³ and the start of a continuing collaborative relationship. Since the mid-1990s AISSG has influenced medical attitudes significantly and taken part in a number of projects with clinicians. The group met with Lih-Mei Liao in mid-1998 to discuss what topics required research within clinical psychology and started to work with Julie Alderson, clinical psychologist at Leeds General Infirmary, to recruit participants for a study; as did members of AISSG USA (founded in 1995 by Sherri Groveman, a lawyer with CAIS) with sociologist Sharon Preves. ISNA's early activities took a more militant form as they donned T-shirts emblazoned with "Hermaphrodites with Attitude" to picket medical conferences where paediatric clinicians were discussing gender reinforcement surgery. ISNA met with resistance from doctors in the early days (Chase 1998b, 2003), but in its 2008 reincarnation as Accord Alliance also started to work *with* doctors. Since 2008, Cheryl Chase has operated under the name Bo Laurent.

Once intersex had emerged from the shadows in the mid 1990s, it became a subject of interest to a number of disciplines (clinical psychologists, sociologists, feminist academics, history of science scholars, ethicists, lawyers, educationalists, and so on). Some publications are interdisciplinary, and with intersexed individuals sometimes co-authoring papers alongside clinicians, psychologists and/or non-clinical academics.

Spreading the word

By 1997 ISNA had linked up with several US academics and started publishing in 'alternative sexuality' publications. An important achievement was the Fall 1997/Winter 1998 issue of *Chrysalis: Journal of Transgressive Sexualities* which was devoted to 'Intersex Awakening' and contained first-hand accounts by various activists and articles by scholars (Chase and Coventry 1997/98). Tamara Alexander, for example, talked from painful personal experience of attempts by doctors "to erase such indeterminate states of being from bodies and minds" having led to a lot of suffering in silence (Alexander 1997). Also in 1997, Sherri Groveman wrote an article covering counselling, the clinical examination, truth disclosure, peer group support, vaginal construction, and gonadectomy and informed consent in AIS (Groveman 1997) and the Winter

3. See Middlesex Centre in bibliography.

1998 issue of the *Journal of Clinical Ethics* was guest-edited by Alice Dreger and devoted the entire volume to the management of intersex, including an article by Groveman (Dreger 1998a). *Intersex in the Age of Ethics*, a book edited by Dreger, contained the articles from the *Journal of Clinical Ethics* special issue and additional articles, including some from the *Chrysalis* special issue (Dreger 1999). It covered a wide range of ethical issues relevant to the treatment of intersex infants, children and adults, represented by first-person narratives of intersexual persons and their families.

By the mid-1990s the internet had started to bring intersexed people together. Both ISNA (early 1996) and AISSG UK (late 1997) had set up web sites, and groups of intersexed people were busy discussing matters of interest in various online forums. AISSG UK has always been somewhat more introspective and less ‘out there’ than ISNA, and confined their early publishing efforts to transcripts of selected intra-group discussions (amongst UK and US group members) in their own newsletter, and later on their web site. Topics aired ranged from the possibility of medicine enabling an AIS foetus to develop a uterus (AISSG Web 1997a), the way medical textbooks portrayed AIS and similar conditions (AISSG Web 1997b), issues around truth disclosure (AISSG Web 1998a), accounts of how XY-women felt on the threshold of adolescence (AISSG Web 1998b) and discussions about the terminology used to describe them in medical records/texts (AISSG Web 1999). The UK group started displaying personal biographical stories submitted by XY-women on its website from 1997 (AISSG Web 1997 to-date).

AISSG UK’s joint ventures have more often been with clinicians and clinical psychologists than non-clinical academics, with forward-thinking Australian paediatric endocrinologist Garry Warne being an early collaborator with, and supporter of AISSG UK. In 1997 I helped him to re-work his ‘Notes on AIS for Parents and Patients’ for publication in booklet form. The original notes had been compiled, with great foresight, for use in his hospital practice back in the dark ages of the mid-1980s (Warne 1997, 2003).

By the late 1990s non-clinical academics were starting to analyse and comment on the activities of intersex patient advocacy groups. In 1998 the first books on intersex appeared. Suzanne Kessler’s volume *Lessons from the Intersexed* (Kessler 1998), which incorporated her key 1990 “Medical Construction” paper as one of the chapters, and *Hermaphrodites and the Medical Invention of Sex* by Alice Dreger (Dreger 1998), both commented on the aims and strategies of the various patient groups that were by that time attempting to influence medical opinion and practice with an overall message that intersex is not (with a few exceptions) an illness or a disease. Dreger continued her interest in this area in later works (Dreger 2006, 2009). US

academic Stephanie Turner examined the sex and gender identity rhetoric of members of ISNA and its indebtedness to feminist and gay/lesbian/transperson theory and practice (Turner 1999) and Emily Nussbaum also traced the rise of the intersex movement in the US, featuring Chase, Kessler, Dreger, Fausto-Sterling et al (Nussbaum 1999). Sociologist Sharon Preves' analyses of sociocultural responses to intersexuality traces the history of intersex medicalisation, considering identity politics and the intersex social movement, and the implication for social reform (Preves 2002, 2004).

In the UK, Peter Broks, a parent member of AISSG UK working as a university lecturer in the Public Understanding of Science, published an article titled 'Trust Me, I'm a Patient' in his university's magazine, exploring the disconnects between clinicians' view of AIS and those of affected individuals (Broks 1999). A table from his article is reproduced here, since it provides a useful sketch of the alternative agendas of the two interest groups:

Doctor/patient agendas (from Broks 1999)

Agenda items	Doctor	Patient
The problem	not fully male	not fully female
The cause	faulty gene	presence of unwanted hormone ^a
Main concern	gender identity	coital adequacy, ^b fertility
Experience of AIS	vicarious, via patient	lived, first-hand
Policy	secrecy	disclosure

a. Müllerian Inhibitory Factor (MIF), also known as Anti-Müllerian Hormone (AMH), produced by the testes of an XY foetus and which inhibits the development of Fallopian tubes, uterus and upper vagina.

b. In female patients (there seems plenty of concern with male adequacy).

A book chapter by UK feminist academic Celia Kitzinger forms a useful summary of the main issues and dilemmas at the start of the 21st century. It focused on psychosocial aspects of AIS and was based partly on material from AISSG UK's newsletter, ALIAS, (Kitzinger 2000).

By the start of the new millennium some US clinicians were starting to take notice of patient advocacy groups, and 2000 saw the formation of the North American Task Force on Intersexuality, a co-operative venture between clinicians and ISNA (NATFI 2000, disbanded in 2001). NATFI aimed not only to rethink the clinical management of intersex but also to come up with a new nomenclature. However the latter didn't happen until the Chicago 'Intersex Consensus' conference in 2005. In a 2000 article Anne Fausto-Sterling evaluates progress in the US since her 1993 'Five Sexes' article (Fausto-Sterling 2000). She explains how clinicians were now taking Cheryl Chase's ISNA campaign more seriously, and discusses the recent books by

Kessler and Dreger and the formation of NATFI. In 2000 Peter Hegarty interviewed Chase for an article in which topics ranged from her personal experience, intersex activism and feminist politics, and the attitudes of doctors and psychologists (Hegarty 2000). UK clinicians set up a similar initiative to NATFI but with a narrower focus (on surgery) and 2001 saw the publication of a ‘Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia’ (BAPS 2001). In 2003 Dr. Garry Warne discussed the formation and evolution of support groups for Congenital Adrenal Hyperplasia and AIS in Australia (Warne 2003).

Patients were now finding their voice and it was no longer so easy for doctors to write about intersex on the assumption that no affected persons would read their words. Robert Marion, a US professor of genetics, experienced this to his cost when he related, under a melodramatic title, how he misled a Mexican AIS woman about her condition (Marion 2000). As ISNA described it in their bibliography: “Although the patient was kept in the dark, Dr. Marion published her story for the entertainment of readers of *Discover* magazine”. Sherri Groveman of the US AISSG had a letter to the editor published in a later issue; and a number of other support group members/sympathisers also wrote directly to the article’s author to complain. In 2001 Groveman joined forces with Kate Scannell MD to write two companion articles in an ethics journal (Groveman 2001, Scannell 2001), in 2002 she had a chapter published in the ‘Patient Perspectives on Endocrine Diseases’ section of the second edition of a well-known endocrinology textbook (Groveman 2002), and in 2006 contributed a chapter to a book on the ethics of childhood surgery (Groveman 2006).

As mentioned earlier, AISSG UK has been closely involved with clinicians at UCLH since the mid-1990s. In January 2002 the support group and UCLH clinicians staged a jointly organised London conference, *Intersex in the New Millennium: A Multidisciplinary Forum for all Involved*, attended by number of support group members (AISSG Web 2002, Creighton et al 2004). The conference aimed to bring together experts-by-training (clinicians) and experts-through-lived-experience (patients and families) to discuss “the current turmoil” in intersex clinical management (widespread non-disclosure and routine genital cosmetic surgery hotly opposed by a number of adult patients and patient groups). Audience feedback sheets showed overall appreciation of the collaboration but that surgeons and gynaecologists were most likely to have experienced anti-clinician feelings at the conference.

ISNA has produced a number of educational resources (ISNA) and in the UK members of AISSG and a CAH group⁴ took part in an educational film, *Gender Trouble*, in which three women with AIS and a woman with CAH talked to the camera about their experiences. The film

was funded by the Wellcome Trust as part of the Sci-Art venture to combine science/medicine (intersex) with art (film-making) (Mortimer 2002). Intersex Initiative Portland in the US published a guide for teachers in women's, gender and queer studies. The author reported (Koyama 2003):

The survey was conducted in early 2001, and the result supported my prediction: most of the scholars who responded to the survey reported that they use intersex to teach about social construction theory, while few bother to actually use materials written by intersex individuals or about their lives.

In 2004 Sharon Preves looked at the mobilisation and methods of intersexed individuals and their allies, used to de-stigmatise intersex and to alter the medical treatment they receive. She explored the intersex movement's use of the mass media, arguing that media attention to intersex medicalisation has been instrumental in initiating clinical reform. Members of the UK and US AISSGs have featured in TV documentaries made or commissioned by the BBC and/or Discovery (1996, 1998, 2000, 2002 and 2011) and by UK's Channel 4 (2004, 2005) and in many newspaper and magazine articles.⁵

As with the Kitzinger book chapter mentioned earlier, researchers and clinicians were by now using material/input from patient advocacy groups. From 2000 onwards AISSG UK had helped several postgraduate students/researchers with their studies/theses, either by supplying information/advice or by recruiting participants (e.g. Alderson 2000, Murphy 2000, Smith 2000, Nahman 2000, Eckert 2003, Gallacher 2005). In 2003 the group was asked by Ingrid Holme to review a paper that she was to present at a meeting of the Postgraduate Forum on Genetics and Society at the University of Sussex (Holme 2003). And 2004 saw the publication of a textbook, *Paediatric and Adolescent Gynaecology - A Multidisciplinary Approach*, essentially an intersex textbook, in which I contributed a chapter on parent/patient issues at the invitation of one of the editors, Sarah Creighton, consultant gynaecologist at the UCLH clinic (Simmonds 2004). My chapter sits alongside chapters by members of the UCLH clinical team and other clinical specialists (mostly members of the British Society for Paediatric and Adolescent Gynaecology, BritSPAG⁶).

2005 was the year of the Chicago 'Intersex Consensus' conference at which a new paradigm of clinical care was formulated, including a new system of terminology. The subsequent publication of the 'Consensus Statement' (Hughes et al 2006) and the adoption of the new DSD-based

4. See 'AHN' in Bibliography.

5. See http://www.aissg.org/12_history.htm and http://www.aissg.org/42_books.htm for details.

6. An organisation, set up in 1999 (first meeting in 2000) by clinicians at UCLH (Sarah Creighton) and elsewhere, with a special interest in improving clinical care for young people with intersex conditions.

nomenclature spurred European clinicians to set up a network to foster advances in (mainly paediatric) clinical management and research (EuroDSD⁷).

A sign of the widening interest was the production, in 2007 by Maura Kelly, of an 'Intersex Factsheet' for the organisation Sociologists for Women in Society. And by 2008 the activities of various intersex patient advocacy groups were forming the basis of an increasing number of academic articles, theses and books. Some writers with quite surprising backgrounds have developed an interest in the field. In 2007 Catherine Harper, who has a background in textile design, wrote up a second PhD in the form of a book on intersex which "draws heavily on the personal testimony of intersexed individuals, their loved ones and medical carers" (Harper 2007).⁸ Another researcher who seems to have had no previous track record in intersex scholarship is Brian Still, a Professor in English with an interest in technical communication and rhetoric. His PhD thesis (Still 2005) and subsequent book (Still 2008) look at rhetoric and Foucauldian discourse in exploring the emergence of a counter-discourse amongst intersex people, aided by the rise of the internet and enabling them to challenge the way they are treated by medicine and society. And Robert Davidson (Davidson 2009) evaluated the inter-group differences of opinion over the recently introduced DSD terminology.

By 10 years into the new millennium intersex was out of the shadows and had become a serious and organised field of discussion and study in specialist medical circles. I teamed up with Melissa Cull, who runs the UK support group for CAH adults mentioned earlier, to co-author a paper on the role of support groups at the invitation of EuroDSD clinicians in continental Europe (Cull and Simmonds 2010). And I collaborated with Sue Elford who runs a UK group for parents of CAH youngsters,⁹ to contribute similar material for a DSD clinical guidelines document (Ahmed et al 2011) initiated by the lead clinician in the Scottish DSD Network (SDSD)¹⁰ who is also a key participant in EuroDSD (see page 135). In September 2011 AISSG agreed to act as the main patient group contributor to a large European study called DSD-Life, with clinical teams from Germany, France, The Netherlands, UK, Sweden and Poland, and which will evaluate the effect of treatment (medical and psychological) on psychological well-being and quality of life.

7. See 'EuroDSD' in Bibliography.

8. In 2001 she had staged a performance-art installation in Ireland titled 'Anatomical Drag', involving textiles and many references to intersex (Harper 2002). In early 2002 she contacted AISSG asking if the support group could supply photographs of ambiguous genitalia for a textiles project and her biography on the web site of Brighton University (where she is now head of the Department of Architecture and Design) says that her book was the culmination of a 4-year study of "textile performativity and desire".

9. CLIMB Congenital Adrenal Hyperplasia Support Group (<http://www.livingwithcah.com/>)

10. See SDSD in Bibliography.

And I continue AISSG's collaboration with the UCLH clinical team via a forthcoming book chapter and journal paper (Liao and Simmonds in press 2013a, 2013b).

Evolution of medical terminology

The umbrella terms used in intersex medicine have been introduced on page 8. The nomenclature in use for the past 130 years or so has pathologised (and masculinised) these conditions. It is archaic, based on mythological concepts, and stigmatises those affected.

'Old' terminology

As seen earlier, male pseudo-hermaphrodite is an umbrella term for a number of different XY intersex conditions and has been used in medical texts and in patients' medical records until very recently. Dreger asserts that "only since the middle of the 20th century has 'intersexed' been regularly substituted for 'hermaphroditic' in medical literature". But in reality, in spite of the advent of chromosomal analysis and the availability of the more modern 'intersex' term, the medical profession has persisted in using the hermaphrodite-derived nomenclature in the medical literature (e.g. Conte and Grumbach 1996), as has the media, for the shock horror effect of such language. Even as late as 2008 some clinical researchers were still publishing papers with the term 'male pseudo-hermaphrodite' in the title (e.g. Simpson 2008).

Part of the attraction of these terms as far as clinicians are concerned has been that they give more granularity than the generic 'intersex' term. For example, the 'male-' and 'female-' versions of the 'pseudo hermaphrodite' term differentiate between the XY-female and XX-male types of intersex, whereas the term 'intersex' does not. But 'male pseudo-hermaphrodite' is particularly offensive to many XY-female individuals by virtue of combining three attributes that are usually abhorrent to them, as far as their identity and self-image are concerned – maleness, falseness, and freakishness.

DSD nomenclature

A 2005 paper by Alice Dreger, Cheryl Chase and colleagues called for the abandonment of all hermaphrodite-based medical terms, showing how this nomenclature pre-dates the modern sciences of endocrinology and genetics, and confuses and sometimes harms those concerned. They suggested what a new taxonomy and nomenclature should and shouldn't do (Dreger 2005).

The new nomenclature introduced at the Chicago conference in 2005 and based on the term Disorders of Sex Development (DSD) had been hatched over several years by a US consortium

of interested parties (DSD Consortium, Dreger et al 2005). It seems to have gained the approval of clinicians and is gaining currency in clinical usage and in the medical literature (Pasterski et al 2010a, 2010b), with Ieuan Hughes trumpeting that “The DSD nomenclature and its spin-offs have arrived at the high altar of medical practice” (Hughes 2010: 161). However, it has not been universally embraced by patients and has been criticised by some patient groups and academics, mainly on the basis of it being a return to pathology, in view of its ‘disorder’ component (AISSG Web 2011). It seems that terminology was not on the Chicago conference agenda as a specific discussion topic, but the new DSD-based system was introduced from the sidelines during the final plenary session, by a US clinician on behalf of the ISNA delegate. A second patient representative (from continental Europe) was present, but, like the other delegates, was not pre-warned that the new terminology was likely to be squeezed in. Thus patient groups and other interested parties outside of the US have only had a chance to voice an opinion after the event (DSD Letters 2006, Diamond and Beh 2006). In the meantime some patient groups have made it known that they are using the acronym to represent *Differences* in Sex Development. These issues are discussed in more detail on page 36.

The new terminology should at least mean that the dreaded mythology-based hermaphrodite terms will gradually disappear from medical practice and literature. But it may take time to filter down to non-specialist clinicians. And today’s young patients only have to go online to come across offensive and archaic medical terminology in publications from the recent past, even if such terms are becoming less common in the current literature.

This appendix has traced the historical background to AIS and other intersex conditions and contextualised the conditions in terms of changes in awareness that have happened in the last 18 or so years, including the controversial issue of medical terminology.

C Appendix - EuroDSD Registry dataset

Overleaf is a copy of the basic patient dataset for the European Society for Paediatric Endocrinology/EuroDSD Registry of patients with intersex/DSD conditions (taken from <https://tethys.nesc.gla.ac.uk/EuroDSD/docs/eurodsdregisterdataset.pdf> and discussed on page 135). Note the emphasis on male genital anatomy (e.g. no estimate of degree of vaginal development).

CORE DATASET – ESPE DSD REGISTRY

Revision date							
Revision author							
Year of Birth							
Local Hospital Identification							
Date of First Notification							
Centre						
Reporting Clinician						
Clinical Presentation							
Sex assigned	Male <input type="checkbox"/> Female <input type="checkbox"/> NK <input type="checkbox"/>						
Phallus Size	Normal Male <input type="checkbox"/> Small Male <input type="checkbox"/> Large Male <input type="checkbox"/> Normal Female <input type="checkbox"/> Large Female <input type="checkbox"/> Chordee <input type="checkbox"/> NK <input type="checkbox"/>						
Phallus Length	Date..... Lengthmm NK <input type="checkbox"/>						
Urinary Meatus	Normal Male <input type="checkbox"/> Hypospadias <input type="checkbox"/> Distal <input type="checkbox"/> Mid <input type="checkbox"/> Proximal <input type="checkbox"/> Normal Female <input type="checkbox"/> NK <input type="checkbox"/> (glanular, coronal) (penile shaft) (penoscrotal, scrotal, perineal)						
Labioscrotal Fusion	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>						
	Labioscrotal Inguinal Abdominal Absent Undescended-Nonspecific NK						
Right Gonad	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>						
Left Gonad	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>						
External Masculinisation Score	___ (0 – 12) NK <input type="checkbox"/> Tanner Stage ___ (1 - 5) NK <input type="checkbox"/>						
Internal Sex Organs	Mullerian <input type="checkbox"/> Wolffian <input type="checkbox"/> NK <input type="checkbox"/>			Modality US <input type="checkbox"/> MRI <input type="checkbox"/> CT <input type="checkbox"/> LS <input type="checkbox"/> LT <input type="checkbox"/>			
Associated Malformation	Adrenal <input type="checkbox"/> GIT <input type="checkbox"/> Renal <input type="checkbox"/> Haematological <input type="checkbox"/> Skeletal <input type="checkbox"/> CNS <input type="checkbox"/> ENT <input type="checkbox"/> Resp <input type="checkbox"/> Heart <input type="checkbox"/> SGA <input type="checkbox"/> Short stature <input type="checkbox"/> Craniofacial <input type="checkbox"/> Non-defined Syndrome <input type="checkbox"/> Other <input type="checkbox"/>						
DSD Classification							
Karyotype	46XY <input type="checkbox"/> 46XX <input type="checkbox"/> Presumed XY <input type="checkbox"/> Presumed XX <input type="checkbox"/> 46XX/46XY <input type="checkbox"/> 45X <input type="checkbox"/> 45X/46XY <input type="checkbox"/> Other <input type="checkbox"/>						
Disorder Type	Disorder of Gonadal Development <input type="checkbox"/> Defect of Mullerian Development <input type="checkbox"/> Disorder of Androgen Synthesis <input type="checkbox"/> Persistent Mullerian Duct Synd <input type="checkbox"/> Disorder of Androgen Action <input type="checkbox"/> Leydig Cell Defect <input type="checkbox"/> Disorder of Androgen Excess <input type="checkbox"/> Cloacal Dystrophy <input type="checkbox"/> Nonspecific Undermasculinisation Disorder <input type="checkbox"/> Other <input type="checkbox"/>						
Actual Diagnosis						
Certainty of Diagnosis Based On				DNA Analysis			
Clinical Features	Certain <input type="checkbox"/> Uncertain <input type="checkbox"/>			Performed	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>		
Biochemistry	Certain <input type="checkbox"/> Uncertain <input type="checkbox"/> NA <input type="checkbox"/>			Abnormality Found	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/> NA <input type="checkbox"/>		
DNA Analysis	Certain <input type="checkbox"/> Uncertain <input type="checkbox"/> NA <input type="checkbox"/>			Further studies	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/> NA <input type="checkbox"/>		
Availability of Further Information				Family			
Case Notes	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>			Parental Consanguinity	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>		
Growth Data	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>			History of DSD	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>		
Puberty Data	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>			History of Infertility	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>		
Urine	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>			Availability of Samples	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>		
Serum	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>			Free Text			
DNA	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>						
Tissue	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>						
Cell line	Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>						
Register ID				Please retain one copy in case notes and send another copy to:- Further copies & Guidance available from Register Coordinator Please file all revision copies together in case notes			
Received							
Entered							
Info Sheet 1							
Info Sheet 2				V.5.03.08			
Removed							
Future Contact – No							

D Appendix - Coding tables

This appendix sets out my NVivo qualitative coding for all those survey questions that provided free text responses, including those that were used in this thesis and those that were set aside for a future study (see “Survey questions not used” on page 70). It gives an idea of the overall response to the survey questionnaire.

The NVivo nodes resulting from an initial round of qualitative coding (see page 76) were grouped under broad categories as set out in the tables below. The italics indicate the six most populated topic nodes for the survey question and the figures in brackets indicate the number of participants talking about each topic. Some text segments may be coded at more than one node.

Most frequent responses

The six most highly populated nodes in the study as a whole were:

Q17: Support from medical system? – *Not offered at diagnosis* (70)

Q23: Alternative outcome? – *Assumed female* (64)

Q34: Disclosure by adulthood? – *Lies or half-truths* (62)

Q36: How terms impacted – *General – negative* (62)

Q47: What do sex and gender stand for? – *Biol-phys vs psychosocial* (55)

Q42: What told partners – *Positive experiences – Good reaction or outcome* (50)

Q15: Source of discoveries

This is additional information volunteered by some participants in the course of giving the source from which they gained various diagnostic elements.

Q15 - Source of discovery - qualitative coding

Category and topic nodes	Description
Swyer issues: <i>Uterus in Swyer</i> (15) <i>Hormone treatments</i> (2) Pregnancy in Swyers (1) Told ‘gonads’, not ‘testes’ (1)	- Swyers women mention having uterus - Hormone treatment in Swyers - Adventures in achieving pregnancy - Testes not mentioned to Swyers woman
Non parent/doctor source: <i>Glimpsing med records</i> (4) <i>TV programmes</i> (2) MPH (1) Family in medical journal (1) 7 cousins at meeting (1) Shock at testes (1) Told to Google condition (1) Didn’t realise intersexed (1)	- Got info from seeing medical records/letter - Saw BBC ‘Dark Secret’ film or US TV Oprah show. - Read ‘[male] pseudo-hermaphrodite’ in library - Discovered article describing her family - 7 affected cousins attended US group meeting - Still shocked at reading this on website - Told by doctor to Google ‘Swyers’ for intersex details - Learned via this study

Q15 - Source of discovery - qualitative coding (continued)

Category and topic nodes	Description
Other: <i>Given TFS as diagnosis (17)</i> Gave medical appt history (1) Experience vs intellectual (1) Inner sense (1) Lack of talking (1) Learnt testes from father (1) Vague details given (1)	<ul style="list-style-type: none"> - Said to have Testicular Feminisation Syndrome - Replied with details of medical appointments - Short vagina (practical vs official understanding) - Sensed some things, prior to full realisation - Lack of talking in family - Father explained presence of testes - Sister amplifies dyslexic participant's vague details

Q16: Clinical display/photography?**Q16 - Clinical display/photography? - qualitative coding**

Category, and topic nodes	Description
<i>Just no (49)</i> <i>Displayed to other docs (33)</i> <i>Just yes (24)</i> <i>Photographed (15)</i> <i>Fended off photo request (3)</i> <i>Tissue samples (2)</i> Appeared in medical quiz (1) Not sure (1) Appeared in medical journal (1) Yes, but OK (1)	<ul style="list-style-type: none"> - Just no, not displayed or photographed - Displayed at consultations/examinations - Just yes, displayed or photographed - Experienced medical photography - Refused request be photographed - Talk of tissue samples taken for research - Agreed to be guinea pig in training exercise - Not sure if ever displayed/photographed - Photos in article about AIS in family members - Yes, but OK about it

Q17: Support from medical system?**Q17 - Support from medical system? - qualitative coding**

Category, and topic nodes	Description
<i>Not offered at diagnosis (70)</i> <i>Yes, was offered (43)</i> - Yes, but refused (7) - Yes, but minimal (5) <i>Obtained later (21)</i>	<ul style="list-style-type: none"> - Not offered at time of diagnosis - Was offered support by medical system - Refused offer - Support was minimal, pathetic etc. - Sought help later

Q18: Biological influences

The coding below is additional textual material offered by some participants to amplify their choices from a list of biological features.

Q18 - Biological factors - qualitative coding

Category, and topic nodes	Description
Info given for 'Other' (25) Extra text (11)	<ul style="list-style-type: none"> - Other features having an impact - Additional text/comments supplied

Q20: Which surgical method?

This is supplementary information volunteered by some participants only.

Q20 - Which surgical method? - qualitative coding

Category, and topic nodes	Description
Gonadectomy comments (24) Vaginal procedures (22) Other genital surgery (6) Don't know or too distressing (2) Biopsies only (1) Malignancy (1)	- Comments on timing & method (laparoscopy etc.) - Name/details of vaginal lengthening procedures - Other surgery, e.g. clitoral reduction - Don't know details or declined to say - Gonadal biopsies only, no gonadectomy - Testicular tumour found

Q21: Features required by society?

This is supplementary information volunteered by some participants only.

Q21 - What does society require? - qualitative coding

Category, and topic nodes	Description
Extra text (13) Text given under 'Other' (8) Can't answer (4)	- Participant annotated their choice with a comment - Suggested additional womanly attributes - Not able to select any features

Q22: Does your own view differ?**Q22 - Does your own view differ? - qualitative coding**

Category, and topic nodes	Description
Yes or no, or minimal response: <i>Just no (agree) or minimal (20)</i> Just yes (differ) or minimal (6)	- Own view not different from society's - Own view differs from society's
Psychological issues: <i>Inner sense or feeling (37)</i> Appellation (2) Harder on self (2) Maternal & caring instincts (2)	- Inner sense of womanhood is important - What you call yourself is important - Judge self more harshly than judge others - These instincts important
Bodily issues: <i>XX and/or reproduction not important (12)</i> <i>External features or expression (10)</i> XX and/or reproduction important (7) Mentions XY (5) Need at least one feature (5) Female hormones (3) Has uterus (1) Having <i>extra</i> things (1)	- XX/reproduction not mandatory - External presentation more important - XX/reproduction part of womanhood - Mention XY in response - Need at least one feature from list - Mention female hormones in response - Mentions that has uterus - Extras (enlarged clitoris?) more an issue

Q22 - Does your own view differ? - qualitative coding (continued)

Category, and topic nodes	Description
Social issues: Notion of ‘real’ or ideal woman (7) Reactions of others (3) Socialisation & sisterhood (3) Displaying male aspects (2) Excluded from girl talk (1)	- Mention notion of ‘real’ or ideal woman - Other people’s views play a part - Socialisation & shared history important - Allowing expression of male elements - Exclusion from talk of periods/babies
Sex and gender: Transsexuals (3) Sexual activity (2) Doctors’ utterances (1)	- Questions whether transsexual qualify - Having libido and vagina important - Inappropriate talk can have negative effect
Indeterminate response: <i>One’s view changes (9)</i> No answer (8) <i>Yes & no (9)</i> Contradictory (5) Don’t know (4) Conflicted (4) A scale, not definite (2)	- View changes with time - No answer given - Ambivalent response - Elements of response seem contradictory - Says don’t know - Participant seems conflicted on topic - It’s a scale, rather than yes/no
Insights: <i>Pragmatic, insightful view (12)</i>	- Responses that seemed particularly useful

Q23: Alternative outcome?**Q23 - Alternative outcome? - qualitative coding**

Category, and topic nodes	Description
Assumed female: <i>Assumed female (64)</i>	- Assumed female development would apply
Assumed male: <i>Assumed male (40)</i>	- Said male would apply (8 of these gave both scenarios)
Indeterminate: <i>Unclear answer (5)</i> Don’t know (4) Evaded question (1)	- Response wasn’t clear - Says don’t know - Response seemed evasive
Humour: <i>Humour (6)</i>	- Responses that used humour

Q24: Family awareness of condition

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q24 - Family awareness of condition - qualitative coding

Category, and topic nodes	Description
<i>Talk of immediate family (31)</i>	- Talk of whether immediate family knows
<i>Just yes, or minimal reply (30)</i>	- Yes, family aware of condition
<i>Talk of extended family (27)</i>	- Talk of whether extended family knows
<i>Just no, or minimal reply (23)</i>	- Family not aware of condition
<i>Cover story or partial info (16)</i>	- Family members given covers story or partial info
<i>Talk of siblings (14)</i>	- Talk of whether siblings know
<i>Talk of husband or partner (13)</i>	- Talk of whether husband or partner knows
Only parents know (10)	- Only participant's parents know
Not male side of family (6)	- Male side of family doesn't know
Parents don't know (6)	- Participant's parents don't know of her condition
Not children (5)	- Participant's children don't know
Secrecy (5)	- Talk of secrecy in family
Carrier issues (1)	- Talk of carrier issues

Q25: Affected relatives**Q25 - Affected relatives - qualitative coding**

Category, and topic nodes	Description
<i>None (56)</i>	- No affected relatives
<i>Sister/s affected (29)</i>	- One or more sisters affected
<i>Carrier status (23)</i>	- Talk of carrier status in relatives
<i>Several affected/carrier (16)</i>	- Several relatives affected or carriers
<i>Aunt affected (12)</i>	- Aunt affected
<i>Not sure (11)</i>	- Not sure if any affected relatives
<i>Niece/s affected (9)</i>	- One or more nieces affected
<i>Cousin/s affected (8)</i>	- One or more cousins affected

Q26: Prefer company of men or women?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q26 - Company men or women? - qualitative coding

Category, and topic nodes	Description
<i>Either (45)</i>	- No preference for male/female company
<i>Prefer women (38)</i>	- Prefer company of women
<i>Prefer men (27)</i>	- Prefer company of men
<i>Discomforts (11)</i>	- Talk of discomforts with one or other gender
<i>More female friends (6)</i>	- More female than male friends
<i>Insights (3)</i>	- Responses that seemed insightful
Mentions lesbian (3)	- Comfortable in company of lesbian women
Misunderstood Q (3)	- Misunderstood question
Mentions XY-women (2)	- Comfortable in company of XY-women
A loner (1)	- Participant is a loner
Mentions gay men (1)	- Comfortable in company of gay men
More male friends (1)	- More male than female friends

Q27: Sexual relationships

The coding below is additional textual material offered by a few participants to amplify their ‘yes/no’ type response to Q27 (which simply asked if they’d had sexual relationship/s and at what age this started). This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q27 - Sexual relationships? - qualitative coding

Category, and topic nodes	Description
<i>Problems (6)</i>	- Not successful in having sex
<i>Men, then women (6)</i>	- Male, then female partners
<i>Not penetrative (3)</i>	- Not had penetrative sex
<i>Abused (2)</i>	- Sexually abused when younger
<i>Reaction to medicalisation (1)</i>	- “Sod the lot of you [doctors?]”

Q29: Equipped for sex?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q29 - Equipped for sex? - qualitative coding

Category, and topic nodes	Description
Yes, feel equipped:	
<i>Just yes (45)</i>	- Yes, feel equipped
<i>Now, yes (12)</i>	- Feel equipped now, not earlier
<i>Yes, with comments (8)</i>	- Yes, with additional info/comment
Lesbian OK (5)	- Feel equipped for lesbian sex

Q29 - Equipped for sex? - qualitative coding (continued)

Category, and topic nodes	Description
No, don't feel equipped: <i>Just no (11)</i> <i>No, with reasons (8)</i> <i>Used to be OK (2)</i>	<ul style="list-style-type: none"> - No, don't feel equipped - No, with reason/s - Used to feel equipped, not now
Indeterminate: <i>Yes and no (21)</i> <i>Working on it (5)</i> <i>Not applicable (3)</i> <i>Not sure (2)</i>	<ul style="list-style-type: none"> - Ambivalent response - Participants are 'working on it' - Said not applicable - Not sure if equipped
Other: <i>Comments on dilation (6)</i> <i>Gonadectomy, libido etc. (5)</i> <i>Clitoral surgery (2)</i> <i>Story (2)</i> <i>Scarring (1)</i>	<ul style="list-style-type: none"> - Gave comments about pressure dilation - Gave comments about gonadectomy, libido etc. - Talked of having had clitoral surgery - Explained at some length, in narrative - Lack of confidence due to scarring

Q30: Met others affected?**Q30 - Met others affected? - qualitative coding**

Category, and topic nodes	Description
<i>Just yes (50)</i> <i>Yes, with comment (30)</i> <i>No (20)</i> <i>Relative/s only (7)</i> <i>Not knowingly (4)</i> <i>Online only (2)</i> <i>Changing the world (1)</i>	<ul style="list-style-type: none"> - Yes, have met others affected - Yes, with comment - No, have not met others affected - Only met relatives affected - Not knowingly met others affected - Met online only - Others seem to want to change the world

Q32: Early suspicions?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q32 - Early suspicions? - qualitative coding

Category, and topic nodes	Description
Bodily issues: <i>Lack of menstruation (45)</i> <i>Development lack (29)</i> <i>Sex & gender doubts (27)</i> <i>Breast development (16)</i> <i>Pubic hair (13)</i> <i>Hernias (9)</i> <i>Tall or short stature (7)</i> <i>Short vagina (6)</i> <i>Scarring (5)</i> <i>Invasive self-probing (4)</i> <i>Infertility (2)</i>	<ul style="list-style-type: none"> - Waiting for period that didn't come - Anxiety about lack of sexual development - Anxiety about direction of development - Late or poor breast development - Lack of pubic/underarm hair - Inguinal (groin) hernias due intra-abdominal testes - 'Abnormal' stature (usually tall) - Knowledge of short vagina - Awareness of scars from childhood operations - Attempts to insert things into vagina - Being told that infertile

Q32 - Early suspicions? - qualitative coding (continued)

Category, and topic nodes	Description
Medical issues:^a Medicalisation (8) Medical lies or half-truths (3) Doctors' crazy utterances (2) Doctors obstructive (2) Suspicion about HRT pills (2) Medical article or record (2) Doctors' focus on fertility (1) Doctors' ignorance (1)	<ul style="list-style-type: none"> - Frequent hospital visits - Half-truths/lies leading to suspicions - Inappropriate words from doctors - Doctors unwilling to provide information - Not told the reason for HRT - Found relevant article or saw own record - Testing for uterus but not for vagina - Doctors not familiar with AIS
Psychological issues: <i>General feeling (19)</i> Not a surprise (8) Secrecy or no talk (8) Felt an outsider (7) Adults' anxiety (7) No real doubts (6) Knowledge colours thoughts (3) Use of humour (2) Wanted a label (1) Denial & pretence (1)	<ul style="list-style-type: none"> - General feeling of being 'different' or not quite right - Not being surprised when learnt things - Sensitivity to 'hush hush' atmosphere - Feeling apart from peers - Picking up anxieties of parents/doctors - Told truth at young age (or accepted story given) - 'Innocent' things acquire significance - E.g. "not consuming enough carrots?" - Wanted a name to give to people - Burying head in the sand
Family issues: Relative(s) affected (4) Family environment (1)	<ul style="list-style-type: none"> - Family members known to be affected - Dysfunctional background

a. Many of the topics under 'Medical issues' are talked about with greater frequency under the Question 34 which asks whether doctors/parent gave truthful information (see "Q34: Disclosure by adulthood?" on page 254).

Some of those who talked about lack of menstruation used mini stories to relate their experience of waiting in vain for periods to start, and covering the following sub-topics.

Q32a - Menstruation stories- qualitative coding

Category, and topic nodes	Description
Menstruation stories: Away from home (3) Taking the initiative (3) False alarms (2) Avoiding doctors (2) Feeling abandoned (1)	<ul style="list-style-type: none"> - Anticipating onset at boarding school or summer camp. - Wanting/seeking medical advice - Thinking they had 'started' then being disappointed - Avoiding appointments for fear of the outcome - Feeling abandoned by God after praying for period

Those expressing sex and gender doubts were sub-divided in a similar way, as follows.

Q32b - Sex and gender doubts- qualitative coding

Category, and topic nodes	Description
Sex and gender doubts: Masculinisation (11) Boys' interests/behaviour (11) Mistaken for a boy (5) Feeling neutral/in-between (3) Inner feeling (2) Attractiveness (2)	<ul style="list-style-type: none"> - Some pubertal development considered male - Tom-boy and rejection of female childhood interests - Comments from passers-by - Feeling of being a M/F mix, or outside of M & F - Inexplicable sex/gender doubts - Feeling that not attractive to boys

Q33: Understanding of condition

Q33 - Understanding of condition - qualitative coding

Category, and topic nodes	Description
Accurate account: <i>Accurate AIS description (46)</i> <i>Accurate Swyer description (5)</i> <i>Accurate 5-ARD description (3)</i> <i>Accurate 17-BHD description (1)</i>	<ul style="list-style-type: none"> - Gave a good/reasonable account - Gave a good/reasonable account - Gave a good/reasonable account - Gave a good/reasonable account
Post-natal: <i>After birth, at puberty etc. (50)</i> <i>Omitted foetal part (21)</i>	<ul style="list-style-type: none"> - Responses re: appearance/development - Responses that ignored pre-birth phase
Vague or inaccurate: <i>Vague (21)</i> <i>Some misconceptions (9)</i>	<ul style="list-style-type: none"> - Gave vague account - Some errors/misconceptions in account
Don't know etc: <i>Didn't know (9)</i> <i>Denial (4)</i>	<ul style="list-style-type: none"> - Not able to answer Q - Don't want to know the details
Special emphasis: <i>Bi-potential emphasis (3)</i> <i>Genetic emphasis (3)</i> <i>Psychological emphasis (1)</i>	<ul style="list-style-type: none"> - Emphasis on common origin of M & F - Emphasis on genetic aspect as main cause - Talked only of psychological aspects

Many participants talked about what happened from birth onwards:

Q33a - After birth, at puberty etc. - qualitative coding

Category, and topic nodes	Description
<i>Body hair (22)</i> <i>Breast development (22)</i> <i>HRT (15)</i> <i>Tall stature (15)</i> <i>No menstruation (14)</i> <i>Gonadectomy (11)</i> <i>Medical procedures (11)</i>	<ul style="list-style-type: none"> - Talk about body hair - Talk about breast development - Talk about HRT - Talk about tall stature - Talk about lack of menstruation - Talk about gonadectomy - Talk about medical procedures

Q33a - After birth, at puberty etc. - qualitative coding (continued)

Category, and topic nodes	Description
General lack of development (9)	- Talk about general lack of development
No ovaries (8)	- Talk about lack of ovaries
Clitoral growth (7)	- Talk about enlarged clitoris
Body form (5)	- Talk about general body shape
Vaginal hypoplasia (5)	- Talk about short vagina
Infertility (5)	- Talk about infertility
Bone density (4)	- Talk about bone density
Foot size (4)	- Talk about large foot size
Gonadal cancer (4)	- Had tumour (or feared cancer)
Hernias (4)	- Mentioned hernia/s
Hormonal action (4)	- Brought hormone action into explanation
No womb (4)	- Mentioned lack of uterus
Deepening voice (3)	- Mentioned deepening voice
Intersex and some female (3)	- Acknowledgement of intersex status
Positive factors (3)	- Mentioned positive factors, apart from condition
Smooth skin (3)	- Having good skin, due androgen insensitivity
All hell broke loose (2)	- Life suddenly changed after certain event
Behaviours & emotions (2)	- Effect of condition on behaviour & emotions
Hips (2)	- Mentioned widening hips
Menstruation via HRT (2)	- Menstruation in Swyers women via HRT
Secrecy (2)	- Talked of secrecy
Wary of intimacy (2)	- Body changes created fear of intimacy
Congenital (1)	- Acknowledged congenital aspect
Looking more male (1)	- Tall, athletic, flat-chested
M-F false dichotomy (1)	- AIS proves M-F dichotomy is false
Natural puberty (1)	- Explained natural female puberty
Perspiration (1)	- Doesn't perspire easily
Scar (1)	- Health visitor drawing attention to abdominal scar
Uterus present (1)	- Mentioned having uterus
Virilisation (1)	- Mentioned virilisation in 5-a-RD

Q34: Disclosure by adulthood?**Q34 - Disclosure by adulthood? - qualitative coding**

Category and topic nodes	Description
Whether truth or lies: <i>Lies or half-truths (62)</i> <i>Truthful disclosure (30)</i> Terminology (6) Uncertain diagnosis (4)	- Having been given lies or half-truths - Having received truthful disclosure - Comments about terminology used - Accurate diagnosis not known
Modes of discovery: <i>Own research (26)</i> <i>Late discovery (23)</i> Confronting doctors (16) Chance discovery (9)	- Finding out on one's own - Discovering truth late in life - Having to directly challenge doctors - Seeing a text, web site etc.

Q34 - Disclosure by adulthood? - qualitative coding (continued)

Category and topic nodes	Description
Psychological issues: Secrecy & lack of talking (11) Effects of non-disclosure (8) Dealing with the information (4) Was not a surprise (2) Strange ideas about cause (1) Felt asexual (1)	- Adults secretive or discouraged discussion - Problems caused by not knowing full picture - Issues of processing the information - Information revealed was never a surprise - Imagination fills the information vacuum - Feeling de-sexed
Bodily issues: <i>Gonadectomy</i> (24) <i>Infertility</i> (17) Hypoplasia (9) No periods (7) HRT (3) Breast development (2) Scarring (1)	- Doctors saying that bad “ovaries” needed removing - Told that infertile, as part of minimal information - Being told that vagina short - Told no periods, as part of minimal information - Mentioned HRT - Talk of lack of breast development - Explanation for abdominal scar
Doctors’ modus operandi: Doctors’ utterances (10) Doctors’ ignorance (10) Communication failure (10) No adult/doctor actually said (7) False assurances (3) Treated as novelty (2)	- Inappropriate words from doctors - Doctors not knowing much about condition - Doctors failing to give proper explanation - No diagnosis (“You have XYZ”) was ever spoken - Doctors giving unfounded reassurances - Treated as, or told that ‘a one-off’
Family issues: Parents in the dark (11) Maternal guilt (3) Consulted relative (2)	- Parents didn’t have the information to give - Taking blame for passing on faulty gene - Asking/telling a relative about condition
Other people: Support group (7) Telling others (5) Relationships (2)	- Talk about support group - Talk about telling others - Talk about relationships

Q35: Which terms had impact?**Q35- Which terms had impact? - qualitative coding**

Category, and topic nodes	Description
Info given under ‘Other’ (9) Strong reaction (4)	- Additional info given under ‘Other’ - Responses giving particularly strong reaction

Q36: How terms impacted**Q36 - How terms impacted - qualitative coding**

Category and topic nodes	Description
General: <i>Negative</i> (62) Dismissive/neutral/positive (12)	- Negative feelings/comments about the terms - Dismissive, neutral or positive feelings/comments

Q36 - How terms impacted - qualitative coding (continued)

Category and topic nodes	Description
Testicular feminisation: <i>Negative (32)</i> Dismissive/neutral/positive (5)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
XY (sex chromosomes): <i>Negative (23)</i> Dismissive/neutral/positive (6)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Testes: <i>Negative (21)</i> Dismissive/neutral/positive (2)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Male pseudo-hermaphrodite: <i>Negative (19)</i> Dismissive/neutral/positive (5)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Genetic male: <i>Negative (19)</i> Dismissive/neutral/positive (4)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Gonads: <i>Negative (16)</i> Dismissive/neutral/positive (3)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Intersex: Negative (12) Dismissive/neutral/positive (4)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Hairless pseudo-female: Negative (7) Dismissive/neutral/positive (0)	- Negative feelings/comments about the term - Dismissive, neutral or positive feelings/comments
Other: Other (2)	- Comments re: hernias and being guinea pig

Q37: Views on DSD terminology**Q37 - Views on DSD terminology - qualitative coding**

Category and topic nodes	Description
DSD favoured: <i>Less freakish/stigmatising (13)</i> <i>Just OK, or minimal answer (13)</i> <i>Better than 'herm' terms (12)</i> <i>More scientific, factual (11)</i> Not so keen on 'intersex' (6) Good for parents (3) Not gender-specific (3) Aligns i/s with other disorders (2) Other (1)	- Better than older (including 'herm'?) terms - Just saying new term better - Specific preference over 'herm' terms - DSD better because more scientific/factual - Not keen on term 'intersex' - Parents prefer it - Good because no M/F label implied - Aligns intersex with other medical conditions - 'Castration' and terms for large clitoris worse

Q37 - Views on DSD terminology - qualitative coding (continued)

Category and topic nodes	Description
DSD disliked: <i>Dislike 'disorders' (20)</i> <i>Just use diagnosis? (17)</i> <i>OK with 'intersex' (13)</i> Implies medicalisation, fixing (8) Too cryptic/clinical, 'herm...' is OK (5) Genetic emphasis (4) I/s people were not involved (2) Prefer 'XY-female' (2) Homophobia (1) Nonsense (1) Disorder = lies & deception (1)	<ul style="list-style-type: none"> - Dislike use of term 'Disorders' in 'DSD' - Why not just use diagnosis? - Happy with the term 'intersex' - 'DSD' implies medical problem needing fixing- - - - Doesn't mean much, even 'herm...' is better - Don't like the XX, XY (e.g. in '46,XY DSD') - Developed by non-intersexed people - Favour the umbrella term 'XY-female' - Medicalise it, so goes away, like homosexuality - "Utter nonsense" - Implies I'm wrong (but lies/deception wrong)
Mix of views: <i>M vs F and spectrum issues (12)</i> Alternatives (8) 'Intersex' as an identity (7) Pros and cons (5) Intersex and trans (4) Age & emotional state important (3)	<ul style="list-style-type: none"> - How various terms express binary or spectrum - Pros & cons of alternative (new) terms - Views for and against use of 'intersex' as an ID - Pros & cons of DSD - Fears of being lumped with transsexuals - Some terms hard on young & vulnerable
No terms work: <i>Why lump together (11)</i> Hate all terms (4) It is what it is (3) Doctors obfuscating (1) Just find a cure (1) Living the label (1)	<ul style="list-style-type: none"> - Why use umbrella term at all? - Hate all the medical terms - It's there, whatever you call it - Use of medical terms to obfuscate - Just find a cure for the condition/s - Exhausting to keep changing one's label
Indeterminate: <i>Don't really care (11)</i> Don't know (2)	<ul style="list-style-type: none"> - Not bothered about medical terminology - No view on the matter

Q38: Feelings about interventions**Q38 - Feelings about interventions - qualitative coding**

Category, and topic nodes	Description
Positive thoughts: <i>Happy (31)</i> <i>Happy, with reservations (28)</i> Banishing maleness (4) Wish gonadectomy earlier (2)	<ul style="list-style-type: none"> - Happy to have had medical procedures - Happy but with some reservations - Glad to have got rid of some male features - Would have liked earlier gonadectomy
Negative thoughts: <i>Lacked info, consent, support (38)</i> <i>Regret gonadectomy (27)</i> Scarring (11) What if (3) Insensitive words (2) Regret genital surgery (2)	<ul style="list-style-type: none"> - Wasn't made aware of nature of the surgery - Wish had not undergone gonadectomy - Problems with surgical incision scars - How would I be if hadn't had surgery? - Insensitive words from medical staff - Regret surgery on external genitals

Q38 - Feelings about interventions - qualitative coding (continued)

Category, and topic nodes	Description
No surgery: No gonadectomy (6) Escaped genital surgery (1)	- Escaped gonadectomy - Escaped genital surgery
Vaginal lengthening: <i>Vaginoplasty (13)</i> Dilation (9)	- Talk about surgical vaginoplasty - Talk about DIY pressure dilation
Hormone treatment: <i>HRT (20)</i>	- Comments about HRT
Other: Misunderstood Q (5)	- Misunderstood the question

Q39: Is it a medical problem?**Q39 - Is it a medical problem? - qualitative coding**

Category, and topic nodes	Description
No (in general): <i>Educate society (32)</i> <i>Informed consent/choice (31)</i> <i>Not appropriate, with reason/s (28)</i> <i>Support, counselling, knowledge (25)</i> <i>Medical issue, but not problem (20)</i>	- Education of society should take precedence - Surgery etc. should be based on info/choice - Medicalisation not appropriate - Need more emphasis on these aspects - Are associated issues (HRT etc.)
Yes (in general): <i>Appropriate, with reasons/s (15)</i> Just yes (3) Medical advances needed (2) Eradicate condition (1)	- Medicalisation appropriate, with reasons - Just yes, appropriate - Need more research into causes and treatment - Just eradicate the condition
Indeterminate: Yes and no (13) Only if life-limiting (13) Not sure (11) More discussion needed (3) Too close to home (1) Not society's business (1)	- Can see both sides of argument - No intervention unless life-threatening - No clear view on the matter - More open discussion needed - Too personal to be objective about question - Society doesn't have to live with it
Other: Unusual comment (2)	- Unusual viewpoint

Q40: Single coherent story?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q40 - Single coherent story? - qualitative coding

Category, and topic nodes	Description
Standard stories: <i>Infertility story</i> (21) No uterus story (10) Hysterectomy story (7) Malformed ovaries story (4) Ovarian cancer story (4) Genetic condition (4) Early menopause story (3) No reproductive system story (3) Bone medication story (2)	<ul style="list-style-type: none"> - Use an 'infertility' story - Use a 'no uterus' story - Use a 'hysterectomy' story - Use a 'malformed ovaries' story - Use an 'ovarian cancer' story - Tell people have 'a genetic condition' - Use an 'early menopause' story - Use a 'no reproductive system' story - Use an 'on bone medication' story
Other people: People's reactions (13) Insensitive enquiries (4) People don't pry (4) Educating people (2) Encouraging questions (1)	<ul style="list-style-type: none"> - Talk of other people's reaction - Insensitive enquires by people - People don't tend to pry - Talk of educating people - Participant encourages questions
Glossing or inventing: <i>Glossing over</i> (21) <i>Invent things</i> (16) Genetic/XY aspects (6) Bodily differences (5) Avoid certain words (4) Own info was late or minimal (3) No, or minimal answer (3) Hard to have single story (2) Emphasis on career (2) Annoyance at secrecy (1) Avoiding intimacy (1)	<ul style="list-style-type: none"> - Tend to gloss over details - Tend to invent things - Talk of whether mention genetic/XY aspects - Talk of whether mention bodily differences - Don't mention certain things, e.g. vagina, gonads - Participant could only relate what she herself knew - No, don't have single coherent story - Have to tailor to people's understanding - Say that concentrating on career - Annoyance at having to keep secret - Being secretive prevents intimacy
Strategies: Feeling one's way (10) Defined levels (10) At crossroads (3) Written material (1) TV programme (1)	<ul style="list-style-type: none"> - Feeling one's way when talking to others - Have disclosure levels, depending on recipient - Changing disclosure strategy - Use of written material to inform people - Use of TV programme to inform people
Very secretive: <i>Very private</i> (15) Never shared full details (7)	<ul style="list-style-type: none"> - Participants very private about their condition - Have never shared full details

Q40 - Single coherent story? - qualitative coding (continued)

Category, and topic nodes	Description
Truth-telling: <i>Only family & close friend/s (15)</i> <i>Telling the truth (13)</i> Sharing with SG peers (6) Yes, or minimal answer (4) Boyfriend knows (3) Using correct terms (3) Public speaking (3) Change of tack (1) Annoyance at openness (1)	<ul style="list-style-type: none"> - Only family and close friends know - Talk about telling truth to people - Sharing full details at support group meetings - Yes, have single coherent story - Boyfriend knows of full details - Don't shy away from using correct terms - Talking at group meetings or in press helps - Changed from denial/lying to being totally open - Having to explain things yet again
Don't tend to explain: No need to explain (10) Tried but no longer explain (2) Over-dramatising (2) Too young to have a story (1)	<ul style="list-style-type: none"> - Don't feel need to have to explain to others - Told enough people, or people have own problems - How to tell without over-dramatising - Participant too young to have developed a story
Other: Insights (5)	<ul style="list-style-type: none"> - Responses that seemed particularly insightful

Q41: What told friends/acquaintances

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q41 - What told friends/acquaintances - qualitative coding

Category, and topic nodes	Description
Standard stories: <i>Infertility story (29)</i> Hysterectomy story (8) No periods story (8) No uterus story (8) Ovarian cancer story (6) HRT story (5) Early menopause story (4) Malformed ovaries story (4) Hybrid story (1)	<ul style="list-style-type: none"> - Use an 'infertility' story - Use a 'hysterectomy' story - Use a 'no periods' story - Use a 'no uterus' story - Use a 'had ovarian cancer' story - Use an 'on HRT' story - Use an 'early menopause' story - Use a 'malformed ovaries' story - Partially developed sex organs
Glossing or inventing: Own info late or minimal (6) Regret lying (1) Don't tell of hypoplasia (1) Ambiguous gender (1) Body hair (1)	<ul style="list-style-type: none"> - Participant's own info was late or minimal - Regret having to lie to people - Don't tell people about vaginal hypoplasia - Only disclose "ambiguous gender" and infertility - Lack of body hair is one of the things disclosed

Q41 - What told friends/acquaintances - qualitative coding (continued)

Category, and topic nodes	Description
Strategies: <i>Genetic condition (9)</i> Tell less often now (4) Defined levels (3) Use technical terms (3) SG literature (1) Done poor job (1) Eases own life (1) Use humour (1) Osteoporosis (1)	- Use idea of 'genetic condition' in telling - Choose to tell less, for varying reasons - Disclosure levels depending on recipient - Use medical terms to obfuscate, or be truthful - Use of support group material to inform people - Done badly in past, so new method - Knowledge helps others understand me - Use humour to ease process of telling - Include brittle bones in explanation
Don't tend to explain: <i>Acquaintances (16)</i> <i>Not revealed anything (13)</i> Not specific (6) Told not to tell (2) Mother dictates secrecy (1)	- Don't tend to tell acquaintances - Not revealed anything to friends/acquaintances - Non-specific answer - Adults advised don't tell others - Mother dictates that should employ secrecy
Other people: Fear gossip or judgement (4) People can't understand (3) Teasing (good and bad) (2) Educating people (1)	- Fear gossip or judgement if tell people - Don't give details 'cos wouldn't understand - Teasing by people can be good or bad - Used to educate people fully, less so now
Truth-telling: <i>Only family or close friend/s (39)</i> <i>Telling the truth (31)</i> Good reaction or outcome (7) Most friends know (5) Bad reaction or outcome (3) Sharing with SG peers (1) Poignant answer (1) Hand forced (1) Eager to tell (1)	- Only tell truth to family or close friends - Talk of truthful disclosure - Experienced good reaction/outcome - Most friends know truth - Experienced bad reaction/outcome - Talking at support group meetings - Tell people about condition and the emotional pain - Doctor talked of "testicle" in front of neighbour - Eager to tell, 'cos rare and friends interested
Other: Insights (1)	- Response that seems particularly insightful

Q42: What told partners

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q42 - What told partners - qualitative coding

Category, and topic nodes	Description
Positive experiences: <i>Good reaction or outcome (50)</i> Accompanying on journey (9) Women partners (2) Revisiting issue later (2)	- Experienced good reaction/outcome - Partner in on the discovery process - Talk of women partners - Discussing issue with partners later

Q42 - What told partners - qualitative coding (continued)

Category, and topic nodes	Description
Negative experiences: Bad reaction or outcome (11) Tried but failed (2)	- Experienced bad reaction/outcome - Tried telling partner but didn't succeed
Other: <i>Physical issues (19)</i> Hopes & fears for future (4) Already knew (3) Promiscuity (1) Avoided question (1)	- Explaining scars, short vagina, lack body hair etc. - Hopes for acceptance, fears of rejection - Partner already knew - Trying to prove her womanhood to herself - Side-stepped the question
None: <i>Minimum or no disclosure (35)</i> <i>No partners (12)</i> Wait 'til serious (4) Avoiding relationships (3)	- Not much disclosing - Not had any partners - Waiting until serious relationship - Talk of avoiding relationships
Intermediate experiences: <i>Telling what knew (18)</i> OK but(10)	- Telling as much as participant herself knew - Experience OK, but.....
Strategies & insights: <i>Strategies (15)</i> Insights (8)	- Talk of particular disclosure strategies used - Responses that seem particularly insightful

Q43: Unease at misleading?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q43 - Unease at misleading? - qualitative coding

Category, and topic nodes	Description
No(t much) unease: <i>No, or minimal response (27)</i> Overcoming it (8) Dispassionate approach (5) Not with acquaintances (5) Secrecy vs privacy (4) Partner knows (3) People don't push (2) Humour (2) Good having secret (2) Living the lie (2) Superseded by other issues (1) Self-sufficiency (1) Not told anyone (1)	- No, don't feel unease at misleading people - Have overcome fear of disclosure - A pragmatic, matter of fact approach - No unease with regard to acquaintances - Difference between secrecy and privacy - Partner knows truth - People don't tend to push for details - Use of humour to ease the process - Is good having a secret - The lie becomes second nature - Sadness at lack of what others take for granted - People have own issues, don't need to take on mine - Not disclosed to anyone

Q43 - Unease at misleading? - qualitative coding (continued)

Category, and topic nodes	Description
(Re)action of others: <i>Reaction of others (13)</i> <i>Effect on relationships (9)</i> <i>Effect on friendship (9)</i> Why no babies (4) Can't correct people (3) Gossip, alternative stories (2) Protecting others (2) Treating people unequally (2)	<ul style="list-style-type: none"> - Talk of reactions of others - Inhibits forming relationships - Distances one from friends - People expect you to reproduce - E.g. re: Caster Semenya, might arouse suspicions - Anxiety about people talking & giving wrong story - Have to consider effect on family etc. - Told some people but not others
Yes, some unease: <i>Lying or deceit (19)</i> <i>Yes, or minimal response (13)</i> <i>Identity problems (11)</i> <i>Fraud or imposter (9)</i> Fear of discovery (6) May forget story (4) Protecting self (4) Unburdening (4) May say too much (3) Means can't explain things (2) False intimacy & drama (1) Self-justification (1)	<ul style="list-style-type: none"> - Unease at lying/deceit - Yes, unease at misleading - Causes identity problems, feeling of fraud etc. - Feel fraud or imposter when mislead people - Fear of being found out - Anxiety about possibly forgetting cover story - Shielding oneself from judgement by others - Want to shout from roof-tops and unburden - Fear that may say too much - Might help explain how I am - Can create inappropriate closeness - Feel need to justify oneself where others wouldn't
Other: Avoided question (3)	<ul style="list-style-type: none"> - Side-stepped the question

Q44: Story changed with time?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q44 - Story changed with time? - qualitative coding

Category, and topic nodes	Description
Yes, for the better: <i>Have more knowledge (17)</i> <i>Less emotional (15)</i> <i>More control over what said (13)</i> <i>Need to tell gets less (13)</i> Found voice & confidence (5) More honest now (4) Support group (4) Changing focus (4) Just yes, or minimal (2) Phased approach (2) Say less now (2) Say more now (2)	<ul style="list-style-type: none"> - With time, had more knowledge about condition - With time, become less emotional when telling - With time, felt more control over what to tell - The need to tell gets less - Have found their voice and increased confidence - Are more honest now than used to be - Role of support group - With time, changed way of telling - Yes, story has changed with time - Gradual revelation - Say less to people now - Say more to people now

Q44 - Story changed with time? - qualitative coding (continued)

Category, and topic nodes	Description
No, or not relevant: <i>Just no, or minimal (21)</i> <i>No, rarely or never tell (16)</i> <i>Still use simple cover story (12)</i> No, always truthful (2) Still in early stages (2)	- No, story has not changed with time - No, because rarely/never tell - Still use a simple cover story - Always been truthful - Still in early stages of exploring disclosure
Problems: Prying comments (3) Explaining to doctors (1) Bad outcome (1) Wishful thinking (1)	- Problem of people's prying comments - Had to explain condition to so many doctors - Always ends badly, whatever the strategy - What would it be like, just to explain everything
Other: Reaction of others (6) Insights (5) Non-useful answer (1) Not answered (1)	- Others may not take it all in anyway - Responses that seem particularly insightful - Didn't really address the question - No response

Q45: Story on AISSG website?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q45 - Story on AISSG website? - qualitative coding

Category, and topic nodes	Description
<i>Useful (33)</i> <i>May do so (16)</i> <i>Email circle only (6)</i> <i>Media presence (3)</i> <i>Possible re-write (2)</i> <i>Other priorities (2)</i> Not the right time (2) Removed from site (1) Fear of exposure (1) Enough practice, with docs (1) Embarrassing now (1)	- Useful to have submitted story for website - May submit story in future - Supplied profile for admission to email circle only - Have a media presence in relation to condition - May re-write web story - Have other priorities - Not the right time at present - Story was on site but now removed - Fear of the exposure it might bring - Have enough practice with explaining to doctors - Web story seems embarrassing now

Q46: Is there a sex vs gender difference?**Q46 - Is there a S vs G difference? - qualitative coding**

Category, and topic nodes	Description
Yes, different: <i>Just yes, different (46)</i> <i>Yes, with comment (23)</i>	- Yes, sex and gender are different - Yes, different... with comment
No, the same: <i>Just no, the same (17)</i> No, with comment (5) Rarely different (1)	- No, sex and gender are the same - No, the same... with comment - They are rarely different

Q46 - Is there a S vs G difference? - qualitative coding (continued)

Category, and topic nodes	Description
Indeterminate response: <i>May have misunderstood (10)</i> <i>Don't know (8)</i> For some, not for me (6) Not thought about it (4) Possibly (4) Don't believe in either (1)	<ul style="list-style-type: none"> - Responded whether own S & G match - Don't know - Different for some, but not for participant - No view on the matter - Possibly different - Don't believe in either
Insights: <i>Insightful comments (10)</i>	<ul style="list-style-type: none"> - Responses that seem particularly insightful

Q47: What do sex and gender stand for?**Q47 - What do S & G stand for? - qualitative coding**

Category, and topic nodes	Description
Sex = biological or physical: <i>Biol-phys vs psychosocial (55)</i> Biol vs societal label (5) Reproduction vs identity (3) Biol-phys vs orientation (2) Nature vs nurture (2)	<ul style="list-style-type: none"> - S = biological/physical, G = psychosocial - S = biological, G = label given by society - S relates to reproduction, S to identity - S = biological/physical, G = orientation - S = nature, G = nurture
Other way round: Feeling vs being (2) Identity vs physical (2) Option vs birthright (1)	<i>(Those who may have confused S & G):</i> <ul style="list-style-type: none"> - Feeling (S?) vs being (G?) - Identity (S?) vs physical body (G?) - Choice (S?) vs medical state (G?)
Sex = internal: <i>Chromosomes vs identity (12)</i> Inside vs identity (2) Birthright vs option (1) Inside vs appearance (1)	<ul style="list-style-type: none"> - S = chromosomes, G = identity - S = internal anatomy, G = identity - S = birthright, G = option - S = internal anatomy, G = appearance
Sex = external: Appearance vs feeling (5) Societal label vs orientation (1)	<ul style="list-style-type: none"> - S = external appearance, G = feeling - S = soc. label, G = hormonal (e.g. gay man)
Sex = activity: Activity vs label (4)	<ul style="list-style-type: none"> - S = activity & phys body, G = own/soc. label
Social construction: <i>Gender constructed (13)</i> Sex constructed (2) Society causes polarities (3) Two identities (2) Identity vs view of others (1)	<ul style="list-style-type: none"> - G = constructed (some saying S = biol.) - S = "genetic construct" & S/G just female - Society creates black & white differences - Sexual & social ids & soc's view of M/F - M/F = self-view, M/W = how others see you
Graded (spectrum): <i>Both are spectrum (7)</i> <i>Gender is spectrum (sex more limited) (6)</i> Sex is spectrum (gender more limited) (3) Tick-box vs spectrum (1)	<ul style="list-style-type: none"> - Both S & G represent a scale/spectrum - G spectral, but S more restricted - S spectral, but G more restricted - S = tick box option, G = spectrum

Q47 - What do S & G stand for? - qualitative coding (continued)

Category, and topic nodes	Description
Indeterminate response: <i>Are the same (cos no conflict) (14)</i> <i>Couldn't answer (9)</i> Are the same (for vague reasons) (6) Misunderstood question (4) Wordplay or language (4) Why does it matter (3) Venus vs Mars (2)	<ul style="list-style-type: none"> - S & G same (participant has no conflict) - Not able to answer the question - S & G same for vague reasons - Misunderstood question - Talk of role of words/language - Why is it important - E.g. Men = providers, women = carers
Unusual notions: Both are physiological (1) M&F vs genetics (1) Physical vs biological (1)	<ul style="list-style-type: none"> - Physiol. chars. equiv. to 2 sociological norms - S = Male or Female, G = genetics of either - S = physical things, G = biological?

Q48: Are you intersexed?**Q48 - Are you intersexed? - qualitative coding**

Category, and topic nodes	Description
Yes, intersexed: <i>Just yes, or minimal (32)</i> <i>Yes, with reasons (28)</i> <i>Yes, but also female (17)</i> <i>Reluctant yes (13)</i> <i>Yes, but not in public (7)</i> Yes, genital appearance (3) Yes, feeling & thinking (1) Yes, female by default (1) Yes, in sex & gender (1)	<ul style="list-style-type: none"> - Just yes, agree, or similar minimal response - Yes, but giving reasons - Yes, but stressed that also female - Yes, agree, but with some reluctance - Yes, but would not acknowledge publicly - Refers to genital appearance - F appearance, but think differently - F by default, as a failed male - Intersexed, in sex and gender
No, not intersexed: <i>Just no, or minimal (12)</i> <i>Feel female (not intersexed) (7)</i> No, with reasons (5) No, but am XY (3)	<ul style="list-style-type: none"> - Just no, disagree, or minimal response - Feel F, therefore not intersexed - No, disagree, with reasons - XY, but not intersexed (e.g. am XY female)
Indeterminate response: Noncommittal (3) Not answered (1) Not sure (1) Yes & no (1)	<ul style="list-style-type: none"> - Statement that didn't answer actual Q - No response - Not sure - Yes/no
Other: Humour (2) Extra-sexed (1) Intersex = political awareness (1)	<ul style="list-style-type: none"> - Used humour in response - Maybe "extra-sexed"? Not a blend - I = pol. awareness, am F with DSD/CAIS

Q49: CAIS more female than XX?**Q49 - CAIS more female than XX? - qualitative coding**

Category, and topic nodes	Description
No, don't agree: <i>Doctors misguided (37)</i> <i>No, disagree, or minimal response (27)</i> <i>Sugar solution (21)</i> <i>No, due infertility (11)</i> Gender more important (7) Patronising or condescending (6) Helps doctor, not patient (5) Periods important (4) Some CAIS women misguided (2) Superficial (2) No female hormones either (2) So are Swyers women less female? (1) What about hypoplasia, lactation (1) Lack androgen benefit (1) Feel outsider (1) Male mastectomy analogy (1) Some lack is normal for AIS (1)	<ul style="list-style-type: none"> - Doctors are misguided in saying this - Just no, disagree with proposition - Sugaring the pill - How more female when infertile? - Gender more influence than biology - Is patronising/condescending - Eases discomfort of doctor - Having periods more important - Fosters denial of intersex by CAIS women - Is superficial view of M vs F - But have to take female hormones - Swyer respond to androgens, so less F? - Practical things (sex, feeding adopted baby) - Normal women benefit from androgens - Lack physiological processes, so outsider - Remove male breast, then more masculine? - Better told symptoms normal for AIS
Yes, agree: <i>Yes, agree (19)</i> Reassuring (2) 'House' episode (1)	<ul style="list-style-type: none"> - Just yes, agree with proposition - Find it reassuring - Perfect woman (but joke is she's a man)
Indeterminate response: <i>Yes and no (17)</i> Superwoman, Barbie, actresses (7) Chromosomes (7) No viewpoint (5) Don't know, or no answer (3) CAIS = most severe form (1)	<ul style="list-style-type: none"> - Can see pros and cons - References to Superwoman etc. motifs - Trumped by having XY chromosomes - Can't comment - Don't know or no response - Most severe form of failed male
Insights: Insightful comments (7)	<ul style="list-style-type: none"> - Comments that seemed insightful

Q50: Authentic in sex/gender?**Q50- Authentic in sex/gender? - qualitative coding**

Category, and topic nodes	Description
Yes: <i>Just yes (not confirming female/woman) (26)</i> <i>Yes, as different sort of woman (18)</i> <i>Yes, authentic female or woman (13)</i> Both are female (1) Is natural, thus authentic (1) Yes, as blend of genders (1) Yes, but OK with XY label (1) Yes, in gender (1) Yes, eventually: - With time (8) - Only when found others (2) - With therapy & support (2)	<ul style="list-style-type: none"> - Just yes, authentic - Yes, as a different sort of woman - Yes, authentic as female/woman - Both S & G are female - Is natural occurrence, thus authentic - Authentic as blend of genders - Yes, but is OK with XY label too - Authentic in gender - Felt authentic with time - Felt authentic when met others affected - Felt authentic with therapy/support
No: <i>Feel a fraud, freak or outsider (18)</i> <i>Just no, or minimal response (10)</i> Inferior female (8) No, but not a man (8) No, unless male & intersex (4) No, due vaginal hypoplasia (2) No, but who cares (1) No, because tomboy (1) No. due XY chromosomes (1) Not in sex, due lack body hair (1)	<ul style="list-style-type: none"> - Not authentic, feel fraud, freak or outsider - Just no, not authentic - Feel self to be an inferior female - Not authentic female, but not a man - Authentic as intersex - Not authentic, due short vagina - Not authentic, but who cares - Not authentic, because tomboy - Not authentic, due XY chromosomes - Not authentic in sex, due lack body hair
Indeterminate response: <i>Yes & no, or it varies (14)</i> Flexible, nuanced view (7) Striving towards authenticity (7) Don't try to fit in (4) Avoided question (3) Core ID vs knowledge (3) What is my S&G? (3) Confused, conflicted (2) Appearance yes, thinking no (1) Hidden disability or secret (1) M-F check-boxes (1) Wish third gender (1)	<ul style="list-style-type: none"> - Yes & no, or it varies - Thoughtful, nuanced view - Sense of striving to be authentic - Don't try to fit into boxes/categories - Seemed to avoid the question - Inner feelings vs knowledge of condition - Not sure about sex and gender - Confused about where fit in with S & G - Appear F, but have psych qualities of both - Authentic as person with hidden disability - Dishonest, ticking F check box on forms - Sometimes wish there was a third gender
Other: Infertility (8) Reaction of others (5) Menstruation (3) Using S&G interchangeably (1) No, matter over mind (1) Yes, mind over matter (1)	<ul style="list-style-type: none"> - Impact of infertility - Fear of others' views/reactions - Effect of lack of menstruation - Problem of medics using S & G as same - Identify as F, but not strictly F - More to womanhood than periods/babies

Q51: How is XY etc. incorporated?**Q51 - How is XY etc. incorporated? - qualitative coding**

Category, and topic nodes	Description
Support from others: <i>Support group</i> (12) Family support & issues (5) Counselling (3) Partner support (1) Friends' support (1)	- Role of support group, meeting others etc. - Role of family in support - Professional psychological support - Helped by partner - Helped by friend/s
Negative issues: <i>Difficulties</i> (22) Feel outsider or different (8) Others' reactions (7) Blame-bucket & obsess (3) Media freaks (1)	- Expressed difficulties with the knowledge - Feelings of exclusion/stigma - Anxiety over what people might think - Blaming things on condition - Media attitudes not helping
Positive comments: Vague positive (10) Resignation or perspective (9) Self multi-faceted (7) Humour (5) Knowledge is power (4) Superiority (2) Faith (1) Tomboy (1)	- Short, general, positive statements - Reaching some equanimity - Other things contribute as much/more - Expressing, or advocating humour - Knowing the truth helps - Feeling special due to condition - Religious faith helps - XY etc. explains tomboy leanings
Focus elsewhere: <i>Ignore or deny it</i> (24) Focus on career etc. (1)	- Try to distance oneself from the knowledge - Compensatory activities
M vs F features: Female attributes (7) Loss of male elements (4) Physical issues (4) Avoid maleness (3)	- Deficiency or excess? - E.g. testes (whether welcome or regretted) - Issues such as vaginal hypoplasia - Distancing oneself from maleness
It depends: <i>Time or age helps</i> (12) It varies (10) Initial shock (6) Doctors' attitude (3) Late discovery (3) Early gender experiences (2)	- Time and maturity make it easier - Varies between/within people - Talk about shock on discovery - Doctors' attitude/words influential - Drawbacks and benefits - Upbringing important
Personal view point of ID: <i>Identity issues</i> (15) Not conforming (3) Orientation (3) Moral stance (1) Who cares (1)	- Talk about personal identity - Not conforming to gender stereotypes - Intersex and homosexuality - Censorial/moralistic stance - Are just chromosomes, who cares

Q51 - How is XY etc. incorporated? - qualitative coding (continued)

Category, and topic nodes	Description
Miscellaneous: <i>Deeper insights</i> (15) Misunderstood question (6) Constant thoughts (3)	- Interesting/insightful responses - Can't give answer - Thinking about it all the time

Q52: Acknowledge male aspects (in ideal society)?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q52 - Acknowledge male aspects (in ideal society)? - qualitative coding

Category, and topic nodes	Description
No, wouldn't like to acknowledge: <i>Just no or minimal</i> (31) <i>No, totally female</i> (10) Already display male side (4) Not part of my ID (4) Better hidden (3) Other things more important (2) No wish to showcase (1)	- Just no, or gave minimal negative response - No because am totally female - Can already give expression to male side - No, because 'male' is not part of my ID - No, because it's better hidden - Other things have more influence on character - Have male elements but no wish to showcase them
Yes, would like to acknowledge: <i>Just yes or minimal</i> (25) Knowing truth, reason (4) Enlarged clitoris (3) Meeting others (2) Yes, natural variation (2) Cf with other conditions (1) If public figures did (1) Loss of testes (1) Whispers & sensationalism (1) Wish family acknowledged (1) Wish I could reply.... (1) Yes, but not t-shirt (1) Yes, but hurt parents (1) Yes, but preserve female (1)	- Just yes, or gave minimal positive response - Self-acceptance by knowing truth/reason - Should be more acceptance of this - Truth aids contact with others - Variation rather than abnormality - "Ideally as noteworthy as haemachromotosis" - Needs well known women to be trailblazers - A piece missing - Dread the whispers behind the scenes - Would have liked family acknowledgment - Wish bold enough to 'tell all' - Yes, but not to the whole world - Wouldn't want to upset parents with new info - Male features but still to be seen as female
Is hypothetical: <i>If ideal, no difference</i> (8) <i>Utopia</i> (7) If ideal, might be male (1) Religious angle (1)	- If ideal society, being intersex make no difference - Would be utopia, so hard to imagine happening - Might have been corrected in utero, thus male - Would be no intersex in a sin-free world
Indeterminate response: Inconsistent statement (5) PAIS yes, CAIS no (3) Evaded Q (2) Not sure (1)	- Response seemed inconsistent - Benefit for PAIS, easier for CAIS - Evaded the question - Not sure what to say

Q52 - Acknowledge male aspects (in ideal society)? - qualitative coding (continued)

Category, and topic nodes	Description
Other: <i>People's reactions (7)</i> Stigma, secrecy & shame (4) Expression vs internalisation (2) Lack of support (2) Androgyny (1) Athleticism (1) Easier if young (1) Genetics vs hormones (1) Non political, educational (1) Trying to be female (1) Who can marry (1)	<ul style="list-style-type: none"> - Would it change people's reactions - Would it reduce stigma, secrecy & shame - Openness could reduce internalisation - Lack of taking therapy (only display to students) - Exploring androgyny - Would like to have developed athleticism - Seems easier for youngsters - XY-women ideal for study of relative contributions - Identify as I, without being political/educational? - Really trying to be female - Authorities need to decide who i/s people can marry

Q53: Observe XX-women?**Q53 - Observe XX-women? - qualitative coding**

Category, and topic nodes	Description
Yes: <i>Just yes, or minimal (28)</i> <i>Compare bodily femaleness (21)</i> <i>Pregnancy & motherhood (14)</i> Femininity (6) Behaviour (6) Sex & relationships (4) Periods (4) Normality (2) Hormonal features (1)	<ul style="list-style-type: none"> - Just yes, observe XX, or minimal response - Yes, compare bodily femaleness - Observe w.r.t. pregnancy & motherhood - Observe their femininity - Observe behaviour - Observe their ease in relationships - Observe camaraderie re: periods - Wonder what is like to be normal - Compare hormonal features
No: <i>Less so now (16)</i> <i>Just no, or minimal (13)</i> <i>No more than others do (13)</i> No differences or all different (7) Not gender related (6)	<ul style="list-style-type: none"> - Observe less so now than after diagnosis - Just no, or minimal response - No more than women in general do - No differences (or everyone different) - Don't observe gender-related attributes
Yes & no: <i>Superiority & benefits (12)</i> Observe men too (3) What if (2) Insights (2) Psychological factors (2) Humour (1)	<ul style="list-style-type: none"> - Talked of superiorities/benefits of being XY - Also observe men - What if normal? Would recognise an AIS? - Responses that seemed insightful - Talk of psychological comparisons - "Married lesbian, so have to be careful!"

Q54: Perform gender?**Q54 - Perform gender? - qualitative coding**

Category, and topic nodes	Description
Comes naturally: <i>Natural</i> (58) <i>Mostly, or fairly natural</i> (17) <i>Natural with time</i> (11) If not woman, then man (1)	<ul style="list-style-type: none"> - Gender comes naturally - Mostly or fairly natural - Becomes more natural with time - Does performing imply I am a man?!
Some performance: <i>Some performing</i> (23) Avoid being feminine (8) Tomboy (6) Not good with flirting (2) Used to be natural (1)	<ul style="list-style-type: none"> - Some degree of performance - Not inclined to try to be feminine - Talked of tomboy tendencies - Not learnt how to flirt - Now changed, to manipulate perceptions
Indeterminate response: Depends on company (5) No fine line (4) Misunderstood question (3) Don't know (1)	<ul style="list-style-type: none"> - Depends on what company in - Not one behaviour or the other - Misunderstood question - Don't know
Other: Non-standard gender(s) (7) Insights (6)	<ul style="list-style-type: none"> - Talk of shifting or non-standard genders - Responses that seemed insightful

Q55: Any male traits?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q55- Any male traits? - qualitative coding

Category, and topic nodes	Description
Body & appearance: <i>Bodily attributes</i> (27) Genetics (7) Hormones (4) Bodily attitude (3) Male clothing (3) Tone of voice (2) Facial hair (1) No, female due oestrogen (1)	<ul style="list-style-type: none"> - Bodily attributes (height, feet etc.) - XY, but that doesn't explain everything - Effect of hormones (M & F) - Walking, sitting with legs crossed etc. - Wear boyish clothes - Low toned voice - Have facial hair - Psychology affected by oestrogen
Physical & practical: <i>Practical skills</i> (13) Strength & athleticism (9)	<ul style="list-style-type: none"> - Good practical skills, incl. map reading - Strong & athletic
Mental skills: <i>Visuo-spatial skills</i> (10) Reasoning & logic skills (6) Numeric & scientific skills (5) Am engineer (2) Seeing both sides (1)	<ul style="list-style-type: none"> - Good visuo-spatial skills - Good reasoning & logic skills - Good numeric & scientific skills - Work as an engineer - Can see things from both sides

Q55- Any male traits? - qualitative coding (continued)

Category, and topic nodes	Description
Character: <i>Directness & dominance (14)</i> <i>Competitive & career (10)</i> <i>Not girly or maternal (10)</i> Tomboy behaviour (6) Male sense of humour (4) Independence (3)	<ul style="list-style-type: none"> - Tendency to directness & dominance - Competitive and career-minded - Not girly or maternal - Mentioned tomboy behaviour - Have a male sense of humour - Like to be independent
Interests: <i>Male likes & dislikes (11)</i> Hate shopping (3) Like computer games (2)	<ul style="list-style-type: none"> - Having 'male' likes and dislikes - Don't like shopping - Like computer games
Social & emotional: <i>Emotions & social awareness (10)</i> One of the guys (6) Libido & sex (3) Get on better with men (2) Asperger's syndrome (1)	<ul style="list-style-type: none"> - Talk of M/F emotional/social awareness - Tend to be 'one of the guys' - High libido - Get on better with men - Has Asperger's syndrome
Other: <i>Just no, or minimal (24)</i> Mixed traits (9) Humour (5) Hard to decipher (4) Just yes, or minimal (4) Feminism (2) Don't know (2) Insights (1)	<ul style="list-style-type: none"> - Just no, no male traits - Talk of mixed M/F traits - Used humour in response - Expressed difficulty teasing out M/F - Just, yes, have male traits, or minimal - Reference to feminism - Don't know - Response that seemed insightful

Q56: Can others tell?

This survey question is not yet coded or discussed in the thesis but may be included in a post-doctoral study.

Q57: Is a S vs G separation helpful?**Q57 - Is a S vs G separation helpful? - qualitative coding**

Category, and topic nodes	Description
Yes, useful: <i>Yes, with reason/s (39)</i> Yes, cos sex may not be F (7) Sex is malleable (4) (Biological) knowledge is strength (2) Just yes, or minimal response (2) Relevance to orientation (2) Yes, new to concept (2) Religion, shame, privacy (1) Performing femininity (1)	<ul style="list-style-type: none"> - Yes, helpful, with reasons - Yes, because allows for non-female sex - Yes, sex is malleable - Anything that explains condition helps - Just yes, helpful, or minimal - 'Normalises' homo/hetero/bi etc. - Yes, although new to the concept - Darwinism etc. If religious, more difficult - "Didn't get femininity handbook"

Q57 - Is a S vs G separation helpful? - qualitative coding

Category, and topic nodes	Description
No, not useful: <i>No, with reason/s (24)</i> Just no, or minimal response (10) No, cos binary still operates (6) No, are the same thing (5) No, cos sex is F (5) No, infertility is main issue (1)	<ul style="list-style-type: none"> - No, not helpful, with reasons - Just no, or minimal response - Not helpful, cos binary system remains - No, they are same thing - No, cos sex is female - No, cos infertility is main issue
Indeterminate response: <i>Yes and no (18)</i> Chromosomes (12) Don't know or confused (10) Misunderstood question (9) Educating society (5)	<ul style="list-style-type: none"> - Yes and no - Reference to XY chromosomes - Don't know or confused - Misunderstood question - Difficulty educating society on this
Insights: <i>Insightful comments (16)</i>	<ul style="list-style-type: none"> - Responses that seemed insightful

Q58: What helped most?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q58 - What helped most? - qualitative coding

Category, and topic nodes	Description
Support in general: <i>Meeting others (39)</i> <i>Support group (35)</i> <i>Support of family & friends (26)</i> <i>Support of partner(s) (22)</i> Supportive clinicians (10) Counselling & therapy (10) Others reflect general norms (2) Family history (1)	<ul style="list-style-type: none"> - Meeting others affected helped most - Specific mention of a support group - Family & friends most important - Partner support helped most - Supportive clinicians helped most - Counselling/psychotherapy important - Seeing others affected as being 'normal' - Talk in family, about family history of condition
Information: <i>Literature & internet (11)</i> Full understanding (9) Dilator advice (1) Known since young (1) Stepwise disclosure (1)	<ul style="list-style-type: none"> - Obtaining information from literature/web - Knowing truth and understanding it - Advice on vaginal dilator use - Knowing since young age - Phased disclosure

Q58 - What helped most? - qualitative coding (continued)

Category, and topic nodes	Description
Personal qualities: <i>Personal qualities (12)</i> Attractive to men (4) Public speaking (3) Helping others (2) Religious faith (1) Good health (1) Having Asperger's (1) Humour (1) Ignoring it (1) Courage to seek help (1) Success in job (1)	- Talk of personal qualities that helped most - Being attractive to men helped - Speaking publicly about condition - Helping others adjust - Religious faith - Good general health - Having Asperger's syndrome - Wrote song: "Technically, I'll always be a virgin" - "Not thinking about it" - Courage to seek medical help aged 45 - Success in working life
Indeterminate response: Don't know (2) No one thing (2) Still confused (2)	- Don't know - No single thing helped - Still confused
Other: Adopting (3) Good disclosure experience (3) Privacy (3) HRT (2) Wishful thinking (1)	- Having adopted children helped - Having had good experience of disclosure to others - Pros/cons of keeping it private - HRT, to keep body healthy - Magic wand, make me female and scars disappear

Q59: What might have helped?

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q59 - What might have helped? - qualitative coding

Category, and topic nodes	Description
Information: <i>Disclosure by doctors (19)</i> <i>Medical information (18)</i> Internet (10) Education of parents (9) Print, TV etc. (5) Relationships, self-esteem etc. (5) Advise dilation (4) HRT & osteoporosis risks (4) Telling others (4) Banish shame (3) Full protocol (2)	- Truth disclosure by doctors at diagnosis - Better medical information - Availability of the internet - Parents being better educated about condition - Availability of info in print, on TV etc. - Advice on relationship possibilities etc. - Vaginal dilation advice, before pushed into surgery - Advice re: osteoporosis risk, and HRT - Advice about being open towards other people - Education of family, so not treated as secret - Doctors should have proper protocol for helping
Support in general: <i>Support (40)</i> <i>Counselling & therapy (31)</i> <i>Others affected (23)</i> Anything in country (2)	- Support would have helped - Counselling/psychotherapy - Meeting others affected - Anything in my country!

Q59 - What might have helped? - qualitative coding (continued)

Category, and topic nodes	Description
Medical: Quality of doctors (9) Better terminology (3) Keep gonads (2)	- Better doctors - Better medical terminology - Opportunity to keep gonads (testes)
Personal qualities: Insights & reconceptualisation (5) Gender roles (3) Develop perspective (3) Be proactive (2) Social construction (2)	- Some concepts that might have helped - More discussion of gender, rather than biology/med - Develop some distance/perspective on condition - Be assertive with doctors, don't worry re: opinions - Concept of gender cf sex, would have been useful
Other: <i>No suggestions (16)</i> Miss America (1)	- No suggestions - Competition winner with AIS cited as good outcome

Q62: Participants' additional comments

This survey question is not discussed in the thesis but may be included in a post-doctoral study.

Q62 - Participants' additional comments - qualitative coding

Category, and topic nodes	Description
Positives: <i>Positive aspects & attitude (40)</i> <i>Increases awareness & sensitivity (24)</i> Philosophical insights (8) Religious faith (4) Doctors did good job (3) One of the lucky ones (3)	- Examples of positive aspects and attitude - Having condition increases awareness/sensitivity - Philosophical insights - Mention of religious faith - Praise for doctors - Luckier than many with the condition
Medical & body issues: <i>Infertility (26)</i> Doctors' insensitivity (12) Doctors' ignorance (11) No periods (9) HRT (8) Hypoplasia (7) Medicalisation (4) Gonadectomy (2) Avoid doctors & hospitals (1) No discussion with doctor (1)	- Talk about infertility - Examples of doctors' insensitivity - Examples of doctors' ignorance - Pros/cons of not having periods - Talk about HRT - Problems of vaginal hypoplasia - Problems caused by medicalisation - Pros/cons of gonadectomy - Quit hospital visits, disliked display to students - Never had frank discussion with a doctor

Q62 - Participants' additional comments - qualitative coding (continued)

Category, and topic nodes	Description
Negatives: Shame & secrecy (22) Self-doubt & hatred (15) Anger & bitterness (9) Effect of non-disclosure (9) Lies or half-truths (8) Pain & emotional suffering (7) Low self-confidence & esteem (5) Denial & pretence (4) Felt an outsider (4) Lack of counselling (2) Taboo & misunderstanding (2) Never grew up (1)	<ul style="list-style-type: none"> - Problems with shame and secrecy - Feelings of self-doubt and hatred - Feelings of anger and bitterness - Negative effect of non-disclosure - Negative effect of lies or half-truths - Pain and emotional suffering - Low self-confidence and esteem - Push it from mind, pretend not there - Felt outside of society - Never offered counselling - General taboo and misunderstanding in society - Still feel 15, waiting for things to happen
Friends, family & relationships: <i>Women's talk & issues (23)</i> Relationships (22) Adoption (19) Other people's reactions (18) Parental factors (14) Promiscuity (4) Seeking approval (3) Who is allowed to marry (1)	<ul style="list-style-type: none"> - Left out of women's talk and issues - Difficulties forming relationships - Talk of adoption, successes and disappointments - Fear of other people's reactions - Effect that parents had regarding condition - Promiscuity as form of validation as woman - Push for approval - Who is a lesbian XY-woman allowed to marry?
Personal issues: <i>Whether always in thoughts (35)</i> <i>Whether proud to be different (23)</i> Career & over-achievement (19) Support (18) Gender & sexuality (11) Hopes for future (4) Direct is best (2) Multi-faceted (2) Wish learned later (2) Wish not told (2) Strange ideas about cause (1)	<ul style="list-style-type: none"> - Whether condition always in thoughts - Whether proud to be different - Emphasis on career and over-achievement - The importance of support - Issues of gender and sexuality - Hopes for the future, personal and societal - Doctors/parents should be open and direct - Lots of things interact with AIS - Wish learned the truth later - Wish had not been told at all - Father exposed to primitive x-rays in 1930s
Societal issues: Included in society (9) Media representation (1)	<ul style="list-style-type: none"> - Whether feel included in society - Media coverage is negative and doesn't help

E Appendix - Participant information sheet

Overleaf is a copy of the information sheet sent to potential participants.

Note: During the course of my project the name of the school within which I studied changed from the School of Social Sciences and Cultural Studies to the School of Law, Politics and Sociology; and the degree programme changed from DPhil (as at Oxford) to the more standard PhD.

PARTICIPANT INFORMATION SHEET

Student/Researcher

Name: Margaret Simmonds – DPhil (PhD) candidate. Email: _____

Research Project Title

Girls/women in inverted commas¹ – facing ‘reality’ as an XY-female

Institution

Department of Gender Studies, School of Social Sciences and Cultural Studies, University of Sussex, Falmer, Brighton, BN1 9RQ.

Project Information

I am hoping you can help me with my DPhil (PhD) project by agreeing to complete a questionnaire about your experience of being an XY-woman. It doesn't matter what your diagnosis is, other than a requirement that you are an XY-female, have a female body form, a female gender identity and that you live as a woman. I am also offering the option of being interviewed, as an alternative to completing part/all of the questionnaire. Interviews would last about an hour, at a location convenient and comfortable for you.

I wish to explore how XY-women acquire, adjust to and live with the knowledge of their condition. My questionnaire topics will cover the following general areas: a) background information, b) finding out and treatment, c) physical factors, d) interactions and telling others, and e) gendered identity. I'd ask how you found out about your condition, what language/terms you heard or read, how you feel about this process and how it may have changed your self-view. I'll be asking how you construct your 'story' or stories (the unvoiced account that's part of your inner identity and the spoken version/s that you might give to others). I am also interested in your views on the nature of sex and gender, and how categories such as 'female' (sex), 'female' (gender), 'woman', 'XY-woman', 'intersexed' might be taken up as part of your identity.

Any interview conversation that you might agree to will primarily be guided by the development of your own thoughts on these topics. You do not have to cover any areas that are private. The study is separate from any clinical care you may be receiving and no clinicians are involved. I'm hoping it will also prove useful to you, to think about and answer my questions. One of my aims is to empower XY-women, by highlighting alternative ways of looking at intersex. After you have provided your input I plan to issue a written summary of some concepts used in feminist gender theory, and maybe ask for your reaction at a later date. Towards the end of the study I hope to set up a focus group: an informal gathering of those who have taken part, so you can give general feedback and meet each other to discuss common issues in person.

Supervisors

Professor Barbara Einhorn (Professor of Gender Studies), Tel: +44 (0)1273 678339, Email: b.einhorn@sussex.ac.uk and **Professor Gillian Bendelow** (Professor of Sociology), Tel: +44 (0)1273 877558 or 678890, Email: g.a.bendelow@sussex.ac.uk.

1. The title refers to some clinicians' use of quotation marks to describe XY female patients as "girls" and "women" in textbooks and research papers.

F Appendix - Participant consent form

Overleaf is a copy of the consent form sent to potential participants.

Note: During the course of my project the name of the school within which I studied changed from the School of Social Sciences and Cultural Studies to the School of Law, Politics and Sociology; and the degree programme changed from DPhil (as at Oxford) to the more standard PhD.

PARTICIPANT CONSENT FORM

Student/Researcher

Name: Margaret Simmonds – DPhil (PhD) candidate. Email: _____

Research Project Title

Girls/women in inverted commas – facing ‘reality’ as an XY-female

Institution

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Participant's Agreement

I agree to take part in this project. I have read an information sheet about the study, understand its aims and purpose, and have received satisfactory answers to any questions. I am willing to fill out a questionnaire/be interviewed¹ and to allow any interview to be audio-taped and transcribed.

I am aware that the data will be processed for the preparation of a DPhil (PhD) thesis and related academic papers, and I give permission for this use of my information. I have the right to comment on any transcript before the thesis is completed. I understand that my participation is voluntary; that I can choose not to participate in part or all of the project; and can withdraw at any stage.

Confidentiality and Data Protection

I understand that my material will be confidential and that nothing that could identify me will be disclosed in the thesis, in any reports on the project, or directly to any other party.

The questionnaire data and any interview transcripts constitute 'field notes' or raw material. No person's data will be reproduced in its entirety in the thesis or any subsequent papers. General inferences will be drawn from a number of participants' data, and isolated quotes/excerpts used to illustrate particular points. Codes or pseudonyms will be used to distinguish between participants.

Computer files and any audio-tapes/transcripts will be kept securely at the researcher's home. No one shares the premises or enters in her absence. At the end of the study any tapes will be erased.

Name: _____ Date: _____

1. Cross out any that do not apply.

G Appendix - Survey questionnaire

This chapter provides a copy of the questionnaire that was sent out to potential participants in the study.

Note: Some of the survey questions/answers were not used in this thesis, but were set aside for a future study (see “Survey questions not used” on page 70).

QUESTIONNAIRE

This **Questionnaire** is part of my DPhil (PhD) study titled *Girls/women in inverted commas – facing ‘reality’ as an XY-female*. Also provided, separately, are an **Information Sheet** and a **Consent Form**.

First, please read the following explanation:

The questionnaire has two parts:

QUICK QUESTIONS (starting overleaf)

These require short factual answers that will enable me to gather general background information on my study population.

IN-DEPTH QUESTIONS (starting on page 5)

These questions seek more detailed responses describing your personal feelings and opinions. This is the part of the study that is of most interest to me and where I’d really value your full contribution.

Because my study as a whole is a QUALitative study (often used in sociological research) as opposed to a QUANTitative study (often used in scientific research) I’m looking in this second part for full narrative, subjective responses that I can analyse for themes, trends and ideas; rather than for short factual, objective data.

In this second part of the questionnaire please imagine that you were being asked the questions in an informal interview situation and have as much space as you need to expand on the thoughts that the questions provoke. I am looking for as much descriptive/narrative text as you feel able to supply for each question.

Some people are happy to express themselves in written form whereas others might find it easier to speak out loud about their experiences, so if you would prefer to respond to the IN-DEPTH QUESTIONS face to face, in an interview scenario, then this can be arranged (see page 5).

Now proceed as follows:

- Do **File** —> **Save As** to save file to disc (perhaps include first name in filename).
- In the saved file, type in your answers where it says ‘A:’
- Do a **Save** at intervals as you write.
- Do a final **Save**.
- Do similar process with the Consent Form.
- Email both documents back to me at _____.
- If possible, please put your first name in the Subject line of your covering email.

Thank you very much. Your input is greatly appreciated.

QUICK QUESTIONS

On the whole, this section requires short answers but feel free to expand somewhat, if you wish, for some of the more open-ended questions. Don't forget to **Save** as you go along.

Background information

Q1: Please enter your name (use an initial for your surname if you wish, but I will use a code or pseudonym anyway if quoting from your material in the final thesis)

A:

Q2: Please give your email address (optional if it contains your name)

A:

Q3: What is your age?

A:

Q4: What is your sex?

A:

Q5: What is your gender?

A:

Q6: Can I ask about your sexual orientation?

A:

Q7: Partnership status (e.g. never had relationships, intermittent relationships, long-term relationship, married)?

A:

Q8: How would you define your ethnicity?

A:

Q9: Do you see yourself as belonging to a particular social class? If so, which?

A:

Q10: Highest educational level reached (e.g. NVQs, 'A' levels, first/higher degree)?

A:

Q11: Do you have any particular religious/spiritual interests?

A:

Q12: What is the medical name of your condition (e.g. CAIS, Swyer Syndrome, PAIS, 5-alpha-reductase deficiency)?

A:

Finding out

Q13: At what age were you first aware of being non-standard or unusual in your sexual development?

A:

Q14: How old were you when a medical diagnosis was made by doctors (even if you didn't gain any information yourself until later)?

A:

Q15: Please indicate how *you* discovered each of the following (e.g. from parents, from doctor, seeing medical records, internet, book, TV programme), and state your age at the time (in brackets). *Example: "Infertile - from parents (10)"*

Infertile –

Vague info about internal organs being

'under-developed' or 'not working' –

Lack of ovaries/uterus –

Would not menstruate –

Short/absent vagina –

Presence of testes –

Presence of XY sex chromosomes –

How learnt that classed by medicine as intersexed –

How learnt name of specific condition (diagnosis) –

(Note: I will use this information to plot charts/graphs, so I need just a source and an age against each item above. I *am* interested in any additional explanatory text you wish to add, but ask that you enter it below this paragraph rather than above. Or it may fit later under 'Finding out and treatment', where I ask if you were given truthful info and what your feelings are about terminology.)

Q16: Have you ever had clinical photographs taken or been displayed to junior doctors (either clothed or undressed)?

A:

Q17: Were you ever offered psychological support by the medical system, e.g. session/s with a clinical psychologist or counsellor?

A:

Physical factors

Q18: Which of these biological factors have had the most power in influencing your view of yourself (please type 1 to the right of the most important, then 2 against the next most important, then 3, etc., for as many items as you wish)?

Absent/sparse body hair –

Absence of ovaries –

Infertility –

Absence of uterus (womb) –

Lack of menstruation –

Presence of testicular tissue –

Short vagina –

Flat chestedness –

Presence of Y chromosome –

Larger than average clitoris –

Tall height –

Other (please specify) –

Q19: Have you had any of these medical procedures (please type an 'X' against any that apply and add your age in brackets)?

Gonadectomy (removal of testicular tissue) –
Genital surgery (clitoral removal/reduction) –
Vaginoplasty (surgery) –
Pressure dilation (non-surgical vaginal lengthening) –

Q20: Where relevant (e.g. vaginoplasty) please give details of the type of procedure.

A:

Q21: What body-related features does the rest of society say nature must supply you with before you can be a girl/woman (please type an 'X' against any that you think apply)?

XX chromosomes –
Ovaries –
Uterus/womb –
Vagina –
Breasts –
Clitoris within certain size limit –
Female body shape/proportions –
Menstruation –
Ability to become pregnant –
Natural menopause –
Other (please specify) –

Q22. Does your own view on what constitutes womanhood differ from those you indicated above? If so, how?

A:

Q23: If your development in the womb after you were conceived had not been unusual because of your condition, how do you imagine your body would have been?

A:

Interactions

Q24: Does all your immediate/extended family know the full details of your condition?

A:

Q25: Do you have relatives who are affected (or who are not affected but are carriers)?
Example: "Sister = CAIS, maternal cousin = carrier"

A:

Q26: On the whole, do you feel more comfortable in the company of women or men (as friends, work colleagues etc. rather than partners)?

A:

Q27: Have you had sexual relationships (and at what age was your first)?

A:

Q28: If yes, were they with men / women / both?

A:

Q29: Do you feel physically equipped for, and able to enjoy sex (on own & with a partner)?

A:

Q30: Have you met other XY-women?

A:

IN-DEPTH QUESTIONS

Please note: For the rest of the questionnaire I invite you to enter *as much text as you can* in order to give a full picture of your experiences, feelings, or opinions.

Q31: Interviews - If you would prefer to provide your thoughts in spoken form, or if you are happy to type them in below and *also* be interviewed (so I can ask you supplementary questions), then please suggest which time/s and place/s are convenient (not a specific date/ time and venue at this stage, just something like “At home in Liverpool on a Saturday”)?

A:

Finding out and treatment

Q32: Did you have a gut feeling there was something unusual in your sexual development *before* you received any concrete evidence? If so, how?

A:

Q33: Could you explain what happened in the womb when you were developing and how your condition made you different from most other baby girls?

A:

Q34: Did adults in your life (doctors and/or parents) ultimately give you a specific and truthful diagnosis (e.g. AIS) or were you left, as an adult, with lies or half-truths (such as “Your ovaries just haven’t developed”)?

A:

Q35: Did any terms that you heard/read when finding out, and realised could be applied to you, have a particular impact (please type an ‘X’ against any that apply)?

XY (sex chromosomes)–

Gonads –

Testes –

Intersex –

Genetic male –

Testicular feminisation –

Male pseudo-hermaphrodite –

Hairless pseudo-female –

Other (please specify) –

Q36: Can you explain how the selected terms affected you?

A:

Q37: Doctors require umbrella terms, to refer collectively to people with various types of intersex condition. In the past these terms have included ‘Male Pseudo-hermaphrodites’ and ‘Female Pseudo-hermaphrodites’. A new umbrella term, *Disorders of Sex Development* or DSDs, (divided into 46,XY DSDs and 46,XX DSDs) is replacing these. For details see www.aissg.org/21_overview.htm#DSD. What do you think of the new terminology?

A:

Q38: How do you feel now about having undergone the medical procedure/s you indicated earlier under ‘Physical factors’?

A:

Q39: Since the late 1800s society has regarded intersex as a *medical* issue/problem in need of correction. Is this appropriate? If ‘No’, what could be the alternative?

A:

Telling others

Q40: Do you have a single coherent story of ‘who you are’ in relation to your condition, or do you gloss over certain things, or invent things, for some people/circumstances?

A:

Q41: What have you told *friends and acquaintances* about the nature of your condition?

A:

Q42: What’s been your experience of explaining things to *sexual partners*? How much have you revealed and what has been the reaction?

A:

Q43: If your unvoiced inner knowledge or ‘truth’ differs to some extent from the story that you sometimes give to others, does this cause you any unease?

A:

Q44: Has the way you explain it to others changed with time? If so, how?

A:

Q45: If your story is on the AISSG website, did you find this a useful exercise (i.e. to have organised your story and set it out in written form for others to read)?

A:

Gendered identity

Q46: Do you think there is a difference between sex and gender?

A:

Q47: What do you think the two terms refer to (without just saying “male and female”, “man and woman” or the like)?

A:

Q48: Are you intersexed, meaning a male/female cross-over of any of the three things (sex chromosomes, gonads, external genitals) said to determine sex, and not necessarily meaning ambiguous external genitals?

A:

Q49: What do you think of some doctors’ statement that CAIS women are *more* female than XX-women because they can’t respond to male hormones?

A:

Q50: Do you feel yourself to be an authentic member of your sex and gender?

A:

Q51: In your view *how* do XY-women incorporate knowledge of their XY sex-chromosomes and testicular tissue into their sense-of-self (whether in a satisfactory way or otherwise)?

A:

Q52: In an ideal society, would you like to have acknowledged the unusual (male) aspects of your body more in forming your identity?

A:

Q53: Do you observe XX-women much and compare yourself to them?

A:

Q54: Does your gender come naturally to you, or does it involve some degree of work, play-acting or self-consciousness on your part?

A:

Q55: Do you have any psychological traits/skills or physical mannerisms that might be considered more male than female?

A:

Q56: Have you ever felt that people perceive you as being unusual and perhaps suspect that you have a sex- or gender-related condition? If so, how?

A:

Q57: If we take sex to refer to the *biological* features of being male/female, and gender to refer to the *social* aspects of being men/women, do you think this distinction between sex and gender is helpful to XY-women? Please give reasons.

A:

And finally

Q58: Is there one thing that has been most helpful in adjusting to your situation?

A:

Q59: Can you suggest one thing (medical information, sociological idea, piece of advice etc.) that was *not* available when you found out and which might have helped?

A:

Q60: Are you familiar with the concepts of sociological/feminist gender theory?

A:

Q61: Do you think that such knowledge might have been helpful at the time you were dealing with information about your condition?

A:

Q62: Please record any other thoughts you may have about your condition and its effects, positive and negative, on your general sense of who you are.

A:

(Note: For this question you might consider, for example a) whether your condition is in your mind on a day-to-day basis, and whether anything in particular triggers a remembrance, b) whether it has given you any special qualities or abilities, c) whether you ever feel proud of your unusual status, d) whether you feel fully included within society, e) whether you feel yourself to be a free agent, or to be constrained in any way, f) whether you push yourself in certain directions to compensate for having your condition, g) what you think of the way doctors/parents handled your situation, and the way society and the medical profession deal with intersex in general.... *or any issues that are important to you, these are just suggestions*).

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Books on intersex

Books on intersex

Date	Author/s	Discipline	Title & publisher
1998	Kessler, Suzanne J.	Social psychologist	<i>Lessons From the Intersexed</i> (Rutgers U. P.)
1998	Dreger, Alice D.	Medical historian	<i>Hermaphrodites and the Medical Invention of Sex</i> (Harvard U. P.)
1999	Dreger, Alice D. (ed)	Medical historian	<i>Intersex in the Age of Ethics</i> (University Press Group)
2003	Preves, Sharon. E.	Sociologist	<i>Intersex and Identity: The Contested Self</i> (Rutgers U. P.)
2006	Sytsma, Sharon E. (ed.)	Philosophy/ethics	<i>Ethics and Intersex</i> (Springer)
2007	Harper, Catherine	Art & design/ cultural studies	<i>Intersex</i> (Berg)
2008	Holmes, Morgan	Cultural studies/ sociologist	<i>Intersex: A Perilous Difference</i> (Susquehanna U. P.)
2008	Karkazis, Katrina	Medical ethicist	<i>Fixing Sex: Intersex, Medical Authority, and Lived Experience</i> (Duke U. P.)
2008	Groneberg, Michael & Zehnder, Kathrin (eds)	Philosopher & sociologist	<i>'Intersex' Geschlechtsanpassung zum Wohl des Kindes? Erfahrungen und Analysen [Sex reassignment for the good of the child?]</i> (Academic Press Fribourg)
2008	Still, Brian	English, technical communication/ rhetoric	<i>Online intersex communities: virtual neighborhoods of support and activism</i> (Cambria Press)
2009	Callahan, Gerald N.	Immunologist/ pathologist	<i>Between XX and XY: Intersexuality and the Myth of Two Sexes</i> (Chicago Review Press)
2009	Holmes, Morgan (ed.)	Cultural studies/ sociologist	<i>Critical Intersex</i> (Ashgate Press)
2009	Reis, Elizabeth	Women & gender studies	<i>Bodies in Doubt - An American History of Intersex</i> (Johns Hopkins U. P.)
2010	Cornwall, Susannah	Theology/religion researcher	<i>Sex and Uncertainty in the Body of Christ: Intersex Conditions and Christian Theology</i> (Equinox Publishing)

(See also <http://www.aissg.org/pdfs/aissg-recommended-books.pdf>)

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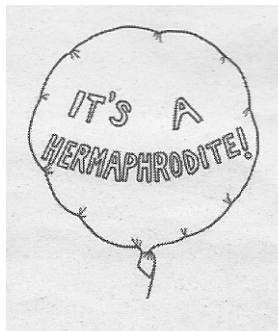
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**Linguistic performativity
(see page 49)¹**

1. Cartoon by Martin, D. (2011) from *This is a Book*. Penguin Books.
