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INFLAMMATORY RESPONSES: UTI & AMR

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Statement

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

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Summary of Thesis

This thesis considers the roles currently set out for patient and public involvement on antimicrobial resistance (AMR) and clinical care in the UK. Taking the example of uncomplicated community-acquired UTI in people treated under clinical guidelines written for women, I conceptualise what alternative roles there might be for different publics and patients. Uncomplicated UTI has long been identified by both patients and health care practitioners (HCPs) as an area of poor patient care and more recently has become a target of antimicrobial stewardship policy mobilisations. The condition has largely been neglected outside of biomedical and policy-orientated literature. This thesis makes a contribution informed by feminist theory by keeping marginalised experiences central.

The thesis argues that public health efforts to engage the public on AMR and clinical efforts to care for people with urinary symptoms largely adopt depressed outlooks. With empirical work based on 29 semi-structured online object-based interviews with participants in the role of patients, 18 supplementary interviews with diverse HCPs, researchers and advocates, and grey literature such as clinical guidelines and engagement materials, I examine how the problem of AMR and UTI is enacted, considering how evidence could be assembled differently in order to enact the problem in a more caring way. Working with Annemarie Mol's concept of ontological multiplicity, I follow the argument that good care for urinary symptoms can be found in clinical experimentation due to the way it works with multiplicity. However, I depart from Mol's work in finding such experimentation not in the practices of HCPs, which I find to be organized around rather singular antibiotic care practices. Instead, I point out a wealth of expertise in the practices of patients who care for their bladders outside of standard uses of antibiotics. Finding pessimism and depression in efforts to conserve antibiotics through compliance, the thesis offers bountiful ways to approach difference.

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Abbreviations

A & E: Accident and Emergency
 ALTAR trial: Alternative to Prophylactic Antibiotics for the Treatment of Recurrent Urinary Tract Infections in Women
 AMR: Antimicrobial Resistance
 AMS: Antimicrobial Stewardship
 ANT: Actor Network Theory
 ANTRUK: Antibiotic Research UK
 BAUS: British Association of Urological Surgeons
 BBC: British Broadcasting Company
 BMJ: British Medical Journal
 BNF: British National Formulary
 BPS: Bladder Pain Syndrome
 BSAC: British Society Antimicrobial Chemotherapy
 BSI: Blood Stream Infection
 CAM: Complementary and Alternative Medicines
 CCG: Clinical Commissioning Group
 Cfu: Colony Forming Units
 CHM: Commission on Human Medicines
 CUTI: Chronic Urinary Tract Infection
 CUTIC: Chronic Urinary Tract Infection Campaign
 DHSC: Department of Health and Social Care
 E. coli: Escherichia Coli
 EAU: European Association of Urologists
 EBM: Evidence Based Medicine
 ED: Emergency Department
 ESBL: Extended Spectrum Beta-Lactamase
 ESPAUR: English Surveillance Programme for Antimicrobial Utilisation and Resistance
 GCSE: General Certificate of Secondary Education
 GNBSI: Gram Negative Blood Stream Infection
 GP: General Practitioner
 HCAI: Healthcare Associated Infection
 HCP: Healthcare Practitioner
 IC: Interstitial Cystitis
 ID: Infectious Diseases
 IE: Institutional Ethnography
 IDSA: Infectious Diseases Society of America
 IV: Intravenous
 LUTI: Lower Urinary Tract Infection
 MDR: Multi Drug Resistant or Multi Drug Resistance
 MERIT trial: D-Mannose to Prevent Recurrent Urine Infections
 MHRA: Medicine and Healthcare Products Regulatory Agency
 MSU: Midstream Urine
 NHS: National Health Service
 NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health and Care Research
PBS: Painful Bladder Syndrome
PCOS: Polycystic Ovarian Syndrome
PHE: Public Health England
PIS: Patient Information Sheet
PPI: Patient and Public Involvement
R & D: Research and Development
REC: Research Ethics Committee
RBC: Red Blood Cells
RCT: Randomised Controlled Trial
RUTI: Recurrent UTI
SDH: Social Determinants of Health
SIGN: Scottish Intercollegiate Guidelines Network
SMI: Standards for Microbiological Investigations
STI: Sexually Transmitted Infection
STS: Science and Technology Studies
TARGET: Treat Antibiotics Responsibly, Guidance, Education and Tools
UKHSA: United Kingdom Health Security Agency
UTI: Urinary Tract Infection
UUTI: Upper Urinary Tract Infection
WBC: White Blood Cells
WHO: World Health Organisation

Introduction

UTI

Urinary tract infections are common conditions, especially in women. They are the most commonly seen bacterial infections in general practice (Lecky *et al.*, 2020) and are one of the most common acute reasons for adult women to seek health care (Butler *et al.*, 2015). We also know that people care for their bladders without contact with healthcare and therefore knowledge of overall population incidence is limited. In a community based door-knocking survey, researchers from UKHSA found that 11% of women surveyed had experienced a UTI in the past year, and 6% reported experiencing more than one in the past year (Butler *et al.*, 2015, p. e702).

UTI is a syndromic term, meaning that it describes a group of symptoms that can be caused by different organisms, anywhere along the urinary tract. However, *E.coli.* is identified as the causative pathogen in 70%-95% of cases (NICE, 2018b, p.7). The pathogenesis of UTI normally relies on the premise of colonisation with endogenous uropathogenic organism. This means that the peri-urethral area is contaminated by bacteria that normally and healthily resides in the nearby gut, but causes disease if colonised in the urinary tract. This is followed by colonisation of the urethra and migration of the pathogen to the bladder. In the bladder, complex host-pathogen interactions determine whether uro-pathogens are successful in colonisation. UTI describes infection anywhere along the urinary tract, including the kidneys (pyelonephritis), bladder (cystitis), or urethra (urethritis). This thesis concentrates on infection of the bladder, of which common symptoms include pain, foul-smelling and cloudy urine, needing to pass urine more urgently or frequently, tenderness in the lower stomach and blood in the urine.

There is broad variation in illness experience of UTI. For some, a UTI is an inconvenient (and often quite painful) incursion into daily life, resolved via self-care measures or use of antibiotics. These everyday experiences can have a significant impact on quality of life (Ellis and Verma, 2000) and a large effect on women's workplace participation (Foxman and Brown, 2003). In this thesis, I attempt to hold these quotidian experiences against more complex and unresolved experiences of poor bladder health.

The Question of Research Questions

Starting a thesis, defining research questions, conducting a literature review, and recruiting participants, involves establishing what it is that the thesis is about. This is also a process of exclusion, of deciding what it is not about. In STS, Karen Barad's concept of the 'agential cut' (2007) shifts the focus from the object of study, the entity to be known, to the process of knowing. The tools, devices and techniques of measuring, of knowing, constitute the phenomenon itself. In this section, I will explain the rationale behind the agential cut I have made, the momentary stabilisation through which I have participated in enacting what is inside and what is outside of the phenomena of 'patient experiences of UTI.' I do this by discussing two mutually constituting areas where the tension was hardest to resolve, stabilising them momentarily to enact a phenomenon stable enough to hold as an object of enquiry. The first such area concerns how to frame the object of study between UTI and AMR. The second concerns issues around diagnosis.

Framing the issue between UTI and AMR

This project had gained funding as part of a Wellcome investigator grant awarded to Dr Catherine Will, looking at how to mobilise on AMR without increasing health inequalities. The grant application laid out a project on patient experience of UTI in the UK, referencing the way that UTI had become important in AMR policy. I stayed close to AMR as a starting point for several reasons.

Firstly, UTI and AMR are materially inseparable. As Hannah Landecker's work on the biology of history sets out, we live in an antibiotic age and so our experiences of bacteria and infection are continuously made and remade by antibiotics. When Landecker says 'bacterial life today is appearing as a specific instantiation of the biology of the Anthropocene: human efforts to control life's productivity became the matter of the world' (2016, p.23), this means that when we experience UTI, we are experiencing relations with different bacteria than patients did in the past, even if antibiotics are not used. Therefore, to study patient experiences of infection, without taking into account the way in which emergent bacterial resistance affects that experience, is to enact an immaterial separation between the 'social' and the 'biological'.

However, there are ethical reasons to take the experience of UTI seriously on its own terms, without putting that knowledge in conversation with AMR. Some of my older participants talked about the continuities of experiencing urinary infection in the 1950s to today. Angela Kilmartin's books, published across the 1970s and 1980s, remain one of the only popular discussions of the issue and autobiographically describe experiences similar to those my participants told of (Kilmartin 1973; 1980; 1986). Despite this continuity of experience, at the time of writing, there is little qualitative social science research published in English on contemporary patient experiences of urinary infection and I have not been able to identify any published history, although Chelsea Saxby's PhD thesis (2021) documents women's patient advocacy around cystitis in the 1970s (including Kilmartin's) and explored the extent to which it connected to the women's liberation movement. There has been some sociological work done on UTI in hospital settings (Rousham *et al.*, 2019; Saukko *et al.*, 2019; Saukko and Rousham, 2020).

How an issue is made between AMR and UTI is of concern to patients who identify a long history of poor patient experience of UTI, combined with attention anew to UTI as the condition becomes a target of AMS policymaking. These patients come together to reflect upon what AMR, and public health mobilisations against it, will mean for them. Throughout the thesis, I refer to 'patient mobilisations', a term which is intended to capture the networks formed when patients come together around an issue and engage in diverse practices such as advocating for diagnoses, organising collective action, sharing care practices and delineating preoccupations (Maslen and Lupton, 2018; Rabeharisoa *et al.*, 2014). How patient mobilisations enact an issue between AMR and UTI is a significant concern of the thesis.

Importantly, AMR interventions in community settings are aimed at 'uncomplicated infections', and use categories derived from clinical practice in order to target these interventions. The definition of 'complicated' is any factor which increases the risk of antibiotic failure. I was interested in how clinically 'uncomplicated infections' become targets of intervention, and how they are in other senses highly complex, and so I was somewhat guided by these categories, whilst also paying attention to the work that categories do.

Cis women are more likely to experience UTI than cis men, and they are treated differently according to treatment guidelines because UTI in men is always classed as a complicated infection. Because of this, uncomplicated infections in women are the target of AMR interventions in a way that infections in men are not. Infections of the lower urinary tract in adult women are 'complicated' only in cases of pregnancy, catheterisation and structural or functional abnormality. My main interest was the experiences of people who are treated for uncomplicated infection, which meant people who are treated within the clinical category of women. However, I also paid attention to how gender worked as a category. Because NHS medical notes only record 'male' or 'female', some people are treated under a clinical category different to their gender. Because of this, I kept my recruitment open to people who did not identify as women.

A remaining area of 'uncomplicated infection' in the community is older women, especially in care facilities. As I started my fieldwork during the summer of the first Covid-19 lockdown, there was little opportunity for me to safely conduct interviews with elderly people. I did not concentrate on these experiences and with retrospect, my interest in UTI in younger women probably reflects both my interest in 'uncomplicated infection', with no apparent cause, and my own experiences with UTI in my twenties. I noted that there was much more discussion amongst clinicians and policymakers about the way in which age-based guidelines create boundaries and categories which do not necessarily reflect the patient being treated, in comparison to other guidelines based around gender or frequency of infection. For instance, the UKHSA diagnostic algorithm for women under 65 years of age (UKHSA, 2002b) notes that it may be suitable for some women over 65 years in the community, whilst the algorithm for women over 65 (UKHSA, 2002a) notes that it may be suitable for some women under 65 in care facilities. Again, I started my research from a younger group of patients but the consequences of this agential cut become important in the thesis.

I decided to pay little heed to the clinical category which separates recurrent UTI from acute. This is because I started the research knowing that these categories poorly map onto peoples' experiences of UTI. A key question of my study was the work that these categories do in practice, and what AMR, and AMR policy, means for patients with experiences across the

spectrum from acute experiences through to the more extreme end. I therefore interviewed people with a range of different experiences of UTI and my aim is to speak across the spectrum of experience. However, my data probably does reflect more the more extreme end of experiences, because people with more extreme experiences may be more likely to make this their issue and engage with researchers.

To conclude this section on framing the issue between UTI and AMR, there are at times reasons for holding the two together, whilst there are also reasons to hold them apart. Having established this, my approach in this thesis will attempt to move between AMR and UTI, observing the way they fold into each other, but at times separating them back out and holding them in different hands. In this way, I will consider in what ways the issues of UTI and AMR combine or resist each other and, importantly, when it is difficult to exercise such control over them. Much of the thesis will address what and who is caught in between and obscured by these difficulties.

Diagnosis

Starting from a medical condition always means that you may miss people who do not use the lexicon of biomedicine to describe their experiences. Importantly for my project and my concern with inequality, it may be that this is especially true of people who are less in contact with biomedicine. Moreover, the story of diagnosis and misdiagnosis was important in the field, to both patient mobilisations and public health work. There would therefore be people using different diagnostic categories whom, at the very least, other actors would identify as relevant. Therefore, I used symptoms as a way to frame my study- thinking of my object of study as 'poor bladder health.' This strategy was used to recruit participants and will be explained in more detail in my methodology chapter. In my literature review of qualitative studies, I review only studies that concern UTI and excluded studies that use the language of other urinary conditions, such as IC or PBS. This is a logistical decision to facilitate conversations with patients, clinicians, policymakers, and an ethical decision to attempt to stay close to both policy and practice, in order to produce useful and practicable findings. The thesis therefore starts from UTI but over the course of the thesis, I will question and break down the categories and processes of exclusion which allow us to produce knowledge.

This thesis therefore is about patient experiences of community-acquired infections of the lower urinary tract in younger patients without a catheter or structural or functional abnormalities, who would be treated under guidelines written for women. This is important to make clear because although it is a large area and a common experience, it is still fairly specific within the greater area of UTI at large. The more I progressed in my project, the more I reflected on the effects of these decisions, this agential cut. Further discussion of the effects of these decisions will be important to the thesis.

Chapter Outline

Chapter one, 'A Disease to be Treated', primarily responds to the question: what do people do when they feel unwell? I ask what people do; when, how and where they seek help. Against the background of patient mobilisations identifying an over-reliance on pathology as a reason why people do not get the help they need, I show how the clinic has primacy in enacting UTI in primary care. Noticing that this is not true of how UTI is enacted everywhere, I ask what makes the diagnosis of UTI cohere together across sites.

In chapter two, 'Encountering Resistance', I ask what happens when people do not get help for urinary symptoms in places they would normally go to for help. This chapter examines what the unforeseen consequences of this might be, especially when these same people live with public health messaging that may poorly fit with their experiences. This chapter traces the making of an issue around UTI for both patients and policymakers and maps different forms of resistance. I recognise a group with very complex messages about antibiotic use and infection and conceptualise ways to do public engagement on AMR differently, using insights from sociology and STS.

Chapter three, 'Becoming a Patient', looks to a future imaginary of care. Looking for how good care is done on the margins, informed by Annemarie Mol's *Logic of Care* (2008), and bell hooks' conceptualisation of the productivity of the margins (1989), I suggest ways of doing care for poorly bladders that could be brought into the centre.

In chapter four, 'Crafting a Good Life', I depart from Mol's work in finding such

experimentation not in the practices of HCPs, which I find to be organized around rather singular antibiotic care practices. Instead, following Jeanette Pols (2013), I point out a role for patients in the expertise of those who care for their bladders outside of standard uses of antibiotics.

In the following section I review three bodies of literature that help to make my argument. Firstly, I conduct a critical review of qualitative studies of patient experience of urinary tract infection. Secondly, I will examine if, how and in what ways patient experience and engagement is important to public health policy on AMR. Finally, I will engage with sociological and science and technology studies approaches to AMR and the role of lay people.

Literature Review

Qualitative Studies of Patient Experience of UTI

I begin the literature review with a critical literature review of the scarce qualitative studies that pertain to patient experiences of UTI. I examine how the importance of engaging with patient experience is presented, how scales and spectrums of experiences are framed, and the extent to which patient experience emerged as a research concern alongside or because of AMR.

Roisin Pill's sociological treatment of cystitis (1987) is the first qualitative study of patient experiences of UTI published in English that I have been able to identify. Published in *Sociology of Health and Illness*, it is also the closest to the tradition I am writing within, and I will discuss it at some length. Pill, a medical sociologist and professor of primary health care research, published an article entitled 'Models and management: the case of 'cystitis' in women.' She interviewed thirty-nine women who had consulted with urinary symptoms within the trial period but had negative microbiological results, and thirty-seven control participants who had not consulted for urinary symptoms during the trial period. Of this control group, fifteen had never had cystitis. This is because the problematic of the paper concerns the way in which patients come to rely on medical intervention because of a concordance of the lay model of cystitis with the biomedical model. Patients can then experience a lack of care if they do not fit the criteria of clinical tests and doctors fail to investigate other reasons for symptoms. In some senses, then, the paper is not about patient experiences of cystitis because Pill is more interested in patients who consult with urinary symptoms, and do not receive a diagnosis of cystitis. Cystitis is here a case study for the concern of 1980s medical sociology with 'lay models' (Kleinman, 1981), with Pill explaining that 'the idea for this paper came from my original interest in the topic of lay health beliefs and whether or not the concept of explanatory were useful in the context of British general practice' (1987, p. 266). Pill published two articles on the subject, collaborating on publications on other issues surrounding patient-doctor interactions (Butler *et al.*, 1998a) and antibiotic prescription (Butler *et al.*, 1998b).

Cystitis made a good case study for Pill in her exploration of lay beliefs in contact with medicine because of the difficulties involved when patient explanations for their symptoms are in tension with doctors' explanations enacted through a process of diagnosis of exclusion, mediated through diagnostic technologies. Here, this has the effect of dividing 'presenting patients into those who have a 'true' disease and those who do not' (Pill, 1987, p. 283). Importantly, she encourages resistance to the 'immediate reflex action of the social scientist to side with the underdog against the establishment' (1987, p. 277), and instead to consider how the setting of primary care, and the insertion of diagnostic technologies, allows for repeated consultations focused on infection, and little effort to explore alternative explanations (1987, p. 279). Another article, using the same data, was published by Pill and O'Dowd in *Family Practice* (1988). It makes the same point but with more explicit directives aimed at general practitioners to keep open other options, avoiding a management approach focused on confirming or excluding infection and encouraging patients to manage their symptoms at home.

The article is striking to a contemporary reader in its lack of discussion of AMR. There are cursory references to overtreatment (Pill and O'Dowd 1988), which is never explicitly linked to AMR, a term and concept which does not appear in the article. Even antibiotics are seldom discussed, with routine references to 'tablets', which mainly appear relevant for the way in which their prescription reinforces the need for medical intervention. This argument in particular emphasises the way AMR does not appear here as an issue, because it so closely parallels arguments made in contemporary AMR policy that a previous experience of antibiotic prescription reinforces the need for future prescriptions, as the patient never experiences the self-limiting nature of the infection (Lecky *et al.*, 2020). Instead, what this paper makes clear is that patient experiences of UTI and urinary symptoms, especially concerning help-seeking interactions with doctors, were hugely problematic and worthy of further study even before AMR became an issue in national and international policy.

In 1998, Elizabeth Rink, a lecturer in a Department of General Practice and Primary Care, published a study in the *British Journal of General Practice*, using interview data from interviews with ninety-nine women who had been diagnosed with UTI in general practice in the previous

five days (Rink, 1998). Like Pill, Rink employs Kleinman's work to present the key problematic as the coming together of lay and biomedical models in the space of the consultation (1998, p. 1115). Again, there is no reference to concepts of AMR. Repeated prescriptions are discussed as problematic due to the lack of talk between patients and GPs about prevention methods, with both being embarrassed to address these explanations for recurrent infection, and instead returning for a prescription to 'treat the attack instead of searching for its cause' (1998, p. 1115). The overall conclusion then, is similar to Pill's, that GPs do not exercise enough clinical curiosity about UTI symptoms and do not engage with lay beliefs as a way of preventing recurrences. For Rink though, this is much more linked to gender, with concluding discussions of embarrassment around sex, and doctors' attitudes to conditions that are specifically 'female'.

In 1999, Kirsti Malterud and Anders Bærheim, from a Department of Public Health and Primary Care, published 'Peeing Barbed Wire: Symptom Experiences in Women with Lower Urinary Tract Infection' in the *Scandinavian Journal of Primary Health Care*. Ninety-four women who consulted with suspected cystitis and had significant leukocytes and bacterial growth on culture provided written answers to open-ended questions on symptom experiences. This study also grounded itself in Kleinman's work on explanatory models (1981) but unlike Pill and Rink, there was no concern with lay theories of causation. Instead, it focuses more on lay language and the argument that doctors needed to improve their understanding of 'people's natural language with respect to medical problems' if they were to 'apply the patient's story as a principal diagnostic story' in the absence of rapid diagnostics (1999, p. 49). Thus, the study compared the language of three traditional lower urinary symptoms (dysuria, urinary frequency and suprapubic discomfort) with the language women used to describe their symptoms, arguing that doctors needed to become fluent in these lay terms. They also noted a broad range of symptoms, including some surprising systemic ones, beyond the traditional three. Where Pill and Rink were more concerned about repeat consulters, especially in the absence of microbiologically positive results, this study is more concerned with the initial clinical diagnosis, without the support of lab results. Despite that, Malterud and Bærheim noted that 19% of their sample reported three or more symptomatic episodes during the last 12 months, and that a substantial part of their data came from these women (1999, p. 52),

hinting at a significant variation in experience, and willingness to engage with researchers on the topic. Again, AMR appears nowhere in this study but it is clear that experiences of UTI are worthy of study for differing reasons across a broad spectrum of experience.

In 2004, David Cook published the results of two surveys in a supplement of *Postgraduate Medicine* which I have been unable to access. However, the abstract provides some details about emergent themes. Again, the main focus was on discordant perceptions between women and healthcare providers. Results showed that half of healthcare providers believed most patients recognised the true causes of UTIs while 30% of patients believed UTIs were primarily diet-related, with bacteria or personal hygiene considered less likely causes. Healthcare providers perceived symptoms of UTI to be less severe than patients did and that short course therapy, increased education and prevention would improve care, while patients felt that over-the-counter options would help. This leads the author to conclude that patients require more education regarding risk factors, prevention strategies, and optimal therapy, while providers require more education about burden of disease. Clearly, without reading the whole article it is impossible to provide a thorough analysis but it is instructive which parts have been pulled out as important in the abstract. This is especially true in that it is the interaction between patient and GP which appears as the key problematic, with education positioned as a remedy.

In 2009, Geraldine Leydon, Helen Smith and Paul Little, primary care researchers based in medical schools and Sheila Turner, a NIHR public health researcher, published a qualitative interview study of women presenting with symptoms of urinary tract infection in the *British Journal of Medical Practice*. They interviewed twenty women from general practice in England who had been randomised to the delayed antibiotic arm of a trial of different management strategies for UTI. 88% had experienced cystitis before this acute episode. The study explored women's self-care strategies and triggers for seeking professional help. This was based on a premise of UTI as a largely self-limiting illness and that '40% of patients with suspected UTI do not have infection' (Leydon *et al.*, 2009, p. e220). It is notable then, that despite the public health perspective visible in Turner's inclusion as author, AMR again appears nowhere in this article which aimed to 'optimise the balance between primary care and self-care for UTI'

(Leydon *et al.*, 2009, p. e219). The authors noted that interviewees were careful to depict themselves as responsible consumers of health services, picking up on the way that the use of health care resources in general is the central concern, rather than AMR specifically. This is a sensitive article that hinges on health practices for UTI symptoms moving between home, work and the clinic, and primary care as a contact point with medicine in the community. Attention is paid to domestic health practices and to what they note as a surprising lack of discussion of lay referral networks, given health behaviour theories, putting this down to embarrassment around UTI and patients feeling to blame. In this way, the authors issue no generalised guidelines about how to navigate implications of the threshold to consult. Instead they conclude that the study is a 'clear reminder of the need to deal sensitively with the 'minor' illness of UTI, to acknowledge the 'primacy of the person', and attend to the unique experience of illness for each individual' (Leydon *et al.*, 2009, p. e224), putting this navigation back into the hands of the individual GP and the patient in front of them. The concluding citation of a comprehensive and seminal textbook of family medicine (McWhinney, 1997) grounds the capacity for decision making in the expertise of general practitioners. It is this which is positioned to resolve the problematic (for both the women themselves and for health economics) over-reliance of women with urinary symptoms on the healthcare system.

In 2010, the same group of authors published another qualitative interview study in the *British Medical Journal*, using data from the same group of patients. This study explored women's views of a delayed empirical antibiotic treatment, to which they had access at any stage. Seven of the twenty women accessed antibiotics immediately, despite being randomised to the delayed treatment protocol, which GPs reported as being due to patient expectation. The authors explain that the strategy of universal antibiotic use in women with UTI was under question because the condition is self-limiting and non-pharmacological alternatives exist, although there is doubt about the evidence for their effectiveness. Here, for the first time, AMR appears as one of two balances against the effectiveness of antibiotics, the other being mounting concerns about increasing workload for self-limiting illness. In that antibiotics and diagnostic techniques are seen to encourage belief in the necessity of consulting a GP for the problem, echoing the concern with medicalisation of UTI that has appeared across this literature review, the two are presented as related. They found that 'women with urinary tract

infection want to avoid antibiotics' (Leydon *et al.*, 2010, p. 5) and were open to alternative management strategies, primarily because they wanted to avoid side effects and to allow 'natural' healing of the body. Having a prescription waiting at reception was reassuring in case of symptom deterioration and to validate experiences of symptoms. They found that both women with and without previous experience of UTI struggled to provide a coherent aetiology and often drew on theories of self-blame or negligence. For the authors, this was significant because they felt that these women might be 'particularly vulnerable to feelings of not being taken seriously when their doctor proposes a strategy of no antibiotic or delayed antibiotic' (Leydon *et al.*, 2010, p. 5). Therefore, the study endorses delay of empirical antibiotics as a management strategy and places emphasis on the need to explain the rationale for such a strategy to avoid implying that antibiotics have not been immediately prescribed because women have not been understood or believed.

Notable in this study are the seven patients who did not delay collecting their antibiotics as recommended. The authors report that all seven described their symptoms in serious terms, quoting one who said she was in 'terrible pain and it was frightening' and that she was 'nearly in tears' (Leydon *et al.*, 2010, p. 4). Patient four, who also did not delay, gave the reason that she had interstitial cystitis, suggesting that she had prolonged experience with urinary symptoms. To me, this is significant in the way that a broad range in experience is visible and captured even within the sample of patients who had agreed to be randomised to a trial with a delayed treatment arm.

In 2013, Irene Eriksson, Birgitta Olofsson, Yngve Gustafson and Lisbeth Fagerström, a group of researchers working in medical schools and life science departments published a qualitative study of older women's experiences of suffering from UTI in the *Journal of Clinical Nursing*. They interviewed twenty women from the age of 67-96, who had had at least two UTIs in the past year and were recruited from medical records in a primary healthcare centre in western Sweden. Four were living in an institution. The article makes no reference to AMR apart from to note that guidelines for treating a UTI varies between countries in reference to the Swedish national antimicrobial stewardship programme, in place since 2006. Instead, the focus is on illness experience of recurrent urinary infection. Women described struggling to

deal with the illness, being restricted in daily life, depending on access to relief and receiving inadequate care, especially when women felt younger women or men clinicians saw it as a condition of elderly women (Eriksson *et al.*, 2014). The authors concluded that the clinical relevance of the study was helping nurses to develop strategies to support these women, namely through educating them in self-care. Self-care strategies did not appear as a theme in the cited interview data and are not discussed in the article. More helpfully, they also conclude, based on interview data that described a lack of further investigation into recurrent infection, that caregivers should not prescribe treatment for the infection episode without ‘finding out how difficult their health problems are and what kind of support or education they might need’ (Eriksson *et al.*, 2014, p. 1392). The study makes clear the burden of illness for these patients but the reasons for engaging with patient experiences apart from to raise awareness of this burden amongst health professionals appear confused.

In 2014, Andrew Flower and George Lewith from a Complementary and Integrated Medicine Research Unit and Felicity Bishop, a health psychologist, published a qualitative study of patient experiences of living with recurrent urinary infection in *Biomed Central Family Practice*. They collected data from the COB (Cystitis and Overactive Bladder) Foundation web forum which at the time was the largest and busiest UK online support community for women with bladder problems, with 5,994 online members (Flower *et al.*, 2014, p. 2). Therefore, unlike all the studies discussed so far, which recruited from general practice, this data is representative of patients who are likely to have more complex experiences as they have self-selected into a specialist web forum. A key theme that emerged was of ‘symptoms that don’t live in the textbooks’, as like Malterud and Baerheim, Flower *et al.* found that patient experiences of symptoms were qualitatively different to those described in medical literature, and expected by clinicians. Flower *et al.* analyse patient relations with clinicians under the heading ‘doctors: heroes and villains’, finding polarised views towards doctors. Importantly, the patients on the forum who expressed positive experiences with care reported not that their symptoms were relieved, but ‘relief (and often surprise) to find that their doctor listened and was responsive to their complaint, that they had read the notes and were informed about the particular presentation of the woman and RUTIs in general. They demonstrated understanding and kindness and were willing to refer to more specialist expertise’ (2014, p. 6). This leads the

authors to describe good care as being ‘not always to great effect’ (Flower *et al.*, 2014, p. 6), which certainly reflects a specific understanding of what good care is.

The effects on everyday life, especially on sexual relationships and expectations for the future also emerged as important themes. Like Pill and Rink, Flower *et al.* describe concern for patients who repeatedly consult and are treated with antibiotics each time. As part of this, the authors explore attitudes to antibiotics, noting attitudes that range from ‘disregarding them in favour of alternative remedies to a more conventional view insisting on the need for antibiotics as a way of preventing a more serious kidney infection’ (Flower *et al.*, 2014, p. 4). AMR is mentioned at the start of the article in the context of its effect on management of the condition. Flower runs a NIHR funded project investigating the possible role of Chinese herbal medicine in treating recurrent UTI and this interest is reflected in the way that a finding of resistance to antibiotics leads to an analysis of complementary and alternative medicines (CAM), rather than a more general attention to patient health practices which do appear in the cited data: ‘I have to avoid spicy food, caffeine, sweet fizzy drinks and most alcohol’ (Flower, Bishop and Lewith, 2014, p. 5). The finding of poor experiences of care, and continued suffering despite antibiotic treatment, is therefore identified for further research not only to ‘identify key elements of good clinical practice and supportive care’ but also to ‘provide a more rigorous assessment of alternatives to conventional treatments such as CAM interventions’ (2014, p. 7). Therefore, the interest of this article emerges in how CAM can intervene in the poor experiences of antibiotic-based care pathways with avoidance of AMR-driving antibiotic use.

In 2016, Michelle Gavin of ‘Friends, Families and Travellers’ (FFT), a charity which works with the Gypsy and Traveller Community in Brighton and Hove, compiled a report for Healthwatch. The report was commissioned following the findings of a previous report produced for the CCG on Gypsy and Traveller use of Urgent Care services locally. Indeed, apart from Ghouri *et al.* and Flower *et al.*, who both used data from online forums, participants in all the other studies were recruited through the health system. The aim of this research was to ‘see if there was any correlation between the initial high levels of health related issues of

bowel/bladder problems/incontinence and lack of accessible sanitation and toilet facilities on unauthorised sites' (2016, p. 3).

There were thirty-four respondents and various methods of data collection were used, including interviews, questionnaires and focus groups. Participants talked about frequent urine and kidney infections and use of antibiotics; 50% had been referred to a specialist and 60% had been admitted to A & E. Many spoke about the normalisation of UTI in Gypsy and Traveller communities and the development of chronic conditions due to repeated infection, including amongst children and pregnant women. Throughout, a strong theme emerges of how the built environment led to limiting fluid and holding urine. Some had moved onto bricks and mortar accommodation and spoke about how having a toilet improved the situation, but all agreed they missed living on-site. In the focus groups, all participants had experienced urine infection. Participants had a range of practices they did to avoid infection, such as avoiding public toilets with a higher risk of 'splash-back', echoing the emphasis on lay practices of prevention amongst patients made by Pill and Rink. Also echoing Pill and Rink, participants explained that their repeated infections had not been investigated, clinicians being un-interested in lay practices which could be useful and instead treating each episode separately.

The report's stated aim is to investigate a potential link between bladder problems and lack of accessible sanitation. Accessible sanitation facilities are something that this community, and FFT specifically, has long campaigned on. What is notable here is the way that marginalised groups, in contact with a statutory organisation such as Healthwatch, can leverage emergent health concerns to get what they need, just as instrumentalised health concerns can also be leveraged against marginalised groups (Knight, 2015). For instance, lay practices of avoiding public toilets due to increased risk of 'splash back' are straight forwardly associated with the kind of pathogenesis stories employed in biomedicine, but without any of the kinds of evidence that biomedicine would require: '[splashback] is known to be a cause of urinary tract infections in women (e-coli)' (Gavin, 2016, p. 8). More broadly, the link between lack of access to a toilet and increased risk of infection is presented as straight forward. The evidence relied on to make this claim appears to stem from participant responses but participants repeatedly

draw attention to how it was only in the course of participating in the research that they had made this link: 'I just thought I had a small bladder and didn't realise it was to do with my living environment' (Gavin, 2016, p. 5).

Although AMR is not mentioned aside from one participant comment that antibiotics are no longer working for her, increased healthcare costs are levied as a reason to address these health issues, with a cost-benefit pathway analysis accompanying the fictionalised story of a young traveller woman, Bridie. When asked how they thought the local authority and CCG could help improve these health conditions within the Gypsy and Traveller communities, Gavin reports that everybody who responded agreed that portaloos facilities should be offered on unauthorised encampments (2016, p. 6). Paying attention to the way AMR may provide a means of resistance for marginalised groups is as important as attention to potential marginalising impacts of AMR policy.

There are strong continuities in Gavin's conclusions and those of the other authors cited here. Gavin concludes that the overall aim is to 'shift the balance of care from urgent response and hospitalisation to prevention and self-care' (2016, p. 18) which picks up on themes of medicalisation and public health frames of self-efficacy found across this literature review. In this context though, it is concretely access to a toilet outside of the caravan which would facilitate this, rather than the self-care or prevention practices which more commonly appear in the other studies. The widespread normalisation of bladder issues amongst the people interviewed echoes findings of repeated, long term experiences of what is supposedly an acute condition and the lack of investigation of this by healthcare practitioners (Rink, 1998; Eriksson et al., 2014; Flower *et al.*, 2014). The severity of illness burden described also picks up on the widespread variation in experience described elsewhere (Leydon *et al.*, 2010) and highlights how illness is experienced across differently situated bodies.

Also in 2016, a team in departments ranging across economics, health economics, marketing, general practice, bacteriology and medical microbiology, published a qualitative study of GP and patient experiences with UTI in the *British Medical Journal* (Duane *et al.*, 2016). This qualitative study was conducted to inform outcomes, research design, and recruitment

strategy in a RCT (Duane *et al.*, 2016, p. 1). The trial was of a behavioural intervention including workshops, audit reports and automated electronic prompts, and a recommendation to consider delayed prescribing for GPs, and multimedia applications and information leaflets for patients. The primary outcome measure was relative number of prescriptions of first line antimicrobials, citing the ‘global public health issue’ of antibiotic resistance and the ‘over-prescription and consumption’ of antibiotics in the community as a main driver’ (Duane *et al.*, 2016, p. 1). Here then, in terms of qualitative research speaking to patients about their experiences of UTI, the relevance of these experiences to the AMR interventions comes through strongly for the first time.

Thirty-two women were recruited for focus groups via senior citizens’ and young mothers’ groups in rural and urban locations in Ireland. Five of the overall forty-two participants (including men) reported having one UTI before, seven reported having had several, and twenty-six reported never having had one. Duane *et al.* used the Buyer Behaviour and Decision-Making Model to evaluate how, when and why someone consults with a GP, and how they evaluate the outcome. Thus, explicitly understanding the patient as a consumer, they attempted to identify what it was that patients needed in order to be satisfied with the consultation. Like Leydon *et al.*, they conclude that patients do not always expect or want an antibiotic, with satisfaction instead being linked to the quality of the consultation, especially reassurance that symptoms will improve. Identifying what the individual patient-consumer wants is key to this and a schematic of three patient profiles are identified to aid this process: young professionals (quick fixers), young mothers (advice seekers), and mature patients (experienced consulters). Findings that half of patients described home remedies before consulting, many sought advice from close family members and many weighed value for money against severity of symptoms were presumably deemed useful for understanding the extent of medicalisation of UTI compared to management of symptoms at home. This echoes concerns in the previously mentioned studies (Pill, 1987; Leydon *et al.*, 2010) about how previous antibiotic treatment reinforces the need for future medical intervention, although this is much more strongly related to AMR than in any of the other studies.

Aside from attempting to understand what could satisfy patient-consumers apart from an antibiotic prescription, the authors also engaged in questioning patients about their knowledge of AMR. In a classic knowledge deficit model, Duane *et al.* found that patients could not define or understand AMR, but when presented with information, reported believing that this type of information would encourage them to question their consumption. Overall then, knowledge about patient experiences of UTI is important here because of the way that it provides information about how to satisfy the patient-consumer outside of prescribing them an antibiotic.

In 2019, Flavia Ghouri, Amelia Hollywood and Kath Ryan, health psychologists and pharmacists, published a qualitative study of women's perceptions of UTIs and antibiotic use in pregnancy in *BMC Pregnancy and Childbirth*. They analysed data collected from the popular parenting website *Mumsnet*. They found that women viewed UTIs to be more common in pregnancy and linked to serious consequences compared to when not pregnant, which encouraged the seeking of antibiotic treatment. Indeed, they found that most women on the forum favoured antibiotic treatment. This leads to a conclusion that 'pre-natal attachment may cause women to focus solely on the risks of a UTI while under-appreciating the risks of antibiotics, particularly the threat from AMR, which is a major global challenge' (2019, p. 7).

Reporting the perception amongst women that pregnancy can make you more susceptible to UTIs, the authors note that this is in fact evidence-based and promoted by NHS public-facing information. However, they go on to state the need to challenge this perception because 'it reflects a medical model of illness that attributes the cause of illness to external factors beyond individual control' (2019, p. 7). Instead, the authors, based on health psychology theory, would rather see encouragement of a 'problem focused coping style through the adoption of preventative hygiene behaviours so that they can appreciate the controllability of this illness rather than rely solely on a medical solution i.e. antibiotics' (2019, p. 7). In some ways, this echoes the theme of a concerning medicalisation of UTI (Pill, 1987; Leydon *et al.*, 2010; Duane *et al.*, 2016). Here, however, medicalisation is not about inadvertently reinforcing the need for antibiotic treatment for a self-limiting infection; antibiotics are standard treatment for a UTI in pregnancy. Instead, the problem of medicalisation is about relying on antibiotics rather

than hygiene prevention measures. It is notable that this strong argument in favour of preventive measures, (for which the evidence is normally understood to be contentious), relies on the authors' self-citation of a systematic review that reported that preventative hygiene behaviour is the only evidence-based intervention linked to a reduced incidence of UTIs in pregnancy 'and therefore the most effective method of avoiding antibiotics' (2019, p. 7).

It is also a reversal of the responsabilisation of Rink's and Gavin's observation that GPs do not engage with lay practices as a way of preventing recurrences. For Rink and Gavin, women had health practices which were largely ignored by GPs whereas for Ghouri *et al.* (2019), women need educating about the advantages of adopting these practices, rather than feeling they can fall back on antibiotics when they do experience infection. Mobilising on AMR is therefore a key reason to talk to patients about their experiences, but only in so much as it provides information on patient misunderstandings, to be corrected by health care practitioners.

In keeping with the change over time I have identified in how studies of patient experience of UTI are increasingly produced with a focus on informing AMR interventions, the next study I have been able to identify documents the development of a resource for the TARGET antibiotic toolkit, UKHSA's antibiotic stewardship programme for primary care. Named the 'Target Your Infection UTI information leaflet', it is a patient-facing leaflet about UTI, intended to facilitate shared decision-making during the consultation and to be taken home by the patient. Published in the *British Journal of General Practice*, the article opens by noting that 'there are few public health issues of greater importance than antimicrobial resistance', and explains how both over and under diagnosis and treatment of lower UTI can drive AMR (Lecky *et al.*, 2020, p. e330). The qualitative study of patient experiences is useful to the research in that they explain that it is understanding patient and GP behaviour during the consultation, using behavioural theory, that will increase the likelihood of success of interventions (2020, p. e330). Therefore, they interviewed twenty-nine women over sixteen who had consulted a GP for UTI in the past 12 months. The patients varied in age, ethnicity and frequency of infection and were recruited via PHE's People's Panel (1600 members of the public who were recruited through a national random sample survey), and participated by

responding to a study information leaflet. They also interviewed twenty GPs who were recruited via RCGP's newsletter. They analysed the data using the Theoretical Domains Framework (a theory of behavioural change) to analyse the factors upon which decisions hinge and used this analysis to produce the leaflet.

The themes emerging from the data are very rich. The authors found that where GPs thought of women as very knowledgeable about UTIs, through experience or lay networks, many women said participation in the research was the first time they had discussed it with other women. This correlates with the findings of Leydon *et al.* (2010). Women also described not knowing what was happening to them on the first experience of UTI, and being surprised to learn of the prevalence of UTI, with some women expressing shock at seeing younger women in attendance at the focus group. The authors note the continuity with Rink's research (1998) with concern as it suggests 'that little has changed in the past 20 years' (2020, p. e336). Where GPs described the typical UTI consultation as straight forward given their perception of patient knowledge, many patients found consultations frustrating, feeling that they weren't being listened to and that the GP viewed UTI consultations as a chance to catch-up with a delayed schedule. GPs reported that women generally expect antibiotics but women emphasised that they did not want a quick fix, instead wanting advice on prevention, relief from pain, and reassurance about the course of illness. GPs stated that patients often consulted late, echoing the findings of Leydon *et al.* (2009), and that this lowered their threshold to prescribe. There were patients who did want immediate antibiotics and the authors noted that this was based upon previous experiences of successful antibiotic treatment.

GPs expressed reticence to give preventive advice due to a lack of evidence, although patients stated that they would value this advice and sought information elsewhere. Here then, like for Ghouri *et al.* (2019), health practices outside of antibiotics lie with the HCP, rather than with patients. On AMR, patients were aware of AMR but the authors note that they described it in terms of their body's resistance to antibiotics. They also expressed concern that antibiotics would not be prescribed in the future.

This data was associated with domains from the TDF, such as ‘knowledge’, ‘skills’, ‘professional role and identity’ etc. These domains were used to compare patient and GP responses, and to identify five areas where there were differing views: barriers to an effective communication and prescribing. The process for doing this is unclear, which reflects the lack of consensus in how the TDR should be deployed (Atkins *et al.*, 2017). For example, one of the barriers is ‘nature of consults: many consults are over the phone, making discussions difficult.’ It is unclear from the data cited why this has been identified as a barrier; GPs reported managing UTI by telephone but said that they ‘carried out a similar routine when consulting face-to-face’ (Lecky *et al.*, 2020, p. e332). As mentioned above, patients reported that they felt rushed, but no-where was this discussed as being due to the telephone. The identification of the barrier ‘lack of skills and materials: to initiate the appropriate dialogue’ appears likely to have been developed to justify the pre-established aim of creating a shared-decision making leaflet, as it is unclear how this has been developed from the data.

Six sections were developed for the leaflet, each aiming to address one or more of the barriers. It is undoubtable that the qualitative work provides valuable insights into how care for UTI patients might be improved but the link between the data and the leaflet, mediated by the TDF, is highly deductive. The authors conclude that the using the leaflet ‘might enhance patient empowerment by either considering and building in preventive measures to their daily lives; better self-care when urinary symptoms present; or recognising when to visit their GP follow the identification of urinary symptoms; all of which may reduce the need for unnecessary antibiotic therapy’ (2020, p. e337). Again, I would argue that the data collected does not obviously support these claims. One example is in ‘recognising when to visit their GP’, which hopes to address study findings that GPs felt patients consulted too late, which led to a low threshold to prescribe. Consulting the final leaflet for information about when to visit a GP with urinary symptoms, all nine of the warning signs of when to urgently seek medical help are clearly signs of serious infection. Therefore, the issue of when to consult is unresolved by the leaflet, apart from when patients have already left it dangerously late. Indeed, the whole leaflet is striking in comparison to the thoughtful discussion of the qualitative data in that it transforms the findings into a knowledge deficit model of patient misunderstanding. Insights such as that patients worried that antibiotics may not be

prescribed in the future, or internalised what they presumed the GP thought process to be, are not taken up. This is not to say that the leaflet is useless, it may indeed facilitate a better conversation, something that could be studied. However, I would argue that this article, along with that of Ghouri *et al.*, demonstrates the need for more clarity about the precise mechanisms through which understandings of patient experiences can lead to better clinical practice and a greater inductive openness to what may be important.

In 2021, health services researchers published a qualitative study of women's 'information needs around urine testing for UTIs' (Glogowska *et al.*, 2022). The study was part of a RCT of urinary collection devices. Interviewing women consulting with suspected UTI about their experiences with urine testing, they found that women did not have the information they needed to produce uncontaminated samples (2022, p. 18). This was cited as a finding that could both support better management of UTI and reduce unnecessary prescribing and antibiotic resistance' (2022, p. 19) as increased information sharing around testing reassured women 'about antibiotic prescribing decisions and giving them a better understanding about when antibiotics might or might not have been necessary' (2022, p. 18). Again here, speaking to patients is a way of addressing AMR through positivist evaluations of patient experience leading to information targeted at knowledge deficits.

Several common themes have emerged in this review of the existing literature on patient experiences of urinary tract infection. There is broad concern about where UTI lies between the home and clinic, and many write against the medicalisation of urinary symptoms, seeing patients managing infection themselves as desirable. Reasons for this range from rather unspecified references to patient 'empowerment', to economist arguments about healthcare cost and workload, to more specific arguments about the way diagnostic technologies and prescriptions reinforce the need to consult for a condition that could be managed at home, leading to poor clinician/patient relations. Evidence is produced of domestic health practices, which are universally recognised as important, although there is some disagreement about where knowledge about domestic health practices lies between GPs, experienced patients and inexperienced patients. This also picks up on the way that a broad spectrum of burden of illness experience is visible across all the studies, seemingly regardless of the way patients

were recruited. Patients with terribly painful and/or long-term experiences, who feel abandoned by healthcare, sit alongside patients with short-term and acute discomfort who are unsure whether they need to consult a doctor or not.

One major reason identified for poor care is lack of investigation of repeated infection, or causes for symptoms beyond infection. Most of the authors cited here found that this was more important to patients than antibiotic prescription. Diagnosis appears as continuously problematic; in both repeat consultors with and without positive test results for UTI, and in one-off consultors who may or may not require empirical treatment. Significantly, I identify a widespread theoretical ambiguity about how better understanding experiences of UTI care could lead to better care. Despite the large-scale interest in an epistemic approach, understanding what people think or believe about UTI and AMR, it is often unclear from this literature why or how the data collected from women about their experiences links to the recommendations given for practice.

Overall, there is a scarcity of existing literature on patient experiences of UTI. Earlier studies drew heavily on Kleinman's anthropological work (1989) but medical sociology and anthropology has largely neglected the condition since then. The bulk of the work that has been done has come from primary care departments, sometimes in conversation with public health professionals or health psychologists/economists. I have shown that AMR only became an interest of these studies more recently. On one hand therefore, it is arguable that it has taken AMR becoming a policy issue on the national and international stage, for experiences of UTI to become an area of widespread academic interest. On the other hand, it is striking that what is now strongly expressed as an effort to conserve antibiotics appeared earlier as an effort to reduce workloads or healthcare capacity. Moreover, the theoretical ambiguity about the extrinsic reasons for talking to patients about UTI may suggest that there continues to be little reason to engage with patient experiences, regardless of the pressing issue of emergent AMR. I will expound upon my own rationale for talking to patients in a later section of the literature review.

Public Health: Engaging with Publics on AMR

This section explores how public health workers and policymakers are thinking about the involvement of patients and publics in mobilising against AMR. I explore why, how and based on what types of evidence patients become the focus of AMS campaigns, and pay attention to what is identified as desirable behaviour on the part of the public. I draw on Will's work (2020) which addresses how this desirable behaviour is to be achieved given the ways the public is understood within public health. I also explore how 'gaps in the evidence' are made, where lack or ignorance is identified, how it is accounted for, and what work is done by enacting such a gap. This section sets out an analysis of existing and developing public health approaches to the relations between the public, AMR and UTI. In the following section, I will outline sociological and STS approaches to AMR and UTI, and set out my own reasons for engaging with publics and patients.

Why Engage with the Public on AMR?

Reducing use of antibiotics for non-bacterial illnesses or minor infections is one of the major public health efforts to address the problem of antimicrobial resistance (MacPherson *et al.*, 2021). In the UK, antibiotics are only normally available with a prescription (although people may have other networks they draw on to access antibiotics such as buying them online, or buying them in countries where a prescription is not needed.) It might seem therefore, that efforts to reduce the use of antibiotics would focus on HCPs. However, significant attention is focused on public behaviour as a driver of AMR.

In the review of qualitative studies of patient experience of UTI, I argued that the importance of engaging with patients came through as a strong theme but reasons cited to do so often appear theoretically under-developed outside of knowledge/information deficit approaches. Where patient engagement on UTI continuously appeared as important even before the emergence of AMR as a policy concern, patient engagement appears as key in AMR policy more generally. The UK's 20-year vision for AMR (DHSC, 2019a) identifies nine ambitions for change, and the ninth of these is to engage the public. Aims identified for societal input into AMR cover a very wide range of interventions, from practising good hygiene, to holding others to account through consumer habits and AMR advocacy directed at public and private bodies, to more passively understanding the risks and benefits of antimicrobials and only using them as directed (DHSC, 2019a, p.17). These aims for public contributions to mobilising

against AMR are imagined to work through very different mechanisms which are not developed within the document. For example, the aim of having publics use antimicrobials ‘only as directed’, whilst also understanding the risks and benefits for themselves and holding public and private bodies to account on AMR, seems to reflect an ambiguity acknowledged elsewhere by public health policymakers: ‘whether it is necessary for people to understand antibiotic resistance (as opposed to merely accepting it) is unclear’ (UKHSA, 2015, p.48). The public role in mobilising against AMR appears in the twenty-year vision as intrinsically important but extrinsic reasoning around the importance of involving the public and how to achieve it appears under-developed.

Patient Expectation of Antibiotics

In the literature review, engaging with patient understanding of UTI and of AMR emerged as important for reducing antibiotic prescription as AMR became a key concern over time. Patient demand, or expectation, of antibiotics is often singled out from other reasons to engage with the public on AMR. Patient demand for antibiotics appears as a major driver of inappropriate prescribing, which in turn is cited as a driver of AMR. For example, the NICE guideline NG63 on ‘changing risk-related behaviours in the general population’, noted that ‘the committee was conscious that to reduce inappropriate antimicrobial demand and use, changes in the behaviour of both prescribers and the public are necessary’ (NICE, 2017, p.27). Changes were targeted at reducing ‘inappropriate antimicrobial demand and use’ (NICE, 2017, p.27). A very explicit discussion of the theoretical underpinnings of such interventions appears in UKSHA’s ESPAUR report for 2020 to 2021 (UKHSA, 2022, p.158):

At the heart of antibiotic overprescribing is a transaction between patient and doctor, which could be described as follows: The patient expects antibiotics, which the GP, who has limited time for the appointment, can feel under pressure to prescribe. If antibiotics are prescribed, the patient credits them for their recovery, even though they might have got better anyway. This reinforces the behaviour, so asking for antibiotics becomes normal.

Will, commenting on the contribution of sociological work to engaging patients on AMR, notes that ‘in considering patients, sociology demands attention to the ‘clinical interaction’ as a negotiated order rather than looking at the behaviour of a particular group separately’ (2018, p. e3). In contrast, what is described in the ESPAUR report is a ‘transaction’, retaining the focus on the behaviour of two separate groups. Indeed, the report describes how ‘using

insights from behavioural science, the campaign sought to influence this transaction' (UKHSA, 2022, 158). These attempts comprised of reducing patient expectation of or demand for antibiotics when they are not needed by providing information about AMR, and increasing prescribers' confidence in 'resisting pressure to prescribe antibiotics when not needed' by displaying posters in the waiting room and giving GPs 'self-care' prescribing pads to have something to give to patients. Two things to note here are firstly that patient expectation is constructed as a key driver of AMR and secondly that it is understood not to be co-produced with the interaction with the doctor, but to pre-exist it, with patients 'primed' with posters in the waiting room not to expect antibiotics before entering the consultation room.

Even more striking in the focus on patient behaviour, preceding the patient/doctor interaction, are the four 'target behaviours' identified to reduce patient use of antibiotics for self-limiting infections in a 2015 behavioural analysis report produced by Public Health England. Four 'target behaviours' required to reduce patient use of antibiotics for self-limiting infections are identified (UKHSA, 2015, p.47). These were:

1. Patient undertakes self-care and/or obtains pharmacy advice for colds, runny nose and/or flu (and does not make a GP appointment).
2. Patient undertakes self-care and/or obtains pharmacy advice for other self-limiting infections as usual practice before considering a GP appointment.
3. Patient does not request antibiotics if attending appointments for self-limiting infection symptoms.
4. Patient acts upon GP advice where antibiotics are not prescribed and self-care is mandated or a delayed prescription is issued.

There are a few things to note here. Firstly, all of these behaviours are neatly divorced from, although related to, the interaction with the doctor, either preceding or following it. Patient 'behaviour' is isolated and therefore to be targeted in isolation. Interventions aimed at patient behaviour are sometimes delivered alongside interventions aimed at clinicians, in what are

described as ‘multi-targeted interventions’, the separate but parallel interventions underlining the notably non-relational understanding of both clinician and patient behaviour.

Secondly, the behaviours describe the ideal, rational behaviour of a patient who most probably does not need antibiotics, and whose doctor is confident to make a clinical decision about their need for antibiotics. They do not address uncertainty in medical practice nor publics who may use antibiotics for non-clinical reasons or who routinely have to use antibiotics for clinical reasons and who do participate in decision-making with their doctors about this. It appears to be a ‘low-hanging fruit’ approach, targeting the easier cases and leaving the trickier cases ‘out of scope.’ Whether and how these easier cases exist remains to be seen. Crucially for this thesis, the effects of cases left out of scope, and effects of being left out of scope, are not accounted for.

Exploring the Evidence that Patients Want Antibiotics

Will argues that sociological work is used as ‘evidence that patients’ desire for an antibiotic affects prescription – implying that people can put pressure on doctors to access medicines’(2020, p.1). I have shown above that it is patient demand or expectation of antibiotics that is most often and most strongly articulated as a reason to engage with the general public on AMR. Often, as in the examples I have provided above from AMR national action plans, no evidence is provided and it is presented as rather obvious that patients expect or demand antibiotics and that this leads to over-prescribing. However, in other places, evidence is cited in support of the idea that patients want antibiotics, and that this leads to over-prescribing. In this section, I will review the main citations that appear in support of engaging patients and the types of evidence these citations provide.

Macfarlane *et al.* (1997) is a study of prescribing for RTI that asked patients about their expectations for antibiotics and professionals about their reasons for prescribing. A quarter of patients received antibiotics when they stated that before the consultation they had not wanted them. However, patients who said that they wanted antibiotics were three times as likely to receive them (despite controlling for illness severity), with patient pressure being reported by GPs as a reason for prescription in more than half of cases where GPs considered

antibiotics were not indicated. This is cited as useful for understanding how patient expectation influences prescribing (UKHSA, 2015, p.23).

Little *et al.*, (1997b) is another citation made in support of ‘patient expectation of, and request for, antibiotics’ (UKHSA, 2015, p.23). This was a randomised trial of different prescribing approaches to sore throat in English primary care. Patients who received antibiotics were more likely to present in the future and the assertion is made that ‘liberal antimicrobial prescribing may cause higher levels of re-attendance’ (UKHSA, 2015, p.23). Another citation used in a similar way is Williamson *et al.* (2006). It is worth noting that this ‘medicalisation’ mechanism, where the doctor validates that the patient’s issue was indeed ‘doctorable’ via antibiotics (Heritage and Robinson, 2006), emerged as a concern (including of the same authors) in the literature review on UTI, even when no relation to AMR was made (Pill, 1987; Rink, 1998; Leydon *et al.*, 2009, 2010; Ghouri *et al.*, 2019). In that context, I drew attention to how Little’s group advised general practitioners to deal with what they identified as a problematically low threshold to consult for UTI symptoms, noting that they issued no generalised guidelines or interventions aimed at patients, but instead emphasised the importance of a good encounter, grounded in the principles of general practice (Leydon *et al.*, 2010). Here, Little *et al.*’s work is used in the Behavioural Insights report as evidence in support of patient expectation and request of antibiotics, mirroring the mechanism set out in the ESPAUR report (UKHSA, 2022, p.158). However, like on UTI, Little *et al.*’s findings here on sore throats focuses more on the interaction between doctor and patient, with repeated references to good communication, validating the patient’s concerns but not prescribing antibiotics (1997b, p. 726). I would argue that Little *et al.* posit poor interaction between doctor and patient as driving over-prescription, not patient behaviour.

Published in 1998, Butler *et al.* found that clinicians often cited not wanting to risk damaging their relationships with patients by not prescribing antibiotics as a reason for over-prescribing for RTI, and taking the patient’s concerns seriously as a way to reduce it (1998, p. 640). Meanwhile, two thirds of patients did not want antibiotics but most commonly said that they had consulted for reassurance, with one man fearing that he had cancer (1998, p. 640). Patient satisfaction revolved more around not being rushed and being taken seriously than being

prescribed antibiotics, and although only one patient mentioned AMR, many talked about problems with using antibiotics, mentioning thrush, rashes and contraceptive failure (Butler *et al.*, 1998, p. 640). The authors concluded that ‘single, simple solutions are therefore unlikely to change prescribing habits. The problem is a cultural one and goes beyond doctors simply not knowing of the evidence from clinical trials’ (Butler *et al.*, 1998, p. 642).

(Kumar *et al.*, 2003), a study on antibiotic prescribing for sore throats, is reported in the Behavioural Insights report thus: ‘patient pressure and expectation were cited among the reasons for prescribing antibiotics “unnecessarily”, in particular where a shortage of consulting time meant that the doctor felt unable to adequately explain why antibiotics were inappropriate’ (UKHSA, 2015, p.23). This study only included GPs and as with Macfarlane *et al.* (1997), it is unclear why this should be cited as evidence that tells us directly about the success patients have in pressurising doctors into prescribing.

Reading the article, it becomes even more unclear why it was interpreted as citing patient pressure and expectation for prescribing antibiotics ‘unnecessarily.’ It is a careful piece of work that cites many reasons doctors give for their own over-prescribing, including scepticism that it contributed to AMR, inequality leading to a lower threshold to prescribe, uncertainty over if patients in fact needed antibiotics, and seeing sore throat consultations as an opportunity to catch up on time and relieve stress. Interestingly, the authors noted that GPs spoke ‘in the abstract’ about patients being dissatisfied and causing confrontation if denied antibiotics but described these as ‘assumptions’ because GPs were unable to give clear examples from practice. Where GPs reported difficulties persuading a patient that they were unlikely to benefit from antibiotics, it was a lack of time to have this conversation that they attributed to causing overprescribing, not pressure from the patient. This research contradicted Butler *et al.*’s 1998 finding that GPs were over-prescribing to maintain the doctor-patient relationship; GPs in this study did not believe that withholding antibiotics damaged the relationship long-term. Instead, nearly all the doctors interviewed believed that listening and effective communication were more important to the doctor-patient relationship than prescribing antibiotics.

Britten and Ukoummune (1997) is commonly cited in support of patient demand driving overprescribing, but the evidence presented in this work that patients' expectations influence general practitioners' prescribing is, in the words of the authors, 'equivocal' (Britten and Ukoumunne, 1997, p. 1510). They noted that patients' hopes of receiving a prescription exceeded both doctors' perceptions and the level of prescribing- over a quarter of patients who hoped for a prescription did not receive one. It was doctors' perceptions of patient hope for a prescription, not patient hope or expectation, that was the strongest determinant of the decision to prescribe. What is not in doubt is that a majority of patients, selected at random from a waiting room, both hoped for and expected a prescription. It is that this influenced the outcome that is in doubt.

It is also worth noting that this study was conducted in 1997 and was not exclusively focused on antibiotics, but all prescriptions. It may be the case that the negotiation of prescription for antibiotics is different to that for other medications, especially when the public may now be expected to be aware of efforts to drive down antibiotic prescriptions. In comparing patient expectation/hope for prescription to doctor's perception, the authors compare that doctors perceived that 56% of patients 'wanted' prescriptions to patient 'hopes', and find a strong association (1997, p. 1507). The distinction between 'wanting' and 'hoping' for a prescription may be important but appears unproblematised. Throughout Britten's career as a medical sociologist and work on the subject, she has consistently argued that much of the evidence on patient expectation is equivocal. In 1995, writing in the *BMJ*, she wrote that this was because 'researchers have not directly defined or measured demand for prescriptions. Instead, studies have focused on doctors' perceptions of patients' demands and doctors' statements that patients' expectations influence real or hypothetical decisions about prescribing' (Britten, 1995, p1084). In 2004, she reiterated this point in the *BMJ*, pointing out that it was only by studying the interaction that we would start to understand more about the dynamics of the consultation.

A qualitative study undertaken by a group led by the Primary Care and Interventions Unit at UKHSA (Cooper *et al.*) was published in 2020. Aims of the review were to determine the practices of diagnosis and treatment of UTIs, identify current barriers to appropriate diagnosis

and treatment, and how these gaps may be addressed through resource development or other measures (Cooper *et al.*, 2020, p. 3). GPs, health care assistants, nurses and nurse prescribers participated in focus groups and patients did not participate in the research. They found that ‘GP staff felt that patients put pressure on clinicians to prescribe for a suspected UTI, and that this is often driven by the dipstick result and previous management experiences’ (2020, p.14). The authors noted that this ‘perception is similar to other qualitative research’ (2020, p.14) which indeed is true, the influence of clinician perception of patient expectation on prescribing is a widespread finding, but the corresponding recommended intervention was directed at patients, with public antibiotic campaigns and patient-facing leaflets recommended (2020, p.14).

Work entitled ‘Reducing expectations for antibiotics in primary care: a randomised experiment to test the response to fear-based messages about antimicrobial resistance’ from public health workers and senior clinicians (Rooke *et al.*, 2020a) was rationalised using (Coenen *et al.*, 2006), arguing that ‘clinicians are more likely to prescribe antibiotics when patients request them or are perceived to want them. Thus, in healthcare systems such as that of the United Kingdom, where general practitioners act as gatekeepers to prescriptions, decisions whether to consult, and whether to request antibiotics for RTIs could each play a significant role in ‘unnecessary’ antibiotic consumption’ (Rooke *et al.*, 2020a, p. 2). It is unclear why messaging directed at patients would be an intervention justified by clinician perception of patient demand for antibiotics alone. The cited Coenen *et al.* (2006) provides evidence about the strong impact of perceived patient demand only. Coenen *et al.* (2013) provides evidence that patient expectations and hopes are independent predictors of antibiotic prescribing, even with controlled symptom severity, but that clinician perception of these views was a stronger predictor. Importantly, asking for antibiotics, which is what Rooke *et al.* (2020a) posit as the rationale for fear-based messaging aimed at patients, was not independently associated with higher prescribing rates (2013, p. 5).

The UKHSA literature review on patient expectation included in the Behavioural Insights report concludes that ‘in summary, it is likely that GPs over-estimate the degree of expectation from their patients’ (UKHSA, 2015,p.24), citing (Britten, 2004). However, patient expectation

is repeatedly identified as a target of intervention in the report (2015, p.6; p.17; p.52), based on the view that ‘the public can also contribute to antibiotic resistance through demand for antibiotics’ (2015, p.17). The continued importance of patient expectation despite the less than clear evidence for its influence on prescribing is seemingly resolved by positing explicit demand as one end of a spectrum: ‘which at the other end manifests through implicit and non-verbal communication (2015, p.52). Potentially, it could be inferred that this implicit and non-verbal communication of expectation for antibiotics is imagined not to be captured in surveys of self-reported demand or expectation. In other words, patients either do not admit in surveys or do not themselves realise that they expect antibiotics, whilst doctors recognise this and are therefore more likely to prescribe.

Just as public campaigns about AMR are positioned ‘as a clinical intervention, subject to similar evaluation as pharmaceuticals’ by the use of controlled trial methodology (Will, 2020, p. 15), the behavioural insights synthesised in the report are transformed into evidence-based and effectiveness and cost evaluations by the processes of NICE guideline development. It is at this moment where claims to knowledge about public behaviour are made into evidence-based policy recommendations, with the development of the NICE guideline NG63 (NICE, 2017), that the limits of the idea that reducing patient demand will reduce over-prescription are made clear. Tim Chadborn, lead researcher on behavioural insights for UKHSA and contributor to the Behavioural Insights report, highlighted in expert testimony given for the development of the guideline that ‘prescribers perceive demand from patients to be much higher than patients report. This is key because it questions how cost-effective it is to change the behaviour of a whole population to reduce demand enough to have the secondary effect on prescriber behaviour of not writing a prescription when it is not appropriate to do so’ (Chadborn, 2017, p.2). Here, knowledge about patient expectation being in some way significant to prescribing does not obviously justify effective and cost-efficient interventions to drive down prescribing.

Another consideration could be that some of the obfuscation over patient demand versus perceived patient demand in research and policy use relates to how AMR policy is enacted in practice. If GPs’ prescribing behaviour is the ultimate aim of behaviour change and measure

of policy success, but GPs feel that patients demand antibiotics, it could be that interventions ostensibly aimed at patients also enact an intervention in the wider conversation between policymakers, clinicians, patients and publics. In other words, such interventions might after all enact interventions aimed at the ‘negotiated order’ of the ‘clinical interaction’ (Will, 2018, p. e3). A public webinar on antimicrobial prescribing in primary care, hosted by TARGET/RCGP/STEP-UP teams on November 25th 2021 was instructive for thinking about this. The day before, the first case of the Omicron variant of Covid-19 had been announced by South Africa as hospitals braced for the impact of Christmas socialising and winter pressures. General practitioners had been delivering the Covid-19 mass vaccination programme on top of normal work-loads, under intense pressure from the tabloid media and the Secretary of State for Health over the provision of face-to-face appointments. Public health workers from the Primary Care and Interventions Unit at UKHSA were careful to emphasise their appreciation of healthcare workers and that they were there to support, not castigate GPs. Within this context, forthcoming work from the TARGET team was cited as evidence contradicting orthodox thought about patient pressure for antibiotics: ‘although it is thought that perceived patient demand drives antibiotic prescribing, a 2021 survey of the general public found that the majority of the respondents trust their health care provider’s advice, and found an increase in those wanting information on whether or not they actually needed antibiotics’ (TARGET, 2021). This work is forthcoming and I am therefore unable to provide an analysis of its contents, but it is worth analysis of the way it shaped the webinar, a contact between public health workers and prescribers. The evidence explicitly addresses ‘perceived patient demand’ not ‘patient demand’. As set out already, there is more evidence that perceived patient demand affects prescribing than that patient demand does.

Significantly, and regardless of what the final work may conclude, the unpublished work was used in this webinar to shift the focus away from patients’ anticipatory desires and clinicians’ perceptions of them towards the encounter between patient and clinician, with GPs being equipped with various tools focused on the quality of the encounter, ensuring patients feel listened to, reassured and are adequately safety-netted. Throughout the webinar, imaginings of the patient role in driving AMR were raised in repeated reference to the difficulties of patient pressure to prescribe by both expert panel members and attendees, although this was

at times challenged by public health workers chairing the discussion. Overall, this webinar was instructive of a move closer to the clinical interaction and further from attempting to change behaviour of members of different groups (patients, clinicians), as well as of resistance to this by GPs who insisted on emphasising patient pressure to prescribe. Indeed, as discussed, several of the articles cited on patient expectation make findings about the importance of the interaction between patient and doctor.

Dealing with Difference: 'Gaps in the Evidence'

Because antibiotics are only formally available on prescription in the UK, and AMR is understood to be a scientific phenomenon requiring scientific knowledge and understanding, attempting to engage people who might use antibiotics on AMR and getting them to reduce their use through target behaviours prefigures them as 'lay' people, not doctors and maybe even not scientists. As Will puts it: 'ordinary people' (2020, p. 1). It is a rather obvious sociological point that there is no such thing as 'the public' but many different publics. Furthermore, ideas of who makes up 'ordinary people' are inflected by race, gender, class (Bhambra, 2017; Mondon and Winter, 2019). The following section will critically review sociological approaches to dealing with difference within the public. The fragmented nature of 'the public' is a key concern of the overall thesis.

In this section on public health approaches to engaging patients on AMR, I argue that difference normally appears as a 'gap in the evidence.' As well as paying attention to what types of evidence are used by public health workers to rationalise what the public role should look like on AMR, it is also worth paying attention to what are identified as gaps or shortcomings in the evidence, and what the assertion of a 'gap in the evidence' achieves. Will, looking at AMS campaigns which attempted to employ discourses of difference between groups, notes that 'experts may be increasingly ready to work with [...] different possible publics' (Will, 2020, p. 26). Importantly though, this readiness comes as experts identify problems for themselves in dealing with such difference within the public. Problems include defining targets of policy, predicting effects of interventions on different groups and predicting how different groups might behave.

For instance, NG63 (NICE, 2017, p.40) identifies a lack of studies looking at people ‘in diverse social, cultural and economic circumstances’, suggesting that inequality is seen as important to intervening in the public role on mobilising against AMR, but is not written into evidence and is therefore poorly understood within the terms of evidence-based interventions. Similarly, it is noted that most interventions aimed at the public have not been designed for people ‘at high risk of acquiring or transmitting infectious disease or antimicrobial resistant strains’ (2017, p.43), defining high risk as those who have ‘a chronic disease, are immunosuppressed, live in crowded conditions, are homeless, have been in prison and have migrated from countries with a high prevalence of infectious diseases’ (2017, p.43). Importantly for this project on UTI, it is noted that this lack of research on higher risk groups is especially true of conditions other than RTI (2017, p.43). Will points out that much behavioural science in this area has focused on the case of respiratory illness as an area where they may be ‘unnecessary’ antibiotic prescribing for viral infections or self-limiting bacterial illness (Will, 2018, p. e4), an observation also made in the NG63 evidence review (NICE, 2017, p.40). It is possible that some of the key issues may differ for different infections, such as UTI, where it is generally acknowledged that antibiotics are indicated in a higher proportion of cases than RTI (Pouwels *et al.*, 2018; Smith *et al.*, 2018). In the TARGET webinar previously discussed, it is also noteworthy that public health workers were keen to emphasise that advice for shared decision making when a patient presents saying ‘I think I need an antibiotic’, did not apply to complicated patients, referring instead to ‘high volume consultations’ (TARGET, 2021). However, we might expect that messaging around AMR, especially concerning patient demand for antibiotics, may have very different effects, meanings and consequences for groups at higher personal risk of AMR. Work on this question is lacking.

The negative assertion of a ‘gap in the evidence’ is productive in establishing the undeniably fragmented nature of the public, whilst declaring that working presumptions might be faulty. Therefore, I tentatively suggest that the ‘gap in the evidence’ on difference is part of enacting the aforementioned ‘low hanging fruit’ approach, which identifies a large central reservoir of easy cases to tackle, leaving trickier cases out of scope. Notably, this assumes that the trickier cases have no effect on the centre, and also may neglect the trickier cases in favour of attention

to 'high volume' interventions. When the marginalisation of trickier cases here corresponds with existing social marginalisation, it calls into question the justice of such an approach.

What to Do About Demand for Antibiotics: Behavioural Science from Education to Non-Reflective Engagements

Identification of knowledge deficits and their correction through education strongly and coherently emerges in both the literature review and more generally in AMR policy as a useful tool to reduce demand for antibiotics. The twenty-year vision is supported by the UK five-year action plan for AMR 2019-2024 (DHSC, 2019b) and here, as in the literature review, the main reason to engage with the public is informational. For instance, the Plan describes how:

Increasing public awareness of AMR to reduce expectations of being prescribed antibiotics is a big component of many stewardship programmes, including those in the UK. We run various public health campaigns to promote behaviour change, and support diverse educational resources, such as those published through TARGET, Health Education England, and the Antibiotic Guardian campaign (DHSC, 2019b, p.55).

Knowledge deficits cited as leading to demand for antibiotics include ignorance of the existence of, or mechanisms of AMR, ignorance of the harmful effects of antibiotics, of natural course of infection, or of low proportions of patients treated with antibiotics that had microbiologically confirmed infection.

However, there is evidence of a widespread pessimism about the effectiveness of existing attempts to engage the general public on AMR. The NG63 committee, who developed the NICE guideline aimed at changing risk-related behaviours in the general population, concluded that there was 'little good quality evidence about the effectiveness of interventions to change risk related behaviours in the general population' (NICE, 2017, p.24). This was because most studies measured knowledge rather than behaviour, (NICE, 2017, p.24) and even where interventions had been effective at reducing prescribing, most were multi targeted at both patients and HCPs, meaning that determining which components had been effective was impossible (NICE, 2017, p.27). There are cursory references to what interventions to reduce patient demand might look like, outside of deficit-model education interventions. The NICE/ UKHSA committee for NG63 noted that 'changes in knowledge do not necessarily lead to changes in behaviour' (NICE, 2017, p.24) and that people needed 'motivation to change and the tools to help them to start behaving differently' (NICE, 2017, p.34). This was especially

pertinent as the committee noted that in some studies the baseline levels of knowledge were very high, leaving little room for improvement (NICE, 2017, p.25).

Expert papers put together for the development of this evidence-based guideline provide an insight into how policymakers evaluate the effectiveness of various public-facing interventions to reduce antibiotic use. Asked about the effectiveness of campaigns to ‘change the public’s behaviour to ensure they only ask for antimicrobials when appropriate and use them correctly, Dr Diane Ashiru-Oredope, UKHSA pharmacist lead for AMR and AMS, reported increased awareness but no evidence of increased knowledge or behaviour change from England’s patient engagement activities (Ashiru-Oredope, 2017, p.4).

Thus, Ashiru-Oredope narrates a change in UKHSA approach from raising awareness to ‘supporting people to take concrete personal and collective action to use antibiotics prudently’ (2017, p.2) around the introduction of the Antibiotic Guardian campaign in 2014. This was a pledge-based behaviour change campaign, developed with health psychologists. ‘If-then’ statements were developed, designed to overcome the ‘intention-behaviour gap’, a strategy through which behaviour change could happen in the absence of knowledge. Ashiru-Oredope concludes that ‘for the first time, using behaviour change strategies, the Antibiotic Guardian campaign has shown evidence of moving from increasing awareness to engagement’ (2017, p.3) and that evaluation showed it be an ‘effective tool for increasing knowledge and changing behaviour’ (2017, p.4). 70.5% participants reported a sense of personal responsibility towards tackling AMR post-campaign, compared to 58.3% pre-campaign. However, more than two thirds of those signed up were health professionals (Bhattacharya *et al.*, 2017), suggesting a limit in its reach to the general public.

An evaluation of the impact of World Antibiotic Awareness Week on public interest also cited limits in reaching a wide audience. Data collected between 2015-2020, using Google trends data as a proxy for public interest, concluded that WAAW ‘may not have effectively improved public awareness of AMR worldwide’ (Keitoku *et al.*, 2021, p. 16). However, here the informational approach was unchallenged, with authors noting that ‘enhancing public awareness is one of the most critical measures to fight against AMR and promote antimicrobial stewardship’ (Keitoku *et al.*, 2021, p. 16). Elsewhere, the results of the evaluation were met with dismay but no surprise. Laura Piddock, scientific director of the Global

Antibiotic Research and Development Partnership (GARDP), set up by WHO, posted the report on social media: ‘spoiler: little impact on public [...] WAAW needs a fresh approach & ‘joined up thinking’ instead of an avalanche of materials on antibiotics to ‘the converted’ (Piddock, 2021).

Looking at major public-facing antimicrobial stewardship campaigns based in the UK and their evaluations in the last twenty years (2020), Will finds a broader trend in what Ashiru-Oredope described in UKHSA’S approach; a move away from informational approaches towards approaches appealing to non-reflective thinking. Will introduces the term ‘shrug’ to describe this, a move to let people think what they will (2020, p. 23) preceding the more familiar ‘nudge’ which describes any intervention which seeks to change behaviour without forbidding options. Where ignorance was at first a problem to be corrected through education, Will sets out how it becomes productive in different ways as public health confronts ‘a public that appears relatively non-responsive and reluctant to change’ (2020, p. 21). Evaluations of public-facing AMS campaigns had shown that many people continued to report ignorance of key facts about infection and antibiotics and even more worryingly, increased knowledge sometimes led to even more unsanctioned antibiotic use (McNulty *et al.*, 2007b; McNulty *et al.*, 2010). Different approaches predicated on emotion and harnessing automatic thinking, such as creating social norms, inviting people to align themselves with a superior group who understood about AMR, or encouraging beliefs that were helpful but inaccurate, looked increasingly attractive as public health workers identified themselves as ‘increasingly unable to affect or predict what people know and think’ (Will, 2020, p. 23). This comes through strongly in recent work from UKHSA which aimed to ‘identify the form of words most likely to discourage people from asking for antibiotics for influenza-like illness, particularly among those with low AMR awareness’ (Roope *et al.*, 2020a, p. 2). This came on the back of a discussion of widespread ambiguity in evidence about effectiveness of public campaigns, and the worry that fear-based messages may not only be ineffective but actually backfire (Roope *et al.*, 2020a, p. 2). There is a consistent focus on patient expectation or demand of antibiotics as a driver of over-prescribing, even as how to intervene in this remains elusive.

In the light of explicit discussion of the risk that knowledge leads to undesirable action, increased awareness is no longer trusted as a route to behaviour change. Therefore, the status

of current attempts to engage with the public on AMR is rather disheartening, reflecting not only a marked loss of confidence in the reflective capacity of the public on the part of public health workers, but also a loss of self-confidence in their own capacity and ability to relate to the public. Reasons to engage with the public on a reflective level have not gone beyond surveying people for themes and knowledge deficits to be addressed by experts.

The aim of having the public practise good hygiene as a way to reduce antibiotic use is a particularly good example of disinterest in reflective engagements outside of informational approaches. Education about personal hygiene appears as absolutely central to preventing recurrence of urinary infection in evidence-based management guidelines, and SIGN, NICE and UKHSA all recommend that all women consulting for UTI are given advice about personal hygiene and hydration (NICE, 2018; 2018b; UKHSA,2002b; SIGN, 2020). NICE even goes so far as to recommend that women with recurrent UTI are offered preventative treatment only if personal hygiene measures have failed to prevent further recurrence, suggesting considerable confidence in effectiveness. In the evidence review for the guideline on recurrent UTI, the committee states that the self-care advice is based on the recommendation from the NICE AMS guideline on changing risk-related behaviours in the general population that people should be given verbal advice and written information about how to manage their infection themselves at home if it is safe to do so (NICE, 2018e, p.8). Asked in the consultation process by the Royal College of Pathologists if there is any evidence that this is an effective intervention (NICE, 2018d, p.27), the response is that ‘the committee made this recommendation by consensus based on their clinical experience, as this may help to reduce the risk of UTI’ (NICE, 2018d, 27). Such experiential evidence is usually considered by NICE to be weak. And yet, the strong emphasis on hygiene is justified with reference to an AMS rationale.

Engaging people consulting for RUTI on hygiene therefore appears to be understood as low-risk, potentially useful, and specifically targeted at reducing antibiotic use. However, this does not seem to translate to a reason to engage with the general public. There have been many campaigns around hand washing, food safety, and using condoms as infection prevention hygiene measures. However, in the case of UTI, I have been unable to identify any public-facing interventions that target hygiene practices as prevention for UTI in the general

public, prior to infection. This seems especially striking given the emphasis on hygiene around sex, suggesting that such hygiene practices could form part of mandatory sex education programmes, including those developed by UKHSA on STIs and AMR. In the literature review, several of the authors picked out the lack of attention paid to hygiene practices in consultations with GPs, although there was some disagreement about where these practices were thought to lie, with patients (Pill, 1987; Rink, 1998) or doctors (Ghouri *et al*, 2019). Therefore, the dissemination and sharing of hygiene practices to prevent these common infections does not seem to emerge as a particularly important reason to engage with the public, despite the continued importance this is seen to have in clinical settings of UTI.

It is highly significant that work on engaging with the public on AMR so far has not included engaging with people who are creating an issue around AMR for themselves and has certainly not managed to engage with what the un-intended effects of a 'low hanging fruit' approach. Instead, public engagement interventions appear to be aimed at people who might very well use antibiotics (and also have done so in the past given the emphasis on re-consultation) but also appear to have very little reflective thought about this experience, and to be likely not in clinical need of antibiotics: the low hanging fruit approach. The issue of which groups exactly are and aren't targets of interventions aimed at the general public is an important one and also raises the issue of who identifies themselves or others as targets, especially when this includes people who use a lot of antibiotics and people already subject to marginalisation.

Behaviour as a Concept

Even as theories of behaviour change have evolved, as I have outlined above, the central concept of behaviour has been little re-examined. Cohn argues that what has remained consistent in behaviour change theory over time is 'the linear order that conceives of various psychological determinants, potentially modified by social norms and triggered by environmental cues, which then determines someone's behaviour' (2014, p.159).

Importantly, a distinction is to be made between behavioural science expertise and the ways it is employed in policy. This was evident as behavioural scientists officially advising the government on Covid-19 measures publicly disavowed the way in which behavioural science was thought about and used by the government (Reicher, 2021). On AMR, when Tim

Chadborn, lead researcher on behavioural insights at UKHSA, was asked to give expert testimony on the development of NICE guideline NG63 on changing risk-related behaviours in the general population, he criticised the focus on education: ‘it is clear that opportunity and motivation are just as important as knowledge and skills (psychological capability) for enabling behaviour change. The focus on education does seem to reflect a commonly-held fallacy that informing people will result in a change in their behaviour (not acknowledging the large ‘intention-action gap’) (Chadborn, 2017, p.2). Here, the type of behavioural science used matters, and Chadborn criticises with some exasperation the use of what can be identified as an earlier, more classic form of behaviourism, according to what we might call ‘journal behavioural science’.

Taking care then to critique ‘journal behavioural science’, Chadborn’s extension of attention to ‘opportunity and motivation’ demonstrates Cohn’s critique of behaviour as a concept, that research is only conducted on pre-defined kinds of behaviours and their drivers, while other health-related activities or variations of what people do in different situations that escape the parameters of measurement are excluded’ (2014, p. 159). This is nicely illustrated by two qualitative studies on UTI conducted in order to inform development of a quick diagnostic reference tool and a shared decision-making resource, (Cooper *et al.*, 2020; Lecky *et al.*, 2020) respectively. The studies included researchers from the UKHSA Primary Care and Interventions Unit and the UKHSA Behavioural Insights Team and both used the Theoretical Domains Framework (TDF), which is a model developed by behavioural scientists and implementation researchers in order to facilitate ‘understanding of the determinants of current and desired behaviours’ (Atkins *et al.*, 2017). In these studies, rich and interesting data generated through qualitative interviewing of GPs about UTI is transformed into the pre-defined domains of the TDF. Aspects which fall outside of the pre-defined domains appear to simply fall away.

Behaviour as a concept, ultimately converging as it always does on the outcome (the behaviour of an individual or a group) is necessarily highly individualising. Relationality is accounted for through concepts such as ‘social norms’ while concepts such as ‘opportunity’ and ‘ability’ are operationalised to try to account for the ways in which individuals are differentially positioned within society. Relationality therefore affects what people do but the

focus always comes back to the pre-defined outcome- what they do, not why. In epidemiological populations, a group of people is a group of individuals. They might have relations which are important (they might even have sex with each other!) but these relations are only important as an input to the model which predicts the outcome; behaviour. Importantly, the focus on behaviour as an outcome also has the effect of converging responsibility for the behaviour upon the individual. And because most behaviour worth changing is behaviour identified as undesirable, responsibility can look like blame. Cohn expresses a concern that repeated studies attempting to better and better understand behaviours and their drivers naturalise such categories and take us further and further from re-considering key concepts (Cohn, 2014, p.160).

This way of accounting for inequality precipitates consideration of what is ideologically at stake in behaviour as a concept. When it comes to health behaviours, looking at how individuals make decisions about their own health, narrow definitions of what affects health is attractive to policymakers. For, it is not flippancy to say that health policy makers are necessarily tasked with tinkering around the edges of inequality. Asked to mobilise on AMR, policymakers can reasonably identify changing the behaviour of members of the public so they do not demand antibiotics from HCPs as a stewardship, but it is much further outside the current political settlement to cast even a very easily achievable measure such as improving the provision of statutory sick pay so that people may stay home and rest with a self-limiting infection, avoiding antibiotics, as a stewardship. Therefore, approaching the public through the concept of behaviour might afford a means of intervention even while it may be evident that the most effective antimicrobial stewardship interventions would be infrastructural. Importantly, this runs counter to many foundational principles of public health, which casts a very broad range of activities as health promoting activities.

As well as being individualising, the outcome focused nature of behaviour as a concept is problematic because it risks losing sight of what success looks like. In the (arguably rare) cases where it is identified that behaviour has successfully changed, this is evaluated as a success. But because the models are geared only towards changing the one targeted behaviour, they do not account for what else might have changed as a result of interventions: unintended consequences. One of the most obvious ways to mobilise on AMR would be to simply ban

antibiotics. That is not desirable because our goal is not just to use fewer antibiotics, but to promote health, with using fewer antibiotics being identified as a key way to do that. Banning antibiotics would result in the very post-antibiotic future which AMS attempts to avoid. A successful behavioural output does not straightforwardly lead to the overall goal of promoting health (which is often seen as the main reason to mobilise on AMR), but is theoretically connected to it via a causal chain. Successful behavioural science interventions therefore rely on the accurate identification of behavioural changes which would ultimately promote health and would not have counter-productive unintended consequences. Importantly, these behavioural changes are connected to health promotion via a rather long chain of logical steps. As outlined previously, four public behaviours are identified: undertaking self-care before or instead of seeing the GP, not requesting antibiotics when seeing the GP, and acting upon GP advice where antibiotics are not prescribed or delayed antibiotics are prescribed (UKHSA, 2015, p.47). These behavioural changes are intended to reduce prescribing in primary care, seeing this as a way of conserving antibiotics, which would lead to better health. The possibilities for interventions and their sequelae to have unintended consequences for health is not a possibility that can be accounted for by models which are focused on whether targeted behaviours have changed or not.

This section on public health has addressed what national state-level efforts to engage with the public on AMR have looked like so far, how they imagine the public, how interventions are rationalised and how they are evaluated. Reviewing the types of evidence used, I concluded that the idea that patient expectation of antibiotic drives over-prescribing is persistent but should not be taken as self-evidently true, opening the door to other ways of imagining publics. Careful work done on this issue mainly by clinically trained primary care researchers and medical sociologists working in medical schools has taken issue with separating off the behaviour of patients and doctors, and pointed towards the importance of communication and what emerges in the relationship between GPs and patients, even as this same work has been used to rationalise interventions aimed at patient demand. However, further qualitative work remains to study the dynamics of this interaction and to ascertain what makes a good consultation for patients, doctors, and AMS. Meanwhile, the turn away from engagement with patients towards employing the tools of behavioural scientists to harness non-cognitive thought processes demonstrates a shying away from what is a difficult

and daunting task. In the next section, I will flesh out the reasons why this is a task worth undertaking. I will outline my own reasons for engaging with patients, drawing on sociological theory and STS approaches to public involvement in science.

Sociological and STS Theory:

STS and Sociological Insights into Participation

As I have argued that the rationales behind public health efforts to engage the public on AMR appear theoretically under-developed, so several authors writing in sociology and STS note more generally the ubiquity of invocations of patient and public participation while ‘the concept itself remains vague’ (Rowland *et al.*, 2017, p88). Nielsen and Langstrup note in the term ‘patient participation a ‘conceptual vagueness, at times rendering it an all-too flexible political trope or platitude and, in practice, resulting in unclear invitations to patients’ (2018, p.259). Samuel and Farsides also note confusion about what is meant by public engagement (2018).

A major critique of attempts at public or patient engagement is the way that apparently participatory events, which go beyond informational, one-way approaches, often end up embodying or reinventing ‘notions of the deficit model within their public interaction activities’ (Samuel and Farsides, 2018, p.354; Wynne, 2007). This is often done when both the public and the issue are taken as highly ‘specific, pre-given and external categories imported into the design and evaluation of participatory practices’ (Chilvers and Kearnes, 2020, p.349). Wynne’s notion of invited and uninvited participation (2007) posits that participation when it is invited often makes this step, which then leads to forms of uninvited participation. Thus, there has been a move to imagine participation not just in discrete ‘participation events’ but by paying attention to how it might already happen in more ‘material, embodied, private, digital, uninvited, everyday, mundane’ ways (Chilvers and Kearnes, 2020, p.3255). In public engagement on AMR, Will points out limited interest in bringing together expert and lay perspectives in deliberative events and little discussion of people who ‘demonstrate knowledge and take independent decisions to use antibiotics, who are figured as problematic antibiotic consumers rather than responsive and reflective citizens with whom to engage’ (Will, 2020, p. 25). Therefore, in the thesis I will pay attention to what forms of engagement

are invited on AMR, as well as what forms of uninvited engagement might already be happening.

From Behaviour to Practice

In this section, I explore how sociological and STS approaches can offer an account of the problem of AMR, the study of antibiotics, and patient experience of infection together. While medical sociology has long been interested in people's experiences of illness, it has largely been AMR that has precipitated sociological interest in such illness experiences alongside antibiotics.

Brown and Nettleton examine 'immunitary moralism' as it appears in *Mumsnet* threads (2017a). A major thrust of their argument is the potential for policies focused on individual behaviour to have unintended, stigmatising consequences. However, this work casts differing accounts as reflecting tensions between antibiotic 'consumption and abstinence' (2017a, p. 305). This way of approaching people's accounts of antibiotic use as 'beliefs' assumes that need for antibiotics (clinical or otherwise) is equally distributed, with differential perspectives on a universal experience. Abstinence is quite clearly limited as a framework for the question of reducing antibiotic use and the work overall struggles to account for why people (sometimes but not always in collaboration with health care practitioners) use antibiotics aside from differing beliefs or choices. Brown and Nettleton's approach echoes the epistemic approach I identified in much of the subject literature review. This reflects earlier sociological interest in patient experience of illness in the 1970s, using the concept of explanatory models to describe cultural ideas or social meanings of illness. Social scientists in the form of anthropologists and sociologists then brought such cultural knowledge to biomedicine, with the aim of working towards a greater congruence between biomedicine and patients, normally through further knowledge exchange: medical education of patients or education of health care practitioners on patient perspectives. This was a traditional, well-defined and secure role for a medical sociologist, acting as informants on the patient perspective to facilitate healthcare governance of populations.

In this role, taking on the power imbalance between patients and doctors which was crucial to working with patient knowledge deficits, doctors and patients are positioned as equals who

both have interpretations or perspectives on disease. Doctors have the scientific facts of disease and patients have their own social context. This is what Mol calls perspectivalism (2002, p. 12). These perspectives are equally valid and unlike knowledge deficit approaches which stigmatised patient knowledge (because it was only interested in it when it was wrong), perspectivalism elevates patient knowledge in such a way that it is hardly recognisable as knowledge anymore; it is authentic experience. This approach has been institutionalised in practices such as patient and public involvement. But perspectivalism delivers us to a place where nobody has a claim on the reality of diseases. Doctors have their own biomedical interpretations or perspectives on disease. Meanwhile, patients are asked by sociologists in interviews how they feel about their disease, what is their experience (Mol, 2002, p.12). Maintaining a nature/culture division but smoothing out the difference between lay/professional perspectives, the perspective of doctors is, under perspectivalism, perhaps even more contestable than those of patients, who have not knowledge, but personal experience (Pols, 2013, p.77). This epistemological focus leaves the ontology of disease itself difficult to grasp at (Mol, 2002).

There is a recognition in the AMR literature that resistance disproportionately impacts the most 'vulnerable'. Efforts to mobilise on these inequalities entails establishing their mechanisms. Here, strictly social explanations about 'lifestyle' or 'culture' are often conceived of separately from biomedicine, in the same vein of nature/culture divisions visible in perspectivalism. In UTI in the UK, analysis of routine surveillance data for antibiotic susceptibility of *E.coli* urinary isolates from the community in Leeds and Bradford in 2010-2012 against indices of social deprivation led the authors to conclude that social deprivation is associated with increased antibiotic resistance for *E.coli* (Nomamiukor *et al.*, 2015). There is also evidence from North West London that analysed the association between age, gender and ethnicity and ESBL Enterobacteriaceae (ESBLE) bacteriuria in urinary isolates from community samples between 2007-2009. They reported that the risk of ESBLE bacteriuria was higher in males, in patients older than 60, and in patients from an Asian background than white patients, with Indian patients having the highest odds (Gopal Rao *et al.*, 2015).

A major effort to account for difference within the public on health has been the social determinants of health (SDH) movement, which has become institutionalised in public health.

The social determinants framework is interested in structural social drivers of health outcomes and in this may appear to share much with medical sociology and anthropology. Yates-Doerr advances several critiques of the modelling practices of the social determinants of health framework that correlate with the critiques I have made of the modelling practices of behavioural science. This is unsurprising, as both are interested in how ‘the social’ drives a pre-defined outcome. SDH is interested in the social as a factor to measure, rather than sociality as a fundamental aspect of life based on relations; health problems have social *elements*, rather than being always-already social (Yates-Doerr, 2020, p.4). As I noted that behavioural models only allow certain structural problems to become visible as a driver of poor health, or antibiotic use, by pre-defining drivers, so Yates-Doerr demonstrates how this is true for SDH- structures such as colonialism or racism are often cast as determinants of health too far removed from health to affect it. And just as I expressed a concern that unintended consequences of the model itself would go un-captured by behavioural modelling, so Yates-Doerr argues that what is taken to be health, and how it is measured, affects health (2020, p.11).

One example of this is the way the social determinants of health tracks certain categories, without accounting for how these categories came to be and are maintained. This is very clear in the way Gopal Rao *et al.* attend to race. ‘Asians’, including ‘Indians’, ‘Pakistanis’ or ‘Asians of any other background’ were more likely to experience ESBLE bacteriuria than White Britons. Note that it is impossible to be British Indian, despite that citizenship has important implications for access to healthcare. These categories are attempts to grapple with the ongoing organisation of power around race, but also participate in that organisation. As Ryan Hatch states: ‘when scientists measure a variable defined as “race” in a body or population, what they are doing analytically is remembering and documenting intergenerational patterns of violence enacted on the bodies of racism’s victims, not studying “race”’ (2022, p. 3).

Black and Indigenous scholars have raised concern about the consequences of this, especially when work is not self-reflective. Ryan Hatch builds on Benjamin’s (2016) work to caution that health disparities function within ‘racial spectacles’ of gathering such knowledge, which ‘sanctions the spectacle itself as antiracist, even if policy makers take the opposite action indicated by the data’ (Ryan Hatch, 2022, p. 2). This is a critique relevant not only to the kind

of work Rao et al. advances, but also to this project. The arguments of Black scholars such as Ryan Hatch and Benjamin reveal the naivety in assuming a theory of change that works through simply exposing inequality (Ryan Hatch, 2022, p. 9). Similar arguments have been made by Eve Tuck (2009). Hatch concludes that the challenge is to have a good account of how such efforts to create a spectacle of health inequalities allow structural inattention to the same inequalities (Ryan Hatch, 2022, p. 10). Gopal Rao *et al.* argue that their demographic data could be used to develop targeting tools based on age, gender and race, to 'identify groups of patients at risk of UTI with ESBLE and [...] aid in choice of empirical antibiotics' (Gopal Rao *et al.*, 2015). Identifying 'at risk' groups from such categorisation practices, and then using this to treat individual patients is a common practice and often helps to assign limited care resources to where they are most needed, but it also risks reinforcing the category, further marginalising and impoverishing the care of that group because it promotes race over racism.

A series of crisis moments have precipitated a re-examination of both the easy split between nature and culture, the corresponding division of labour between natural and social scientists, and the ceding of natural and clinical science as a domain to scientists and clinicians. Examples include new biotechnologies, anti-vaccine movements, a growing trans-exclusionary feminist movement and movements that employ the language of social constructionism to deny climate change. The flattening out of differences between lay and professional expertise and the elevation of situated knowledge to authentic and uncontested 'experience' began to look more worrisome.

Science and Technology Studies as a field has been massively influenced by Latour's response to these crises. Latour's *We Have Never Been Modern* (1993) opened up and expanded the social by arguing that the modernist distinctions between nature and culture never existed¹. Instead, human and non-humans enact together a phenomenon. In this case, humans like doctors, bosses, partners, and non-humans such as microbes, treatment algorithms, telephone cables which allow us to call the clinic, antibiotics etc. participate in enacting together an experience of urinary tract infection. As Law points out, the 'social' disappears as a basic analytical category in STS because the real is enacted relationally in practices; elements in a system

¹ It is noteworthy that Indigenous scholars particularly have pointed out that they never collaborated in such distinctions (Todd, 2016).

achieve their form and character only in relation to each other. Therefore, there is no external 'social' to shape the system although there may be 'a temporarily stabilised effect of [those] webs in which particular parts of that web are generated and treated as 'social' (Law, 2008, p. 634). Therefore, my theoretical approach moves from behaviour to practice, departing from studying culture, meanings and the social in isolation, and looking to how reality is done and co-produced in practice. In this thesis, I mainly use Mol's terms of 'enactment' to describe the coming into being of networks and assemblages through relationality (Mol, 2002).

A Feminist-Materialist Ethic

A major criticism of Latour from feminist science studies has been that the specific understanding of non-human agency presented marginalises ethical and political concerns (Giraud, 2019). Latour is not unconcerned with politics and, as outlined above, major political crises partly precipitated *We Have Never Been Modern*. But the particular political orientation that emerges from Latour's decentring of the human is most famously encapsulated in his casting of a gun shooting at a human as a 'electrical conductor, good and evil flowing through it effortlessly' (Latour 1993, p.31). The non-human gun becomes a neutral conductor, with the hybridity between the human and the gun becoming its own object. Ontology is separated from politics. In *Living a Feminist Life*, Sara Ahmed criticizes this political orientation for the way in which it claims that events such as one person shooting another can ever be meaningfully understood 'at the ontological level, [as] simply an event that takes place', divorced from social and political relations patterned by inequality and oppression (2017, p.156).

Other work, such as Alaimo's *Exposed* (2016) has explicitly embraced, extended and, crucially, politicized Latour's metaphysical conceptualisation of the object world. The foray of social science into social constructionism that I have described, an alternative to biological realism, has, as Alaimo puts it, 'performed invaluable cultural work' in liberating some oppressed peoples from biologically-rooted arguments of inferiority (2010, p.8). Wilson states that 'the rejection of biology has made us who we are, it is spliced into the DNA of feminist theory (2015, p.30). Some women resisting appeals to the inferiority of biology of female sex have been able to leverage social constructionism as a defence. Often these hard-won gains seem fragile and social constructionism worth defending. But it has been undeniably been less

successful as a form of resistance for other groups. Race and class as a technology of power (Hall, 2017; Lentin, 2020) have proved able to sustain themselves despite social constructionism, as well as able to ground themselves in culture as well as nature.

Thus, Tuana approaches the splitting of nature/culture and retreat into social constructionism as a matter of epistemic irresponsibility. She argues that in our over-reliance on the vocabulary of social construction, we as feminists have left intact a fixed and essential biology (1997). A striking instance of the problems with manoeuvring the terms of debate entirely into the realms of the social, is the reliance of trans-exclusionary feminists on the argument that trans women are not women because sex is immutable biology while gender is a socially constructed hierarchy which feminists should have no business with. Therefore, for materialist feminist and anti-racist scholars, social constructionism's limited success as a form of resistance to power has precipitated a move parallel to Latour's, away from the nature/culture binary, but accompanied by an insistence on political dimensions. A materialist feminist ethics compares the 'very material consequences of ethical positions and draws conclusions from these comparisons' (Alaimo, 2010, p. 7).

In Karan Barad's conceptual work, the concept of 'intra-action' shifts from two opposing poles (nature/culture), to the *relata*, the relation itself. The emphasis on the relation does not leave the binary intact, but posits that 'distinct agencies do not precede, but rather emerge through their intra-action' (2007, p.33). However, unlike Latour, the focus is less on the ontological status of the world and more on exploring and grounding entanglements between humans and nonhumans. This is because, as Tuana points out, it may be desirable to continue to draw on separations between the natural and the social if we are to apportion responsibility and accountability for instances wherein human action or inaction has exacerbated 'natural' phenomenon (2008, p.193). The stakes of this are that some groups bear more responsibility for such actions, while others experience the consequences more keenly, with climate change being the obvious example. Alaimo's concept of 'trans-corporeality' therefore acknowledges that the human is always intermeshed with the more-than-human world, (2010, p.2) and recognises the disproportionate toxic loads carried by racialized, gendered and working-class bodies as 'a particularly vivid example of trans-corporeal space' (2010, p. 22). Roberts rejects a romanticisation of entanglement on the basis that it misses that 'certain groups of people are

and always have been entangled in shit' (2017, p. 596). Tuana therefore invites us to think in terms of the porosity of nature and culture, rather than fluidity. This is intended to emphasise that distinctions can be made between the two, but that such distinctions are not of a natural kind (Tuana, 2008, p.193).

This post-humanist STS literature which accounts for power is useful for bringing the social and the natural together in the study of microbes, infection, inequality, and AMR. As a way to approach difference within publics, it asks not epistemological questions about what we (or indeed 'they') know about an AMR that exists 'out there' in the world, and how we know it, but ontological questions about how AMR is co-produced. Because of this, Landecker describes how the history of biology is always already the biology of history (2016). Such STS approaches conserve doubt about seemingly self-evidential scientific facts to bring insight into why, how, and what is at stake as AMR is enacted as a problem.

Multispecies ethnographies explore 'contact zones where lines separating nature from culture have broken down' (Kirksey and Helmreich, 2010, p. 546). Paxson's 'Pasteurian microbiopolitics' (2008) and Lorimer's 'antibiotic approach to life' (2020) aim to historicise the ways humans have lived with microbes. Both concepts describe nineteenth and twentieth century efforts to secure 'progress' through the control and eradication of unruly microbial ecologies. Paxson makes implicit reference to Foucault's bio-politics, hinting at how the administration of healthy (or unhealthy) populations through public health measures intrinsically involved the control of microbes. Both Paxson's and Lorimer's schematics risk over-dichotomising the historical contingencies of human relations with microbes, positioning historical relations as concerned with pathogenicity only. Barad's concepts allow for an understanding of pathogenicity as an intra-action between host and microbe, rather than an innate quality. However, multispecies practices can indeed be positioned against a dominant framework of biosecurity, of protecting the body, (and the body politic) from the foreign microbe. This project has taken place during the Covid-19 pandemic where bio-securitisation of borders has been a key tool to control the spread of infection. Multispecies practices that have attracted scholarly attention include research animals, therapy animals, cheese-making, beer-making, water sanitation, and so on. Here, I am interested in how patients who live with hard-to-treat bacterial UTI find ways to do health, sometimes using

antibiotics and sometimes not. This entails paying attention to microbial scales, alongside macro scales of structural inequality. Analytical attention to the more-than-human is not about a fascination with non-humans, it is about reckoning with the way humans are always entangled with non-humans, including in joyful, pleasurable, violent and deathly relations. It is through these relations that the real is relationally enacted in practice. The feminist-materialist approach that I take here, then, can compare the material implications of different relations, and draw ethical conclusions about what is good from this.

Women's Health and Intersectionality

McKnight and van der Zaag argue that although healthcare used to be an integral concern of feminist work, the materialist turn has pulled feminist theory towards the sciences and away from engaging them as a 'field of operations for women's oppression' (2015, p. 125). Indeed, surveying the field, it seems that since the women's health movement, most work has been done in two of the arguably most developed fields of feminist medical sociology; sociology of reproduction and of HIV. UTI has largely been neglected even in feminist work. Another reason for this may be its location within the organisation of healthcare work. For example, in the recent UK government's report on women's health strategy, UTI was absent, appearing only as a secondary consequence of shortcomings in the main clusters of what was identified as women's healthcare; menstrual health and gynaecology, sexual health and contraception, fertility, pregnancy, menopause, gynaecological and other cancers, mental health, violence against women's and girls and mental health. Another reason why feminist work on healthcare may have progressed slowly outside of these fields is because doing work on women's health requires holding gender as a central category, a task which raises significant anxieties.

Holding Gender Together

This women's health movement in the UK was dominated by middle-class white women and often treated womanhood as a category of un-interrogated marginalisation (Thomlinson, 2016). Because of this, there are a set of questions around the usefulness of 'women's health' as a concept. Much discussion on women's health places an emphasis on the gendered dynamics of the patient/doctor encounter and how women are not believed about their symptoms (Fearn, 2021; Upmark *et al.*, 2007). This reflects second wave feminist conceptualisations of

both women and men as sex classes. Because second wave theorists saw women as a sex class as maximally oppressed, this conceptualisation ignores how other factors such as race or class come to matter. The idea that all men are inherently abusive can have dangerous consequences for men of colour, especially Black men, whilst ignoring the ways in which women can enact and maintain violence. Moreover, this conceptualisation of women as a sex class struggles to account for the ways in which people who are not women, including trans and non-binary people, are affected by the ways that patriarchy has shaped medical care.

Jennifer Nash's *Black Feminism Reimagined, After Intersectionality* (2019) recalls how intersectionality is often summoned to remedy these issues. Intersectionality is a product of Black feminist theorising about the specific location and situation of Black women in the US. The term itself is linked to legal scholar Kimberlé Crenshaw's two articles which set out how the law failed to account for the ways Black women could be harmed by both race or sex discrimination simultaneously, using the visual metaphor of a traffic intersection (Crenshaw, 1989; 1991). Crenshaw's work looked for redress for Black women in law but also addressed how antidiscrimination law itself could oppress Black women. Around the same time, Patricia Hill Collins published *Black Feminist Thought* (1990) which expounded the framework of a 'matrix of domination.' Having greater purchase in the social sciences, Hill Collins' work has generally been understood as being less focused on identity than intersectionality, and more focused on how structures of power in everyone's lives shift according to social location. A longer history of theorising the specific situation of Black women in the US tends to start with the words attributed to Sojourner Truth in 1851, 'Ain't I a Woman?' and Anna Julia Cooper's 1892 *A Voice from the South*, which is largely seen as the first full articulation of Black feminism.

Like Nash, Johnson notes how Black feminist theory, specifically intersectionality, is enlisted in mainstream feminism (Nash, 2019; Johnson, 2020). However, where for Johnson Black feminists have to arrive to 'remind' white feminists that their experiences cannot possibly represent those of all women, for Nash, white feminists themselves hail Black feminist theory 'as the remedy to (white) feminism's ills' (2019, p. 4). A narrative of the salvific arrival, in the 1990s, of intersectionality into the ills of 70s, 80s and 90s white feminism shores up this role for intersectionality (2019, p. 82). One significant difference is setting: both Johnson and Nash

speak primarily to feminism within the academy but Johnson speaks of the UK where Nash's argument is particular to the US. This is significant, a key question for Nash is what it means for intersectionality to have to come to occupy the centre of women's studies (Nash, 2019, p. 2), and the relationship between Black studies and women's studies, both of which do not exist in the same way in the UK. However, Nash's analysis of the figure of intersectionality as both 'peril and promise' (2019, p. 13), 'the medicine required to fix the ailments of the present, and the toxic dose that could fatally kill feminism' (Nash, 2019, p. 134) captures much of the anxiety intersectionality both inspires and quells about the coherence of women's studies, feminism and women's health as categories in the UK too.

Nash's central argument is that the treatment of intersectionality and Black women as 'salvific figures' where Black feminism's primary task is to 'discipline so-called white feminism and women's studies' has produced defensiveness as 'the hallmark of the felt life of US academic black feminism' (Nash, 2019, p. 136). The problem for Nash with this role for intersectionality is multiple. Primarily, her concern is what defensiveness does to Black feminism and Black feminists, conscripting them constantly into policing roles, policing intersectionality as a possession and therefore foreclosing 'radical dreaming which includes but also exceeds intersectionality' (Nash, 2019, p. 138). She also extends a concern with where this role for intersectionality locates structural racism; Black women are called to dismantle a racism that is located in 'the hearts and minds of white women' and can be 'dismantled through recognition' (2019, p. 86). Wanting instead to see a surrender of possessiveness, letting intersectionality move and transform in 'unexpected and perhaps challenging ways' (2019, p. 80), Nash shifts Black feminism from a description of bodies to a description of modes of intellectual production.

Transformations of intersectionality are not beyond critique in Nash's argument. Nash critiques 'colourblind intersectionality' which she sees in the work of Carbadó and Ehrenreich, lacking a political investment in the margins and seeing all of us as having intersectional identities, although some (such as white men) are intersectionally privileged. This is what Johnson refers to when she reports white women using intersectionality as a way to centre ourselves (Johnson, 2020). Moves such as these (which move beyond the specific location and

situation of Black women) is one of the factors which has led to criticisms of intersectionality as identitarian, disinterested in material circumstance or how identities are formed, instead dealing in stable and fixed identities. 'Colourblind intersectionality' breaks Crenshaw's analytic from the longer history of Black feminist theorising around concepts such as jeopardy, and Nash argues that it is moves such as this which leads to a 'intersectional originalism', a defensive response from Black feminists to attempt to define a 'true' intersectionality. Nash says that Black feminists often respond to anti-identitarian critiques of intersectionality by positing others as earlier than Crenshaw (Nash, 2019, p. 55), drawing a longer lineage of the true meaning of intersectionality. In the place of this originalism, which she argues is not accreditory but harmful to Black women, Nash asks instead for a reflection on 'why would an analytic centred on black women not be palatable or desirable as a field-defining analytic?' (Nash, 2019, p. 76). This insight is theoretically important to the thesis.

Theories of Change

Another reason I want to posit for the under-development of work on gender and health is also related to issues of race and coherence in the field of women's health. There is a body of scholarship in gender history which observes the use of accounts of misery in the British women's health movement (Waters, 2016; Strimpel, 2022). Looking specifically at the feminist periodical *Spare Rib*, which she describes as 'Britain's key forum encouraging the articulation of political selfhood rooted firmly in the taxonomies of bodily disorder and pain' (2022, p. 236), Strimpel analyses the way in which 'shared misery' was politicising, connecting individual experiences to a wider feminist movement. This movement was dominated and led by white women. However, by the late 1980s, Strimpel argues, personal accounts of ill-health and sexist handling by the medical establishment had been replaced by questions of race, internationalism and intersectional oppressions (2022, p. 234). Strimpel's argument goes that because these changes took place against a backdrop of new institutional arrangements in women's health [...] denuding organisations of their early focus on group sharing of experiences' (2022, p. 235), there was need for 'a 'reckoning with who had been included in and excluded from the sisterhood- including the sisterhood of misery- in the 1970s and early 1980s'(2022, p. 235).

This analysis seems to imply that because the institutional organisation of women's health changed just as Black women were more included in the women's health movement, there was little opportunity for women of colour to participate in the 'sisterhood of misery.' However, thinking with Phipps's specific conceptualisation of 'political whiteness', (Phipps, 2020), and with Hatch, Benjamin and Tuck on what Tuck calls 'damage centred' research (Tuck, 2009), I express a discomfort with the use of misery in mainstream feminist work on women's health. I suggest that the way the women's health movement has historically used, and continues to use, misery as a feminist strategy of politicisation is politically white². Phipps theorises the ways in which whiteness is predisposed to woundedness (2020, p. 68) and that this woundedness, because it stems from lost entitlement, reflects white supremacy (2020, p. 69).

For Phipps, woundedness produces victimisation, which, importantly, can be imagined or genuine (2020, p. 6). In the area of women's health, victimisation is genuine, women have bad experiences of healthcare because of the way patriarchy shapes and structures medicine. But politically white work on women's health produces victimisation in a specific way, by invoking a lost entitlement to good care; it says 'look how badly we are treated', it is shocked. This vocative strategy reflects an intimate relationship with the state; it speaks to the state and expects to be heard. This is the theory of change and it reflects an understanding that bad treatment is a glitch, a mistake that will be rectified once it is pointed out to an unnamed but presumably powerful decision maker; good care was the expectation. This is a white theory of change because, as Hatch sets out for the US but is true in different ways for the UK, it misunderstands that 'racism is a core building block of the infrastructure of state biomedicine' (Ryan Hatch, 2022, p. 1).

The specific arrangements of how healthcare is done in the UK reveals another reason why a

² Here, I face the same problems as Phipps in her analysis of 'mainstream feminism.' She writes that defining feminist as white and privileged risks (re) constituting it as such, and erasing the contributions of feminists of colour (2020, p. 5). Here, in arguing for a shift away from damage based health research, I imply that this work is not already been done elsewhere. However, I would argue that the mainstream of work on women's health remains politically white. This could also be because outside of political whiteness, women's health does not emerge as a singular issue (Lorde, 2012).

theory of change which works by exposing bad experiences of healthcare to an un-specified and presumably powerful decision-maker belies a miscalculation of the political arrangement. This thesis explores care mainly within primary healthcare settings. I worked on this thesis during the Covid-19 pandemic when general practitioners, working to deliver the vaccination programme alongside their normal duties, came under intense attack from the tabloid press and even the Secretary of State for Health. GPs know that patients are at risk because of poor care (Campbell, 2022) and are themselves vulnerable to power even as they enact it. Moreover, general practitioners are a feminised workforce, being one of the few specialities where women far outnumber men. These are important points for AMR, where strict divisions of labour between patients and HCPs sometimes over-emphasise lay/professional differences, given that we can all be or become patients. Therefore, a theory of change which relies upon the revelation and description of poor experiences of care, positing women against men and patients against HCPs, runs out of steam once GPs themselves recognise the unsafe conditions they practise within. Tuck, writing about research across 'disenfranchised communities' (2009, p. 409), but with a particular focus on Indigenous communities, qualifies her argument to say that there was a time and a place for damaged-centred research, in order to expose inhumane living conditions (2009, p. 415). The same may be true of women's health; we inherit a legacy of feminist health research and activism. However, like Tuck, in my work I want to make an shift, away from the exposition of misery as a key political strategy, towards the moments when misery co-exists with resistance. We could look for where good care does exist within the system as it is, moments of internal resistance in a healthcare system which has been systematically defunded and leaves both patients and HCPs in dangerous situations.

Feminist Health Research

More recent extensive feminist health research has been done in the areas of reproduction and HIV, often using intersectionality theory and often more in touch with the United States. This work points to what may be important in thinking about womanhood as a category of marginalisation in contact with healthcare. Bridges, in an ethnography of pregnancy as a site of racialisation in the US (2011), found that where bitter 'birth wars' had been fought over issues such as the midwifery/medical based model of care in white-led women's patient consumer movements, many of the Black women she interviewed did not even know if they were being cared for by a midwife or a doctor (2011, p.87). This did not reflect ignorance, but

that the terms of debate as set out by middle class white women did not speak to the experiences of women who had historically been excluded both from obstetric practice and from feminist critique of that practice.

Sarah Ramey's description of her hard-to-treat UTI is a rare published account of UTI in English (2020). A former speech writer for President Obama, her story starts in a dorm room at Harvard University. Having had a UTI for six months, her physician parents sent her to see a 'top-notch urologist.' She describes a horrific and non-consensual experience of urethral dilation (when the urethra is torn, supposedly in order to relieve pressure) and then urosepsis. She also describes good care: 'top-shelf, nuclear-grade antibiotics pumped into me by the gallon, and it seemed like every doctor at Sibley Memorial Hospital came to sit by my side, making sure the doctors' daughter pulled through. I was extremely well taken care of' (2020). What Bridges' critique can help us to see here is not that Sarah's individual experience was any less horrific because she is white and middle class, but that what good care is may be different for different groups of women who have had different histories with healthcare. For Sarah, good care included 'nuclear-grade antibiotics'. Other women may be more likely to be over-treated with antibiotics, but will never know there has been a harm, and their voices will not emerge in this issue, or in this thesis. This is not an epistemological difference about cultural preferences for care, but ontological- what good care is is different for different groups.

I have detailed several reasons why womanhood can be seen as fractured to an extent that it begs questions about the sustainability of women's health as a framework. Olufemi considers a similar question in response to fractures within feminism itself. She concludes: 'womanhood, the central pillar under which we gather to make our demands, is not real. It is only a vantage point that we use strategically to lessen the brutality we experience' (Olufemi, 2020, p. 142). We might also consider the benefits of conducting 'feminist health research' as a political project, rather than 'women's health research' which is more narrowly defined and often inaccurate to describe those affected by patriarchy in medicine.

While my sample includes people situated in various points in specific societies, my analysis

aims to hold the position of Black women as central and look out from there. It is for this reason, informed by theorists such as Nash, Benjamin, Ryan Hatch, Tuck and the Combahee River Collective, that my analysis does not seek to expose bad treatment, or provoke shock, to appeal for change. Instead, drawing on feminist legacies of resistance alongside pain and hooks' conceptualisation of the productivity of the margins (1989), I attempt to document and archive care practices and imagine what a good future might look like within infrastructural constraints.

Antibiotics as Infrastructure

A major strand of sociological work on AMR critiques a focus on knowledge deficits, and 'inappropriate' use of antibiotics within a patient-doctor dyad. Instead, this work points to how antibiotic practices are both part of, and the results of, relations built around material and relational infrastructures. Landecker's 2016 article set out the historical scaling up of production of antibiotics, and notes how they became 'infrastructural to the production of many other things at scale' (Landecker, 2016, p. 20). Chandler picked up on Landecker's pitching of antibiotics as infrastructure to highlight the work antibiotics do in 'defining what is possible' in allowing 'humans to become shaped into more reliable and productive units of labour' (Chandler, 2019, p. 9). The advent of antibiotics changed the scale and processes of global systems of production and reproduction in ways which have largely only been theorised since AMR has become an international policy issue. Brown and Nettleton point out how antibiotics often appear as replacements or substitutes for the availability of time to recover from illness in discussions about infections and work inside or outside of the home (2017a, p. 308). Antibiotics allowed the large-scale industrialisation of agriculture by removing the need for diversity in stock and in hygiene practices (Hinchliffe and Ward, 2014). Other examples which demonstrate the scale at which antibiotics became central to modernity include the military-industrial complex and biomedicine as a whole (Bud, 2007). Antibiotics are central to most hospital work as prophylaxis for surgery and treatment for those with lowered immune response during chemotherapy.

Much of this work emphasises how what prescribers and users of antibiotics do is because of infrastructural constraints or conditions including precarious work (Nabirye et al., 2021), institutional hierarchies (Broom *et al.*, 2014), accessibility of healthcare services (Broom *et al.*,

2017), and diagnostic un-certainty (Street, 2012; Broom and Broom, 2018). Willis and Chandler's conceptualisation of antibiotic use as a 'quick fix' has been influential in thinking about how antibiotics can mitigate some of these infrastructural deficiencies (2019). But of note is the way in which conceptualising of antibiotics as infrastructure centres them in accounts of how health is done. Meanwhile, UTI is but one good example of the way in which health is done in different settings, between the home, work, school, the clinic, involving antibiotics at some points and in some places and not in others. In this study therefore, I remain open to what health practices may be, beyond antibiotics.

Practice Theory: What People Do

As a way to approach what people 'do', note that there is not self-evidentially much in between 'behaviour' and 'practice'. Indeed, behavioural scientists often talk about the practices which make up behaviour. Therefore, the terms 'health behaviour' and 'health practices' are imbued with meaning about alliances, collaborations and complicity. This is important because behavioural science scales up drivers of behaviours to make theories, models which are capable of intervening on the national scale needed by public health workers. Therefore, this is not a call for nuance. Nuance is often inhibitive to the abstractions involved in the practices of theory making (Healy, 2017) and population level models need ways to generate generalised insight and build theory. My concern is with the information and data that is used to populate these models.

The materialist turn I have just described emphasises how more-than-human materiality participates in the enactment of social relations. The social and material ordering of what people do is a fundamental sociological concern, drawing on theory foundational to the discipline. Bourdieu's concept of habitus shares a concern with what behavioural science approaches as 'non-cognitive thinking', describing how 'every social order systematically takes advantage of the disposition of the body and language to function as the depositories of deferred thoughts that can be triggered off at a distance in space and time' (1990, p.69). This disposition is 'the embodied logic of sedimented history' (Sterne, 2003, p.375) and accounts for how what we do becomes engrained and normalised even as it can change over time. New materialist approaches in multi species ethnography well capture the socio-materiality of this. However, just as 'practices are not held in place by meaning alone' (Hand, *et al.*, 2005, p. 10)

as epistemological research into social or cultural meanings supposes, they are also not held in place by materiality alone, as availability of material circumstances is necessary but not sufficient for a practice to become routinized. This highlights a limitation of much sociological work done on antibiotic use so far which has an explicit focus on antibiotics. Instead, Hand *et al.* describe how it is the relations between materiality, conventionality and temporality that make a practice. Therefore, meanings and materiality are important but are de-centred in favour of a focus on the specific configuration of these dimensions and their relations, stabilised and ordered into a practice.

Insisting that practices emerge through and within specific social, material and temporal arrangements, Hand *et al.* argue that for this reason, ‘measures that focus on isolated technological solutions, or that address consumers as equally isolated economic actors are unlikely to have the desired effects’ (2005, p. 9). Instead of focusing on changing an isolated behaviour of an individual, or groups of individuals, they argue that by paying attention to how practices hang together, there are in fact more ‘points of leverage and opportunities for interventions than are generally supposed’ (2005, p. 10).

Hand *et al.*’s example is showering as it is done in the UK, and efforts to shift people towards a less resource intensive practice. Importantly, they underline that people do not ‘use water’ but consume it in the course of important and valued practices such as showering, cooking and cleaning (Hand *et al.*, 2005, p. 9). Likewise, in this case, people do not ‘use antibiotics’ in an isolated way but sometimes use them in the course of ‘doing health’ as a practice. Here, I have grounded this claim in social practice theory but it should be an obvious point: what people do is not normally an attempt to gain access antibiotics; people do things (we might call them health practices) in attempts to feel well and sometimes this involves antibiotics. Efforts to reshape practice around infection and antibiotics depends on the conjunction of multiple factors and mono-dimensional efforts to persuade people to avoid antibiotics are unlikely to be effective. This is also another reason to de-centre antibiotics in our sociological analyses. As Blue *et al.* point out, ‘the tendency to “tell the story” of one practice at a time makes it difficult to see how practices [...] interact and how transformations ripple across the

plenum of practices as a whole' (Blue *et al.*, 2021, p. 3). Therefore, 'health practice' is a wide term which does not pre-define what health is, or what activities might be a health practice.

Practice theory works with the idea that practices emerge through and within diverse social, material and temporal factors. Accounting for power and politics is therefore central to people's health practices. For, while health behaviour is the outcome of the individual who does the behaviour, their psychological processes being altered by factors around them, health practices emerge from and within that specific context, and ours is a context heavily patterned by differential power relations. Interpretations are therefore partial, specific, about what happens there and then. This does mean that the value of social practice theory is different to that of behavioural science – it is far less concerned with identifying the determinants of behaviour, separating them off into (crucially) measurable categories, and producing theories of intervention. But ethnographic methods of investigating local minutiae and the resulting insights, on the specific and local qualities of what people do, might be useful for building into such large-scale methods. My claim is foundational to the craft of ethnography: looking at the spatially and temporally grounded specifics of what people do and don't do every day to do with their health, will help provide a general insight about how best to mobilise to improve health, mobilising on AMR being an important part of this given the situation we face.

Ethnography

How can ethnography generate generalised insights in a different way to behavioural science? Behavioural science generates generalised insight by studying drivers of behaviour, organising them into categories (or codes) then scaling them up into models to take to social problems, naturalising the codes in the process as they are taken from one study to another. Yates-Doerr ends her critique of SDH by asking how to bring lessons gained through ethnography about a health problem elsewhere. She concludes that this is to be done by 'not scaling them up but attuning them to other socio-material conditions at hand' (2020, p. 17). Specificity is intrinsic to the ethnographic method. Specific problems require temporally and spatially specific attention. Ethnographic approaches to health problems do involve processes of abstraction, of scaling up from the local. But unlike behavioural science, codes are

generated from the data collected, rather than applying pre-defined codes to the data. In this way, local insights will not replace population level models, but may be complementary by capturing different things. For instance, above I argued that using pre-defined domains of what affects health is attractive to policymakers who are limited by political status-quos. Not defining these domains in advance but generating them from the data means that sociology is often much more wide ranging in defining what a health practice could be, and therefore perhaps less attractive to policymakers as an approach.

However, it is important to be clear that sociological, ethnographic coding does not capture authentic, un-mediated data to be coded. Myriad variables from where you look to get the data and your positionality as a researcher affects what the codes are. What ethnography does by situating the researcher in the research, is account for and respond to the interventions made by the method itself. So where to look? Importantly, the ethnographic method conserves a lot of doubt about the answer to this question. Unlike more epistemologically-driven research methods, which seek to evaluate what people know about a pre-defined issue (AMR), in order to reduce pressure for antibiotics on clinicians or increase pressure on politicians, ethnography is open to what might be found and where. This is not a relativist position- health is a good and sickness is a suffering. But it is a position which maintains that it does not know what health is in advance of a long-term commitment to observing and listening for how people do health.

Where behavioural science starts by identifying a behaviour in need of targeting, and then asks how best to intervene to change this targeted behaviour, my ethnographic approach starts with the very basic sociological insight that when people feel ill, they often seek out ways to feel better. This insight prompts us to ask a very different question, and, crucially, one much closer to a goal of promoting health: what do people do when they do not find help in the places they would normally go to get help? What ways have they found of feeling healthy? What can they tell us about how to thrive when the scalable, industrial, standardised practices we have come to rely on no longer help us feel healthy? Only ethnographic research will answer these questions. By paying attention to the diverse, non-scalable, precarious practices cultivated by those living on the margins, we can learn about how to live without

antibiotics and we can understand what else happens as a result of interventions targeted at reducing antibiotic use: unintended consequences.

Methods

Positionality

For me, this research started with my own experiences of urinary tract infection. When I was eighteen, intense, unexplained pain became a UTI when my mum, who herself has never experienced a UTI, drove me to urgent care where my urine was dipped and antibiotics prescribed. I had never heard of a urine infection before that point. The relief was almost instant but from the second year of my undergraduate degree I began to suffer with debilitating urinary symptoms. I did not always consult the doctor because my symptoms were practically constant but flared up into huge crises, at which point I would consult the doctor and be prescribed antibiotics. I was studying modern languages and took the infection to Spain with me on a year abroad, swapping out the NHS's packets of Macrobid for sachets of what I now realise must have been powdered Fosfomycin. Thinking back, I'm not sure that I really thought of them as antibiotics at the time. These were the drugs that the doctor gave me when I had an infection, and the one they gave me in Spain was like a refreshing lemony drink.

My doctors seemed to understand one infection, read on a dipstick and treated with three days of Nitrofurantoin. But when I described daily intrusive symptoms that disrupted my life, my bladder feeling it was flipping around, without the searing pain of an 'active' infection, doctors appeared to be non-plussed by what I was describing. I was treated with course after course of antibiotics. There were other symptoms that I didn't connect to UTI at the time; a strong metallic taste in my mouth that lasted for days and the times I suddenly lost control of my bladder in public places. These were disorientating and seemed alien to what 'a UTI' was. I panicked, becoming desperate and thought I was losing my mind, not knowing what symptom could next appear as a result of this supposedly simple infection.

I thought it was odd that this illness had never been mentioned to me while I was growing up, at school or at home. For the first time at the age of twenty-four, I looked online for what other people were already doing on this issue, finding groups such as Bladder Health UK and CUTIC on Twitter. I had only followed these groups for a matter of weeks when I saw them advertising a PhD position for a project on UTI. I had never planned to do a PhD but was looking for a job at the time. The advertised PhD required a research proposal and a master's

degree in a related area. I had just finished a MPhil degree and had written a medical sociology dissertation on socio-legal aspects of childbirth, which touched on many issues relevant to this research; including marginalisation and feminist health research. During my studies, I would often wake up in the early hours of the morning in extreme pain, and then lie in the bath to help with the pain, drifting in and out of sleep, until it turned 9am and I could call the GP. The GP would prescribe me antibiotics over the phone and my partner would go across town to pick up the prescription from the surgery and then to the pharmacy. After a while, I would get ready and go out to the library to study medical sociology. I had never thought of my own experiences with health, illness and medicine in an academic sense until I saw the advertised PhD through the patient groups. This is how I began this project, starting from my own experiences.

Feminist Epistemology

The question of what it meant for the project to be a researcher with ‘lived experience’ is important. In interviews carried out for the development of the TARGET UTI leaflet, researchers were keen to point out that interviews were carried out by trained researchers with no clinical knowledge or personal experience of UTIs (Lecky *et al.*, 2020, p. e331). This was painted as a strength of the research as researchers ‘could not bring unconscious bias to either the interviews or data analysis’ (Lecky *et al.*, 2020, p. e336). Against this way of prizing ‘objectivity’, feminist philosophers of science developed theories of ‘situated knowledges’ (Haraway, 1988) and ‘standpoint’ (Harding, 1992), which do not claim to see ‘from above, from nowhere’ (and therefore from an unmarked dominant position) (Haraway, 1988, p.589), but from a situated location. Haraway explains that ‘feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and objects. In this way, we might become answerable for what we learn to see.’

Alongside such feminist philosophers, a tradition of ‘scholar-activism’ works against insinuations on researcher ‘objectivity’ and the idea that personal experience introduces bias. During the course of the research, my own position as someone with ‘lived experience’ of UTI led people to ask me if I considered my work to be activist work. Although some researchers in the positivist tradition attempt to deny that they participate in the production of research, with the research being an objective reflection of the world, untainted by ‘bias’ or ‘values’,

they are wrong. All researchers participate in the production of their research. Therefore, those of us who acknowledge our own participation are not necessarily activists. There are questions about who is comfortably able to claim their research as activism. When people of colour work on race, this work is often devalued because it is considered 'activism' and therefore not empirical. On the other hand, white scholars are often more able to claim their work as 'activism' without censure. This is perhaps especially true of white women working on gender like myself because of the way that gender equality has been institutionalised in the university.

What I offer in this thesis is not activism, it is empirical analysis of social relations from a feminist standpoint. This analysis may be well be useful to activism but it is not the same thing as activist organisation and mobilisation because, being empirical, it does not define what the goal is in advance. An example of what research activism might look like on this issue is starting with a research question like 'why are women denied antibiotics for UTI?' This defines in advance that gaining access to antibiotics would be a good, which I did not do. All of this is not to say that the research does not enact or participate in enacting different futures. Research is not isolated from the rest of the world in the university and the process of doing research; describing and analysing relations certainly can enact a different future. Indeed, anticipating these futures through a theory of change can affect the terms of analysis. But activism is not the main activity of research, which is analysis. So while I do not consider the analysis I will offer in this thesis to be activism, the question, when I was asked it, pertained more to the level on which I would be engaging with the matter at hand. And indeed, it is clear that my own experiences as a patient affected the production of my research data and findings. As a 'patient' myself, I cared deeply about what happens for people with bladders that make them feel unwell. Therefore, I have a feminist standpoint with patients which I theorise using standpoint theorist's Dorothy Smith's institutional ethnography (IE) (Smith, 2005; Cupit *et al.*, 2021).

Ethical Approval

Institutional Ethics

As outlined in the previous section, I aimed to talk to people about their experiences as they happened, in order to get at the way that bladder health, and good care, is enacted in practice.

Here I list the permissions I was granted by the Social Sciences & Arts C-REC at the University of Sussex in order to do this; an essential part of the research process. The process for this was to fill in an online form detailing research intentions and potential ethical risks, with research documents such as participant information sheets and consent forms attached. This was then returned to me with a certificate of approval.

		Date Granted	Permissions Granted
1	ER/EK403/2	March 2020	Scoping interviews with community experts.
2	ER/EK403/3	July 2020	Online patient interviews, recruited through community groups or circulating a recruitment poster online.
3	ER/EK403/5	December 2020	Eliciting photographs of objects from participants. Scraping social media for data, anonymised data from closed forums such as closed Facebook groups and anonymised data from open forums such as Twitter, websites, open chat forums. Approaching people for informed consent where I wish to name them.
4	ER/EK403/6	May 2021	Recruiting through a poster posted in physical offline spaces.
5	ER/CW82/10	October 2020	Added as a named researcher on wider project permissions to interview scientists, clinicians, policy makers etc.

Situational Ethics

As a corollary to institutional ethics, I developed a praxis of situational ethics (Hennion and Vidal-Naquet, 2017). Situational ethics attends to a duty of care to participants by approaching each research situation as a unique situation requiring reflexivity, discretion, flexibility and innovation. Unlike institutional ethics, which is a one-time engagement with ethics to be approved or not, situational ethics is an ongoing process. I was particularly informed in my approach by the BSA's guidelines on situational ethics in digital research (Davies *et al.*, 2017). An example of the way I applied situational ethics alongside institutional ethics came in my response to the difficulties of capturing talk about bladder health 'as it happened.' People talking about UTI and doing bladder health as it happened were visible online in forums such as *Mumsnet* and *Reddit*. However, these forums restrict research recruitment and it was impossible to recruit anyone for interviews from there. I applied and gained ethical approval to collect data about UTI that already existed online on websites and forums, with set provisos (ER/EK403/05). This would have been a valuable data stream and would have captured

people doing bladder health, without having to engage people for whom bladders were not a priority in a somewhat lengthy research process, or having to recruit online which was difficult given restrictions. For instance, although *Mumsnet*, which has been a data collection site for sociologists working on AMR before (Brown and Nettleton, 2017a), restricts researcher recruitment to one poorly visited thread, data scraping is permitted if *Mumsnet* is acknowledged in the research. However, I eventually decided not to do this, informed by considerations within a situational ethical framework. The first surrounded restrictions around taking screenshots in some of the online groups, as well as concerns about some of the illegal or ethically problematic practices I would have captured (even if in anonymised form). The second concerned the extent to which my participants clearly valued their anonymity, taking advantage of the opportunity to review their transcripts. The third surrounded experiences with personal contacts which provided opportunities for reflection on what participation meant. I know of two people in my personal life who suffer extremely badly with urinary symptoms. One of them knew about my research and avoided talking about it with me. I took this as a refusal of engagement which I respected and never brought it up with them. The other was a close family member's colleague, who discussed it at length with my family member as a friend. I asked about the possibility of speaking with her, but was told it would be inappropriate given the stress the colleague was under. For me, this is a sign of how difficult it may be for some people to speak about this issue, or to engage with research about what is an ongoing and unresolved, time consuming, painful and emotionally taxing illness. Using situational ethics, I therefore decided not to scrape online spaces for data although I had gained institutional approval to do so. I did use anonymised quotes from patient groups (never individual patients) posting in open forums such as *Twitter* and websites.

Others' Perceptions of Me and of the Research

Patients

Having experience of hard-to-treat urinary symptoms gave me a head-start in understanding what some of the sensitivities might be when talking to patients. Many patients have had poor experiences of care and are mistrustful of researchers. For patient mobilising around UTI, this is especially true where it is felt that researchers do not understand the difference between a chronic and a recurrent UTI, and even more so if they worry that an interest in AMR means producing evidence for reduced access to antibiotics. My recruitment poster did not mention

AMR, but my PIS did. Approaching people through AMR in this way would have had an impact on my data. Firstly, as aforementioned, for some participants, there was significant anxiety about the potential impact of this research on policy, practice, or discourse surrounding access to antibiotics. Secondly, as Eborall and Will note, research participants often do work to avoid being seen as ‘pill poppers’ (2011), a phenomenon which may be exacerbated by stating research motives surrounding AMR. Several of my participants seemed reassured by my identity as a UTI patient, which was mediated through my understanding of issues such as the difference between an acute UTI and a hard-to-treat UTI, and my use of certain medications which were at the time mainly only used by people in contact with mobilisations on AMR. When approaching these patients, my own experiences meant that I knew on exactly which issues I would have to show my cards in order to be accepted. When I spoke to patients unconnected to other patients, I anticipated that our shared illness experience might reduce embarrassment or shame.

The way that my own position as a UTI patient participated in producing the data is related to the way that feminist sociologists have argued the benefits of woman-to-woman interviewing (Oakley, 1981) – that shared gender subordination could work to create a sisterly research relationship. Oakley put forward that women researchers could achieve this by giving advice and support in the research relationship rather than merely taking from participants, as captured by Kvale in a metaphor of the researcher as a miner, extracting what they need from the participant (1996, p.3). In 2016, Oakley reflected on her original research of the 1980s and herself echoed and accepted what had been the main criticism of this interview strategy – that it lacks an awareness of how not all differences, perhaps especially racial difference, can be subsumed by shared gender identity (2016, p.196), or additionally in my case, a shared illness experience.

All participants re-calibrated their participation and resistance as they learnt more about me and the research. One patient who takes part in online mobilisations had clearly been comforted by my own identity as someone with hard-to-treat UTI but when she asked me about my own experience, and I told her that I chose not to use long-term antibiotics, she seemed taken aback and wary. This wasn’t the only difference that would not be subsumed

by other shared experiences or identities. One participant declined to record her race or ethnicity, a reflection of the way that participants attempted to exercise control over the research process. This attempt perhaps felt especially necessary because I am racialized as white, given the way data on racial difference has been used in healthcare to target different groups, but also because participants recognise that research findings are not under the control of the researcher.

Nevertheless, the principle of interactional, active interviewing is generally defended: 'most seem to agree that the best way to find out about women's lives is to make interviewing an interactive experience' (Cotterill, 1992, p. 594). This is a feminist epistemological practice because it does not perform the 'god trick' (Haraway, 1988), where interviewer is unmarked knower and interviewee is subject to be known. And yet, there are risks of harm with interactional interviewing as a feminist research practice. Creating a relationship with the interviewee that goes beyond the formal researcher/participant, sociologist/woman relationship risks blurring the boundaries of informed consent that the relationship was founded on and potentially encouraging participants to divulge more than they might later feel comfortable with. Finch expressed these concerns: 'I have emerged from interviews with the feeling that my interviewees need to know how to protect themselves from people like me' (1984, p. 80).

Participant Resistance

However, I emerged from the interview process with quite different feelings than Finch. As I came to data analysis and looked over the sum of my data, it was clear that the interviews conducted towards the end of my data collection project however were stronger than the early interviews. Thinking back and reflecting on what had changed was therefore a useful process. Firstly, reading over the transcripts of interviews done by Dr Ulla McKnight, the post-doctoral fellow on our joint project, was invaluable; seeing how she had asked directly about what it was she wanted to know gave me confidence that this was a good approach. I had avoided doing this for a couple of reasons.

I had responded to theory which emphasised the co-construction of the interview by

participant and researcher by being deliberately vague in my questions. Moreover, I had felt that the process of applying for formal ethics approval strongly emphasised the harm that researchers could do to participants. This can undoubtedly happen, to varying degrees within the range of different projects that the board considers. But I found the concerns of institutional ethics quite paralysing, rather than a productive engagement with situational research ethics, which more came from helpful and thoughtful discussions with my supervisors and with Dr McKnight. Working in an area so fraught with controversy and extremely personal experiences had also led me to feel anxious about either putting words into my participants' mouths, or inadvertently leading them to tell me what they might perceive I wanted to hear. In this way, closeness or proximity to the research topic at hand had created distance from engaging with participants.

On reflection, I had, I realised, not paid my participants the respect of their full participation in the research. In fact, rather than being harmed by my research practices, participants often pushed back on my questions, gently but firmly telling me I had got things wrong, as in any other conversation, or declining to answer questions at all. I realised that I had, for all the reasons above, thought of my participants as somewhat defenceless subjects of my research. Instead, and to my surprise, participants overwhelmingly cast their participation as 'a favour' telling me that they were happy to help me out. As Bhopal argues, power is not something that you either have or have not. Instead, it operates on a continuum (2010, p. 193) with researcher and participant occupying different positions at different times.

The reflection that I had not paid my participants enough respect was a particularly stark observation when I interviewed my own sister for the research. I had avoided interviewing her because we had so many conversations about the research, given our shared experiences of hard-to-treat UTI, that I felt co-construction would be an understatement of the interview we would produce. However, as I was nearing the end of my data collection period, she moved house and, joining a new GP practice, had an experience so remarkable in attempting to access care that I felt it would be a missed opportunity to not record her experiences. In any case, this experience would have informed my thinking and it seemed more ethical to formally record what had happened as interview data. Our close relationship gave me the sort of

granular 'as-it-happened' insight into care that I had otherwise struggled to capture working online. After discussion with my supervisors, I decided to go ahead with an interview. I was surprised by how the interview went. She told me about things important to her experiences of UTI that I had known about but totally forgotten, and would never have thought would be relevant to her experiences in any case. She also surprised me in how different her experiences were from mine. In this case, I had not paid my own sister the respect of her participation in the research. Overall, a reflection was that the institutional ethics system understands vulnerability as weakness, whereas participants invariably had ways to resist and protect themselves from researchers amidst vulnerability.

One participant ended the interview by laughingly saying that she would end the interview that she had told me all her trauma, although this did not seriously worry me on an ethical level. Another woman who had never participated in research before, told me with some surprise that she had really enjoyed the experience, and that I should please get in touch with her if there were any other opportunities to contribute to the research. She had become extremely upset during the course of the interview and was not in touch with anyone else who suffered with repeated UTIs. Another woman who had horrific experiences with care, and importantly, with research, told me that she was glad to participate in the research because she felt it would make a change for others even if it was too late for her. Only in one interview did I worry about what had happened. This interview was with a participant who mobilises online around access to long term antibiotics. When I interviewed most participants, I did not know yet what my research findings would be or even what I was looking for. This ethnographic openness was in many ways uncomfortable in how it demanded working with un-certainty. However, in other ways it was a comfortable position to occupy because I was coming to each interview with real openness. As I conducted this interview towards the end of my data collection period, I felt that the window of ethnographic openness was closing and I knew more or less what my research findings would be and how they might clash or provoke anxieties within certain interested groups.

Most patients who had unresolved urinary symptoms accepted what I was doing without much curiosity which is an important research finding; here was an issue which, to

participants, obviously and self-evidentially merited further research. Towards the end of one of my early interviews, it became clear that one of my patient participants thought I was a medical doctor. I told her I was not, assured her she had the opportunity to review her transcript, and amended my recruitment materials to state that I was a sociology researcher, not a doctor, and that this research would not affect care.

Ben Vincent, in work on ethical recruitment and participation of trans participants, emphasises the importance and significance of transparency with marginalised groups (Vincent, 2018) because of historical practices and ‘concerns over whether a given project will have an explicit, positive impact’ (Vincent, 2018, p. 5). Vincent argues that in the spirit of this transparency, researchers should share the importance of the work, what brought you to it and what you hope to achieve, whereby ‘my personal values are vital in assessing the meaning of my work’ (Vincent, 2018, p. 7). I of course agree that it is important to come to research with intentions to have a positive impact on participants’ lives. And Vincent’s point is specific to trans participation; generalised hostility to trans people’s wellbeing may mean that intention is less of a given. However, there is a danger in overemphasising intention – harm can be done without intention and research can enact futures which are out of the control of the researcher. Therefore, what I take from Vincent’s work is a commitment to transparency about the multiplicity and messiness of intentions in research practice. An example is that although all my interviews were conducted with informed consent and participants were given the opportunity to review their interview transcripts, participants cannot have known how their experiences would be represented in my analysis as I myself did not yet know this, the analysis arising from the data.

Interactional Interviewing Off the Record

When people say things off the record this means they want you to know it as a researcher but they do not want you to record it. Therefore, this is another example of participants not being defenceless subjects of research, but attempting to control the research process and outcomes. There were a few occasions when people told me things in interviews that they said at the time they would not want recorded. This was either said in the course of the interview and therefore recorded, transcribed, removed and then checked with the

participant, or, more commonly, after I had turned the voice recorder off. These off-the-record comments overwhelmingly related to attitudes towards antibiotics and especially long-term antibiotics.

The primary element of people speaking 'off the record' was myself. Nearly all of my patient research participants with unresolved symptoms wanted to know about my own health or asked me if I had found anything in the course of my research that helped. This was normally at the end of interviews when I asked them if there was anything else they wanted to say or anything they wanted to ask me. This is an important research finding; for some participants, it seemed a reason for taking part in the research was that they identified me as someone who might know things that could help them. Others were clear that they did not want my help or advice but just wanted to hear about my own experiences. Perhaps this was an effort to 'place' me but it normally took place after the interview, although before they had approved the transcript. Normally, I turned the voice recorder off and spoke with participants for a while about my own experiences. I recognised that it may be important to share my own vulnerability as participants had shared theirs but I was also anxious about responsibility for what might be interpreted as medical advice. Many of my participants are or have been, like me, vulnerable in their pain and so medical advice from a clinically un-trained stranger held more weight than it might have done otherwise. I found myself speaking more about my own experiences when I was trying to ask a participant about something more delicate, or where I was worried about them interpreting my questions about AMR and antibiotics as moralising. I was always strongly aware of when the voice recorder was on or off and this reflects some of the anxieties I felt about interviewing people who were not experiencing good care, had identified me as someone who might help them feel better, and I had identified as being in a vulnerable position.

There is also a huge amount of 'informal data' which relates to things I have seen or heard online or in the course of daily life which I either did not have ethical approval to record, or I chose not to record for ethical reasons. I could not absent these things once I had come across them, and I also could not remove myself from situations where I might come across them, reflecting the use of patchwork ethnography. This informal data inevitably informs my

thinking and was recorded in field notes.

Recruitment

I recruited nearly all of my patient participants online via my recruitment poster, one got in touch with me after seeing my recruitment poster in the toilets of a local pub and a few others were recruited through word of mouth or snowballing. Online, I shared my recruitment poster in different places. This included in places where people were already discussing and mobilising around UTI as an issue. Of the data included in the data set, seven out of twenty-nine participants were aware of other patients mobilising around this issue online, although they had very varied investments in different mobilisations. A further one was aware of such mobilisations when I asked her, but did not speak about it otherwise in the interview. I wanted to recruit participants who both were and were not in touch with other patients mobilising on this issue to see how this differentially affected their experience. Most of these participants who got in touch with me 'out of the blue' had extreme experiences and described shock and surprise at recognising themselves in my recruitment materials. I tried to think about places online where people may be talking about bladder health, or issues surrounding access to good care, and posted my poster there.

Recruiting during Covid-19 lockdowns, I was concerned that I might have missed people who were less online. When lockdowns ended, I therefore pinned posters in different physical spaces where I thought people who I wanted to hear from might be. Places that agreed to display my poster included Aldi, Lidl and Primark staff rooms, Dunelm main window, local independent pharmacies, and local pub toilets. I also asked colleagues to share my poster in community spaces where people may be talking about UTI that I might not be able to see or have access to. For example, my colleague acted as gatekeeper for me in sharing my poster in *Facebook* groups for women of colour.

Scale: Knowing Who to Interview

The issue of scale was one that I had to think about a lot while recruiting and interviewing. As mentioned before, it is an impossible and in some ways an undesirable task to determine how many people have urinary tract infections. Not everyone identifies their symptoms with the medical terminology of UTI, some never come into contact with the healthcare system,

caring for symptoms at home, some episodes of UTI treated within the healthcare system are not coded and therefore counted as such, and bladder health is done differently in different places, as will be discussed later in the thesis. I knew that there were people who had very extreme experiences with their bladders but I did not know on what scale this was or how to find these people. There will be people, or groups of people, talking about this issue, that are not visible to me from my standpoint. Moreover, it is likely that groups of people more visible on this issue have different experiences of UTI because of their visibility. An instance of where this might be important is if people who have more contact with the medical system have different experiences of bladder health because they have more contact with antibiotics. Doing interviews across a broad range of experiences of bladder health, from the most everyday to the most complex, allowed me to compare and contrast between these experiences.

Deciding Who to Interview

Most people who expressed interest in participating were interviewed. However, there were a few people whom I declined to interview. This was because I had kept my recruitment materials deliberately vague. My recruitment poster asked 'do you have experience of urinary symptoms including: pain around the bladder, needing to go to the toilet more often or urgently, pain when you pass urine, can't go to the toilet, or any other symptoms from your bladder?' Here, I employed vagueness in order to avoid excluding people who did not use the same language as me, language I have borrowed from biomedicine. I knew that some people would not identify with the terminology of UTI for multiple reasons. Patients mobilising around UTI online identify people who have received non-infective diagnoses such as PBS or IC as relevant to research on UTI because of diagnostic uncertainty. There are also other groups who may not use biomedical terms, such as those who care for their UTI symptoms without contact with the healthcare system. However, there were some experiences of urinary symptoms that were indeed less relevant to the questions I had, mainly involving urinary incontinence with no other symptoms. Prospective participants who described only incontinence or some other urinary issue which seemed largely un-related to infection, bearing in mind the issues patients raise around diagnostic fallibility, were individually responded to, explaining the reasons why they would not be interviewed. As described before, this data was not recorded as it was before a process of informed consent had been undertaken. On occasion, prospective participants who had come across my poster

approached me describing horrendous and unresolved experiences and, not being in touch with anyone else suffering from similar issues, wanting to be involved in the research. When they did not fulfil my recruitment criteria (normally because they resided outside of the UK) but expressed great interest in being involved, I sometimes interviewed them anyway as I felt it may have been unethical to deny them the opportunity to connect with other patients through the research. I will be aware of the effects of these decisions in my data analysis.

As questions of marginalisation, precarity and vulnerability were important to the research, I needed to ensure it was reflected in sample. However, I kept an open and humble definition of what marginalisation might be or mean. This was because I did not presume that I could always anticipate what marginalisation was, whilst also knowing something. Therefore, my overall approach was to be open to what I might find during the interview while making every effort (as described above) to facilitate the inclusion of groups we know from previous work would be important to understanding how marginalisation affects the experience of poor bladder health. This was especially important because of the online nature of recruitment; I often had little idea of the person I would be interviewing before I began the interview.

Patients were offered a £20 shopping voucher in compensation for their time, which was funded by the project budget. Participants recruited through one of the major *Facebook* groups were not offered this as the moderators made it clear that this was a condition of access. In the final data set, this applied to one participant only who was the moderator who had set this condition herself. One participant never claimed the participant payment after I sent it to her. Other participants (GPs, microbiologists, researchers, patient advocates) were not offered payment.

I did not find that it was easy to recruit for this project although as it is my first experience of social research, and I had to recruit mostly without leaving the house, I am unsure how this would compare to other projects. Mundanity, intimacy and complexity are all reasons why people might avoid engaging with researchers and bladder health can have all of these aspects for different people. An overall issue was that people who may experience poor bladder

health and have valuable insights about care ‘as it happened’, but did not identify it as an issue for themselves in their lives, were often reluctant to participate in research. It was much easier and far more comfortable to recruit people who identified an issue for themselves in bladder health and although my participants’ experiences do sit along a spectrum of experience, my dataset reflects the more extreme end of experiences of bladder ill health. Indeed, as I mentioned before, several participants whom I recruited from places unconnected to other UTI patients expressed surprise that there might be other people with similar experiences, and emailed me to participate with enthusiasm. Participants whom I recruited through UTI groups etc. were often glad that research was being done in this area, although they were often also mistrustful of my motivations for doing the research, and to what ends I would use data.

Clinician, Scientist and Policymaker Recruitment

I recruited one GP, who mobilises on UTI online, through approaching her via email. Two other GPs spoke anonymously. One I recruited through a personal connection and the other I approached after I saw her commenting on UTI research on her personal social media page. These GP interviews are supplementary only to the main dataset, which is with patients. Of the four microbiologists, one I recruited through a personal connection, two through Twitter, and one through Facebook. I recruited laboratory scientists, statistician and clinical researchers through directly approaching them via email. All HCPs spoke in a personal capacity.

Interviews

I interviewed twenty-five patients for this project, three general practitioners, one pelvic physiotherapist, four microbiologists, three laboratory scientists, one statistician, two clinical researchers and seven people I have called ‘patient advocates.’ These are people who spoke on behalf of patients but may have also spoken about their own health. All participants were interviewed by me via *Microsoft Teams* or *Zoom* apart from two participants who provided written responses. One of these was because the participant suffered from a medical condition which made it extremely painful for them to speak. The second was because when I approached them, I discovered they had already given time to the project in the form of an interview with a member of the project team then on sick leave (hence why I had not known

this). I asked for consent to use our written correspondence as data, which they were happy to do.

All of the interviews were recorded onto my computer with the interviewee's consent and later transcribed either by me or by a transcriber. The interviews lasted about one hour but sometimes lasted around two hours. This was always at the patients' initiative and I checked in at the one hour mark if they wished to end the interview there or wanted to carry on. All patients spoke anonymously. All other participants were given the opportunity to speak identify themselves or speak anonymously. All participants were given the opportunity to review their transcript after the interview and to retract anything they were unhappy with. Two patient participants, Nicole, and one other, got in touch with me after I sent them their transcripts for approval to tell me that they no longer were happy with what they had said as they would now say such different things. I asked both if they would consider doing a second interview with me. Nicole agreed and having reviewed the second interview, was happy for me to use both interviews as data. The other patient participant declined a second interview but was happy for me to use the data with some references to elements she now felt uncomfortable with removed. Feeling that this would distort the interview data, I decided to remove her interview from the data set, although this experience itself inevitably became important for me to think with.

I recorded demographic data by verbally asking participants their name, age, occupation, country of residency and how they describe their gender and race or ethnicity. Given my focus on inequality, I was keen to pay attention to how factors such as age, class, race and gender participate in relations with poorly bladders and care. I did not set out to interview non-gender conforming people given the way that this community is over-researched by cis researchers. I am very grateful to both the work and the time that Dr Ben Vincent gave me in considering these issues (Vincent, 2018). However, the three participants who were not cis-gender brought important experiences to the study of what is often understood as a women's health problem. I did make an effort to recruit people of colour but I did this by ensuring my recruitment poster would be in lots of different places, rather than explicitly targeting people of colour. Both of these choices were attempts to grapple with researching issues deeply

imbricated in inequality whilst avoiding hyper-identification of already marginalised groups as targets of health research, which risks re-marginalisation.

Participants varied in terms of gender, age, socio-economic background and how they described their ethnicity or race but I have chosen not to present much of the demographic data collected. This is because, informed by IE, I maintain my focus on analysing care, not people. While inequality clearly does participate in how a person experiences ill health and care, this was not necessarily captured in the questions I asked or the interview as a whole. Both what I know and what I may not know about my participants informs my analysis.

Consent

Most of my patient participants approached me via email to participate, having come across my recruitment poster. There were a few whom I approached on social media to let them know of the existence of the project. I gave them my email address and asked them to send me an email if they wished to participate, leaving them the space to come back to me or not. When I heard from participants, I asked a few preliminary questions about themselves, the answers to which I did not record because I had not yet gained their consent to do so. If they met my recruitment criteria, I sent them a participant information sheet and a consent form. I asked them to read over the PIS, and let me know if they had questions or doubts and if not, to send me back the consent form. Having checked with the REC administrator, I told participants that they did not need to 'wet sign' consent forms, which would have entailed having access to a printer and a scanner, but could type their name and send the consent form back to me. After I received a completed consent form, I could receive photographs (participants often sent these through at the same time) and schedule an interview.

For participants participating outside of a patient role, I sent the relevant participant information sheet via email prior to meeting and then, having checked they had read the PIS, I read the consent form aloud, recording this process and their answers. This was to enable participation with minimum paperwork for clinicians participating in my research during the additional stress and time constraints of the Covid-19 pandemic. The recording was stored separately from the recording of the interview itself to ensure anonymity.

Doing Research Online

Due to the Covid-19 pandemic, I interviewed all participants online, using either *Zoom* or *Teams*. Research about UTI had been undertaken using semi-structured telephone interviews before the pandemic. Ghouri *et al.* conducted telephone interviews about UTI with women in the period July 2018-January 2019 (2019) and Glogowska *et al.* in the period December 2016-February 2018 (2022). Neither expound on the reasons for this in their articles but remote interviewing is a useful strategy for research about UTI for the same reasons that UTI is often managed over the phone; UTI is an infection that moves between the home and the clinic. Symptoms often begin at home and both the domestic practices people do instead of or as well as seeking medical help, and the point of entry into the healthcare system are concerns of the research. Therefore, there are great advantages to interviewing people in their own homes. People were able to pull things out from their domestic context to show me, such as letters from clinicians, medications and mundane objects such as hot water bottles, all of which participate in enacting UTI. Moreover, there were many occasions when participants (or indeed I) had to re-schedule an interview at the last-minute due to ill health. This is a hazard of interviewing people who live with an unresolved health condition. Therefore, remote interviewing made the research more accessible to people living with poor health, and helped me to gather data on their experiences. As people became more comfortable with remote connections during the pandemic, I was able to make the most of this way of working. Also relevant was the issue of scale I addressed above, I did not know before commencing the research how many people had complex experiences of UTI and interviewing online allowed me to reach a geographically disparate population around the UK, as well as to explore how geographical location affects experiences as AMR and infection have important spatial dimensions. In this way, I was able to stay true to the spirit of what I had wanted to achieve designing the project before Covid-19 through careful consideration of what was gained and lost, presented and absented by my methods. Below I consider how to capture the practices of doing UTI as it happens, without participant observation. Even before Covid-19 related restrictions on face-to-face research, I could not observe people living with UTI, as several of the most relevant practices would be too intimate for observation.

Description of Method

Object Photographs: Studying Practice and Understanding 'un-tellable' experiences

Interview were semi-structured. An early finding was that some participants had complex experiences but struggled to speak at length about these experiences. On the whole, these interviews reflected experiences of care which resolved their symptoms, even if they did sporadically re-occur. This seemed to limit the fluency with which they talked about their experiences. I therefore introduced an object-based interview method, detailed below, which was designed to facilitate talk about 'un-tellable' experiences of doing bladder health in talking through objects.

As outlined in the theory section, theories of practice emphasise more-than-human agency. Relying on talk based methods such as interviews therefore risks missing more-than-human materiality as different methods present and absent different things (Law, 2004). There has long been methodological concern about the performativity of talk in research and the way in which it may not capture materiality. In policy-related research, the question of what people do is high on the agenda but self-reported data is often understood to lack reliability. In sociological research, an understanding that the methods do not describe social realities but also create them (Law, 2004) means that interview data cannot be understood as providing a transparent window onto life 'beyond the interview' (Rapley, 2001, p. 305). The co-creation of the interview between participant, researcher and method is perhaps especially pertinent when people feel that they need to do moral work in interviews. In this research, participants were aware that the project related to AMR, and this had performative effects on participation and on data.

Observation has often been regarded as the sociological 'gold standard', a tool for researchers to verify and triangulate statements made during interviews. However, this has been criticized by Atkinson *et al.*, who point out that 'field researchers must not assume that what is done should enjoy primacy over what is said, and that therefore observation and interviewing stand in opposition to one another. Actions, we argue, are understandable because they can be talked about. Equally, accounts- including those derived from interviewing- are actions' (2003, p.132). Therefore, without understanding observation as a means to verify dubious statements made in interviews, we can understand talk as a way of

presenting ‘tellable’ (more shocking or unexpected) experiences. This then means that silences must exist around less ‘tellable’ experiences. Indeed, as noted, some participants had struggled to speak fluently about their experiences, especially where they had had experiences of care which had resolved their symptoms.

Importantly here, mundane activities and practices are untellable precisely because of their mundanity. Bourdieu’s habitus does not function at the level of explicit consciousness but is embodied in physical or linguistic dispositions (1990). Because of this, habitus is ‘un-tellable’. Moreover, of relevance here are sociological renderings of experiences as tellable or not. DeVault notes that women may be limited in disposal of language to talk about ‘mundane’ action in the kitchen (1990, p.3). When asked about mundane practices in a talk-based interview, participants must rely on memories and descriptions of practice. Martens argues that while this talk is good at getting at the organisational dimensions of mundane practices, such as the reasons why you do something a certain way and at a certain time, it is considerably limited in getting at activity, what you actually do and how (2012).

In a study of dish-washing practices, Martens resolves these problems by combining interviews with 24/7 video footage of the kitchen (2012). She references the advantages of conducting the research ‘in the setting common to the investigated practices’ as it allows the researcher to question aspects of the unfolding practices which are normally taken for granted’ (2012, p.8). Clearly, this would not be possible for my research given its intimacy and pandemic setting. Francis *et al.* developed a practice journal for the collection of sensitive data about intra-vaginal practices, using pictures to get at the practices (2013). However, this data was gathered to assess the prevalence of pre-defined intra-vaginal practices, in order to evaluate their effect on a healthcare intervention in a trial setting. Given the ethnographic orientation of my work, being open to what a health practice might be, I did not want to pre-define what people might be doing to care for themselves.

Moving away from a focus on triangulating data, Woodward combines several different methods in a research project about jeans, paying attention to what takes place in the spaces between different methods (2016). Woodward noted that while participants struggled to talk

fluently about jeans, they could talk more easily about particular styles in different times in life. Object interviews based on the materiality of jeans therefore elicited much more detailed accounts of life histories. Woodward offers the example of archaeology as a tradition of thinking through the material to understand peoples' practices (2016, p. 362) and this is a useful way of thinking through the continuities and discontinuities between objects and practices.

Working more explicitly with social practice theory, and therefore adding considerations of space, time and embodiment to materialism, Maller and Strengers complemented interviews with scrapbooking (2018). They created a 'practice memory scrapbook' which contained different images of comfort and cleanliness practices. Examples of images include an electric fan, a slice of cucumber, and a swimming pool. Echoing Woodward's reference to archaeology, Mallers and Strengers describe the scrapbook as a visual provocation for interviews which would 'assist in looking for fragmentary clues of past and present practices' (2018, p.69). A limitation of the method, as identified by the researchers themselves and also aforementioned as a concern in relation to Francis *et al.*'s practice journal, is that discussions with participants may well have been limited by the range and type of images presented in the scrapbook. However, using pre-supplied and therefore un-familiar images, was theorised to provoke a process of applied defamiliarisation, encouraging participants to reflect on the absence or presence of materials from practices performed either now, or in the past. Pre-providing images was useful in providing social licence to talk about depicted practices, even if they were perceived as embarrassing or inconsequential. Maller and Strengers end by suggesting that extensions of the practice memory scrapbook method could be explored by 'asking participants to bring their own images to represent past and present practices' (2018, p.71).

Photo elicitation is a common method in social science research. It is especially commonly used in research with children in order to stimulate a response and to aid memory recall (Marcella-Hood, 2021, p.3). Therefore, it has traditionally involved the researcher pre-selecting images, and showing them to participants during the interview. Photo-elicitation

involves ‘the insertion of a photograph by the researcher into a research interview to evoke information, feelings, and memories’ (Shaw 2021, p.1).

Photovoice, a method of using participant-produced photos, emerged as part of the action research tradition, especially in development contexts. The introduction of photovoice as a method is attributed to researchers Wang and Burris in the early 1990s, as part of their work to improve women’s reproductive health outcomes in rural farming communities in Yunnan, China. The purpose of photovoice in this research was, as explained by the researchers, ‘to promote a process of women’s participation that would be analytical, proactive and empowering’ (1997, p.179). Given its roots in feminist health research (Catalani and Minkler, 2010, p. 439), photovoice is often used to research women’s health issues in marginalised groups, and researchers cite ‘the methodology’s unique capacity to engage hard-to-reach groups and to elicit open and honest conversation’ (2010, p. 448). Crucially to the method, the theory of change centres around empowerment. Social change is theorised to occur through the empowering process of participants participating in conceptualising the research design and analysing research data. For this reason, Liebenberg sets out that qualitative studies which use photo elicitation methods to gather data, but are not situated within a participatory action research framework, are not accurately described as photovoice (2018, p.7). This project is not participatory action research because the research was conceptualised, designed, implemented and analysed by me, alongside the wider research team.

Object-Based Interviews

The method I designed was imagined as an object-based interview, rather than a photovoice method. Due to constraints placed on face-to-face research interactions during Covid-19 lockdowns, the photos enabled a digital version of object interviews. Prior to the interview and after a consent process, I asked participants to gather together and photograph things which they use to look after their bladder. For ethical reasons, I asked that they did not include any people, body parts or photos of people. This photo was designed to have several purposes. Firstly, it was designed to prompt reflection on practices, making them more easily re-collectable during the interview by pulling things out of their life, gathering them into one place, and then putting them back away afterwards, as I was asking them to do in an interview. This ‘homework’ before the interview, at a time when we were being asked to stay

home for all but essential reasons, with limited access to face to face medical provision, highlighted domestic practices of caring for UTI in the home. Secondly, I used the photos as a sampling tool. Where people had provided lots of different things, this was theorised to reflect a different experience than where people had provided fewer things, especially if antibiotics featured.

This method of photographing objects was useful for me in that if people are tinkering with care for their urinary health, attempting to care for their bladders at home without seeking medical attention, or trying out different things in an effort to feel well when they don't get care in the places they normally go to for help, I needed a method that would capture this tinkering towards new embodied practices across materiality, temporality and conventionality. Using multiple qualitative methods in this way was therefore intended to allow me to see differently, as much as to see more.

I applied for and was granted ethical approval to elicit photographs alongside interviews in October 2020 (ER/EK403/05). This meant that I had already conducted some patient interviews (seven). I provided participants with my own photograph of things I use to look after my own bladder as an example. This photo was also on the recruitment poster and included my bed, my bath towel, my water bottle, some red bush tea, a packet of nitrofurantoin, some D-Mannose tablets, a Pyrex jug, a mobile phone and a condom. Sending this to participants alongside the request for them to make their own photo, I emphasised that this photo reflected me and my experiences and they should think through what they use and their experiences. This introduced patients to my own experiences with urinary infection without having to explicitly talk about it in the interview but helping participants to 'place me'. The example also provided some idea of what I was imagining as a response as I felt the description alone may be too abstract and intimidating for people to start with a blank page. Moreover, through the example, and particularly in the inclusion of a condom (broaching the subject of sex) and the towel (including mundane objects) I aimed to retain the social acceptability advantage of pre-providing images that Maller and Strengers spoke about, without pre-defining what practices might be. Going through this process before the interview undoubtedly changed the interview experience and indeed, was intended to do so. I hoped that it may encourage

participants to think about their practices, rather than provide a perspectivalist account of how they feel about UTI. It was clear to me that some of my participants attempted to do the work they thought I wanted them to do in providing a perspectivalist account of UTI, and I'm sure this was encouraged by the way my recruitment materials used the language of 'experience.' They often started the interview by talking about things like 'emotional baggage'. The photos therefore functioned as a technology for shifting the conversation more towards practices, although meanings of illness (such as emotion) are of course important to practices. When I received the photo, I looked through it and made sure I could identify everything on there. I then arranged a time and date to meet with the participant online for an interview.

Ethnography

My methods were ethnographic even if they fall outside of the traditional anthropological ethnographic approach. A traditional ethnography would not have been possible in research conditions under Covid-19 lockdowns. But, as Günel *et al.* point out, Covid-19 restrictions on long term, traditional fieldwork are only the latest in a series of crises in such ethnographic practices (2020). Divisions and boundaries between home and field could no longer be maintained, for multiple reasons, even before I had to conduct my fieldwork from my bedroom. Effort to maintain such divisions implied much about who were researchers were (i.e. personally distanced from the field) and was most keenly felt by gendered and racialized workers, who often have responsibilities which take them away from extended periods of fieldwork. I therefore employed Günel *et al.*'s concept of patchwork ethnography to conceptualise the way I used fragmentary data alongside the 'long-term commitment [...] and slow thinking that characterizes so-called traditional fieldwork' (Günel *et al.*, 2020).

My ethnographic approach was influenced by grounded theory (Glaser and Strauss, 1968; Charmaz, 1990, 2008a, 2008b; Glaser and Holton, 2004; Clarke, 2005), and particularly the version laid out by Charmaz, one of grounded theory's predominant theorists, especially in health research. For a discussion of different versions of grounded theory, see Reichertz 2019. Grounded theory is an emergent method which means that it 'begins with the empirical world and builds an inductive understanding of it as events unfold and knowledge accrues'

(Charmaz, 2008a, p. 155). From the start, the iterative impulse of grounded theory was helpful; it lent theoretical consideration to what I was doing; adjusting my research design according to what I was finding. For, as Charmaz, says, 'by adopting emergent methods, researchers can account for processes discovered in the empirical world and direct their methodological strategies accordingly' (2008a, p. 155). Grounded theory strategies make this method explicit (Charmaz, 2008a, p. 156). This was especially pertinent to the issues of scale and salience of illness experience described in detail above. However, it would not be true to say that I was drawn to grounded theory for what is normally understood to be its foremost tenet: the minimisation of preconceived ideas about the research problem and data (Charmaz, 2008a, p. 155).

Glaser and Strauss's 1967 *The Discovery of Grounded Theory* was the first schematic explanation of grounded theory. Their theorisation of this issue about preconceived ideas is crucial; they instruct researchers to conduct research without preconceptions from earlier theory and research, and yet simultaneously to have a sense of which theoretical leads to examine from data. Glaser still insists on the exclusively inductive nature of grounded theory: 'to undertake an extensive review of literature before the emergency of a core category violates the basic premise of grounded theory- that being, the theory emerges from the data not from extant theory' (Glaser and Holton 2004, p.46). However, Thomas and James (2006) argue that the notion of theorizing entirely through induction is epistemologically dishonest and Reichertz states that 'someone who knows nothing about this world will not be able to say anything about the particularities of the world' (2019, p.13). Indeed, all research takes place within and because of a context. As Charmaz says on this issue, a 'fine line exists between asking theoretical questions and applying extant concepts' (2008a, p. 157). Clarke argues that grounded theory ends up erasing standpoints and differences because of the way it seeks to eliminate what is brought to the research before the research is begun (Clarke, 2005). This is a fair criticism of Glaser's conception of grounded theory. However, Charmaz recognises a long tradition of grounded theorists researching issues they themselves have personal experience of and acknowledges the 'subjectivity of the researcher's involvement in the construction and interpretation of data' (2014, p.14). Nonetheless, she warns researchers in this position that if they 'start where they are at' they 'may risk importing preconceived ideas into the study' and

advises them to engage in reflexivity and invoke grounded theory strategies in order to 'challenge their previously taken-for-granted assumptions' (Charmaz, 2008a, p. 163). A fine line indeed, but it is important to bear in mind how far both of these arguments are from a methodology which starts from a hypothesis, as in common in natural and clinical sciences, a behaviour to be changed, as in behaviour change, or a goal, as in activist organising. Therefore, rather than evaluating how convincing these two arguments are, what has become clear to me is that grounded theory requires, because of the way its theoretical categories emerge from and are grounded in the data (Charmaz, 1990, p. 1162; 2008b, p. 163), an openness which is antithetical to defensiveness.

Coming to the Research: Applying Extant Concepts?

Considering UTI, AMR and especially the concern for the effects of policy mobilisations on AMR set out for me by the project as it had been funded, an issue has been made by patients mobilising online in collaboration with certain HCPs and sometimes other researchers. The issue concerns patients who are undertreated for acute UTI and then, bacteria surviving in their bladder, develop a UTI which will only be treated by antibiotic courses longer than those standardly prescribed within the NHS. The issue then becomes about gaining access through antibiotics, which is complicated by three factors. The first is that what is actually a chronic infection, embedded in the bladder wall, appears to clinicians to be a recurrent infection because of the way embedded bacteria are periodically released as free-floaters into the urine. This leads to treatment of each episode as a new infection, with standard 'short' courses, and attempts to prevent recurrence through a focus on lifestyle behaviours such as diet or hygiene. The second is that diagnostic tests do not pick up on a number of infections, perhaps especially embedded infection, leading to diagnosis with a non-infective syndrome and a corresponding retreat from antibiotics as the solution on the part of HCPs and sometimes, patients themselves. The third is that clinicians are reluctant to prescribe such long courses, whereas the patients involved believe this to be the only effective treatment. Patient groups invest significant resources in ensuring that research findings accord with this issue and sometimes, they are joined by researchers who collaborate in bringing the issue into academic spaces, even as they connect it to wider themes, such as a more explicitly feminist concern with the body.

At the start of my study, I was defensive of parts of this issue, a defensiveness I felt because this was a story that made sense with my own experiences in a way that the clinical story I was getting from my own interactions with HCPs did not. Treating me again and again for new infections did not explain why I kept on getting them or why I had so many urinary symptoms in between episodes. People with experiences like mine did not seem to exist in the clinical story offered to people being treated for UTI. Others will have their own reasons. This defensiveness leads to a situation where research consists in gaining familiarity with the issue, then verifying who does and does not concord with it, and exploring the effects of this. Doing research in this way, there is very little space for new understandings or analyses to emerge. This is significant for several reasons.

Firstly, an ethical reason. Health research, and perhaps especially publicly funded research, is not (or should not be) a commodification of what patients are already saying. Medical sociologists have in the past acted as 'the patient voice', but it is not ethical for researchers to build their careers by reporting within elite circles what patients are already saying on social media. For an engagement with why what researchers say about a research subject is different in nature to what respondents say, consult p95.

Secondly, in terms of praxis, I am concerned by the type of futures that could be enacted by a focus on the maltreatment of patients by HCPs, and eager to allow space for new analyses or understandings to emerge. I came across in the course of my research two instances of places where relationships between patients and HCPs have totally broken down. The first surrounds the use of mesh and the second is Lyme Disease. Both have important connections with UTI; the mesh scandal lies at the nexus of urological care and feminist health, and the Lyme controversy centres around access to antibiotics for an infection that is often perceived by clinicians to have resolved. Polarisation (of one group against other) can be an important tool in building movements against power and anger can have an important role in world-making, and has been carefully theorised in Black radical feminist traditions (Lorde, 2007; Cooper, 2019). However, defensiveness is distinct from anger.

Supervision

Supervision was a space to discuss and reflect on the process of research, especially ethical aspects. The guidance of my supervisors was especially key as I recalibrated my research design around Covid-19 restrictions and ensured that my plans were in line with the aims of the wider project. In Spring 2021 one of my PhD supervisors and the project PI, Dr Catherine Will, began a period of sick leave which continued until September 2022 as I was in the final stages of writing up. Under the supervision of Dr Liz McDonnell and Professor Bobbie Farsides, and the mentorship of Dr Ulla McKnight, I continued to reflect on Catherine's priorities for the project and her presence in absence became clearer as my thinking developed. I came to understand more about the rationales for the project, beyond my own experiences. I am grateful that supervision became a space where I was comfortable to share my uncertainties and vulnerabilities. This allowed me to develop an ethnographic openness to what I might find.

Becoming Open

I am able to identify a moment in the research where I was able to overcome defensiveness and develop an ethnographic openness. This experience led me to believe that efforts to polarise HCPs and patients, with researchers indulging in an antagonistic dynamic, binds patients into a narrow position where all that can be done is police the contours of an issue as it is already established. If I was defensive because of the way that my experiences were met with a clinical story that did not make sense, I overcame this when I met clinicians who met my resistance with no resistance, no answer to my accusations but an open acceptance and commitment to working towards the kind of future I also wanted; one where people with experiences like mine are well cared for. I began to understand my goal as allowing space for new ways to understand and approach the issue of UTI and AMR to emerge. To facilitate a more collective conversation, finding ways to mobilise on AMR taking account of the co-production of the interests of patients, policymakers and HCPs, and building relationships that allow the surrender of defensiveness, and an openness to trying new practices of caring for UTI. A starting point is recognising that although HCPs and policymakers do hold power over patients in important ways, they also will be patients themselves and will have relational ties to patients. In the meantime, both AMR and policy mobilisations against it continue apace, highlighting the stakes of the task ahead.

For me, Charmaz's warnings against starting 'where you are at' (Charmaz, 2008a, p. 163) does not preclude a researcher standpoint. What she argues for is not neutrality but reflexivity. Institutional ethnography (IE) is an approach developed by Marxist feminist Dorothy Smith in the context of the women's movements of the 1980s. Smith was critical of sociological practices which unwittingly promoted institutional interests (Cupit *et al.*, 2021, p. 22). As Cupit *et al.* note (2021, p. 32), although the role of ethnography is increasingly recognised within healthcare, most researchers with clinical roles have conducted research from their own standpoint. Indeed, this is true of most of the qualitative research on patient experiences of community UTI (Leydon *et al.*, 2009; 2010; Duane *et al.*, 2016; Ghouri *et al.*, 2019; Lecky *et al.*, 2020; Gbinigie *et al.*, 2022; Glogowska *et al.*, 2022). Smith explicitly directs 'taking sides, beginning from some position, with some concern' (2005, p.1). The patient standpoint was not a standpoint I adopted, but one I already had.

Institutional Ethnography

Smith describes IE as a 'sociology for people', which was opposed to sociologies 'in which people [are] the objects [...], whose behaviour is to be explained' (Smith, 2005, p.1). Because of this, IE does not aim to produce data, and analytically is not drawn into parts of data, which are concerned with thick descriptions of local culture. In this, it is very different from traditional anthropological approaches, with extensive periods of fieldwork in a specific place. IE does not study people, or even their experiences, but studies how institutional contexts enter into and organise people's lives, producing empirical maps of the relationships between what happens to patients and the routine features of care systems (Sinding, 2010). The analysis of social relations, coordinated by texts [...] and the dominant forms of knowledge embedded in them, [...] are the primary object of study (Cupit *et al.*, 2021, p. 24). Forming part of a long tradition as understanding the margin as a space of 'radical openness' from which we can learn (bell hooks p.156), IE offers a useful set of tools for tracking the work that people on the margins of healthcare do to feel healthy, without further marginalising groups which struggle to access care through identifying and studying them.

IE is done by starting from one person and attempting to track these accomplishments

through the ‘empirically available pathway between service users, producers, administrators and policy makers’ (Sinding, 2010, p. 1657): work. Smith explains that by work is meant ‘what people do that requires some effort, that they mean to do, and that involves some acquired competence’ (Smith, 1987, p. 165). Work is that which is done and achieved, locating IE inquiry in ‘the actualities of what people do on a day-to-day basis’ (Smith, 1987, p. 166). These practices which may be visible as work or invisibilised but is not confined to wage labour or what otherwise renders activity accountable within a particular institutional order (Mykhalovskiy and McCoy, 2002, p. 24). IE populates its empirical maps by asking questions such as ‘what work do people living with UTI do? How are they involved with healthcare?’ This is similar to grounded theorists Corbin and Strauss’ exploration of the three lines of work which emerged from their data on managing chronic illness at home (1985) but work in IE is totally ‘empirically empty’ waiting to be filled (Mykhalovskiy and McCoy, 2002, p. 24). Therefore, it is not bounded by a specific setting but can travel across different settings, an important aspect for studying UTI.

IE is an ethnographic approach because it takes the localised experiences of different people in different places and settings, and produces an insight about the way institutional orders impose standardised frameworks. Through detailed and ethnographic descriptions of what work people do to get good care across different space, and crucially, time, we can see specifically how access is more easily granted for some to others. It is in mapping often-invisible relations and how they co-ordinate people’s everyday lives and experiences that allows the researcher to work in the interest of the standpoint group (Cupit *et al.*, 2021). But IE also has the ethnographic commitment to maintaining doubt about what it is that we want to know about the field in advance. Smith describes how it is the experiences of people in the standpoint location (here patients) that ‘directs attention to a possible set of questions that have yet to be posed or of puzzles that are not yet formulated as such, but are ‘latent’ in the actualities of our experience worlds’ (1987, p.89).

The social world is understood as an ‘accomplishment of human actors’, with IE attending to ‘these accomplishments as they unfold through time, under definite material conditions’ (Smith, 1987; 2005). IE rejects conceptualisations of social structures and social norms because

they reflect a sociality that is external to the 'ongoing activities of actual individuals' (Smith, 1999, p.232). This means that answers to the question of why some groups don't get good care would not be answered by answers like 'misogyny'. Such social structures do shape what happens, but IE directs attention more to what actually happened (Sinding, 2010, p. 1661), in order to 'specify the precise nature of the systemic problems' (Sinding, 2010, p. 1656), why health inequalities arise, why certain groups do not get help when they look for it, or have to do extra work to access it.

There are similarities and major differences between Actor Network Theory (ANT) in the materialist feminisms I have set out, and IE. Both are concerned with the way that forces not easily visible (normally because of the way they have become taken for granted) organise and enact reality. They share a similar ontology which rejects study of how an established social order affects the world, with IE viewing the world 'being produced and brought into being through the social practices of people' (Smith, 2005, p.34) and Latour arguing that there is 'no social force available to explain the residual features other domains cannot account for' (2004, p.4). Because of this commitment to the emergent nature of sociality, being enacted through and not prior to the enactment of the world, both approaches 'privilege practices over principles and study them ethnographically' (Mol, 2002, p. 33). A major difference is that in IE, reality is enacted through practices of people, whereas in ANT, agency without intentionality or cognition can enact reality. A good example is how in IE, text is important because institutions often enact themselves through standardising work across different locations and it is often written documents that standardise and co-ordinate the work across different places. Therefore, studying texts makes visible the social relations that co-ordinate people's work. Importantly, unlike in discourse analysis, in IE texts are active; they not only reflect but also enact work. But in ANT and its successors, such as feminist materialist-semiotics, texts themselves can have agency.

ANT has a generalised symmetry principle which means that 'the same type of explanation should be used for all the elements that make up a heterogeneous network, whether these elements are devices, natural forces, or social groups' (2012, p.124). Therefore, IE's focus on human action is incompatible with ANT. However, it has often been pointed out, including

by Latour, that there is no theory in ‘actor network theory.’ There is no conceptual explanation but a methodological attention to non-human actors.

As detailed in the literature review, feminist science studies has argued that the specific understanding of human and more-than-human relationality presented by ANT marginalises ethical and political concerns. Moreover, because of the generalized symmetry principle, the network must be described before moral or political positions can be taken. Therefore, looking at relational assemblages of humans and non-humans, ANT scholars often ask questions such as ‘how might this patchwork of realities be enacted in different ways?’ (Law, 2007, p.13). Similarly, Giraud calls for ‘an ethics of exclusion’ which pays attentions to ways of being that are foreclosed as other entangled realities are enacted (Giraud, 2019). Thus, politics is always an activity secondary to description of the network, a position which causes Mol to repeatedly imply that it is an activity to which she will at some stage turn, but not here: ‘somehow, questions need to be asked about the appropriateness of various enactments of the body multiple and its diseases. I don’t ask such questions here’ (Mol, 2002, p. viii). She continues: ‘the question this study provokes is how the body multiple and its diseases might be done well. Instead I’ll map out the space in which it may be posed’ (Mol, 2002, p. 7). This repeated deferment of the stakes of doing disease well seems at odds with some of the concerns of medical sociology and anthropology (Pols, 2013; Kingod *et al.*, 2017) and specifically IE, having roots in Marxist feminism, a primary political project to affect material change through an understanding of the precise mechanisms of how things happen.

What I take from grounded theory is the need to overcome defensiveness, to locate in yourself as a researcher an openness to inductive theorising. What I take from IE is a way of taking up the openness of grounded theory within a conceptual frame for taking a standpoint, as well as a way of studying health inequalities without studying patients, and making them hyper-visible. This is especially important for people of colour, immigrants, LGBTQ+ people, people living in poverty, who are often hyper-visibilised and targeted in medicine, and the tabloid press. Working with a standpoint (which I characterise as acknowledging a disjuncture between what standpoint informants know and how they are known, and wanting to change something) is not opposed to grounded theory but is opposed to activism (which I understand

as knowing what it hopes to achieve in advance.)

Data Analysis; Code Development and the Experience of Analysing Data

All of the interviews conducted were analysed using NVivo. I only imported all the transcribed interviews into NVivo once they had all been transcribed. Before this, I had (inevitably) analysed data in my head, and then, taking an iterative approach, integrated knowledge generated in early interviews into later interviews. This is in line with a grounded theory approach because although grounded theory approaches are mainly inductive, they are also 'more than only inductive, because they encourage researchers to make conjectures and check them, and therefore to engage in deductive reasoning as inquiry proceeds' (Charmaz 2008b, p.156). This is how theory is built.

I was extremely familiar with my data, taking time to read over each interview and get to know them. However, I was encouraged by my supervisor to use NVivo for a more formal data analysis period. I began by coding very generally, going through interviews line by line. For example, I developed a code entitled 'time and temporality' to which I coded anything that had to do with time. As I coded to this theme, I began to notice that much of the data I was selecting was people reflecting on the way they (or patients they cared for) had delayed care. In this way, more analytical codes developed from these general codes. Sometimes, I developed a more analytical code title from a descriptive code because I was unhappy with the analysis latently contained within the description. For example, I developed a code entitled 'not being listened to.' I struggled to articulate why I felt that this code did not express the richness of the data. Data analysis overall did not feel like an activity that lent itself to solo working. My thinking greatly benefitted from discussing the theoretical codes that were developing with Dr Liz McDonnell, Esther Rottenberg, Dr Ulla McKnight and Anna Ogunbode but the codes were developed by me. To continue with the example, it was in discussion with my supervisor Liz that we reached an understanding that the idea of 'not being listened to' implies a fixed dynamic between patient and doctor, although it takes a standpoint on how this dynamic should go. Instead, the data I had coded under this code spoke more to people's experiences of getting help through a negotiated order, which contained moments of shifting roles between doctor and patient.

Going through interviews line by line, interview by interview meant that the final interviews were coded next to more codes than the first ones. I found that NVivo helped me to maintain an inductive analysis in useful ways. I was surprised to find that things which I had thought of as very important in my data did not emerge as important from the data coded in NVivo. Codes at this point were still fairly descriptive, although I was building in more analysis as I went along. When I reached the final interview, I reviewed my codes and engaged in a more deductive process, as per Charmaz's guidance. On paper, I made a mind map including all the codes I had developed in NVivo in one colour pen, as well as ideas from notes I had made during the research, and ways of thinking about things that I had developed through the research in a different colour pen. I then went through all my interviews again, coding and re-coding interviews, changing codes, deleting them and creating new ones. Simultaneously, I tried to think about connections between codes and others ideas in order to build up themes and ultimately, a theory.

Corbin describes how grounded theory researchers must go beyond describing the contents of data: 'to become theory, major concepts or themes must be woven around a central or core category to form a highly integrated and abstract framework that explains who, what, where, when and how of a phenomenon' (2011, p. 29). Charmaz agrees that theorizing is important because description and induction alone cannot bring new ideas into the world, cannot make social action comprehensible (2008a). The reason why description and deduction cannot do this is because, as Reichertz states, participants cannot and do not describe and explain what they do and why. People struggle to accurately describe what they do and what they tell others is a part of their image they present to others and with others (researchers) (2019, p.12). Researchers then 'try to discover the social order, the trajectory and meaningfulness of the whole' (2019,p.14), by speculating on things like how their own positionality co-produced research data. Reichertz puts it bluntly but this is a serious engagement with what is an unpronounced premise of nearly all research; 'this is the reason why researchers and not respondents have the last word' (2019, p.19); researchers build a theory from what respondents say. Sitting with the partiality and situatedness of these insights on the part of the researcher is part of a feminist research practice (Haraway, 1988). This is abductive reasoning – theories are not found in the data but created by researchers with much

knowledge and interpretation in dealing with the data.

At the end of this abductive process using a mind map, I had built up several parent codes, from which I mapped codes onto a rough outline plan of the thesis, deciding which data to use where. From this, I developed two themes for my chapters- one which was concerned living with UTI- what people do when they feel ill, including how, when and why they access care. The second concerns resistance- how people, patients, clinicians and policymakers mobilise around UTI and AMR, and construct an issue. The third and fourth considers futures, what good care might be in the centre given what we have found on the margins.

Chapter One: A Disease To Be Treated

Seeking Help When in Pain: Diagnosis

When people feel ill or in pain, one of the things they sometimes do is seek help from medicine. In patient mobilisations, diagnosis appears as a major flashpoint of controversy amidst worries about how diagnostic technologies impede people from getting the help they need. Patients mobilising online around UTI often identify an overreliance on pathology to the detriment of clinical care or the patient story, as they experience symptoms that look, smell or feel like a UTI but tests don't find bacteria. Against this rather Foucauldian background, I explore participants' (both those in touch with patient mobilisations and those not) experiences of seeking help and what happened in the process, alongside analysis of how diagnosis is enacted, co-ordinated and routinized (Mol, 2002; Berg, 1992) in clinical guidelines (Moreira, 2005, p.1975). To do this, I draw extensively on Mol's work in *The Body Multiple* (2002) which sees disease not as a stable entity, looked onto from different perspectives by patients and clinicians, but as a multiple accomplishment of many parts coming together. This chapter contributes to the developing field of sociology of diagnosis (Jutel, 2009) by arguing that in practice, diagnosis is teleologically related to treatment, rather than the opposite, which is the logic pictorialized in diagnostic pathways. This includes an argument against (mis)diagnosis in itself as a focus of scholarly attention, instead directing attention in the next chapter to processes through which neglected others are excluded from care (Puig de la Bellacasa, 2011). The concern in this first chapter is with one of the things that people do when they get ill, that is, seeking help from medicine. An exploration of what happens outside of the clinic follows in later chapters.

Several participants told me of their experiences of receiving a negative test result:

Liz: I went back to the doctor and they were like, oh it's a UTI. I got three days of antibiotics. It didn't do anything. I then went back, I got seven days. It didn't clear it. And then by this point my testing, my dip tests and my, I think the culture, was showing as there was nothing wrong with me. So I was left in an awful state by my GP who had decided to tell me it was just my anxiety which was horrific to hear.

Natalie: They kept telling me I didn't have one and I was losing my mind. 'Cause I knew I had one. I can feel it. I'm the patient. I can feel the symptoms. I know what I've got. Don't tell me I haven't when I have.

Nicole also received a negative test result:

I've had this happen to me lots of times. I know that I've got an infection, I can feel it, I'm living with it, but my, my sample gets sent off, but it comes back. "No further action required." And then you're just kind of left. So I think with this, it is quite misunderstood and, they almost, I don't if they don't believe you... that's what it feels like a little bit, that they don't believe you 'cause you've gone back so many times and they're telling you almost "the computer says no. The computer says no."

These controversies centre around who is believed about the reality of UTI: *'I know that I've got an infection, I can feel it'*: *'I'm the patient. I can feel the symptoms. I know what I've got'*. Reality is mediated by diagnostic technologies and captured in a diagnostic category. For some people, diagnostic technologies and the patient story coincide; the patient describes a UTI, tests indicate a UTI and this is unproblematic. But in the extracts above, pathology and the patient story are no longer signs of a single, unified object: a UTI. Moreover, the patient story is not enough to counter the objectivity of the technology: *'the computer says no'* and symptoms are not real in that they are psychological: *'my GP had decided to tell me it was just my anxiety which was horrific to hear.'* The patient story and the pathology seem to point to different things. This moment carries a lot of anxiety in mobilisations around UTI, which Liz, Nicole and Natalie were all in touch with. One way to resolve this clash between the clinic and pathology is to discard either the patient story or the diagnostic testing. Maybe the patient is mistaken, imagining the pain, lying, or at the very least, experiencing psychosomatic symptoms. In that case, *pathology* has primacy. Or maybe the testing is inaccurate, unspecific or insensitive to the reality of UTI and the *clinical* has primacy.

Diagnosing a UTI

Patient mobilisations often make this move of questioning pathology by stressing how diagnostic technologies access the reality of UTI in practice. The current gold standard test for UTI is the midstream urine (MSU) culture. The suggestion that an un-cultured UTI may underlie continuing symptoms has appeared in journal science since the 1980s (Stamm *et al.*, 1982; Maskell *et al.*, 1983). Standards for Microbiological Investigations (SMIs) co-ordinate laboratory standards for the testing of urine across the four nations of the UK. Urine microscopy is recommended for all symptomatic patient groups with the presence of white blood cells (and sometimes also red blood cells, and epithelial cells) used as a criterion for

urine culture³ (UKHSA, 2019, p.17). The SMI describes how ‘in a carefully taken specimen, significant pyuria correlates well with bacteriuria and symptoms in most patients to suggest a diagnosis of UTI. Significant pyuria is defined as the occurrence of 10^7 or more WBC/L (10^4 WBC/mL), although higher numbers of WBC are often found in healthy asymptomatic women. A level of $>10^8$ WBC/L ($>10^5$ WBC/mL) has been suggested as being more appropriate in discriminating infection’ (UKHSA, 2019, p.17). Labs have local authority over the thresholds used between $>10^8$ WBC/L and $>10^7$ WBC/L.

Once the decision has been made to culture a specimen, the SMI describes the process for the interpretation of culture thus:

Studies conducted in the 1950s remain the basis for interpreting urine culture results showing that bacterial counts of $\geq 10^8$ cfu/L ($\geq 10^5$ cfu/mL) are indicative of an infection and counts below this usually indicate contamination [...] In specific patient groups, counts between 10^8 cfu/L (10^5 cfu/mL) and 10^5 cfu/L (10^2 cfu/mL) may be significant. A pure isolate with counts between 10^7 and 10^8 cfu/L (10^4 - 10^5 cfu/mL) should be evaluated based on clinical information or confirmed by repeat culture. Overall the confirmation of a UTI requires the demonstration of significant bacteriuria by quantitative culture (defined according to patient group or specimen type). Routine culture methods may not be sensitive enough to detect low bacteria levels (eg $\leq 10^7$ cfu/L / $\leq 10^4$ cfu/mL) and increased sensitivity will be achieved by increasing the inoculum size [...] Increased inoculum sizes are also required for persistently symptomatic patients without bacteriuria if the patient has recurrent “sterile pyuria”, or for specimens where lower counts are to be expected (UKHSA, 2019, p.20).

Patient mobilisations argue that these testing processes are unable to grasp the reality of UTI. CUTIC, the Chronic Urinary Tract Infection Campaign, states this on its website and argues that a clinical history is the best way to access a diagnosis: ‘Relying on inaccurate tests sees many thousands of UTI sufferers misdiagnosed or even dismissed as ‘problem patients’ [...] The most useful thing that doctors can do is to listen to their patients and ask them detailed questions about their symptoms and how they started’ (2022).

Critiques often include reference to the age of the data upon which thresholds for classifying a UTI are based (Kass 1957) but this is accompanied by un-bracketing how these diagnostic

³ Although there are exceptions to this criterion, such as in immunosuppressed patients.

processes are done in practice. In this, patient mobilisers join a tradition of patient activists who blur boundaries of credibility making and divisions of responsibility in the production of biomedical knowledge (Epstein, 1996). Problems identified for testing technologies in capturing the reality of UTI include:

1. False assumption of sterility of bladder: Kass' technique was developed before the 'discovery' of the urinary microbiome, the finding that 'almost every adult female studied to date is bacteriuric' (Hilt *et al.*, 2014; Brubaker and Wolfe, 2015; Finucane, 2017b; 2017a; Price *et al.*, 2018, p. 206). Therefore, the Kochian assumption of a correlation between abundance of colony forming units and causation of symptoms is doubted (Malone-Lee, 2021, p.101). Within newer models of the urinary microbiome, a UTI may be better understood as a dysbiosis rather than an invasive colonisation (Price *et al.*, 2018; Neugent *et al.*, 2020; Worby *et al.*, 2022).
2. Different populations: Kass' work was based on specimens from women suffering from acute pyelophronitis, and women who had asymptomatic bacteriuria in pregnancy (1957).
3. One species perspective: Kass' original description of the technique of plating 1 μ L of urine onto Blood and MacConkey plates and incubating aerobically at 35°C for twenty-four hours (Kass, 1956) remains largely unchanged, although the media used in NHS labs is now more likely to be specialist and proprietary. Nonetheless, the technique was designed to culture aerobic gram negative organisms, especially *E.coli*. As Price *et al.* point out, 'given that standard urine culture was designed to detect *E.coli*, its results affect broad epidemiological statements concerning UTI' (2018, p. 207). This means that colonisations of more fastidious organisms may not be culturable on a standard urine culture and poly-microbial UTIs may be underestimated as mixed growth is often dismissed as contamination of the sample (Price *et al.*, 2018, p. 207) (Malone-Lee, 2021, p.104).
4. Testing of free floating urine: a urine culture and a dipstick test a specimen of urine from the bladder in order to test for the 'presence and multiplication of

microorganisms...with associated tissue invasion' (UKHSA, 2019, p.9). Testing urine is therefore a proxy. However, there is evidence that bacteria may evade both immune surveillance and antimicrobial action by invading the epithelial lining cells of the bladder (Mulvey *et al.*, 2001; Maskell, 2010; Horsley *et al.*, 2013; Lewis *et al.*, 2016; De Nisco *et al.*, 2019). Patient mobilisations therefore argue that Chronic UTI has a different pathophysiology to acute UTI, making testing inappropriate (Malone-Lee, 2021, p.127).

This is the background of anxieties about the relationship between care and diagnostic technologies: doubts surround the ability of diagnostic technologies to capture the reality of UTI. I started my exploration of what happens when people seek help from medicine by asking participants about their memories of the first time they did this. Many participants remembered this first experience in detail.

Becoming a Patient

Minna told me:

Erm well, the first time I actually got it, I didn't know what it was because I never had a UTI before. And I just had like, really strange symptoms that came out of nowhere. I was like, had high fever and weird like tingling, stabbing, pain in like my lower pelvis and like towards like the pubic bone. And there was something strange and I had to go to toilet all the time, but it was like stinging. I was like, have I like cut myself when I've been shaving or something like, is there something, you know? And then I phoned the doctor and they were like, oh, that sounds like a UTI. I was like...I had like.... I had to Google what it was.

Sophie also remembered the experience in detail:

Yeah, so I had my first one in 2012 and I mean, my memories are quite hazy. What I remember is I didn't know what it was. And I went, the thing that I remember is, I went to the toilet, I was with my friends in a restaurant, and I went to the toilet and I just remember being like, I can't leave the toilet. I don't remember... definitely the symptoms weren't the same as they are now, but I just thought, I can't, for some reason, I can't get off the toilet. I had no idea what it was. I don't know if I'd even ever heard of a UTI. So, I spent ages in the toilet and then I eventually came upstairs and everyone was like, what's wrong with you? And then [...] it took me a very long time to get any treatment because I didn't know what it was and the symptoms weren't so severe that I rang the doctor immediately or something. So it went on and on. It probably took me two weeks to speak to a doctor.

There are several things to learn from these excerpts. The first thing to note is that even people who sometimes refer to themselves as 'UTI patients', did not seek help for a UTI. They sought

help from their GP for painful symptoms. They feel pain and sooner or later (later in Sophie's case), describe their pain to a doctor who diagnoses them with a UTI: a clinical diagnosis. Both Sophie and Minna only became a UTI patient by going to the doctor because of pain. Note how both Sophie and Minna look back at what was happening to them, the pain that felt like a shaving cut, and the feeling of not being able to get off the toilet, and refer to this feeling when asked about the first time they got an infection. But this is working backwards and incorporating those experiences as symptoms of what became enacted as a UTI. If they had never gone to a doctor, they would not have become a UTI patient.

Not everyone visits a doctor every time they feel ill. Outside of the clinic, sometimes people have pain that feels like a shaving cut or feel that they cannot leave the toilet, and they do not seek help from a doctor. People who never become a UTI patient but experience urinary pain that might have led them to be diagnosed with a UTI, had they come into the clinic, were always less likely to be captured in my sample. However, a UTI can be enacted outside of the clinic. For instance, Steph, described her first experience with UTI thus:

Steph: *'I think I was nearly 19 when I first got one.'*

Eleanor: *'And what happened then?'*

Steph: *'That's the first time I ever had the burning pain. It absolutely killed; I was very bloated as well. It was like my stomach was on fire.'*

Eleanor: *'Do you remember where you were?'*

Steph: *'Er, I think the first time I noticed I must have been in someone's house because I tried, 'cause I thought I needed the toilet and then nothing happened and I was very confused. I rang me mum actually.'*

Eleanor: *'And what did your mum say?'*

Steph: *'Yeah, she used to be a nurse so she just said it's probably this. Get a doctor's appointment and go and get some cranberry juice and you'll be fine.'*

Eleanor: *'OK yeah and then is that what you did? You went to the doctors?'*

Steph: *'Yeah, uh, huh.'*

Eleanor: *'And was that when the doctor told you it was an infection?'*

Steph: *'Yeah they did a urine sample and then they just give me the antibiotics.'*

Steph's pain had been enacted as a possible UTI before she saw the doctor, but note how this is referenced by Steph to be due to her mother's proximity to healthcare. When she sees the doctor, a urine test is performed and Steph describes the enactment of a UTI via the prescription of antibiotics.

We do not know exactly what it was that Minna or Sophie or Steph said and did not say that led them to be diagnosed with a UTI. We know from policy documents the types of things the HCP should have had to understand, according to policy, in order to diagnose a UTI and to exclude other diagnoses (UKHSA, 2002b). According to NICE and UKHSA, UTI in this patient group can be diagnosed entirely clinically when patients describe things which cause the HCP to rule out urethritis, vaginal discharge, STIs, and genitourinary syndrome of menopause, as well as describing (or the doctor observing) at least two of three key diagnostic signs/symptoms: dysuria, new nocturia and urine cloudy to the naked eye. When people describe only one or none of these three key symptoms/signs, diagnostic technology in the form of a dipstick is enlisted to participate in the diagnosis. But even when diagnostic testing is used⁴, the clinic has primacy in this area of medicine because it is only people who came to the clinic complaining of certain types of pain who have their urine dipped and become UTI patients. The patient story is therefore not external or additive to the practices of enacting disease through diagnostic technologies, it is integral: it 'either opens up or forecloses further moves along the diagnostic and therapeutic track' (Mol, 2002, p. 41).

⁴ Very few of my participants aside from Steph could recall whether diagnostic technologies such as dipstick testing were involved in their first diagnosis of UTI and this probably reflects an untellable experience in the sense that they were diagnosed with a UTI regardless.

Figure: UKHSA /NICE Diagnostic Algorithm for UTI in Primary Care

Diagnosis of urinary tract infections: quick reference tool for primary care

Flowchart for women (under 65 years) with suspected UTI

Excludes women with recurrent UTI (2 episodes in last 6 months, or 3 episodes in last 12 months) or urinary catheter^{1D,2D}

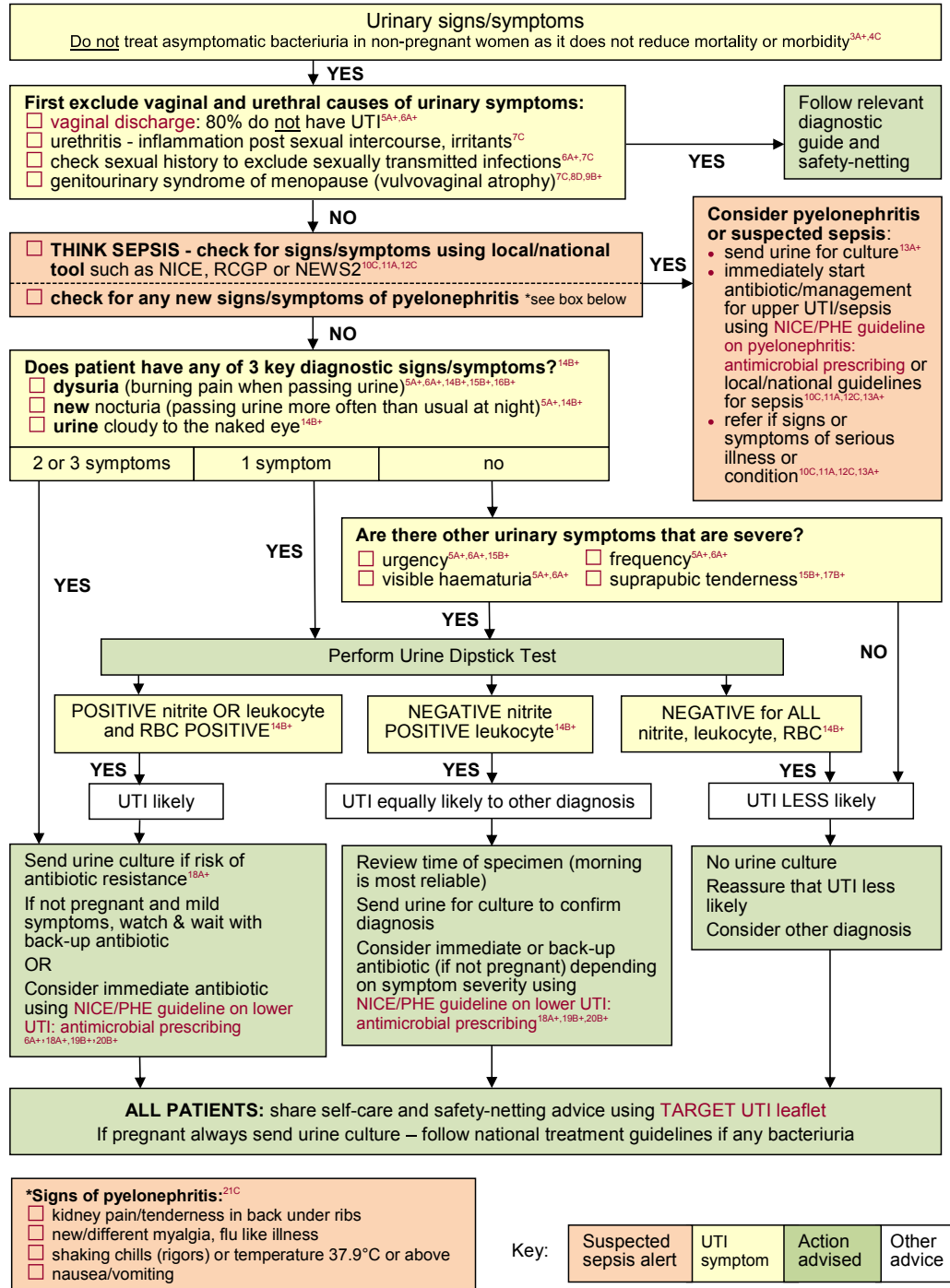


Figure 1- NICE/UKHSA Diagnostic Algorithm for UTI in Primary Care. Crown Copyright UKHSA.

Who is the UTI patient?

Notably, diagnosis takes account not only of what the patient says and what the doctor sees, but also who the patient is. This UKHSA/NICE UTI diagnostic algorithm is designated only for use in women under 65 without a catheter, providing percentage figures of the likelihood of a UTI *in this patient group* given clinical information and results of diagnostic tests.

Participants often drew attention to the ways in which who they were opened up or foreclosed certain diagnostic paths. Sophie told me how her age participated in what HCPs felt was likely to be causing her pain:

They think, oh, we've got loads of these students, they'll get UTIs all the time. But also, it was very stark, when I was young like that when it first started, every single time [...] they'd say oh, we need to rule out chlamydia so every single time they'd do a chlamydia test. They don't do that anymore, but when I was young, they would.

It is not only who you are or what you say that is important to enacting disease. It is also how you are perceived by others. Aleks is transmasculine, and described his most recent experience of seeking care for UTI thus:

When they were asking me the diagnostic symptoms and things, trying to diagnose me over the phone or whatever, the man I was talking to was like, 'oh, do you have any burning or swelling', and I'm like, 'yeah, there's pain', and then he was like, 'do you have any swelling on your scrotum?', because he could only hear my voice and not see me, and I guess he didn't see anything else on my record. And I panicked and I said, 'I don't have that', and there was just a silence for like thirty seconds and he was like, 'you don't have that?', like the most terrified I've ever heard somebody. And I was like, oh no, yeah, I had to very nervously explain what trans people are to him or that I am one. And after a minute or two, I think he understood what was happening, but that was just a very weird little moment, and eventually they had me go into another level of the facility to do the sample, and then just prescribed me the antibiotic, so that was the whole process.

Hearing what was perceived as a male voice on the phone, the HCP begins a clinical diagnosis by asking questions about the scrotum, setting off down quite a different diagnostic path. When the HCP is corrected that he is talking to a trans person, he readjusts his diagnostic track, a UTI is diagnosed, and antibiotics prescribed. Therefore, it is not only what a patient says or does not say which enacts a clinical diagnosis, but also what is understood by the HCP

and who the patient is, as well as who they are perceived to be. These are all clinical tools used to enact a diagnosis.⁵

Many participants reported that their HCPs felt that a UTI was totally normal for women, as Tanya says: *'I've got my GP surgery telling me that I'll grow out of this and that it's quite normal for a young woman to be affected like this.'* Abigail said: *'It wasn't even discussed. I just got lots of infections when I was pregnant and they were just like, oh, well, you know, that's what happens when you're pregnant, you get lots of UTIs, that's just normal. But I had a lot of UTIs. But, yes, even then, it wasn't really discussed.'* Anna concurred: *'But it's just, it's just that thing of, getting past that thing of there's nothing wrong with you. You know, you know, just go home and drink a lot'.* For participants, these expressions of the 'normality' of UTI on the part of their HCPs formed part of an explanation of why there was limited help available despite what they experienced as a heavy burden of illness: because HCPs considered that UTI is to be expected in women and is therefore barely pathological, barely a disease to be enacted. Therefore, pain becomes clinically insignificant – it might still be important to manage pain in itself but urinary pain in a young woman points to little wider pathology.

Using clinical risk categories in this way is a key technology of clinical medicine in diagnosing and creating UTI patients and then setting them off down a therapeutic pathway. It is a key way in which care is provided for patients who come into the clinic seeking help for pain. It is the way to get help for pain. It is also a way in which help fails to materialise, through perceptions of pain as clinically insignificant. The 'subjective' patient story is not additive to the facts of diagnosis, even when 'objective' diagnostic technologies are involved. However, the patient story is not taken at face value. Patient perception of pain, as well as HCP perception of patient pain, in addition to who you are, and who you are perceived to be, all participate in the enactment of disease. Categories of race, class, gender and age which are always already lived together in endlessly proliferating ways by people differently positioned

⁵ Importantly, this is not bias. Bias suggests that there is a disease waiting to be enacted and who the person is, or who the person is perceived to be, affects whether the disease is enacted or not. Here, there is no disease waiting to be enacted prior to clinical considerations which include how the person is perceived.

in specific societies, participate in the enactment of disease. These are durable categories which do not exist in nature but emerge in relationality.

Diagnostic Technologies in the Clinic- Dipsticks

In the clinic, it is when the patient articulates complaints specific to UTI that the HCP starts to look for signs of the urinary tract infection they expect to find. This very routine is standardised in policy by the NICE/ UKHSA diagnostic reference tool. For, although the patient attends complaining of urinary symptoms, this diagnostic tool starts from 'suspected UTI' (UKHSA, 2002b) – the HCP is already looking for the signs of the disease they expect to find. As above, who the patient is perceived to be participates in the HCP's expectation; UTI is a very common diagnosis in the patient group enacted by the reference tool. Sometimes, there is clinical doubt about the diagnosis of UTI, when fewer than two of three key diagnostic signs are understood by the HCP to be present. In this case, a dipstick is enrolled to participate in the diagnosis. Notably, a urine dipstick does not give a positive or a negative result for UTI. The dipstick tests for the presence of nitrites, leukocytes and red blood cells (RBC) in the urine. Importantly, it is expected that the outcomes of these tests may not coincide with each other. But this does not imply incoherence. Instead, the outcomes are drawn out of their signifying role. Instead of being signs of a single disease (UTI) underneath, they signify different, multiple objects: nitrites, RBC, leukocytes. Therefore, one measure may be negative, another positive, and neither needs to be discarded in order to make sense of a single diagnosis, for they are measures of different objects, not of UTI. But, they may be co-ordinated to form a single one. A positive test outcome for one of these is a reason to treat, two is more, three is even more. Mol conceptualises this form of coordination of clinical care as addition (Mol, 2002, p. 68), emphasising that adding and subtracting test outcomes does not attempt to explain how they 'hang together inside the body. Forget about the body. Just add up your findings' (Mol, 2002, p. 68). The addition and subtraction of dipstick test results is then joined by other additions or subtractions. HCPs are advised to consider factors such as symptom severity, if the patient is pregnant or not, and the timing of the sample in deciding how to treat. These factors are added or subtracted not to the likelihood of there being a UTI there underneath, but to the consideration of whether to treat or not, and whether to treat immediately or to 'watch and wait.' Therefore, the task of the HCP is not to create singularity by reference to a

pre-existing singular object in the body (a UTI). Instead, it is to create what Mol calls a 'composite object' out of 'the disease to be treated' (Mol, 2002, p. 70) and what Berg earlier called 'a solvable problem' (1992, p.155). Looking back at the flowchart, labels 'UTI likely', 'UTI equally likely to other diagnoses' and 'UTI LESS likely' are incidental to the 'action advised' which is not aligned with the enactment of the disease beneath, but from the addition and subtraction of multiple potentially contradicting signs of a UTI that should be treated or not. Therefore, the question is not 'what is the matter?' but 'what to do?' (Mol, 2002, p. 69; Berg, 1992, p.155).

Why then, if a dipstick does not provide a negative test result for UTI, are diagnostic technologies so often identified by patients as a major problem in clinical care? Liz told us why:

By this point my testing, my dip tests, and I think the culture was showing as there was nothing wrong with me. So I was left in an awful state by my GP who had decided to tell me it was just my anxiety which was horrific to hear because, one, I work in mental health and I know what anxiety is and what it isn't. And they kind of just left me, to be honest.

Enacting a composite whole, 'the disease to be treated' out of multiple potentially non-coinciding signs is a task (Mol, 2002, p. 70). But as already outlined, the HCP is already looking for signs specific to UTI because that was what they expected to find, especially in this patient group that the patient is perceived to belong to: women under 65. This highly clinical diagnosis of UTI is used as a starting point, rather than symptoms themselves. This is pictorialized in the diagnostic pathway which is labelled 'Flowchart for women (under 65 years) with suspected UTI' (UKHSA, 2002b). From this starting point, the task of enacting a 'disease to be treated' other than a 'UTI to be treated' would be tricky. Therefore, when signs do not add up to 'a UTI to be treated', the flowchart ends with 'reassure that UTI less likely' and 'consider other diagnosis.' No 'disease to be treated' has been successfully achieved, only a disease *not* to be treated: antibiotics will be not prescribed for a UTI. This is the opposite of what happened to Steph when she described the enactment of a UTI through being prescribed antibiotics. Thus, Liz says: the dipstick was '*showing as there was nothing wrong with me*' and describes feeling abandoned. Therefore, in my analysis, a problem with the relationship between diagnosis and care for urinary symptoms is not about the dominance of diagnostic technologies, but about the dominance of one clinical diagnosis (UTI) over that which clinical

diagnoses depend on: symptoms. Liz felt abandoned because no help for her painful symptoms was available following a negative test for leukocytes, RBC, nitrites.

Selecting Signs: Urine Cultures

This routine of reaching for UTI as a diagnosis and expecting to find it when presented with urinary symptoms is standardised in the diagnostic pathway provided by UKHSA and NICE. But how are signs selected? After all, most urine dipsticks test for a lot more than RBC, leukocytes and nitrites. When Mol says ‘Don’t try to explain how they hang together inside the body. Forget about the body. Just add up your findings’ (Mol, 2002, p. 68), this is how she finds clinical care being done in practice. Here, we can see that it is also how care for UTI in primary care is co-ordinated in policy. But what counts as an addition or a subtraction, and in which combination? The fully referenced flowchart calls on an evidence base to calibrate which signs are relevant. In clinical care, as I have just shown, calibration is towards a ‘disease to be treated’, an answer to the question ‘what to do?’ But in the selection of which signs are relevant, signs are calibrated around which ones have the most predictive value of a microbiologically confirmed UTI (UKHSA, 2020, p.23; Little *et al.*, 2010). The dipstick is validated against another diagnostic technology: the urine culture. Therefore, although the ways signs are used clinically may not be concerned with explaining how they hang together inside the body, the selection of such signs is. The selection of signs seems to grasp at a singular, coherent ‘microbiologically confirmed’ UTI underneath.

So does this imply that the UTI enacted in the clinic is of a lesser reality than the UTI in the laboratory? This would suggest that if only we could innovate technological ways to bring the laboratory closer to the GP surgery, we would have a better grasp on the reality of UTI. We could better match the people who come in describing pain that seems specific to a UTI to those whose urine would sprout a significant growth of bacteria on a culture dish. Is it that the UTI of the laboratory is more real than the UTI of the clinical story? Again, patient mobilisations gather around this issue: resisting the ways that pathology seems to have dominance over the clinical.

Ontologically Multiple UTIs

In some sites, the pathological does have dominance over the clinical in enacting UTI. Emily, a consultant microbiologist who runs a NHS diagnostics lab in a large urban hospital, describes how clinical concerns are often irrelevant to who becomes a UTI patient in the hospital:

We process in our lab, or we receive in our lab, about five or six hundred urine samples a day. A day! So, about half of them are from the community and about half of them are from the hospital. Now I am utterly confident that there are not 300 patients a day coming through ED that have a suspected UTI, so...

In the hospital, pathology alone often decides who becomes a UTI patient. When I visited an NHS diagnostics laboratory, Alice, the consultant microbiologist, met me at the coffee shop near the entrance to the hospital. Families and patients milled around; the coffee shop and the atrium was familiar ground – we could all relate to what happened there. Alice picked me up, walking fast, and we wound through different parts of the hospital, the pharmacy, the cash desk, out through a back door to a car park. We stopped at the consultants' car park, an easy access point to the hospital for late night on-call arrivals; the doctors are essential to care. But looking across the car park, Alice pointed out a huge building also fairly close to the door to the hospital building. The size of the building was striking, it mirrored the hospital building across the car park. But patients don't go there. When we entered the pathology centre, a 'centre of excellence', looking out from a viewing platform, the laboratory is an impressive vista of huge, multi-million-pound flashing and beeping white machines and people walking around in white lab coats. If the hospital atrium had seemed starkly new and expensive in the middle of a deprived neighbourhood, looking out over the pathology centre depicted a scene of huge investment of public resources. I went down onto the urine benches and watched as urine was delivered to the lab from the community and from the hospital. The urine, in test tubes, goes through urine microscopy, images flashing up on the computer screen next to it: those with visible RBC and WBC passed along for culture.

I sat on a chair at the computer next to a biomedical scientist as she viewed an image of the culture plate, looking for 'pure growth' occasionally comparing it back to the plate, and issuing a result. The hospital lab is where pathology is done; the patient doesn't go there, urine is taken from the patient, cultured, and a report is sent back to where the patient is,

recording if there was significant bacterial growth or not. This is what a UTI is in this site, compared to the UTI in the GP's surgery which can be pain on weeing, visibly cloudy urine, and newly needing to wee at night. And yet, all of the microbiologists I spoke to emphasised a task that went beyond enacting the reality of a 'disease beneath' on a urine culture. There seemed to be some ill effects of pathology alone deciding who becomes a UTI patient. Tom, a consultant clinical microbiologist told me:

People were dipping urine for all sorts of reasons. We said, well, don't send it to us, if you don't think they've got a UTI, because we'll grow stuff.

The dipstick is used in the hospital not only for those patients who come in complaining of pain which seems specific to a UTI, but for '*all sorts of reasons.*' Therefore, in the hospital, the dipstick calibrated to a urine culture is not used to enact a composite object 'UTI to be treated', out of the addition and subtraction of symptoms and signs, but indicates the likelihood of a possible positive urine culture. When this positive urine culture comes, Tom struggles to enact UTIs to be treated out of these results produced in the laboratory: the UTI to be treated is more than just growing stuff on a urine culture. As Alice also told me, this often involves chasing clinical details after the fact: '*With hundreds of urines going through, I can't chase those. So, you know, sometimes I'll write comments on saying, you know, unable to interpret due to poor clinical details, or, please help us by giving us better clinical details.*' Deciding what to do, enacting a disease to be treated, is a task; Alice asks for help.

For this reason, the report that is sent from the lab back to where the patient is varies from site to site as actors tinker with different ways to best achieve the task of enacting a composite object of a 'disease to be treated'. Many of the microbiologists I spoke with told me about experimenting with different ways to enrol other HCPs in the task of successfully enacting a 'UTI to be treated' out of the data they produce in their labs. For example, Emily told me that in her lab:

we report out urine culture results with antibiotic susceptibilities released, and you know, there's lots of research saying that that's such a strong cue for prescribing. You know, down to the order that you release the antibiotic susceptibilities in. Like our lab system is defaulted (and we can't change it, unfortunately) to report all the antibiotics in alphabetical order, but we know that that means that people will just read the top one. You know, that, just order that you report in even. So, even if the order impacts that person's decision making, it's such

a strong cue for antibiotic prescribing. And we've changed things, like a few times over the year we've dabbled with a few bits and pieces. Like for example not reporting any susceptibility results on certain samples or patient groups and I still do that occasionally.

Emily attempts to emphasise that the growth on the culture plate is not the reality of the 'UTI to be treated', which is a composite object made up of much more including symptoms, clinical categories, bacteria on culture plates and potential treatments. She wants people to consider that just because they have received a culture and susceptibility report indicating growth, they do not need to prescribe antibiotics.

Therefore, the UTI on a urine culture is not closer to the reality of a UTI than a UTI on pain on urinating, urine cloudy to the naked eye and newly passing urine at night. In primary care, people enter the clinic seeking help for pain and it is only those that enter the clinic articulating complaints which seem specific to UTI who will become UTI patients. In primary care, it is the clinic which leads in enacting a UTI even as diagnostic technologies also participate. But in the hospital, or in other settings where people are already in contact with medicine for other reasons, such as care homes, what often happens is akin to screening of the hospital population for a UTI. And yet, as Emily points out, all the samples are processed together, about half from the community and half from the hospital. How do these ontologically multiple UTIs hang together as UTI? Just underneath the title 'Flowchart for women (under 65 years) with suspected UTI', the flowchart draws attention back to urinary signs/symptoms as a starting point (even though a UTI has already been selected) and warns: 'Do not treat asymptomatic bacteriuria in non-pregnant women as it does not reduce mortality or morbidity' (UKHSA, 2002b). This warning reminds us that what makes UTI hang together as one is not the disease beneath, but what to do. In the absence of symptoms, the answer is to do nothing. The work achieved by the 'microbiologically confirmed UTI' appears to contradict this. But, as the rationale for the development of the diagnostic pathway explains: 'No symptoms or signs or combination was able to confirm UTI with absolute certainty [...]. Therefore, the steering group discussed and agreed that a strategy of using a combination of clinical score and urine dipstick will optimise correct use of antibiotics' (UKHSA, 2020, p.23). Therefore, the question again here in this site (even as it is not stated in these terms) is not 'what is the matter', but 'what to do' and more specifically, whether to prescribe antibiotics

or not. Diagnosis does not mediate treatment, as might be expected from the directional flow of the diagnostic pathway, travelling from symptoms down through diagnostic technologies, to end at treatment. Instead, here, treatment mediates diagnosis. This is perhaps most explicit as both Alice and Tom, independently of each other, identify the treatment as useful for the diagnosis:

Tom: I mean, if you're really sure you're getting better with antibiotics, then great. I'm not going to say that you don't have infections, and we suspect that 20 per cent of infections are culture negative, we don't know why that is. So I'm not too...you know, just because you can't grow bugs, I don't really have a problem with saying they do have...they might have an infection.

Alice: I mean from my point of view I always say a really good test of whether or not you've got the right diagnosis is if they get better on the antibiotics.

We might consider that what they identify as the work antibiotics do in revealing if '*they might have an infection*' or testing '*whether or not you've got the right diagnosis*', is in fact the work of demonstrating if the patient would benefit from antibiotics. The ontological status of UTI is multiple, a UTI is different in the GP's surgery than it is in the laboratory, and it is different again in A & E or in a care home. And yet, they hang together and can be co-ordinated across each other. The ontological status of UTI in clinical policy does not grasp at what UTI is by nature everywhere, but in specific sites. A problem, then, is the way that the question of what to do to about urinary symptoms turns so centrally around whether to prescribe antibiotics or not (which is why it can so easily be transformed into a question of if a UTI underlies symptoms or not), rather than what to do about often painful and intrusive urinary symptoms.

It seems that AMS interventions may have the potential to exacerbate this. Certainly, a technology such as the NICE/ UKHSA diagnostic pathway is understood as an AMS intervention because of the way it focuses attention upon whether the patient is likely to benefit from antibiotics or not. But here I have begun to explore the consequences or side effects of the insertion of such a technology into the clinical encounter – pulling UTI out of urinary symptoms in such a way may work to foreclose other ways of caring for painful bladders. On the other hand, or maybe even moreover, a key finding from my literature

review of qualitative studies of patient experience of UTI was that there was a lack of care outside of antibiotics long before AMR appeared as a key concern.

Nothing Coheres – It's a UTI or Nothing

On the urine benches in the microbiology lab, the only disease to be treated that can be enacted is a UTI. In the GP's office though, painful urinary symptoms may lead the HCP to look for signs of other diseases they expect to find, and a different disease to be treated is enacted. We saw the beginning of this process with Aleks, and how it quickly changed direction once the HCP understood more about the gendering of Aleks' body. But sometimes, no disease to be treated is enacted, nothing coheres to form a composite object. Sometimes this does not present much of a problem, as when Olivia told me about her experience:

I guess I haven't had one in quite a while, but I'm just trying to think about the last time I did, I think it was about a year ago. I can't even really remember, it was just...I think it was kind of I'd slept with someone new, felt irritation, I kind of panic about these things as well, like I'm a bit of a freak with things like that, so I'm always...like as soon as I think there's something not right, I'll go down to the clinic. But yeah, I think I'd slept with someone new, just wasn't feeling right, and then went and got checked. And that time I think it didn't end up being a UTI, it was completely fine, but I had similar symptoms to that before, so it was just irritation, I felt like I needed to go to the toilet loads but actually didn't need to, and that's what I've experienced in the past as well, so there's been a few occasions like that. But yeah, I think in the past, not that particular time but in the past I've taken antibiotics to help clear it up and I think before as well I want to say that...I want to say that it went away on its own, but I'm not sure if that's just me remembering it incorrectly.

Olivia, like Minna and Sophie, felt painful symptoms and consulted a doctor. In fact, she had symptoms very similar to Sophie, who also described being unable to leave the toilet. But a UTI was not enacted. In fact, nothing much was enacted: '*it didn't end up being a UTI, it was completely fine.*' Unlike Liz and Nicole, Olivia does not make much distinction between the times she has experienced these symptoms and been prescribed antibiotics, versus the times she has left the practice empty handed: '*I think in the past, not that particular time but in the past I've taken antibiotics to help clear it up.*' Olivia's focus is on the symptoms, and sometimes she uses antibiotics to help stop them. Not a UTI to be treated nor anything else coheres out of Olivia's symptoms but this is not a problem; Olivia went home satisfied and the episode ended.

Not for the First Time...

In Mol's example of atherosclerosis (a build-up of plaque in the arteries) in the Netherlands, it is pain that brings the patient to the doctor and, describing pain specifically on walking, the patient is taken to the vascular surgeon's office (2002). But this process of becoming an atherosclerosis patient happens only once. And once it happens, you are an atherosclerosis patient for life. Your atherosclerosis will become part of your life and lifestyle and when you seek medical attention, it will be noted that you are an atherosclerosis patient. You will be enrolled in chronic care infrastructures (Langstrup, 2013) and chronic living (Wahlberg, 2020) including preventive regimens to defer what will otherwise be a deterioration of your condition. UTI is not like atherosclerosis in this respect. If you come into the GP's office complaining of pain specific to a UTI and a UTI is enacted, you will most likely be prescribed antibiotics. You will walk out of the clinic door to the pharmacy, pick up the antibiotics and go back into your daily life, back to bed to recover, or back to work. Maybe you will take the antibiotics, maybe you won't. Once that episode is over, you will not become a UTI patient again until another UTI is enacted.

Minna and Sophie, after the initial experiences described above, both became people who often found themselves calling the doctor for help. But when they call for the second or third and perhaps especially the tenth or eleventh time, it is clearly unlikely that they would call again describing pain that felt like a shaving cut or being unable to get off the toilet. With repeated experience of similar types of pain, sometimes people do seek help for a UTI or even look to be prescribed antibiotics. This is identified as a problem across literature pertaining to 're-consultation.' Very notably, this is not only a concern that emerges in the context of AMR mobilisations, but also in older literature where concerns clustered more around burden on the healthcare service more generally.

Other people continue to seek help for pain. For example, Sandra is a 58-year-old woman has been diagnosed with UTI in the past and has also been diagnosed with unprovoked vulvodynia, which is a pain syndrome. Let's take some time to read what she says at length.

...I know the symptoms of a UTI but because I can't tell the difference, it was so acute. And when I went to produce the specimen, it was cloudy and I knew, it was unusual for me to

ever, that was the first time ever to produce a cloudy specimen of urine, so I'm not sure if that's significant or not. Usually it's dipstick it's a protein or whatever and they say oh yeah, you've got a UTI and they give...but I was on holiday in the States, three nights with my husband wanting to show him the city, and I got these symptoms and it was terrible. It was really, really, really bad- I had to get off a bus, negotiate to be let off the bus, I had to find the nearest clinic and go in there 'cos I had insurance, and I laughed when I got back to the UK because they tested me for a pregnancy test, they did a pregnancy test without even asking me and I thought, pregnancy test? My stomach was out like this, I was post-menopausal. So, and they didn't tell me about that. And they said, oh yeah, you've probably got a UTI, we'll give you these antibiotics. And then they changed those antibiotics when I got back and then I still had the symptoms and I didn't have a UTI. See, I feel really tired even talking about it. It's just, you know, to think that one in four women have this, I don't think so! I've never met another woman who's got these symptoms, or maybe they don't talk about them, these sort of symptoms you know...

Sandra is a registered and practising nurse. She tells me *'I know the symptoms of a UTI'*; and undoubtedly, she will have had lots of experience with UTIs over her clinical career as well as her personal experience. Elsewhere in the interview, a memory came to her of sitting drinking pints of water with her mother, when they both had urinary infections. But what Sandra tells me in this disorientating interview, and how she tells me it, is confused, confusing and painful. She reels off scattered mentions of the many medications she has tried and darts between different symptoms that worry her, adding another and another, lingering over a particularly worrisome one, distracted from her train of thought by the possibility that she might have cancer. The interview, like so many I took part in, was painful and emotional. In this extract, she tells me about an experience of being away from home and needing to seek help: *'I got these symptoms and it was terrible.'* She gets off a bus, finds a clinic and seeks help for pain. When she gets home, she seeks help again: *'then they changed those antibiotics when I got back and then I still had the symptoms and I didn't have a UTI.'* Despite that Sandra has lots of experience with UTIs, what emerges most strongly from her account is still pain: she lives with unbearable pain that she finds exhausting even to talk about, whether a UTI is enacted or not. Living with this pain and feeling bewildered, she continues to seek help for pain. Like Olivia, no disease to be treated is forthcoming, nothing coheres. But unlike for Olivia, the episode does not end and Sandra continues to have to seek help for pain in huge crises that totally overwhelm her and punctuate her life.

Patient Participation

Earlier I identified as a problem the way that care for urinary symptoms is very closely co-ordinated around the question of whether to prescribe antibiotics or not. This is because HCPs are already looking for the signs of the UTI they expect to find. When signs and symptoms indicate that a patient is unlikely to benefit from antibiotics, the question of what to do becomes very difficult: *“No further action required”: ‘And then you’re just kind of left.’* It is then an often insurmountable task to enact a disease to be treated out of painful symptoms: *‘by this point my testing, my dip tests and my, I think the culture, was showing as there was nothing wrong with me.’* This is the ‘computer says no’ described by Nicole. The only disease to be treated that can be enacted on the urine benches or in the clinic using the UTI diagnostic pathway is a UTI to be treated. So when patients describe receiving ‘negative tests’, this is relational; it is a negative test in relation to what was being looked for, not only on the part of the HCP but also on the part of the patient: a UTI to be treated. When the patient consults for pain, no object has yet been enacted even if UTI is a diagnosis that is (too) readily looked for in this patient group. But when people seek care for a UTI, pathology can end up contradicting the UTI the patient has identified. Crucially, this is not always by enacting a different disease. Sometimes (even often) nothing coheres, no disease to be treated is successfully enacted.

Here I want to mark a shift in my writing. As I move to exploring the ways in which patients participate in maintaining a narrow focus on urinary infection and antibiotics, I want to explore how patients collaborate with HCPs in maintaining singularity. I am talking about a negotiated order that I have participated in. This is not an attempt to distribute blame for poor clinical care for urinary symptoms. Instead, it is to provide background for what I will explore in chapter three- a consideration of what prevents us as patients from even momentarily letting go of UTI and trying out new things in different places. Nicole, Liz and Sandra all live without getting help for painful urinary symptoms. But where Sandra continues to seek help for pain, what Liz and Nicole describe is their own participation in the task of attempting to enact a UTI to be treated.

Going back to Sophie, I asked her about her most recent experience of seeking care:

I had symptoms so I filled... in my GP surgery, you cannot really call them. They ask you to fill in an e-consult. So I filled in the e-consult one evening and I didn't hear anything by about 2:00 PM the next day. So I rang them and I said, 'yeah, I've got a UTI, I need some antibiotics'. And they said 'you need to ring 111', which is what the e-consult said to me. But I said 'no, no, I don't need to ring 111. I know what this is, I just need antibiotics', and they said 'no, you will anyway, because we're at full capacity'.

So I rang 111 and they said 'OK, call your GP back and tell them they need to see you within two hours'. I didn't hear anything the whole day. So the next day I rang 111 again and I said 'I didn't hear anything yesterday' and they said 'OK, you need to be seen within two hours'. (Laughing) But I mean 24 hours has passed! 'But you don't need to call them, we'll contact the GP surgery'. And I still didn't hear anything.

*Then it was the next morning, I got a call from the GP practice and they said that I needed to come in with a urine sample. Now, I've had, honestly probably a hundred UTIs and it just seems ridiculous, that they would want to dip my urine. Uhm, and you know, this is a *nightmare* for me. I've got a toddler at home who...it's clear as day it's a UTI! The urine's cloudy, it's spasms, it's a UTI. I've got a toddler at home who's just developed a cough. I've got two toddlers at home, right? I don't have a job, OK, but it's difficult to go down and dip my urine. But they said 'no, it's... it's our...it's our policy. We will not prescribe antibiotics unless you come in to drop a sample off'. So I go in to drop a sample off. I still don't hear anything. It's going on and on[...] And then finally it gets to the evening. And finally, a nurse called me up and you know, it's as if she's totally out of it. She said to me: 'well, your urine did have traces of leukocytes in so...' (Laughing with frustration). 'So I can't say for sure but I think it's a UTI.' And I just said 'no, it's a UTI'.*

Here, Sophie starts from pain: *'I had symptoms so...'*, it is this which causes her to seek help. But she seeks help for a UTI: *'I've got a UTI, I need some antibiotics.'* This is different from the first time Sophie sought help for what was later enacted as UTI, when she eventually sought help for pain which she had been living with for some time but which had become difficult to manage on her own. Meanwhile, Sophie's GP practice tells her that they will not *'prescribe antibiotics unless you come in to drop a sample off.'* Here, they articulate that pathology is necessary to their enactment of disease. Clinical considerations are still important (it is the clinical which has established that it is a urine dipstick test which is relevant here), but it is not sufficient. By the time Sophie drops a sample and speaks to a nurse, she is intensely frustrated with her experiences of seeking care and more specifically, that the clinical story is not sufficient to enact a UTI: *'this is a *nightmare* for me. I've got a toddler at home who...it's clear as day it's a UTI! The urine's cloudy, it's spasms, it's a UTI.'*

Based on clinical symptoms which are very familiar to her and based on which a UTI has been enacted before, Sophie enacts a UTI. Her enactment of a UTI at home was bolstered by previous experiences of positive microbiology and she therefore felt that diagnostic technologies only had the potential to delay care for the pain she was experiencing. Many participants reported that it was an unnecessary hurdle to have to consult a doctor each time, especially amidst difficulties in accessing care, given that they had already enacted a UTI at home. For example, Sarah expressed similar frustrations to Sophie:

I understand that we want to be careful that people don't get resistant to things but like, no one's taking cystitis antibiotics for like a joke. And women, are getting quite seriously ill quite quickly. So, I do think they should just be like over the counter or like if you've had one, you automatically get like a free pass onto like getting them. I think it just wastes a lot of NHS time when you come in and you already know what's wrong with you. I guess like, I've had my urine sent off to be grown like hundreds of times and it always comes back with a bit of blood and blood proteins, and I know that really well.

The Chronic Urinary Tract Infection Campaign (CUTIC) also worries that care relates to pathology as foundational: 'Unhelpfully, guidelines from the National Institute for Health and Care Excellence (NICE guidelines in England, SIGN guidelines in Scotland) – the body that produces treatment guidelines for England and Wales – insist that a positive dipstick and MSU are needed to diagnose a urinary tract infection in patients who have not got better after initial antibiotics' (CUTIC, 2022). National guidance on this issue varies. All national guidance takes care to note that urine culture is not required in the routine management of women with lower UTI and that diagnosis should be clinical (SIGN, 2020, p.4). As SIGN sets out, urine culture has other uses: 'the main value of urine culture is to identify bacteria and their sensitivity to antibiotics' (SIGN, 2020, p.3), including contribution to surveillance data. However, NICE sets out that 'the diagnosis of recurrent UTI should be confirmed with urine culture' (NICE, 2018e, p.7).

Regardless, Sophie's experience of seeking care was bad. Will invites us to notice multiplicity in policy compared to practice, alongside the more familiar comparison of the ways in which what happens in practice is more diverse than what is mandated in policy (Will, 2017). In policy, Sophie would not have had to drop a urine sample into the surgery because in policy, ways of enacting UTI are more multiple than they are in the practice of Sophie's surgery. Moreover, in policy, there is more than one group of UTI patients. Sophie would have been

recognised under the diagnosis of 'recurrent UTI', a group of patients who are offered a different treatment- currently only antibiotic prophylaxis for six months. When antibiotic prophylaxis is stopped, clinical guidelines set out that people with recurrent UTI have 'rapid access to treatment if they have an acute UTI' (NICE, 2018d) which was not the case in practice for Sophie who had to wait for two days to speak to a nurse who eventually prescribed her antibiotics.

The problem for CUTIC is about accessing antibiotics, as it is for Sophie and Sarah. Access to care in general practice is under increasing pressure due to budget cuts and under-investment in the workforce. Moreover, access is unequally distributed (Nussbaum *et al.*, 2021), and is strongly associated with health inequalities (Starfield, *et al.*, 2005). Access is indeed a major problem for primary health care. But at the same time, Minna and Flora describe something different:

Minna: I recognize straight away when I get any symptoms and stuff like that, but they don't really ask more questions and that, they just say right OK, I'll prescribe you this and that, if you don't feel better in x amount of days, come back. So they've stopped taking pee samples and stuff like that, or any further testing, any blood testing or whatever they want to take to get to the bottom of it. It's just firefighting. So as soon as I feel the symptoms are coming on I just phone up and they just give me a prescription and that's it [...]

Every time I kind of take it, I feel I'm like, like, letting them win. Like I'm, you know, again I'm taking a prescription they're giving me, instead of fighting to get it investigated so it's a bit, you know, mixed emotions. I'm happy as it's you know, it's sorting out my pain, but I'm also annoyed that I'm giving into the easy option and not pushing for them to investigate.

Flora: I think there was one occasion where they said, yeah, we've seen this before, it's fine, we're just going to send you a prescription down to our local pharmacy. And I thought, oh, that's unusual, do you not want to test my wee? And I just thought it was very kind of, oh okay, well if they've seen it that many times before, fine. And at that point I thought, this is about to really kick off, I'm not going to argue with a clinical professional, at this point I just want to get my medicine and get better; which is the completely wrong way to look at it.

They describe being dismissed by an antibiotic prescription. Antibiotics make Sophie, Sarah, Minna and Flora feel better and in that, their lives would be less painful if they could access antibiotics more easily. None of them want to take antibiotics: Sophie joins Flora and Minna in describing 'it feels like an admission of failure if I have to get the antibiotics.' For Sophie, this is related to failure in preventing urinary infection. Minna and Flora express something

different; they both feel that they let themselves down by accepting an antibiotic prescription because they therefore participate in enacting a UTI to be treated. Minna and Flora therefore contemplate a task ahead of them, the task of enacting another object from their pain aside from UTI, which is not a diagnosis which seems to help them. But from where they are, and without the collaboration of a HCP, the task is mammoth.

Like Sandra, none of them can get help. What Sandra, Sophie, Sarah, Minna and Flora all describe is a struggle to become someone who needs help managing symptoms they live with on a near constant basis, rather than someone calling up with a UTI for the first time. All of them find themselves banging up against a brick wall again and again. They need someone to care for them, to notice their abandonment and pain, to sit with them in that long-term pain and think about what to do next. These are patients who have been abandoned, left to navigate life with often very painful symptoms. They are not patients who are recognised in clinical policy, continuously appearing as ‘out of scope’.

Inequality and Difference

Poor clinical care for urinary symptoms is often explained by reaching for sociological explanations of who is believed about the reality of UTI and why. This is often how inequality, especially gender inequality, appears, as a vector of epistemic (in)authority in analyses of seeking care. But Sophie’s detailed description of her attempt to get help is instructive. She laughed semi-hysterically as she told me about seeking help for symptoms which are highly familiar to her, only to be pushed from pillar to post. She was badly let down. But what is interesting is that her experience is not one of total control, of domination so tight over a network of care that there is no space for her testimony to speak loudly or authoritatively enough to say she needed help. It was something else that was stopping her from getting help.

I have shown here that the real is relationally enacted in practice. Therefore, as Law sets out: ‘if these practices were to change, then the real would also be done differently’ (2008, p. 634). What would it mean to change practices of enacting UTI? Again, structural analyses of gender may imply that it would take a lot in a system co-ordinated and governed by patriarchal interests and actors. But in noticing multiplicity as I have done here, we can see that difference is everywhere, difference lies *within* the network of practices which make up clinical care, not

without. That UTI and urinary symptoms are done differently everywhere does not threaten the network of clinical care. Instead, as Law says, these relations are 'relatively invulnerable precisely because they are not highly connected. Invulnerable because when one is undone the others are not pulled down with it' (Law, 2008, p. 641).

Care for urinary symptoms manages to sustain itself because, not in spite of, the way that people who aren't helped can always come back next time and be treated as if they were seeking help for the first time. Or the way that they can give up on getting help and not come back to medicine, instead caring for symptoms at home. Or the way that in other places, people with no clinical symptoms can be harmed with antibiotics that they did not benefit from, even as they will never know this. This doesn't pull down the whole system, these practices are adequately independent from each other, adequately multiple and distributed that the network can be maintained. The resulting poor care that many people experience when they seek help for painful urinary symptoms therefore, is not as a result of a coherent order of total domination which dismisses what women say about their own bodies. Instead, it is the result of practices that are poorly co-ordinated, and non-coherent, not dominant. It is much more like neglect than domination. Sophie was not dominated and bossed around but cast aside, moved on, shifted around.

Within this sensibility to inequality, poor care is not (often) the result of doctors who don't mind seeing their patients in pain, or who think that women are imagining pain. People may have very bad experiences with individual HCPs. But my point in the thesis is that this is a sufficient but not a necessary experience of poor clinical care for UTI. The analysis of domination which posits un-caring doctors as refusing good care to women relies upon the maintenance of strict boundaries between who is a patient, who a doctor, who a woman, who a man, who is healthy, who is in pain etc. Instead, where you are positioned is relational to time and place, from a multiplicity of different positions. Inequality can be multiple within the system, a thousand tiny and disorientating abandonments rather than an all-encompassing grip.

Conclusion

I started this chapter with the concerns of patients mobilising online that the patient story is routinely disregarded in favour of diagnostic tests which are poorly able to capture the reality of UTI. These patient mobilisations question UTI testing by stressing how testing is done in practice. I looked at what happens when people seek help for urinary symptoms and how testing is used clinically by looking at how diagnosis is done in practice, through interview data, and co-ordinated in policy, primarily through the NICE/UKHSA diagnostic guideline. I show that in community care settings, clinical considerations have primacy in care for UTI - the patient story is not additive but integral to deciding who becomes a UTI patient. But this is not the case everywhere. Elsewhere, I found that pathology alone often decides who becomes a UTI patient. On a trip to an NHS diagnostic lab, where urine samples from different settings are processed together, I explored what makes care for UTI hang together across these different sites. I concluded that care is not organised around revealing the reality of UTI at all (a task which patient mobilisations identify tests to be deficient in), but around the question of what to do.

And yet, people continue to experience a lack of care for painful symptoms. People are abandoned when care is overly focused on one clinical diagnosis over that which clinical diagnosis depends on: symptoms. A UTI to be treated (a solvable problem) is readily achieved, especially in some patient groups, while the task of enacting any other disease to be treated often appears monumental. Patients can participate in this when they seek help for a UTI rather than for symptoms. This is why the question of what to do about painful symptoms can so easily be transformed into the question of whether to prescribe antibiotics or not.

Importantly, it could be the case that stewardship attempts which intervene in the question of whether to prescribe antibiotics or not by pulling UTI out of other urinary symptoms have the potential to exacerbate that. Although Mol identifies multiplicity in different regimes co-existing in different places in the hospital, she does see clinical ways of working as under threat (Will, 2017, p. 295) arguing that 'with sufficient effort' a mode 'may well come to dominate the other modes that are already at work' (Mol, 2002, p. 182). As Nettleton and Burrows argue that medical knowledge can be seen to have been dislodged from its

‘traditional’ institutional base’ (2003, p.180), Moreira argues that there have been ‘transformations in the organisation and understanding of medical knowledge and practice, particularly with the emergence of evidence based medicine in the 1990s’ (2005, p.1975), and Stevenson *et al.* (2021, p.113703) argue that such changes are underway as ‘clinical decision-making is increasingly rooted in health ‘intelligence’ from information science as opposed to practitioner intellect’.

This is echoed in mobilisations around UTI and more generally in Street’s arguments (2012) which both note an apparently pre-development clinical regime: ‘in the developing world, tests are far less available and the doctors depend heavily on their clinical skills. We should argue that they may well practice [sic] better medicine than in the developed western world’ (Malone Lee, 2021, p.14.) In the next chapter, I entertain these arguments about the restriction of the clinical in AMS policy. Looking at how evidence is assembled to enact the problem of AMR and UTI, and how rationales are shared with publics, I explore how AMS public engagement has participated so far in pulling care for UTI out of urinary symptoms in order to better match those who would benefit from antibiotics with those with a UTI lying beneath. Moreover, continuing my focus on patient participation and a role for different publics, I explore the moments when patients come together to collectively resist these AMS efforts, providing alternative ways of doing disease that make sense with their experiences.

Chapter Two: Encountering Resistance

Natalie: It's all over the TV now on adverts where they talk about resistance and in actual fact, they're actually causing the resistance. They're causing it to happen because they're treating people wrong.

In this chapter, I explore how evidence is assembled to enact AMR as a concern in relation to UTI in public health work. I question who is invited to participate in and who might be excluded, and therefore harmed, by such an assemblage. An overall argument of the chapter is that public facing assemblages are much less multiple than the evidence that enacts them. Faced with publics and patients that are inevitably different and multiple, such singular approaches risk providing messaging which poorly matches people's experiences. In this case, it is the people who are most affected by the issue who are also living with poorly applicable messaging. Sometimes, these people take collective action to resist what they perceive to be misguided targeting. Therefore, this chapter encounters resistance by firstly participating in evidence making around antimicrobial resistance, and secondly by noticing how patients resist existing mobilisations on AMR. I end by suggesting ways that evidence could be assembled differently to enact concern around AMR and UTI in a more caring and collective way.

From Matters of Fact to Matters of Concern, to Matters of Care

STS trains us not to take problems for granted but to question how evidence is assembled and performed in order to enact a problem. A critical constructivist argument might trace the interests and impulses in how evidence is assembled to *construct* the problem of UTI and AMR. But as Latour notes, expressing weariness with critical constructivism, this mode of argumentation too often ends up weakening claims to reality (2004, p.237), which is one reason democratic participation in it has been so worrisome. For example, climate change deniers have employed critical constructivism in order to deny the reality of climate change. In questioning the 'matters of facts' of AMR, I risk ending up implying that AMR does not really exist, but is a smokescreen for human interests, impulses and values. In revealing vested interests and values, the critic deconstructs and destroys.

In doing so, the critic isolates themselves, as they are the only one who can reveal, who 'lifts the rugs from under the feet of the naïve believers' (Latour, 2004, p.246). The isolated critic

makes an issue only on the margins, decrying power from the centre, often by using ready-made critiques which poorly describe the relations in the network. Latour decries a 'eulogy of the margins' obsessed with the power of the centre (1993, p.122). Therefore, he opposes 'matters of fact' with 'matters of concern', where critics do not destroy but offer 'gatherings' (2004, p.246), arenas for participants where 'things' and 'issues', 'matters of concern' come to be and persist because they are worried over and concerned with. Thus, to show how things are assembled is not to dismantle them, but to enrich and affirm their reality by adding further articulations of how they hold together and cohere through concern. The critic's role is to detect how many participants are gathered in a thing to make and maintain its existence (Latour, 2004, p.246). This includes all who are involved in a thing's political ecology from whichever standpoint, all who care about it and thus sustain it as a matter of concern. Here, paying attention to how care holds things together replaces excessive critique and suspicion of socio-political interests, keeping an issue in the domain of participatory democracy, rather than marginalised as an issue for activists or critics only. In this way, by counting all the concerns attached to a thing (whatever their political impulses), all those who care for it, democratically, we might affect change in the use of the thing. This cares for the issue, not allowing it to become neglected and marginalised.

Maria Puig de la Bellacasa moves from Latour's 'matters of concern' to 'matters of care' by redrawing the genealogy of what matters of concern was responding to (2011). Drawing more explicitly on feminist thinking, she directs a political focus to what becomes a matter of care. For, when Latour and Haraway both critique the isolated and singularly empowered critic, slightly different critical genealogies are traceable. For both, the critique picks up on a wider ANT impulse, the symmetry principle, that all explanations should be given equal consideration prior to local examination of the network. For Latour, this entails a mistrust of minoritarian ways of politicising things. Latour's mobilisation of care encourages a 'balanced articulation of involved concerns' and therefore can function as a call to moderate critical viewpoints. But for Haraway, the critique is grounded in feminist standpoint theory, which never occupies the centre in the god-trick and is comfortable with partiality and marginality (1988). Thus, Puig de la Bellacasa invites us not to 'throw out critical standpoints with the bathwater of corrosive critique' (2011, p.91), and to see standpoint theory in techno science as

not just transformative of knowledge, but also of practices and socio-material configurations. She asks not only to notice who is assembled to make a thing cohere through care, but also who could be harmed by an assemblage and fails to be counted, or assembled in the staging of an issue, and why. Giraud articulates a similar call to politicize care's exclusions in her 'ethics of exclusion' (Giraud, 2019). Politicisation for both Giraud and Puig de la Bellacasa reflects not an obsession with power or domination but a concern with unloved others (2011, p.94), noticing who is excluded. Where anything could be thought of a potential matter of concern, Puig de la Bellacasa calls on feminist standpoint theory to inform what we as researchers care about, to insert ourselves into our work, to make issues that generate care, and therefore to speculate upon how things could be assembled otherwise (2011, p. 90).

Thus, informed by Latour's and Puig de la Bellacasa's approach, I aim to avoid weakening the claim to reality of concerns about AMR and UTI by avoiding feasting as a critic upon the uncertainty and weak links in the evidence which is assembled to construct a problem. Instead, I come to the matter as a matter of care, paying attention to who is doing caring, how and for whom. This includes noticing all who are included in the staging of the matter of care, and the concerns that animate them, and who is excluded, and the concerns that animate them. Locating my own standpoint as a patient and as a researcher, I draw on what I care about in order to make visible the exclusions of those who could be harmed by the assemblage and are in need of care, and consider how things might be assembled differently in the thingness of the problem of AMR and UTI. Therefore, let us examine what participants there are, what coheres and comes together to enact the issue of AMR and UTI, not to deconstruct the problem, but to think about how it might be assembled otherwise.

[The Staging of UTI and AMR in Policy: Where and How Does Concern Emerge?](#)

It is worth a warning that this is not a light read. As I trace how community UTI becomes a problem for AMR, I draw on sources from expert interviews, clinical guidelines, policy papers, and journal science. This is crucial for my later argument, which compares how a problem is enacted compared to how the public is invited to engage with the problem. But it is also of importance to note the effort involved in this task of accounting for how the issue of UTI and AMR coheres through care.

Primary Care

Primary care includes GPs, community pharmacists, opticians, dentists and sexual health clinics and is intended to be a patient's first point of contact with the healthcare system, the 'front door' of the NHS. As Kamenshchikova explains in her study of health care infrastructures in Russia, GPs are in 'constant contact with communities, thus are primarily responsible for providing information about antibiotic treatments and AMR to patients' (2021, p. 5). GPs routinely prescribe antibiotics for non-life threatening infections of the respiratory tract, of the urinary tract, skin infections, and wounds (Dolk *et al.*, 2018). This is in contrast to secondary care where antimicrobials are prescribed for a much wider range of uses, including for prophylaxis before surgery, and for life threatening infections. Therefore, although hospitals only account for around a fifth of total antibiotic prescribing, this is where most broad-spectrum agents are used, which have the greatest potential to drive resistance (Roope *et al.*, 2020b, p. 8). Using broad-spectrum antibiotics can create a selective advantage for bacteria such as *Clostridium Difficile* or bacteria resistant even to 'last line' broad-spectrum agents, meaning that patients are more likely to suffer from a multi drug resistant organism infection than if they had been treated with a narrower spectrum antibiotic (Tamma *et al.*, 2017).

Nonetheless, major AMS programmes concentrate on primary care. TARGET is the national primary care AMS programme, developed by UKHSA and the Royal College of General Practitioners, along with other professional bodies. In 2018, researchers from UKHSA's National Infection Service published a set of work, 'Appropriateness of antibiotic prescribing in English Primary Care', as a supplement in the Journal of Antimicrobial Chemotherapy. They noted that 'primary care is a natural target for antimicrobial stewardship interventions because 'outpatients are frequently prescribed antibiotics for self-limiting and/or non-bacterial infections, and because primary care accounts for approximately three-quarters of human antibiotics prescriptions in the UK' (Dolk *et al.*, 2018, p.ii2). The stated aim of this work was to provide evidence of the baseline for government ambitions to reduce inappropriate antibiotic prescribing (Dolk *et al.*, 2018, p. ii2). For in 2016, in response to the O'Neill report, the UK government had set a target to reduce national inappropriate antibiotic prescribing by 50% by 2020 (DHSC, 2016, p.6). The modelling completed in the supplement identified at least 20% of the antibiotics prescribed in UK primary care as inappropriate (Pouwels *et al.*, 2018).

This modelling was cited in the UK's five-year national action plan 'Tackling Antimicrobial Resistance 2019-2024' as (DHSC, 2019, p.54).

Researchers from the Antibiotic Review Kit (ARK) Hospital study contrast hospital prescribing with prescribing in primary care: 'given the need to initiate antibiotic therapy urgently in life-threatening infection, limiting antibiotic overuse in hospitals depends on prescribers undertaking an early antibiotic prescription 'review and revise' at around 48-72h after a patient starts antibiotic treatment' (Roope, 2020b, p.2) while 'reductions in antibiotic use have been achieved in primary care by raising the threshold for starting patients on antibiotics', citing TARGET (Roope, 2020b, p.2). Therefore, efforts to reduce inappropriate prescribing in primary care by heightening the threshold make up a key part of national policy going forward, based both on the volume of prescriptions, and on the identification of a large proportion of those prescriptions as inappropriate. The association between antibiotic use and emergent resistance is well established (Goossens, 2009; Costelloe *et al.*, 2010; Bryce *et al.*, 2016) and such a response is in line with the global response set out in the World Health Organisation's Global Action Plan, which as MacPherson *et al.* note, 'has primarily framed AMR as a problem of excess, centring overall reduction in antibiotics use as the main goal' (MacPherson *et al.*, 2021, p. 2).

I argue that the case of trimethoprim functions as a warning of the consequences of antibiotic prescribing in the community. Trimethoprim is a drug predominantly used to treat UTI, although it is sometimes prescribed for other conditions. What is noteworthy here is the way that trimethoprim established antibiotic use in the community as an important driver of AMR. Until recently, trimethoprim was the most commonly prescribed antibiotic for the treatment of lower UTI (Croker *et al.*, 2019, p. 4). However, in 2016, 34% of urine isolates in NHS laboratories were found to be resistant to trimethoprim, which was an increase on 29.1% in 2015 (UKHSA, 2017; UKHSA, 2014). Amid concern about growing trimethoprim resistance amongst urinary isolates, in 2014 UKHSA revised their guidance, recommending that nitrofurantoin should normally be the first line treatment for uncomplicated UTI in primary care, unless the patient has a particularly low risk of resistance. In September 2016 therefore, the NHS England Quality Premium Scheme financially incentivised the switch from

trimethoprim to nitrofurantoin, and by 2017, prescriptions had fallen below 50% (Croker *et al.*, 2019, p. 4). Widespread prescribing of trimethoprim for UTI had driven resistance while isolates with resistance to trimethoprim would most often be treatable with other commonly used agents. We can start to see how concern about AMR in primary care surrounds the emergence of ambient resistance rather than the emergence of untreatable infections. This argument will be developed in the remainder of the chapter.

UTI Becomes a Target

Once primary care has been established as a 'natural target for antimicrobial stewardship interventions' (Dolk *et al.*, p.ii2) on the basis of the high proportion of self-limiting or non-bacterial infections and the high proportion of total prescriptions (Dolk *et al.*, p.ii2), UTI then becomes a target. For within primary care, Dolk *et al.* found UTI to account for 21% of all prescriptions that they were able to link to a condition, the highest of any condition (2018, p. ii6). The same group of researchers, Smith *et al.* (2018), found that 25% of antibiotic prescriptions in non-pregnant women with non-recurrent UTI were inappropriate. Notably, this figure of 25% of antibiotic prescriptions for UTI being inappropriate is a lot lower than for other conditions, such as cough (90%), sore throat (87%) and rhinosinusitis (89%). Antibiotic prescriptions for these respiratory tract conditions are much less often warranted and were targets of earlier AMS interventions. In the following section, I go through the specifics of how the trickier case of UTI becomes a target.

A Self-Limiting Infection: Heightening the Threshold for Antibiotics and the Threshold to Consult

In chapter one, I argued that only people who come into the clinic complaining of specific symptoms will become UTI patients. Therefore, coming into the clinic in pain functions as a self-selection for clinical diagnosis, medicalisation of symptoms and prescription of antibiotics. However, as I showed in the literature review, worries emerge in policy about the threshold to consult for UTI being too low, leading to the medicalisation of symptoms which could have been managed at home, and the prescription of antibiotics. Olivia presents her own behaviour as problematic in exactly the ways that policymakers worry about when she says: *'I kind of panic about these things as well, like I'm a bit of a freak with things like that, so I'm always...like as soon as I think there's something not right, I'll go down to the clinic. But yeah, I think I'd slept with someone new, just wasn't feeling right, and then went and got checked.'* Encouraging

people to care for their symptoms at home, as Olivia's HCP did, is seen as a key antimicrobial stewardship. The TARGET patient facing materials for UTI include a patient information leaflet with referenced self-care advice for instances where a patient has consulted the GP and has been recommended either self-care and pain relief, self-care alongside a delayed or back up prescription, or self-care alongside immediate antibiotics (UKHSA, 2020).

Caring for infections at home, or using a 'watch and wait' approach, is seen as a stewardship because of the idea that uncomplicated UTI may be 'self-limiting' without antibiotics i.e. the host immune system will resolve the infection. A key background to this is the overwhelming (and of great influence on AMS policy) evidence that many infections which antibiotics may have been prescribed for in the past are in fact self-limiting, and antibiotics do not significantly shorten recovery time, even if recovery time is lengthy (Little *et al.*, 1997a; Little *et al.*, 2005; Williamson *et al.*, 2007; Thompson *et al.*, 2013). This reflects some of the gains made in reducing prescribing for RTI, with data on the time for 90% of patients to recover being cited in TARGET patient information leaflets (UKHSA, 2020). Therefore, antibiotics represent more of a potential harm than a potential benefit to patients with self-limiting infection.

However, it is important to note that the evidence for the self-limiting nature of UTI is much less clear than for other infections. SIGN and IDSA do not recommend a delayed prescribing approach, seeing withholding antibiotics as unjustified, whereas NICE recommends commencing antibiotic use if there is no symptom improvement in 2 days. Hoffmann points out that 'the NICE guideline recommendation of waiting for 2 days does not appear to be informed by research, and it is also unclear whether the 2-day timeframe is from the start of symptoms or from first consultation (2021, p. 721). Hoffmann *et al.* conducted a systematic review of data from placebo arms of clinical trials for antibiotic intervention for UTI. This data showed that approximately a third of patients (excluding patients with recurrent UTI) improved without antibiotics by 7-10 days (Hoffmann *et al.*, 2020, p. e721). The authors conclude that this data could be used to guide shared decision making with patients but it is not clear how to distinguish the two thirds of patients who would not recover without antibiotics, from those who would. Moreover, unlike a lot of other infections, evidence shows that in the case of UTI antibiotics do considerably shorten recovery time; NICE cites Little *et*

al., 2009 (NICE, 2018b, p.7) which shows symptoms resolving after an average of 3.3 days in women treated with an antibiotic to which the pathogen was sensitive, 4.7 days in women treated with an antibiotic to which the pathogen was resistant, and 4.9 days in women with infection not treated with an antibiotic. The acceptability of symptom resolution in either 4.9 days or 7-10 days is also unclear, especially considering non-clinical reasons for prescribing and the entrenched stratification of resources to facilitate recovery time.

A low threshold to consult is seen as problematic for the threshold to prescribe antibiotics. Crucially, as I set out in the literature review, the link between a low threshold to consult and a low threshold to prescribe antibiotics necessarily relies on the idea that the patient can influence the prescription outcome. Andrew, a professor of primary care and practising GP with a special interest in UTI told me about this concern through the lens of pharmacy prescribing: *'I'm concerned enough about the fact that if people go to a pharmacist, I think it'd be much harder for a pharmacist not to prescribe an antibiotic than prescribe. Whereas as a GP, I feel quite confident not to prescribe and say to somebody, look, it sounds like your symptoms are relatively mild at the moment, how do you feel about watching and waiting, seeing if things improve on their own.'* There are undoubtedly concerns that HCPs feel it is difficult to refuse an antibiotic prescription, even if these concerns are not shored up by published evidence.

Elsewhere though, much work has gone into disentangling the threshold to consult from the threshold to prescribe antibiotics, in working out what else patients in pain might need to be cared for by a consultation with a HCP, apart from antibiotics (Leydon *et al.*, 2009; 2010; Duane *et al.*, 2016). Much of this work is sensitive to the need to avoid implying that the experience of a UTI is trivial, just because the very specific intervention of prescribing antibiotics is unlikely to be of benefit (Leydon *et al.*, 2010, p. 5). Indeed, worries about a low threshold to consult do sometimes appear in ways which seem to dismiss pain. As we saw in data in chapter one, 'female' gender categories are sometimes used as a clinical technology to downgrade the clinical significance of pain, which can have the unintended consequence of removing symptoms from the purview and remit of a HCP. Another example of the way that pain can sometimes be dismissed in worries about a low threshold to consult came in a public seminar 'Doing Better for UTI Patients' hosted by BSAC in November 2020. Alistair Hay,

professor of primary care, discussed data which noted that a much greater proportion of patients who consult for uncomplicated UTI in Netherlands return a positive urine culture result for UTI than in the UK (Butler *et al.*, 2018). Hay stated that this ‘speaks to me about potential differences in the thresholds at which patients choose to consult and in the United Kingdom, I think we need to be just cautious that our population may have quite a low threshold to consult.’ Here, a low threshold to consult is attributed to cultural factors which differ between the UK and Netherlands and the response is to be more reticent to prescribe, based on the low proportion of culture-positive UTIs.

More commonly though, concern about the link between the threshold to consult and the threshold to prescribe stems from the idea that the patient who takes antibiotics will never get to know that they would have got better anyway, and so will come to rely on antibiotics for symptom relief which they could have got elsewhere, with less potential for harm. In policy-related literature employing elements of behavioural science, this is often conceptualised as medicalisation leading to ‘low self-efficacy.’ Sometimes though, worries that evidence poorly captures people’s experiences of pain (i.e. it is not reasonable to expect people to care for symptoms at home) are taken at face value. Research clearly recognises the tensions in attempts to heighten the threshold to consult so that people who might have gone to a HCP for help with urinary symptoms are discouraged from consulting at all, and in using symptom severity to identify what might be a self-limiting infection and what isn’t. NICE’s guideline on anti-microbial prescribing for lower UTI (2018a), as well as UKHSA’s diagnosis tool for UTI (2002b), recommends that severity of symptoms is taken into account when deciding whether to prescribe an immediate prescription or a back-up prescription. Research led by Christopher Butler, professor of primary care and often described as an ‘opinion leader on UTI’, reports that ‘there may be a “gap” between clinicians’ perceptions of the severity of their patients’ symptoms and the perceptions of patients themselves. This is because, as Butler *et al.* state, ‘knowledge of the symptom burden experienced by patients comes largely from clinical trials, which may not reflect the majority of episodes in the community or during routine primary care’ (2015, p. e702).

Diagnosis and Empirical Treatment

Where concern around self-limiting infection surrounds the idea that people with UTI have more potential to be harmed by antibiotics than to benefit from them, concerns around diagnosis and empirical treatment surround the notion that people consulting with urinary symptoms may not have a bacterial infection. This issue is often said to be complicated by the fact that the gold standard diagnostic test, the MSU, is not available at the point of care. But HCPs treat UTI empirically, prescribing antibiotics based on a mixture of clinical signs and symptoms, as described in chapter one. Clearly, people who do not have a bacterial infection will not benefit from antibiotics more than they will be harmed by them. Keeping antibiotics away from these people is therefore a key aim of AMS policy.

Duration of Antimicrobial Treatment

The recommended duration of antimicrobial treatment for UTI in clinical guidance is three days of nitrofurantoin 100mg modified release (NICE, 2018a). NICE recommends this on the basis of a Cochrane Review (Milo *et al.*, 2005) on the duration of antibacterial treatment for uncomplicated UTI in women. The review included 32 RCTs and assessed the effectiveness of 3 day courses compared to 5-10 courses. As NICE points out in their evidence review for the development of the guideline, ‘there was no significant difference between antibiotics given for 3 days compared with antibiotics (all comparisons: same or different antibiotic), given for 5 to 10 days.’ (NICE, 2018b, p. 28). Milo *et al.* stress that the rationale for investigating shorter courses is the hypothesis that they may be equally effective to longer courses and are ‘associated with less side effects and lower costs’ [sic] (Milo *et al.*, 2005, p. 3). AMR is not explicitly mentioned but there is growing momentum to provide evidence on the efficacy of shorter courses, given evidence that the best way to minimise resistance is to take antibiotics for no longer than necessary (Rice, 2008; Llewelyn *et al.*, 2017). Within medicine, this is sometimes referred to as the ‘Shorter is Better’ movement. As a team from UKHSA noted, writing in the BMJ, this is a change in strategy: ‘historically general practitioners have been taught that antibiotic courses should be long enough to prevent the development of antibiotic resistance in the infection that is being treated, based on evidence of the emergence of resistance frequently being related to suboptimal dosing of penicillin in the treatment of *Streptococcus Pneumonia*’ (Pouwels, *et al.*, 2019b, p. 1). However, the paper goes on to explain that ‘current concerns relate to the development of resistance in common commensal bacteria,

rather than in the ones causing the infections, where there is increasing evidence that the opposite is true- the longer the exposure to antibiotic the greater the development of antibiotic resistance, which then leads to a greater risk of resistance in subsequent infections' (Pouwels, *et al.*, 2019b, p. 1). For NICE, this strategy is codified in NG15, the guideline on 'AMS: Systems and Processes for Effective Antimicrobial Medicine Use' (2015), which recommends that when antimicrobials are prescribed, prescribers should 'follow local (where available) or national guidelines on prescribing the shortest effective course' (NICE 2018a, p9). This strategy means that when shorter courses are shown to be insignificantly different to longer courses, shorter courses are recommended. Concern surrounds ambient resistance in commensal bacteria, not necessarily untreatable 'superbugs' in the pathogen being treated.

This type of 'ambient' resistance is a concern, even if infections may remain treatable, because the link between antibiotic use and resistance is not confined to simple associations between the specific antibiotic used and resistance to that antibiotic (Ironmonger *et al.*, 2018, p. 1). Instead, concern about AMR in primary care is much more ecological. Ironmonger *et al.* studied antibiotic prescribing and antibiotic non-susceptibility over four years in the West Midlands. Using statistical modelling, they found that (relatively) small increases in antibiotic prescribing for respiratory conditions in the winter months increased antibiotic non-susceptibility in bacteria causing unrelated infections (namely UTI), treated with a different antibiotic, within the same practice population (Ironmonger *et al.*, 2018, p. 793). This phenomenon is called co-selection; bacteria can share resistance genes horizontally, through means other than vertical inheritance or mutation. A team from UKHSA studied selection and co-selection of resistance among *E.coli* by antibiotic use in primary care (Pouwels *et al.*, 2019b). They found that amoxicillin use for RTI was associated with increased amoxicillin and ciprofloxacin resistance among UTIs caused by *E. coli*. Areas with higher use of trimethoprim also had higher levels of ciprofloxacin and nitrofurantoin resistance in *E. coli* urinary symptoms. They hypothesised that 'these positive associations between prescribing of a particular antibiotic and resistance against another antibiotic suggest that co-selection may play a role' (Pouwels *et al.*, 2019b, p9). Antibiotics can select for AMR among bacteria that are carried by the host at the moment of treatment. The microbiota can therefore form a reservoir of resistance, meaning that treatment for one infection with one antibiotic may make another

much harder to treat, as well as giving resistant bacteria the opportunity to gain an ecological niche and cause symptoms; an infection.

Conclusions about the clinical implications of theoretically possible co-selection are necessarily cautious because the data is so complex. For example, the authors noted that ‘the positive association between trimethoprim use and nitrofurantoin resistance is not likely due to co-selection, but may be due to the possibility that CCGs with high trimethoprim usage have more patients on long-term treatment or prophylaxis with trimethoprim and nitrofurantoin (Pouwels *et al.*, 2019b, p9). I.e. where trimethoprim use is high, nitrofurantoin use is also likely to be high. Another problem is that measuring the proportion of non-susceptible organisms relies upon clinical data. When few tests are determined, a higher proportion of the samples are resistant as more complicated or severe infections will be the ones selected for culture. However, the authors cite an area of high prescribing, the North-East of England, as an example of a region with a relatively high-test rate and still relatively high resistance (Pouwels *et al.*, 2019b, p.7), which motivates and sustains their concern. Indeed, what is important to my argument is not necessarily the reliability of the evidence base itself but how and where AMR emerges as a concern. Here, we see the way that concern surrounds resistance reservoirs at a population and individual level, even as individual infections remain treatable.

Gram Negative Bloodstream Infections

The TARGET antibiotics UTI resource suite, which is hosted on the RCGP website and is aimed at HCPs, explains that the UTI section of the TARGET toolkit was designed to ‘support the Government’s ambition to halve inappropriate prescribing of antibiotics to help facilitate the NHS Quality Premium targets related to reducing gram-negative bloodstream infections (GNBSIs) and inappropriate antibiotic prescribing in at risk groups’ (TARGET, 2021). This is echoed in the published development materials for the resources which state:

Escherichia coli is the main cause of bloodstream infection in the UK and is responsible for more than one-third of bloodstream infections cases in England each year [...] Independent risk factors for ECBSI [...] include experiencing or having treatment for a UTI in the previous month, having a short- or long-term urinary catheter, and being a woman. We may be able to prevent and reduce ECBSIs if we effectively diagnose and manage community acquired UTIS in adults (Cooper *et al.*, 2020, p. 2).

Moreover, in Scotland, the rationale for the development of the 160 SIGN guideline also notes a link between community UTI and *E. coli* blood stream infections: 'Reduction of *E. coli* bacteraemia rate is a national target in Scotland to be achieved through enhanced surveillance programmes and targeted interventions. Effective management of UTI and appropriate use of antibiotics, where required, are both important in achieving this' (SIGN, 2020, p8). The vast majority of bacteraemia onset is in the community and has a urogenital source (Abernethy *et al.*, 2017, p. 367). Concern about community-acquired UTIs in adults therefore appears to be intimately related to GNBSI. Blood stream infections have a high mortality rate and often necessitate the use of broad spectrum antibiotics. (Diekema *et al.*, 2003).

There are several things to note about the links between community UTI, GNBSI and AMS policy. The pathways between UTI and GNBSI are well recognised as highly complex and demanding of further research. Inadequate treatment of community UTI in primary care is often cited as a probable cause of bacteraemia (Abernethy *et al.*, 2017, p. 370; Lishman *et al.*, 2018, p. 790). In work funded by UKHSA, the authors concluded that 'treatment failure in UTIs is an important risk factor for the development of *E. coli* bacteraemia. Hence prompt diagnosis and appropriate treatment of UTIs - the most frequent underlying focus of *E. coli* bacteraemia identified here and in the literature - with antibiotics to which the organism is susceptible are key in limiting progression from UTI to bacteraemia and severe sepsis' (Abernethy *et al.*, 2017, p. 370).

This work makes it clear why properly treating upper UTIs properly is key for preventing *E.coli* BSI: to prevent the infection progressing. However, from here it is not clear why lower UTI is at all important. For, there is little evidence that even antibiotic treatment of bacterial cystitis to which the responsible organism is susceptible is likely to prevent progression of the infection to pyelonephritis and therefore onwards to bacteraemia. Authors of the Cochrane Review on duration of antimicrobial treatment for lower UTI note that 'it is not clear whether untreated UTI can progress to pyelonephritis, and if so how often. Progression to pyelonephritis probably occurs at a very low rate' (Milo *et al.*, 2005, p. 3). In the NICE evidence review for the clinical guideline on uncomplicated UTI, evidence from a systematic review (Falagas *et al.*, 2009) on antibiotics versus placebo for uncomplicated cystitis in non-pregnant

women found that ‘the incidence of pyelonephritis did not differ significantly between those who received antibiotics or placebo’ (NICE, 2018b, p.25). SIGN also concluded that ‘treating patients who have LUTI with antimicrobials does not significantly affect risk of pyelonephritis compared with treatment with placebo’ (SIGN,2020, p.17). Antibiotic treatment vs. placebo for cystitis has no significant effect on progression to pyelonephritis. Indeed, this evidence is used as a rationale for driving down prescribing for LUTI in the community.

However, antibiotic treatment (both susceptible and non-susceptible to the organism being treated) does have other effects. There is evidence that previous treatment for a UTI is the largest independent effect associated with bacteraemia from a urogenital source (Abernethy *et al.*, 2017), and high resistance rates to the most frequently prescribed antibiotics (trimethoprim and co-amoxiclav) for these patients were important to this. In an ecological study, an increase in prescribing of both trimethoprim and nitrofurantoin was associated with an increase in *E.coli* bacteraemia (Lishman *et al.*, 2018, p. 792). This suggests that use (including overuse) of antibiotics in the community increases selective pressure on *E.coli*, driving resistance and leaving patients at risk of subsequent severe infection when they have an infection to which treatment fails.

This was an ecological study and as the authors note, it is therefore not possible to draw a direct causal link between prescribing for UTIs and total *E.coli* bacteraemia (Lishman *et al.*, 2018, p. 797). This is important for two reasons. Firstly, the vast majority of bacteraemia occurs in elderly populations and elderly women are at the highest risk (Jackson *et al.*, 2005). Treatment and diagnosis of UTI in the elderly is problematic as altered mental status (delirium) is often seen as a symptom of UTI, indicating the use of urine dipsticks. In systematic review, the link between delirium and UTI does not emerge clearly (Mayne *et al.*, 2019) and elderly people in care settings may often be confused. Moreover, the urine of elderly people is often bacteriuric regardless of symptoms, leading to difficulties in decisions about when to treat, especially when patients are poorly able to communicate symptoms. AMS policy has therefore discouraged the use of dipsticks in the over 65s, attempted to clearly define which clinical symptoms should be present in order to prescribe (SIGN, 2020; NICE, 2018a), and to facilitate effective treatment of UTI. It might seem that UTI in younger groups

is of lesser importance, as their infections are less likely to progress to BSI in any case. However, what is shown ecologically is that widespread use of antimicrobials in the community (potentially regardless of who they are prescribed to) drives resistance in urinary isolates which then leads to an increase in GNBSI (Lishman *et al.*, 2018; Pouwels *et al.*, 2019b).

Relatedly, nitrofurantoin is not used for upper UTI or BSI, as it reaches only low concentrations outside of the bladder. Therefore, resistance to nitrofurantoin may appear to have limited effect on treatability outside of the bladder given that antibiotic treatment does not reduce the risk of pyelonephritis. However, evidence that an increase in nitrofurantoin prescribing was associated with increases in *E.coli* bacteraemia (even as higher proportions of nitrofurantoin to trimethoprim prescribing was associated with a decrease in *E.coli* BSI) shows the ecological nature of AMR, where antibiotic use can have multiplicitous and unexpected effects.

The evidence here shows that at an individual level, people who had a higher exposure to antibiotics were at higher risk of developing a serious infection. At the same time, it also shows that the effects of antibiotic prescribing are not limited to individual bodies, body parts, or categories such as ‘elderly’ and ‘young’. Again, the importance of AMR in primary care is highly ecological and ambient.

When UTI Cannot Become a Target

I have noted how UTI becomes a target of policy making on AMR. In this section, I analyse the moments when UTI does not become a target of policy making to explore how this in turn could affect inclusions or exclusions from concern.

Recurrent UTI and Antibiotic Prophylaxis

Recurrent UTIs requiring antibiotic treatment have long been identified as important for AMR. Although it is accepted that antibiotic prophylaxis is effective in preventing recurrent UTI whilst treatment is ongoing, (Albert *et al.*, 2004), concern emerges about the implications for the emergence of resistance. This concern is visible in the comments on the guideline consultation document for NG112, on recurrent UTI, where there is considerable

disagreement about the recommended use of antibiotic prophylaxis. For instance, the Royal College of Pathologists commented in comment 87:

The evidence review provides very little support for the effectiveness of antibiotic prophylaxis, and it is disappointing to see such a strong support for prophylaxis in the guideline. There appears to have been insufficient consideration of the public health consequences of antibiotic resistance in the support for prophylaxis (NICE, 2018d, p.27).

This was a particular concern because although NICE recommends a review of prophylaxis after six months, in practice it is often used for much longer because, as acknowledged here by NICE, prophylaxis is often only effective while treatment is ongoing. The guideline committee responded that they had considered the evidence on antibiotic prophylaxis, which showed antibiotic prophylaxis was effective for preventing urinary tract infection, and were aware of the quality of the evidence. However, taking into account the risk of antimicrobial resistance with antibiotic use, they ‘agreed that antibiotic prophylaxis should only be considered when other management options had not been successful’ (NICE, 2018d, p.27). Therefore, the recommendations on antibiotic prophylaxis were retained.

Methenamine hippurate was raised by diverse stakeholders as a potential non-antibiotic management option (NICE, 2018d, p.4; p.8; p.10; p. 19). Indeed, methenamine hippurate was included in the evidence search. However, the committee was unable to recommend methenamine as it was significantly inferior to nitrofurantoin prophylaxis (NICE, 2018b, p.27; 2018d, p.6). This is instructive of the way that AMR cannot emerge as a concern when outcome measures are orientated around effectiveness in treating the pathogen and therefore unable to capture unintended consequences.

Under-treatment

In practice, HCPs often do not comply with clinical guidance. Some of these instances of non-compliance emerge as ‘inappropriate prescribing’ at a policy level (Smieszek *et al.*, 2018; Smith *et al.*, 2018). But in the first attempt to quantify inappropriate prescribing in English primary care, and, globally, one of only a few attempts to quantify inappropriate prescribing at the national level (Smieszek *et al.*, 2018, p. ii39; Smith *et al.*, 2018), the methodology used to define inappropriate prescribing is careful and cautious. Theoretical ways to assess the appropriateness of antibiotic prescribing by comparing patient data with prescribing

guidelines, or comparing observed prescribing with benchmark estimates of ideal prescribing proportions were dismissed (Smieszek *et al.*, 2018, p. 12). This was because indicators which inform prescribing such as symptom severity are often not coded for, and HCPs sometimes prescribe for non-medical reasons. Therefore, expert elicitation was used to quantify ideal population-level prescribing for conditions in which antibiotic therapy is only sometimes appropriate. The AMR 5-year national action plan from 2019-2024 noted gaps in knowledge around antibiotic use, stating: ‘it was only relatively recently that the guidance for treating uncomplicated urinary tract infections (UTIs) recently changed from seven to three days. There is clearly a balance to be struck between adequately treating the infection and not treating for longer than necessary; in many cases, that balance will vary according to individual circumstances and requires further research’ (DHSC, 2019b, p.56). That restricted access to antibiotics may represent a lack of patient care is recognised. However, concern about under-treating urinary infection does not seem to emerge as a concern for AMR⁶ in the same way as it does for other bacterial infections. For example, patient compliance with antibiotic regimens to treat STIs has long been sustained as a concern to prevent further transmission (Rice, 2008, p. 494; Tisler-Sala *et al.*, 2018). Conversely, in the case of urinary infection, I suggest that the apparent lack of concern about under-treatment and persistent infection is due to the absence of transmissibility. While resistance has been shown to pool locally, (Nomamiukor *et al.*, 2015; Ironmonger *et al.*, 2018; Pouwels *et al.*, 2019b), the clinical significance of onwards transmission of UTI is usually understood to be minimal. Therefore, under-treatment may be of concern, but it is not a concern for AMR in the same way that is true of other bacterial infections, especially those that are sexually transmitted.

What I have shown is that the assemblage within which UTI is enacted as a problem for AMR is extremely diverse, involving many different groups and even different body parts. Concern about UTI and AMR involves the bladders of elderly women, the bladders of young women, kidneys, infections of the respiratory tract, many different antibiotics, blood streams, care homes, urinary *E. coli* isolates, reservoirs of resistance in faecal or vaginal commensal bacteria, reservoirs of resistance shared between a GP practice population, etc. This multiplicity is not a problem in itself but in the next section I show that it problematically clashes with the

⁶ With the important exception of UTI to GNBSI pathways.

singularity of public health messaging which, I argue, focuses on resistance in the pathogen to the antibiotic being used. This argument about multiplicity in public health work reflects the argument made in chapter one about missing multiplicity in clinical care. Therefore, a wider argument forms about how to approach uncertainty.

Engaging Publics on AMR and UTI: Assembling Evidence and Sharing Rationales

I continue to draw on relational-materialist approaches from STS as I turn to consider how evidence is assembled and problems enacted in public-facing rationales. I follow Rosengarten and Michael in the view that interventions are not fixed entities, but change and can multiply as they are implemented locally and evidence about their implementation is produced (2009). As Holt *et al.* point out, ‘this “evidence-making intervention” approach contrasts with a traditional evidence-based approach which tends to assume that evidence is gathered first to define an intervention, and the intervention is then implemented unchanged as a singular entity (2019, p. 1537). Inserting myself, what I care about (Puig de la Bellacasa, 2011) and especially my standpoint with patients (Smith, 2006; Cupit *et al.*, 2021), some enactments might be more beneficial to the more-than-human actors involved than others. Therefore, my analysis, far from revealing interests as an isolated and detached critic, becomes part of problematisation and evidence-making.

A Superbug Imaginary

On 8th May 2018, NICE published guidelines for the treatment of UTI (NICE, 2018a), in collaboration with UKHSA. Professor Mark Baker, director for the centre of guidelines, said in a press release: ‘we recognize that the majority of UTIs will require antibiotic treatment, but we need to be smarter with our use of these medicines’ (NICE, 2018f).

The 2018 anti-microbial prescribing guideline for UTI was NICE’s first guideline on UTI in adult women. It appears then that AMR was a reason to standardise prescribing for UTI. More specifically, the rationale for the guideline emerges as co-ordinating reductions in the number of antibiotic prescriptions issued for UTI by heightening the threshold for prescribing. This is explained to be an anti-microbial stewardship by Dr Susan Hopkins, then deputy director for AMR and HCAI at Public Health England: ‘Our surveillance shows that more than a third of laboratory confirmed *E. coli* UTIs display resistance to key antibiotics. We are therefore

urging GP practices and hospitals to follow the new guidelines so they can prescribe antibiotics appropriately to their patients. This will preserve our antibiotics so that they not only save lives today but can continue to save lives tomorrow' (NICE, 2018f). The resistance that Hopkins refers to appears in Appendix A of the guideline development documents which provides a summary of 2019 of surveillance evidence from the 2018 ESPAUR report (NICE, 2018g). The rationale explains that 'the most common causative pathogen in uncomplicated UTIs (approximately 70 to 95% of cases) is *Escherichia coli*' (NICE, 2018g, p.5) and that resistance of *Escherichia coli* in laboratory-processed urine specimens as of March 2018 was 30.3% for trimethoprim (varying by area from 27.1 to 33.4%), 7.5% for pivmecillinam (varying by area from 4.1 to 15.7%), 9.9% for cephalexin (varying by area from 8.1 to 11.4%) and 2.5% for nitrofurantoin (varying by area from 2.0 to 3.6%) (NICE, 2018g, p.5).

In Hopkins' statement, reducing prescriptions of antibiotics for UTI appears as a stewardship linked to concerns about resistance in laboratory-processed urine specimens. The reference to resistance in '*E.coli* UTIs' seems to imply that the foremost reason for reducing prescribing for uncomplicated UTI is to avoid the mainstreaming of multi-drug resistant urinary isolates, causing un-treatable UTIs. I argue that this public-facing rationale mobilises what I call a 'superbug imaginary' of AMR. This concept draws on Brown and Nettleton's (2017b) work on 'superbugs', which connects them to wider socio-cultural imagery of infection and contagion from outside. Hopkin's statement implies that concern about emergent resistance centres on the pathogen- we must avoid inappropriate or un-necessary treatment of infections because of the risk that resistance will emerge in the responsible pathogen itself.

Importantly, this comes in a context of public-facing information and education campaigns promoting this understanding of AMR. Decades of public health messaging informed the public about the risks of resistance developing in the pathogen as the result of not completing a course of antibiotics. Explanations of antimicrobial resistance were based on a clonal model which had its basis in a synthesis of Darwinian evolution and Mendelian genetics (Hinchliffe, 2021, p. 11). The idea that sub-lethal doses would lead to evolutionary selection for resistance, as well as the non-toxicity of most antibiotics, led clinical researchers to advise long and high doses, and techniques like combination or sequential prescribing, to avoid allowing persistent

(and resistant) strains to achieve re-colonization of the patient (Bud, 2007; Rice, 2008; Podolsky, 2015). A systematic review of research about the British public's knowledge and beliefs on AMR in 2016 found that, from an informational point of view, campaigns had been successful: most people identified failure to complete a course of antibiotics as inappropriate behaviour (McCullough *et al.*, 2016). National campaigns globally continue to use this message, and it has been used by the WHO as well: 'always complete the full prescription, even if you feel better, because stopping treatment early promotes the growth of drug-resistant bacteria' (WHO, 2015). The reasoning for such messaging is neatly summarised in the current GCSE Biology specification, which mandates children to learn that 'patients should complete their course of antibiotics so all bacteria are killed and none survive to mutate and form resistant strains' (AQA, 2016, p.64). As I noted earlier, GPs were also historically taught that antibiotic courses should avoid suboptimal dosing. Importantly, this public facing rationale is different from the rationales I discussed in the first half of this chapter, where I explored how evidence is assembled in order to enact concern about AMR and UTI in primary care. Here, the rationale follows concern about one bug (the pathogen), one drug (the treating antibiotic) and one body part (the bladder). In the next section, I argue that the singularity of this public facing rationale is problematic when it provides messaging which poorly maps onto the experiences of inevitably multiple publics.

Compliance, Coherence and Multiple Publics

Mol also comments on how multiplicity is (not) done in public health. Indeed, this is one of her reasons for pointing to clinical skill as a place to find good care, because she finds there the specification that good care depends on (2008, p. 67). For Mol, public health glosses over specifics, noting that where good care is what is good for you, public health often approaches collectives as groups of individuals, scaling up what is good for one individual (2008, p. 67). This one size fits all approach runs into problems when messaging does not match with people's experiences: 'this way of glossing over specificities is questionable, if only because once people find out that the advice they have been given does not apply to them, they may ignore all further advice even if it is appropriate (Mol, 2008, p. 68).

In my work, I found that this mismatch between messaging and people's experiences 'on the ground' was sometimes glaring and generalised. The most striking example of this comes in

the 'Keep Antibiotics Working' Campaign, UKSHA's ongoing AMR public engagement campaign. A checklist poster, designed to be displayed in settings including GP surgeries, lists conditions that antibiotics are and are not needed for (2019). Antibiotics are listed as not needed for 'most cystitis' but needed for 'urinary tract infections.' Across the literature and in public facing materials, cystitis is described as a UTI. Indeed, the first sentence of the NHS digital page on cystitis describes the condition thus: 'cystitis is a urinary tract infection that affects the bladder' (2022). We can expect that patients being prescribed antibiotics by their HCP are often told that they are indicated because of a case of cystitis. This is an egregious example of where messaging appears to contradict itself as well as the experiences of the many people who are prescribed antibiotics for 'cystitis'.

More usually though, examples of messaging not making sense with people's experiences are less generalised (i.e. would make little sense to anyone). Instead, what I observed is that in the case of AMR and UTI, the people who are most affected by the issue are also the ones who live with poorly applicable messaging. Messaging is not aimed at the most affected, or even the most 'at risk', as we might expect with public health messaging. Instead, an undifferentiated public, that I will argue probably does not need antibiotics, is the imagined target of intervention. Another way of thinking about this is that AMS policy (messaging but also in clinical care) does not account for the expertise people living long term with urinary symptoms have developed. This is the low hanging fruit approach that I identified across AMR policy in the literature review. Here, I will examine its consequences.

Experiences Not Making Sense with Clinical Story

What I mean by the 'people most affected' by the issue of UTI is people who are living with experiences of urinary symptoms which do not make sense with the clinical story they are offered. These experiences emerged strongly in my data- here I quote a few of the most illustrative examples:

Tanya: To be honest before all of this even started, I didn't realise that urine infections were something that could keep coming back. I didn't even realise that that was something that could happen. I just thought women maybe got one to two a year and that could be potentially the worst it would get.

Nicole: I still feel like I've got the same infection that I had from April 2019. I feel like it's the same infection that just has never gone away properly. That's what I feel like. But because

I've already got the infection. It kind of....it will flare up so that you have bad flare ups with it and then it will subside a little bit and then it will flare up again and I can't pinpoint what makes it flare up. So it's not like every time you have sex, it flares up. Or every time, every time you drink alcohol it flares up. Like that's not, I have nothing to pinpoint it on. Just, I'll just go about my normal day, and then the next day it'll have flared up for no reason whatsoever. That I know of, anyway.

Sophie: The way a GP looks at UTI, it's a very simple case. You've got a UTI. Let me just prescribe Nitrofurantoin. But it's very stressful from a patient point of view when that's not your experience. You know, in the past it's been, well, my bladder hurts every single day. So do I permanently have a UTI or does...there was never any explanation for what that was [...] if you look on the NHS website, it will tell you, a UTI will probably go away on its own but if it doesn't then you'll need to have antibiotics. That's so, so dissimilar to what my experience is, that I wonder if something has like gone wrong.

Minna: Sometimes it's just like... I get like a raging infection out of nowhere and I'm... I don't know what's happening. 'Cause my partner... he works at sea so he's away half the month every four months. So I'm like... I haven't had sex for like weeks on end... so I don't understand, you know, it's just coming out of nowhere.

Jules: You don't know what to do, because the antibiotics are obviously not going to help, and not only they are physically not going to help by killing the infection, but you also feel in your mind that, oh, what is this? I don't know what it is, I don't know what to do about it, so you feel really bereft and sort of really at a loss.

A common theme is the way that these people live without an explanation for their symptoms, not recognising themselves in how a UTI is described, even as they are sometimes treated for UTI when they come into contact with medicine. They do not understand what is happening to their body and it is a scary and isolating experience, living as they do without getting help or even a coherent explanation of why they experience such hugely painful symptoms out of nowhere.

As I touched on in chapter one, care for UTI sustains itself through incoherence. It is because these poor experiences of care are marginalised that care is sustained. This is neglect not domination. I observed different ways of marginalising these experiences and preventing them from impacting on standardised care for UTI. Foremost was maintaining the clinical story of simple UTI by treating only what could be treated, what was expected to be found; a simple UTI. Two senior consultants, the first an infectious diseases specialist and the other a clinical microbiologist described the marginalisation of difficult cases thus:

HCP: *I wouldn't want to say it's a small patient group, because I suspect it probably isn't, to be honest [...] the problem is because we don't understand –and this is true of so many different aspects of medicine – but yeah, medicine has a way of not understanding something, and therefore putting it away in a box – oh, too hard, I'm not going to worry about it. And I suspect there's an element of that.*

HCP: *I was talking to a surgeon the other day, he just does knees, that's all he does, is knees. You know, that's one joint in the body and that's all he does. But he loves that and that's what he's interested in. But if you go along and try and get him really excited about a hip patient he's not going to be interested. So, you have to understand that I think when patients don't fit into our boxes and our interests we're very quick to try and push them off to someone else and put them in someone else's box and someone else's interest.*

What both HCPs describe is a supremely clinical outlook; when there is nothing to be done, nothing to be found when a specialist looks for what they expect to find, the problem must be passed onto someone else. But in these tricky cases of unresolved urinary symptoms, it is not clear who these specialists might be, no-one seems to recognise what they expect to find on clinical examination and therefore no-one seems to have many care practices to try. Therefore, these experiences are put '*away in a box*', not to trouble care or the clinical story of UTI. This means that people with prolonged symptoms which clearly go beyond an acute UTI are often treated for acute UTI when they come into the clinic:

Tanya: *They would constantly try and brush this under the carpet [...] I've had a lot of frustrating phone calls with them, but I think the most frustrating one I had was actually when I got that urine infection after the six [prophylactic] month course. Because the doctor I spoke to [...] But it seems to be that all of the doctors up there, it doesn't matter who you speak to, they all sing from the same song sheet.*

Laura: *When you're not fine, you're an anomaly and then the clinician just sees you the next time and if you have a positive culture, oh you have a UTI, let's give you three to five days of antibiotics [...] it's just the standard approach every single time and there is no escalation point for a lot of clinicians.*

This leaves people living with experiences which do not make sense with the clinical story they are offered, an intensely frustrating and isolating experience. This is the context within which people I have identified as amongst the 'most affected' by issues surrounding AMR and UTI messaging are living with policy level mobilisations on AMR.

Invited Participation

If I have identified this group of patients, this public, as amongst the most affected on the issue of UTI and AMR, it is instructive that this public is not invited to participate in policy as a patient public. UKSHA's 'Antibiotic Guardian' Campaign provides links to a series of patient stories to 'show how AMR has affected individuals' (2014). The story about community UTI comes from BBC News and features a young woman, Kelly, who was diagnosed with a UTI by her GP and took antibiotics (2014). The antibiotics relieved her symptoms at first but she later had to return to her GP with continued symptoms. A culture determined non-susceptibility to the antibiotic she had been given, as well as to many others: a multi-drug resistant infection. On her GP's advice, she went to the hospital for IV antibiotics, but had to present to secondary care again ten days later as her condition deteriorated, ending up in intensive care.

Kelly's story is real and my interest here is not in analysing what she says, but in the way her story is employed as a 'patient story' in engaging the public. Here, as in many patient stories on AMR, the genuinely antibiotic-needing patient is enrolled to remind others (who do not need antibiotics) that they should not use antibiotics un-necessarily. Kelly describes how she thinks antibiotics are being overprescribed, leading to greater resistance. This is curious as a strategy to deter antibiotic use, because it seems quite obviously unlikely that anyone thinks of themselves as using antibiotics un-necessarily. It may seem more likely that HCPs may indeed recognise that their prescriptions were not clinically indicated. Therefore, I express doubt that this imagined public exists as well as suggesting that such messaging may even undermine confidence in HCPs to make the correct prescribing decisions. Kelly's story was about how she did urgently need antibiotics and yet serves only as a reminder not to use antibiotics. In my view, this employment of Kelly's story represents a missed opportunity to reflect upon moments when antibiotics are needed, and the consequences for people who use them.

Similarly, the WHO recently inaugurated a 'WHO Task Force of AMR Survivors.' They invite 'survivors', being 'those who themselves survived a drug-resistant infection', to advocate for accelerated AMR mitigations efforts and greater investments in AMR' based on their

‘legitimacy to advocate’ (2022). Again, strict divisions of ‘eligibility’ are held between those who genuinely need antibiotics and are ‘victims’ or ‘survivors’ of AMR and those who do not need antibiotics and use them unnecessarily. This is striking given one of the main problems for clinical use of antibiotics is uncertainty surrounding who would benefit from antibiotics.

The people I spoke to often used antibiotics to manage life with unresolved urinary symptoms. But they are not identified, nor identify themselves, as what WHO terms as ‘victims’ or ‘survivors’ of AMR. I asked Sophie if she considered herself to be suffering from AMR:

Well, no, because when I’ve had a culture come back recently, it said that I was fully sensitive. So I don’t know, but I’ve definitely I... I just don’t know honestly, I don’t know.

The implications of recognising yourself as a ‘victim’ or a ‘survivor’ deserves a lot of attention, especially in the gendered context of uncomplicated UTI as these terms pick up on debates and discourses within the area of sexual violence against women and girls. This is out of scope here as I am concerned with a group who are not invited to consider themselves as victims or survivors of AMR. Suffice it to say that one thing that such a designation does, which I am arguing would be helpful in this case, is to recognise a lack of care. Throughout the thesis, I make the argument that care for urinary symptoms is circumscribed by antibiotics. In the previous chapter, I showed how patients can participate in maintaining a singular focus on antibiotics inside the clinic when they seek help for a UTI. Here, outside of the clinic, feeling that access to antibiotics is under threat, I argue that patients living with complex experiences of UTI often do not recognise themselves as people for whom antibiotics have not helped, even as they are often repeatedly prescribed more antibiotics. In the next chapter, I consider what it would take for people in pain to think of themselves as people for whom antibiotics have *not* helped, rather than people who would be well if only they could access antibiotics at the appropriate dose and duration.

Just as this group of patients often do not recognise themselves as amongst the most affected by AMR, they are also not recognised as such by the role set out for patients in AMS mobilisations. Evidence shows that the current guideline treatment for uncomplicated UTI has a treatment failure of around 21% (Milo *et al.*, 2005). Recognising treatment failure as a

form of AMR would mean recognising different groups as lacking care from antibiotics, and needing to find care in different places. But treatment failure outside of in-vitro resistance is rarely recognised as AMR. For instance, in 2019, research was published in *Nature* on one mechanism of bacterial antibiotic tolerance and re-colonisation that does not involve the acquiring of specific resistance genes. They showed that bacteria can adopt a cell-wall deficient state during antibiotic treatment and then transition back to the walled state with antibiotic withdrawal. Importantly, ‘unlike previously described dormant persister cells, L-forms can continue to proliferate during what can be long (typically 5–14 days) periods of antibiotic treatment’ (Mickiewicz *et al.*, 2019, p. 6). This was still theoretical work outside of a human model but responses to it tell us much about what we talk about when we talk about AMR. The research was picked up by BBC News in a story headlined: ‘Bacterial Striptease Evades Antibiotics’ (Gallagher, 2019). In the story, Professor Laura Piddock, director of scientific affairs at the Global Antibiotic R&D Partnership, told the BBC:

This is an interesting academic story, but [...] I do not view this as a mechanism of antimicrobial resistance 'as we know it', this is a response to exposure to an antibiotic that allows the bacteria to survive in the presence of the drug.

Again, I argue that AMS public engagement effort work within a superbug imaginary which poorly reflects how the problem of AMR and UTI is enacted in evidence and upon which interventions have been designed. This leads to a situation where people’s experience of interventions poorly maps onto the rationales they are being given. This may be somewhat inconsequential for most. But it is often not so when people most affected by the issue identify themselves as targets of policymaking which poorly maps onto their experiences.

Identifying Yourself as a Target of Policy Making

Not being identified as the antibiotic needing patient (like Kelly) in AMR policy mobilisations, people sometimes identified themselves as targets of unnecessary antibiotic use in policy making.

Laura: I think the spotlight being shone on UTIs for AMR is going to be terrible for the patients with this problem. It's so easy to look at this and say, well we use the most antibiotics here, therefore we should stop using antibiotics there and we're going to end up with all these multidrug resistant UTIs but really, we're just going to end up with a whole load of women that cannot live their lives anymore because nobody considered what kind of treatment would help [...] it frustrates me so much that we're just trying to take antibiotics away from women who cannot survive and live a quality of life without them. It's troubling how much funding

is coming up for that right now and yet it's impossible to get funding to document the patient perspective on this, so, it's a huge discrepancy between the two.

Liz: I definitely think that GPs and doctors are scared to prescribe it because of the AMR thing. And like you said about before, about, like, media, I think it is everywhere. I think I was even listening to a 'Guilty Feminist' podcast and I think someone mentioned it on that. And I was like, okay. So, yes, it is everywhere. And AMR is a problem. I see how it can be a problem. I just think, yes, some of us are the victims of that.

Sarah: Like I don't understand, I understand that we want to be careful that people don't get resistant to things but like, no one's taking cystitis antibiotics for like a joke. And women, are getting quite seriously ill quite quickly.

Sophie: It [AMR] really worries me, I feel like I'm contributing to the problem. But...you know...I've got absolutely no way of not contributing to the problem.

People who have experiences of UTI which clearly go beyond 'uncomplicated' are continually offered a clinical story of uncomplicated UTI. Meanwhile, they live with messaging which emphasises non-use of antibiotics in uncomplicated UTI based on a superbug imaginary. The mismatching of these rationales, combined with identifying AMS as threatening access to antibiotics (which often represent the only care available), rather than a mobilisation that cares for people who need to use antibiotics for complex infections, risks unintended consequences. In the next section, I offer an alternative way of conceptualising a role for reflective, antibiotic-using publics as a public for AMR.

[A Reflective \(Antibiotic-Using\) Public for AMR](#)

Across state level approaches to antimicrobial resistance in the UK, the issue of public engagement and involvement remains difficult for public health. Wellcome, funders of this research, published a 2019 report on communicating AMR, joining others in a continued emphasis on both the importance and the disappointing failure of public engagement approaches so far, noting 'a low-volume and specialist conversation on social media' (2019, p.8). This is a familiar theme, thinking back to the literature review, there is depression and some exasperation at the limited success of attempts to create a public for AMR. This is what WHO attempts to do with the taskforce of AMR survivors. I argue that people living with extreme and unexplained experiences of urinary symptoms often engage in careful reflection about AMR, and could be recognised as a reflective antibiotic using public. Here, I provide

an example of this reflection, focused on the issue of antimicrobial duration. Natalie, who has a role as a leader of patient mobilisations, told me:

So yeah, the short courses that obviously that you're putting into the body, at first it will work, but obviously you're putting in little bits, and leaving it, putting it in again and leaving it. So the body recognizes what it is [...] And so obviously, that's where the resistance comes from. I think the way that they're treating people now. You see... you go into GP surgery and the hospital for instance. And it's all over the TV now on adverts where they talk about resistance and in actual fact, they're actually causing the resistance. They're causing it to happen because they're treating people wrong.

This account clearly picks up on public health messaging around the importance of finishing the course to avoid allowing vertical inheritance of resistance genes. My interest here and throughout, is not to evaluate Natalie's knowledge against the latest evidence. Instead, it is to notice that there is here an antibiotic using, reflective public presenting itself as a public for UTI and AMR, wanting to engage in careful consideration and deliberation and assembling AMR as a matter of care. Sophie told me:

Sophie: But you know, that message of take them until, you know, that thing we always had drilled into our head, take the full course until all the bacteria are killed. All my bacteria are not being killed. They never have been. So what does that mean? And it's the same as when they say things like take....in the past I have done things like, you know, where I've taken one dose.

Eleanor: *Yeah, why?*

Sophie: Because I just had a little bit of a twinge, I've taken one dose, but I worry about taking antibiotics and I just don't know what I'm doing and I feel quite worried about doing that, but I have done in the past and then then I thought to myself, well, it's a legitimate treatment when they give you one dose after you've had sex and how do they know I don't have bacteria in my bladder there, how is that any different? See the whole thing doesn't make any sense. I'm very confused.

Both Sophie and Natalie, their experiences not making sense with rationales which emphasise avoiding vertical inheritance through sub-optimal antibiotic dosing, question the science of AMR. They identify that the superbug imaginary they have been offered as a reason to not use antibiotics clashes with their experiences, including because of times when they have been prescribed a 'sub-optimal dose'. Here is an opportunity for collective deliberation on AMR with people with very complex messages about antibiotic use.

Explicit Refusal of Engagement with this Antibiotic-Using Public

Careful and deliberative conversations are taking place on this very issue, discussing the public role on assembling evidence around the mechanisms of antibiotic action and drivers of resistance. In 2017, Llewelyn *et al.* published in the BMJ, calling for the end of messaging that failing to complete a prescribed antibiotic course drives resistance. Llewelyn *et al.* encourage 'policy makers, educators, and doctors to stop advocating "complete the course" when communicating with the public (Llewelyn *et al.*, 2017, p. 1). Further, they state that they 'should publicly and actively state that this was not evidence-based and is incorrect' (Llewelyn *et al.*, 2017, p. 1).

But, there is an explicit refusal of engagement with reflective antibiotic-using publics. Staying with the issue of antibiotic course length, WHO guidance on the question in January 2020 emphasised following your doctor's advice about choice and length of antibiotic course, on the basis that doctors have 'had years of training and has access to the latest evidence.' While there was an acknowledgement that shorter courses have advantages, these related to reduced cost and side effects, as evidence that shorter courses may be just as effective was presented as 'emerging' and only true for 'some infections.' Moreover, the aim of antibiotic action was 'to completely kill all bacteria' (WHO, 2020). In the UK, public health advice shifted around 2016 to messages about taking antibiotics 'exactly as prescribed' and 'following your doctor's advice' (Llewelyn *et al.*, 2017). Messaging around completing the course has been rather quietly replaced, without contradicting previous advice.

At the time of publication, there was significant mainstream media coverage of Llewelyn *et al.*'s piece. Prof Helen Stokes-Lampard, chair of the Royal College of General Practitioners, told *The Guardian*:

It's important that patients have clear messages, and the mantra to always take the full course of antibiotics is well known - changing this will simply confuse people (Boseley, 2017).

The status of current attempts to engage with the public is rather disheartening, reflecting not only a marked loss of confidence in the reflective capacity of the public on the part of public health workers, but also a loss of self-confidence in their own capacity and ability to relate to

the public. While patients like Sophie and Natalie point out the ways in which they struggle to square the circle of clinical treatment, AMS messaging and their own experiences, public engagement interventions appear to be aimed at people who might very well use antibiotics (and also have done so in the past given the emphasis on re-consultation) but also appear to have very little reflective thought about this experience, and to be likely not in clinical need of antibiotics. I say this because messages which dodge reflective engagement and instead direct trust in clinical advice are clearly unlikely to seriously engage people who have reason not to trust that their health care practitioners can care for them (even if they maintain good relationships with HCPs). People who feel unwell and do not get help in the places they normally go to for help do a number of inventive and experimental things, including with prescribed pharmaceuticals such as antibiotics, in order to feel better, as Sophie described: *'in the past I have done things like, you know, where I've taken one dose.'*

Ignoring this and choosing instead to engage only with a non-reflective public who probably don't need antibiotics leaves us back where we started, trying to find ways to engage with an apparently recalcitrant public. It remains an empirical question if this imagined public, made up of 'low hanging fruit' cases of over-use of antibiotics, exists. Moreover, such an unspecified and unspecific account of who messaging is aimed at, fails to account for what might be the side-effects of exclusions from the issue of AMR. As Mol reminds us, a worry is that if we lose people on one part of the message by approaching them with generalised and universalised messaging inappropriate to their experiences, they may give up on all further advice even if it is appropriate (2002, p.68).

Another example of failing to share complexity with publics, instead opting to direct messaging at a vast majority of uncomplicated cases comes in messaging around diagnostics for UTI. In chapter one, I explored the ontological reality of UTI in the context of patient mobilisations identifying and resisting an overreliance on technologies of pathology, such as urine dipsticks and MSU cultures, to the detriment of clinical signs including the patient story. I argued that UTI in primary care is enacted clinically, but that this is not true everywhere, noticing that elsewhere, such as in the A&E or in care homes, UTI is often enacted pathologically, with no clinical input at all. But the UTI enacted on the culture plate was not

of a stronger reality than the UTI enacted clinically. It therefore became a question what makes UTI 'hang together' as an ontological referent across different sites. What is the reality beneath? I answered this by finding that diagnosis of UTI is not organised by revealing biological reality, but enacted in practice by answers to the question of if antibiotics should be prescribed. This rather singular care practice in the context of the care that antibiotics are able to provide appeared in chapter one as a reason for poor care.

Here, looking at assemblages of concern around UTI and AMR, I argue that quite a lot of public facing rationales and messaging does indeed suggest that the UTI enacted in the clinic is of a lesser reality than the UTI enacted pathologically. A local NHS AMS campaign, 'Seriously Resistant', asks members of the public to pledge to become antibiotic stewards: 'Understanding when you should use antibiotics will mean they still work for you when you really need them. Pledge now to act differently next time' (2022). One of the four key facts to understand in order to act differently next time relates to UTI: 'On average only 45% of the women prescribed antibiotics for a UTI had the infection.' So just over half of all prescriptions for UTI are identified as inappropriate.

These statistics, a common feature of AMS campaigns, are based upon research such as that by Butler *et al.*, who conducted a primary care observational cohort study to measure the proportion of women patients who had a positive urine culture, compared to the number who were prescribed antibiotics. They found that in England, 'up to 70% of females with symptoms attributable to UTI are found not to have a UTI confirmed microbiologically when routine urine culture is performed' (Butler *et al.*, 2017, p. e830). In research settings, there is considerable problematization of the relationship between microbiological findings, and therapeutic response to antimicrobials. However, in AMS campaigns, a 'true UTI' often emerges as that visible on a culture plate. I argue that mobilisations on AMR which pulls UTI out of urinary symptoms, constructing strict boundaries between those with 'microbiologically confirmed infection' and those without, those who need antibiotics and those who don't, threatens to make care even more circumscribed by the question of whether to prescribe antibiotics or not, neglecting what else might be done to care.

Finding a Story that Makes Sense

Jules described a moment when their pain and experiences were recognised by a health care practitioner:

And I really felt that she knew, and I described my experience, and she said...she listened and she said, yes, it's consistent with other people that have been to my office and said similar things, and she took it seriously. She examined me.

I cannot overstate the moment of this significance. What happened here in this moment of 'recognition' is not that this HCP believed Jules about their pain where others hadn't. Indeed, Jules describes a series of positive encounters with HCP who had tried to help them with their pain. Instead, recognition meant that the HCP found in their clinical examination what they expected to find, what they were already looking for. Jules' body was doing what the HCP expected, even though this was pathological. I argue that this moment of recognition, when a HCP finds in clinical examination what they already expected to find, is a moment of huge significance and meaning-making for a patient living in pain without getting help or even a coherent explanation for the ways in which your body is behaving, continually being offered a story which doesn't make sense, and living with AMS messaging aimed at a non-reflective public who uses antibiotics but shouldn't.

Sophie also describes a moment when she was offered a different clinical story, a story that made sense of why she continued to experience UTI symptoms after antibiotic treatment. She explained what this meant to her:

It was all so confusing at that time because my cultures would come back negative. So I was just so confused. I've also got anxiety because my aunt has a history of kidney, kidney cancer and things like that, and I was just thinking, why does my kidney hurt all the time? The uncertainty is just very stressful. I just remember thinking I just don't...I just don't understand what the situation is. Now I've read this embedded UTI theory, although I've got no reason, no way of knowing if it's correct or not, at least it is an explanation and that does help psychologically a lot.

In the next section, picking up on the reference to 'embedded UTI', I explore what happens when patients are offered this moment of recognition through a coherent clinical story, which mounts resistance to the targeting of UTI and reduction of access to antibiotics.

Un-intended Consequences and Un-Invited Participation: Mounting Resistance

Not being invited to understand themselves as amongst the most likely to be affected by AMR, people using antibiotics to care for complex experiences of urinary symptoms instead sometimes identify themselves as targets of policy making. AMR policy which focuses on non-uses of antibiotics for uncomplicated UTI therefore has un-intended consequences as people mount resistance to this targeting: uninvited participation (Wynne, 2007). Sometimes, this resistance makes the familiar move of directing attention to other problematic uses and users of antibiotics. Natalie asks:

What I don't understand is how somebody can go into a GP practice with a skin infection and get six months of high dose antibiotics. But yet, someone with a serious infection in a very important organ receives three days. A pet receives two weeks, three weeks. Why are we different to pets?

Here, and across these types of mobilisations, there is an argument that individual health is sacrificed for the societal good of AMS. Absolutely key to this is the idea that under-treatment of an acute infection led to bacteria invading bladder urothelial cells, causing a chronic, or 'embedded' UTI. Citations such as Horsley *et al.* (2013) and Penaranda *et al.* (2021) are used in support of this. Importantly for my argument, where public health has shied away from reflective engagement on uses of antibiotics, and clinical care often marginalises difficult cases, failing to provide a coherent clinical story, elsewhere others offer opportunities for such patient involvement. Unlike reluctance to share that concern about AMR does not centre exclusively or even primarily on resistance in the pathogen, collaborative mobilisations between select HCPs and patients around 'chronic UTI' engage fully on the risk of AMR as a result of sub-optimal treatment of the pathogen. In March 2019, embedded UTI specialist James Malone-Lee, who advocated long-term, high-dose antibiotic courses, responded to Pouwels *et al.*'s earlier cited attention to course duration in the *BMJ*:

In our enthusiasm for limiting antibiotic consumption we may be failing a significant minority. We dismiss their treatment response failures and persistent symptoms because negative results from discredited tests falsely reassure. We sentence these poor people to life-changing, painful chronic lower urinary tract symptoms, denying them legitimate treatment to comply with guidelines informed by dud tests. These are modern-day, sacrificial lambs, placed on the altar of the god of AMR (Malone-Lee, 2019).

These mobilisations, unlike public health mobilisations, do recognise a lack of care for this patient group. Note how Malone Lee uses the language of victimhood - ‘sacrificial lambs, placed on the altar of the god of AMR’ - which WHO reserved for those receiving a piece of paper recording in-vitro MDR. This fits with people’s experiences, offering a coherent story and going to extensive efforts to engage in deliberative discussion, publishing a whole book (Malone-Lee, 2021), which stands in sharp contrast to refusals of reflective engagement on the part of public health. Importantly, as in the above extract from Malone-Lee, patients are encouraged to recognise AMS mobilisations as a threat to them. Absolutely key to enrolling new participants in this matter of concern and therefore building a movement, is the idea that persistent or chronic UTIs could have been prevented with greater access to antibiotics. This argument has appeared in diverse places (Devlin, 2019; Malone-Lee, 2021), and is widespread on social media, as clinicians involved in patient mobilisations conjure a superbug imaginary to argue that sub-optimal treatment has led to residual infection. The Guardian reported in 2019: ‘Dr Catriona Anderson, a GP specialised in treating UTIs agreed that a shift towards prescribing three-day courses of antibiotics meant that some patients were being left with residual infection. “If you have a thousand enemy soldiers coming over the hill, you don’t just send in a single sniper,” she said. “You need to go in and hit the infection hard. If you just tickle the bug with an insufficient dose of antibiotic, you drive resistance”’ (Devlin, 2019). For mobilised patients, idealised care for even uncomplicated, acute UTI therefore becomes orientated around more antibiotics. I asked Liz what she would like to see happen when a young woman goes into a GP describing symptoms that seemed to indicate a UTI: *‘I would like for them to give her a long course of antibiotics and then if she still doesn’t feel well, I would like them to extend the course or try another one.’*

This is significant because it is a different phenomenon to what I have identified so far. So far, I have pointed out that people with complex experiences of UTI, who appear as ‘out of scope’ of clinical care, often identify themselves as targets of AMS policy mobilisations aimed at uncomplicated UTI. But here, these patient mobilisations attempt to enrol experiences of uncomplicated UTI, warning that AMR policy mobilisations risk health and that people should consider insisting on antibiotics. I argue that these popular threats of uncaring AMR mobilisations are an un-intended consequence of refusing to engage in collective and

deliberative discussion with antibiotic-using publics. What Liz says is a careful reflection on good care rather than a misunderstanding of science.

Assembling the Problem in a More Caring Way

This patient group of people with complex experiences of ostensibly antibiotic susceptible infection, who often use antibiotics, are not patients who are imagined by many of the ways used to imagine patients. The reflective antibiotic-using patient doesn't exist in behavioural science and as I have shown, there are only traces of their experiences in clinical policy. But these experiences are important, both intrinsically and extrinsically; people live with and experience UTI and AMR daily and also live with public health messaging around them. These people may enact forces that are not captured by behavioural science, taking collective action and enacting different futures to the outputs imagined by behavioural models. Therefore, let us contemplate these futures, taking into account these experiences, and theorising what ways there might be to assemble the problem of UTI and AMR in a more caring way.

Chilvers and Kearnes emphasise that participatory practices are co-produced and have multiple effects that shape and are shaped by 'techno-scientific, political and social orders (2020, p.354). Humility is a key concept, allowing a role for expertise in knowing what we know, but with an openness to what we do not know or may be known elsewhere. Therefore, I provide below some opportunities for collective deliberation, not from above, by noticing what information is missing and needs sharing, but by noticing what is salient to different publics as issues form through participation (Wynne, 2007).

Opportunities for Collective Deliberation

Nitrofurantoin

Nitrofurantoin resistance in *E.coli* urinary isolates continues to be low: ranging between 2.9-3% in the English national data from the first three quarters of 2021 (UKSHA, 2022.) One convincing explanation for continued low nitrofurantoin resistance in *E.coli* is the 'fitness cost' associated with acquiring nitrofurantoin resistance, and that even nitrofurantoin 'resistant' isolates grow significantly less well in the presence of therapeutic levels of nitrofurantoin (Sandegren *et al.*, 2008). Indeed, as Pouwels *et al.* point out, nitrofurantoin use may actually

select for *E.coli* susceptible to amoxicillin and trimethoprim because ‘nitrofurantoin resistance genes are, in contrast to trimethoprim and amoxicillin resistance genes, not frequently found on mobile genetic elements with multiple resistances or correlated with multiple resistances in other ways’ (Pouwels *et al.*, 2019b, p. 9). This does not mean that reducing antibiotic use (including nitrofurantoin) for LUTI is not a worthwhile aim of AMS policy. But it does mean that there might be ways to recognise those most implicated in worries about AMR, and to share more about the futures they face. Nitrofurantoin is often active against even MDR isolates (Sanchez *et al.*, 2014) and this could be salient to share, especially considering the role of catastrophizing in pain responses (Ae *et al.*, 2018).

The ALTAR Trial

I already noted the limited ways to formally account for the advantages of non-antibiotic treatments over antibiotic treatments for recurrent UTI, given evidence that antibiotic prophylaxis with nitrofurantoin is more effective. In the ALTAR trial on methenamine hippurate prophylaxis (Harding, 2022), it was patient and public involvement that shaped the trial design in such a way to account for the advantages of non-antibiotic interventions. The PPI group defined the non-inferiority margin as one episode of UTI per person per year. The production of evidence on ‘acceptability’ is a well-established role offered to patients (Moreira, 2002, p.1981), often drawing on the strictly defined roles I have critiqued throughout the thesis, where patients add value-laden ideals about how they feel about disease to the value-free ideals of science and medicine. Nonetheless, a major achievement of the trial is the way in which this role manages to account for the co-production of the societal and individual benefits of avoiding antibiotic treatment where possible. Too often, these benefits have been presented as societal in nature, opposed to individual patient wellbeing, as the sacrificial language of victimhood suggests. As Irwin *et al.* argue, STS often engages in critiques of participation initiatives by evaluating them against principles of democratization of science which ‘can make it difficult to acknowledge and pay serious attention to the varieties of engagement that are very much less than perfect but still somehow “good”’ (Irwin *et al.*, 2013, p.120). Such inventive, experimental and risky ways of accounting for collective mobilisations between patients and healthcare practitioners on AMR and UTI can be seen as a step towards a more collective conversation.

Conclusion

I showed in the previous chapter how clinical care is organised around antibiotics although antibiotics have not been able to care for everyone in the past, now or in the future. At the same time, this threatens to become ever more the case as AMR policy pulls the question of whether to prescribe antibiotics out of other questions about care. When we try to think about what people do around antibiotics, care is paramount. People take antibiotics to try to feel better. Separating AMS from care does seem to imply that there is some concern outside of care, outside of what would be best for you. I have found that, within an ecological understanding of AMR, no-where in UK AMS policy it is suggested that an individual should be deprived of antibiotics if they are more likely to benefit from them than to be harmed by them. It is therefore worth reflecting on how concerns about AMR, when separated conceptually from care, can become a threat, even as intentions are caring.

When my participants spoke, as Sarah did, about ‘cystitis pills’, or Madalina talking about ‘some pills’, and Renata not knowing to distinguish an antibiotic from other types of medications, this could be read as a knowledge deficit. As a reason why people continue to use antibiotics, misinformation often appears, with increased education appearing as a remedy. And indeed, non-clinically trained patients are different to HCPs in their relation to medical knowledge. Education may be a way to engage with patients and publics on a reflective level, assembling rationales and therefore participating in intervention-making, rather than assembling evidence and then putting it in action as an ‘evidence-based intervention’.

But keeping with AMR as a matter of care, another way to read this is that people are focused on what they need to feel better, regardless of what they know about antibiotics. Indeed, many of my participants spoke in terms that I coded as ‘avoiding medications’, talking about themselves as the ‘kinds of people’ who don’t like to take pain killers or un-necessary medication, including antibiotics. Arguably, this kind of explicitly performative talk does not tell us much about practice. But it does tell us that people know to perform this kind of talk, and perhaps especially within the context of an interview which touches on AMR. This challenges the idea that education alone is enough to get people to decrease their use of

antibiotics. Instead, people need to trust and have access to different ways to feel better, beyond standard uses of antibiotics. The next chapter considers what it would take for this to be true for patients living in pain.

In this chapter, I have argued that public health has a depressed outlook on the public's apparently limited engagement on AMR, and on public health workers' own ability to relate to the public. Attempting to maintain AMR as a matter of care, I express an optimism about the flourishing ways to care outside of antibiotics. This is not a conservationist, depressed outlook to preserving, guarding and restricting access to antibiotics, but a multitudinous bounty of different ways to care, including those that have been cultivated by people over decades and could now bloom. Recognising people who don't get help from antibiotics for urinary symptoms as a reflective public for AMR and UTI, we can look to their care practices for ideas. This is a role for this public that I set out in the final data chapter.

Chapter Three: Becoming a Patient

Good Care

In chapter one, we saw people seeking care for urinary symptoms in the clinic. I argued that it is because clinical care for urinary symptoms so closely revolves around antibiotics that care often runs out of course. People struggle to become people in need of care, rather than people who need to be repeatedly prescribed antibiotics. Clinical care for urinary symptoms threatens to become even more orientated around the question of whether to prescribe antibiotics or not, as AMS interventions focus on that question, rather than the question of what to do about painful symptoms. Crucially though, outside of the clinic, people do become people in need of care. They become people who are constantly doing things and not doing things to care for their bladders. This chronic living (Manderson and Wahlberg, 2020) takes up time, it affects paid work, leisure, sex, family, big moments in a life: it can become part of someone's identity outside of the clinic. As Langstrup points out through her concept of chronic care infrastructures, the home as the outcome of an ongoing and mediated interaction between self, other and place (2013, p.1011) is not unchanged by the tasks of chronic living. Such chronic care infrastructures have consequences. In the previous chapter, I explored unintended consequences enacted by unruly others when their experiences poorly map onto messaging aimed at an un-differentiated public within a 'low hanging fruit' imaginary.

In this chapter, I keep these marginalised cases central and pay attention to where good care for urinary symptoms may be found. I do this by drawing on Mol's theorisation of the nature of good care. Mol muses on the differences and contingencies between care and cure, noting that 'in practice [...] the activities categorised as "care" and "cure" overlap' (2008, p. 1), giving the example of dressing a wound. Caring for a wound also cures it. Many of the diseases that send people to their doctors nowadays are chronic in character (Armstrong, 1995; Wahlberg and Rose, 2015). And part of living with chronic illness is making it liveable, making it bearable, even though there is no cure. Therefore, chronic diseases are good places to learn about crafting a good life through care practices.

In a section on chronicity and antibiotics as cure, I analyse what happens when chronic UTI is conceptualised through a curative imaginary (Kafer, 2013; Dryden, 2021). De-centring

antibiotics as care, I notice what happens when antibiotics no longer seem to offer cure: practices of cure and practices of care start to look more similar. In her work, Mol looks mainly to the clinical work of HCPs for more multiple ways of caring. However, my theorisation of good care in this chapter leads me in the next chapter to people who care for bladders with practices that range beyond standard ways of using antibiotics, including those using antibiotics. This is a refusal of the marginalisation of tricky cases and a recognition of the need to hold care and AMR together. This chapter contributes to the overall thesis by questioning what it would take for those who identify themselves as targets of policy making on AMR to see themselves as a public for AMR. Here, noting Chilvers and Kearnes work on how participation is co-produced and emergent (2020), I suggest a participative role for the thesis in encouraging people to recognise themselves as a public for AMR.

Antibiotics as Care

As I laid out in the previous chapter, one thing that people sometimes do outside of the clinic when they don't get help and their experiences don't make sense with the story they are offered, is come together to take collective action. Sometimes people call themselves 'chronic UTI' patients. A chronic (or embedded) UTI has been specifically enacted in patient mobilisations, in order to differentiate it from an acute UTI, or recurrent UTI (a series of acute UTIs). In this, it does the work of recognising a person's experiences, providing a story that makes sense, explaining why you have become someone who constantly cares for their bladder when it is often impossible to become this person inside the clinic. It says, you are not the only one and what is happening to your body is recognisable. It recognises pain and recognises the work that goes into caring for a poorly bladder without getting help from the places you would normally go to for help.

'Chronic' normally refers to a disease that cannot be cured. Many diseases, such as diabetes, are chronic in the context of access to healthcare, but otherwise could soon kill you. Often the distinction between chronicity and death centres around global health inequalities. In this way, what diabetes is, is not only about the biological 'real'. What diabetes is is determined by many other things that all come together to enact the disease category 'diabetes.' This is not about meaning. Diabetes doesn't *mean* something different to someone who does not have access to insulin because of health inequalities. It is something different on an ontological

level. People with diabetes cannot change what it means to them and in that way, feel better. They have diabetes and no access to insulin and therefore they will probably die. The real of chronicity is therefore related to care and cure, as well as to the 'biological real'.

But chronic UTI as it is currently enacted in patient mobilisations is chronic because cure is denied based on a misunderstanding of this biological real, rather than because cure is not available. A chronic UTI is often described in terms of the way it differs on a pathophysiological level from acute UTI. As I described in chapter one, the reality of UTI (what a UTI is) is important to patient mobilisations. At the moment, many (though not all) patient mobilisations around chronic UTI in the UK centre around gaining access to long term, high dose antibiotics through one of the few specialist UTI clinics in the UK and the US. The headlines go: 'there is a solution to agonising cystitis!' (Hodgekiss, 2022). This message of cure is increasingly spread far and wide, in newspapers and on TV, which means that everyone can find out about the cure. Chronic UTI enacted in this way is chronic because the cure is denied, rather than because there is no cure available. And in the specific contexts within which these patient mobilisations take place, cure in the form of antibiotics is denied to specific groups on the basis of diagnostic tests failing to grasp the biological reality of CUTI. Uncaring diagnostic technologies and patriarchy as enacted in the patient-doctor relationship are the block in front of you getting what you want, what would cure you, as expressed here by a feminist critique of clinical care for UTI, using patient stories: 'mother and daughter, Jill and Liz, have suffered UTIs all their lives but still have to insist that GPs prescribe beyond the restrictive limits on the type, length and dosage of antibiotics' (Conry *et al.*, 2021). Here, antibiotics figure as cure for UTI, and patient choice, insisting to the GP, is the means to access it. In this conceptualisation, inequality mediates who is more able to wield their patient choice and who is taken as an 'unreliable witness to their own illness' (Conry *et al.*, 2021).

I emailed Nicole, who described not being believed about her pain on the basis of negative test results for UTI in chapter one, to ask if she was happy for me to use her completed transcript as research data. She told me that, although she was happy for me to use the data, she would now respond quite differently to my questions. She kindly agreed to my request to do a second interview to explore these issues further. Nicole told me that, her urinary

symptoms having now resolved, she thought differently about what had happened between her and her GP:

I was going back to her on a regular basis saying, I've had this UTI, it hasn't quite gone away. And she was believing me, it wasn't like she ever thought I didn't have a UTI 'cause that wasn't the case for me. I think, you know, she was very good, after I'd been back to her a few times she was like, I think, we need to send you off to a urologist which is, you know, that's what she's been taught at medical school. And you know, she was very good and helped me find somebody, you know, she did believe me. And even when I went off to seek care elsewhere, she was very supportive of that and said there's nothing else that I can do for you, I don't know what to do. So yes, we'd welcome to learn more about, you know, how someone else thinks they can treat this.

What to make of this? In Nicole's case, the problem wasn't that her GP didn't believe her that she was suffering. She maybe didn't even doubt that she had an infection. Diagnosis was not the problem. The problem was that the GP didn't know what to do about it. Faced with this problem, Nicole had exercised her patient choice, perhaps even her consumer choice, by going off to seek care from a doctor who not only believed her, but also offered a promise of cure in prescribing long term, high dose antibiotics. I asked her why she did this:

Eleanor: *Can you just describe that time and the decisions that you were...how you think about that time and those decisions now?*

Nicole: *Well, I think you feel like you're out of options. So, when your GP can't help you and when, obviously, what she is prescribing you isn't helping, and she's, obviously, referred you to a urologist and followed all the things that she's supposed to do. And the urologist can't help you and, you know, when you've tried everything that your GP has suggested, but you're still not happy with the answers because you're still suffering. Then you look for alternative, you know, answers because you want an answer, this is...people want an answer for their problems. So, I think when you get to that, kind of, desperate road, you're willing to, sort of, try something that you haven't tried before to see if that helps.*

Nicole's GP tried to care for her. But none of the GP's care practices, which centred around prescribing antibiotics, made Nicole feel better. This left Nicole feeling neglected: *"No further action required."* And then you're just kind of left.' This is where we left chapter one- once antibiotics seem unlikely to help, there is little alternative explanation for painful urinary symptoms. Next, the GP did what Nicole recognises she was supposed to do and referred Nicole on to secondary care. Secondary care (the urologist) could not help. As her GP and the urologist didn't know what to do, Nicole went to a place where the doctors made it their business to know what to do. Here was a place where there was a hope of feeling better. These

doctors tried to care for her. They were, for her, among the only people who tried to extend the options of what might help, to lengthen the course of care which was soon running out. This is not a small thing, especially when you are desperate and neglected and there is pressure for doctors not to 'try' or to tinker, but to 'adhere' and 'comply.' These doctors in private practice had more care practices than the urologist and the GP, but still they only really had one care practice to try: more antibiotics. Nicole describes the singularity of the care she experienced:

So, I was expecting, you know, like a vaginal examination, and bloods, and like cameras and all of those things, even if you had had them before in the NHS I would still, sort of, expect...I was expecting to go there and have all of that, sort of you know, before being prescribed anything. So yeah, I don't know how I feel about it now really, but when you're there and you just want to try something new, you don't really mind that everybody tries the same thing because you just give it a go too, you know, because you've tried everything else.

Nicole was prescribed long-term, high-dose antibiotics. But this didn't care for Nicole, who developed a condition which she worried was a side effect, and not feeling reassured when she sought advice, she stopped taking them. Therefore, when that one care practice of prescribing antibiotics didn't work, this is where the focus on patient choice starts to feel a bit stuck in the mud; Nicole couldn't choose her way out of this situation; there were no choices left. As Mol says: the point of bad care 'is not that others will boss you about, but that nobody cares. A hole opens up and you fear that you will fall right through it' (Mol, 2008, p. 85). And as Nicole says: '*people want an answer for their problems*'. She wanted to feel well.

In my argument thus far, UTI is problematic because of the way care practices for UTI have so narrowly centred around antibiotics, leaving little room for alternative ways of caring. To back this up as the central problematic of care for UTI, note that I showed in my literature review that UTI has historically been challenging in highly recognisable and familiar ways before AMR emerged as an issue of concern. Care for UTI has centred narrowly around antibiotics whilst antibiotics have never been able to care for everyone, not now, not in the past, and certainly not in the future.

As Mol says, the critique of healthcare which argued for patient choice 'whether it is true or not, it is no longer engaging. It tells us nothing new' (2008, p. 89). We can't find good care for

persistent urinary symptoms just by flexing our will power because, as I showed through Nicole's case, our choices soon run out of course. Instead, Mol cares for us by giving us another way of looking at it. For as Mol lets us see, what you want maybe doesn't capture all that is important in seeking care because what you want, more than anything, is not to feel ill. But you do.

De-centring Antibiotics as Care

Antibiotics might be good care. They might make you feel better, in which case, they have cared for you. But is it necessarily antibiotics which define good care for UTI, as is implied by campaigns for GPs to prescribe 'beyond the restrictive limits on the type, length and dosage of antibiotics?' I suggest not, by exploring what care looks like when we de-centre antibiotics, by speaking to people who can't use antibiotics. I spoke with Ruth who found herself diagnosed with an extended spectrum beta-lactamase (ESBL) *E. coli* infection, a multi drug resistant bacterial colonisation of her bladder.

Eleanor: Okay. And then what happened after that? So you've found out that you're colonised with EBSL...

Ruth: Well, I was having symptoms, chronic symptoms and I always felt like I was getting an infection. That first year, I was treated with antibiotics still. When I felt symptoms coming on, I panicked, I thought I don't want to not treat this because I might end up with a kidney infection and sepsis, you know. So, I was pretty on top of it when I felt symptoms get a little worse. But I was also worried because I felt my options were going to run out because I have EBSL which is only treatable by a few antibiotics. And so, I felt that at one point maybe I would have an infection that wouldn't respond to it (the carbapenems) and I might die.

It is hard to express in writing the emotion carried by this story. As I spoke to her, Ruth's voice shook. She felt that she might die if she used the one thing that would help her manage her painful everyday symptoms; antibiotics. She goes on to describe how this fear of the consequences of using antibiotics led her to discuss with her doctors and take a different approach:

Soon after speaking with them, I felt like I was starting getting a kidney infection, I felt symptoms flare. I called the doctor and he said, well, here's a case where, what do you want to do? You can definitely get antibiotics or do you want to try to keep it at bay. So, I said I'm going to do everything I can to ward it off.

So I took...at this point, I was only taking D-mannose and some extra water. I drank a lot of water. Tonnes of water. He said the more I drink, you have a vessel with bacteria, there's two types of bacteria, the one that's colonised and the free-floating. The free-floating cause the

acute infection. The more you drain them out, drink fluids and urinate them out, the less number you have in your bladder, the less likely you're going to have an acute infection. The free-floating cause acute infection.

So I drank and I drank and I took electrolytes to make sure I didn't drink too much. And steadily. And urinated as much as I could to flush it out and it passed. And that was the first time I said to myself, I think I have a clue as to how to manage this. I won't be able to cure it but I'm going to try to manage it. So, I did more research, looked up more things and that's when I started learning more about, well, managing the condition and minimising the free-floating bacteria and doing what I could.

It is worth reflecting on what is at stake here. My argument holds that the diagnosis of CUTI as it is currently enacted is enacted through an imaginary of antibiotics as cure. If, however, you don't have an infective diagnosis then, many worry, antibiotics (the cure) will be off the table. Instead, you will be offered painkillers, and bladder washes, you will never be able to do the things that make life good again, like drinking coffee or orange juice or having sex. And, crucially, you will never feel better, this is your life now. You will have a chronic disease in the sense of most other chronic diseases, where there is no cure, rather than a chronic UTI where you are denied cure. Common chronic disease categories of the bladder include non-infective inflammatory conditions such as IC or PBS. Often, in patient mobilisations around CUTI, an understanding of the 'real' of the disease, the meaning of biology, appears as integral to accessing cure. A diagnosis of IC or BPS/PBS becomes akin to being told there is nothing wrong with you, as expressed here in this article written in popular women's magazine *Refinery 29*: 'current testing of patients with chronic UTI symptoms is insufficiently sensitive to pick up many infections. This means that patients are frequently told that there's nothing wrong or sent away with a diagnosis of interstitial cystitis (IC) or bladder pain syndrome. These are chronic, incurable diseases with no known cause' (Arnold-Foster, 2022). Only patients who *know* that diagnostic technologies cannot possibly have excluded infection can access cure, an understanding encouraged by those clinicians who see cure in long term high dose antibiotics: 'it is common for a patient with appropriate symptoms to be undiagnosed on negative culture[...] Heytens *et al.* have claimed that: "the woman that is visiting you with typical urinary complaints has an infection. There is nothing more to explore." The culture misleads' (Malone-Lee, 2021, p.ix). Interestingly, this reflects a similar understanding of the relation between knowledge and practice and epistemology and ontology as in informational attempts to engage with the public on AMR, analysed in the literature review. It is presumed

that the answer of the question ‘what to do’ depends on what is known about the biological real. Diagnosis is a description of biological reality.

But note how the stakes of the difference in ‘what to do’ between non-infective diagnoses such as IC/PBS/BPS and CUTI soon break down for people, like Ruth, who can’t use antibiotics: *‘I won’t be able to cure it but I’m going to try to manage it.’* Caring and curing start to look more similar to each other when we look at practices rather than knowledges or meanings. It is presumed that the distinction between IC and CUTI is about the ‘real’ of the disease: is this an infective disease or not? And indeed, care practices may differ depending on if this is an infective disease or not. It is not necessarily unimportant to attempt to know this. But it is often presumed that people who live with or mobilise around non-infective diseases of the bladder such IC or PBS are unaware of CUTI and that if they could just be exposed to this different way of knowing the ‘real’ of disease, they would be rescued. But sometimes they are using categories in a different way, not to describe the ‘real’ of the disease, but to consider what will help them practise a good life. This is shown when they doubt the care provided by antibiotics, sometimes even as they do not doubt it as a cure for UTI. They balance the long-term consequences of long-term antibiotic therapy against symptom improvement, by citing evidence such as (Warren *et al.*, 2000), a randomized, double-blinded placebo controlled pilot study of long-term antibiotic therapy for IC patients, which showed a larger increase in adverse effects compared to symptomatic relief, as well as a sizeable placebo effect.

My argument is not concerned with a correct account of the pathophysiology between IC or CUTI. It is not about attempting to describe the ‘real’ of the disease category at all, it is about what category might be of more use to us, what might make us feel better, improve our material condition. Once we stop thinking of diagnostic categories as an attempt to describe the ‘real’ of disease, to say that IC is a diagnosis of exclusion does not mean that it is a useless category. It is not if a diagnostic category reflects the ‘real’ of disease in a body that matters, it is if a category cares for you (Mol, 2008, p. 63). And in this way of understanding good care, people who have been diagnosed with IC or PBS might also use antibiotics if they make them feel better.

Becoming Chronic

What if chronic UTI was chronic in a more traditional sense, as in, a condition that we will need to find ways to live with long term? Letting go of curing UTI and instead focusing on caring for urinary symptoms may allow us to give up on policing what people may say or do about poorly bladders and instead to experiment and tinker with care towards finding more multiple ways of feeling better. This is not at all easy to do. Firstly, we will have to start to think of ourselves as ill. But it might be easier to think of ourselves as people who are chronically ill if we can trust that there will be care, if not cure. This is a very hard thing to place trust in when you know what it means to live without care. But I am not asking for pessimism about chances for cure, I am asking for ambition about care and where it might be found. Sophie was reluctant to use long term antibiotics, but felt pessimistic about her chances for care:

And then about a week later, I had another one, another one, another one, another one, I had maybe, I don't know, seven in between August and December. And my GP seemed to be quite relaxed about it. He just would prescribe me three days of nitrofurantoin [...] I'd heard at this point about this embedded UTI theory and taking antibiotics long term. My life is just ruined, I've got no quality of life, I would go out of the house, you know, I've got two kids by this point, a newborn, well, a young baby and a toddler. And I would go out of the house, just to the park, five minutes away from my house, and I would be wetting myself, it was horrendous, I'd be having these spasms, stuck on the toilet. I had to call my husband to come home from work a few times. It was really awful. I was feeling really anxious, couldn't leave the house, so I said I think I need to do this high dose.

Sophie knew what it meant to live without medical care and felt that antibiotics was the only care on offer. The state of care for people who find themselves with urinary symptoms that won't go away is desperately bad. In my argument, this is not because doctors won't give us what we want and need, but because in the centre, co-ordinated across healthcare institutions by texts, for example in centrally mandated guidance, care for urinary symptoms keeps on running out, there's nothing else left to try and the patient is abandoned and neglected. Hard to treat urinary symptoms are therefore marginalised and de-institutionalised, a common condition left to the edges to be dealt with only by 'specialists.' This is why it is hard to trust that we will not be abandoned if we surrender defence of our one chance of cure. We know what it is like to live without care or cure.

What does it mean to have been neglected and pushed to the margins of medicine? Black women in the US, ill with an intimate condition and not having found care elsewhere, seek care from a 'specialist' doctor who is publically open about his virulent anti-Black racism. In the UK too, de-institutionalisation, where 'specialists' with somewhat singular care practices provide care detached from wider healthcare can also be unsafe as they can therefore fail to care for the whole person. The margins are not a safe place, and this lack of safety has disproportionate impacts on patients who are already oppressed in society. In 1989, Black feminist bell hooks conceptualised what it meant to have a standpoint located in the margins: 'this space of radical openness is a margin - a profound edge. Locating oneself there is difficult yet necessary. It is not a "safe" place. One is always at risk' (1989, p. 19). It is because of this specific position of Black women in British and US society that it is in Black feminist work that we find theorisations of what it means to be on the margins, living without care from the centre. Commenting on this position, the Combahee River Collective Statement famously stated that 'if Black women were free, it would mean that everyone else would have to be free since our freedom would necessitate the destruction of all the systems of oppression' (2014). Building an analysis of how to care for urinary symptoms that keeps Black women central (Nash, 2019), care on the margins that endangers Black women can never be good care. It is not incidental to this care that it is not good care for Black women. Whilst saying that good care would happen in the centre is a description of idealised care, we could overcome pessimism about our chances for care, and work towards imagining a good future.

A good future for UTI is not one where we patients can access whatever antibiotics we want. For even if that happened, it would be one (very important) step removed from a good future, from feeling well. Let us be more ambitious; a good future for caring for urinary symptoms is one where people feel good and well, either with infection or without. A good future would be one where you can do things that make life good for *you*. It is definitely about living without pain. Maybe it's also about being able to start your day again with your morning coffee that you used to enjoy so much and had to cut out, maybe it's about being able to enjoy sex without worrying about the consequences. How we get there, how we make our lives liveable is the question- what is good care for urinary symptoms? And can we trust that if we surrender cure, surrender policing what people say about cure in long term antibiotics, we will not be

abandoned again? It is not risible to want to be comforted by the thought that you might one day get better. Let me respond with care. Being ambitious about where we might find care might help us find practices that make us feel better. And if we feel better, then we need not be concerned with cure. For we will end up where Mol started, that care and cure look remarkably similar *in practice*.

Where is Good Care for Urinary Symptoms?

It may indeed have been that good care for UTI does not yet exist; my point here is about idealised good care, and what it would look like. But I asked you to trust that you will be not abandoned again if you surrender your chance of cure; to be optimistic about where care might be found. Mol says: 'suitable repertoires for attending to bodies can be found in the consulting room' (Mol, 2008, p. 31). The idea that antibiotics might be part of caring for a UTI, if they make you feel better, but if they don't, then you should try something else, is a profoundly *clinical* idea; this is where Mol grounds her theorisation of care. To answer how it would happen and what it would look like if centralised care was not standardised, but instead was diverse, inventive, precarious and comfortable in uncertainty, we can look to the foundations of clinical skill. I noted in my literature review a qualitative interview study of women presenting symptoms of UTI in English general practice by foundational figures of primary care research (Leydon *et al.*, 2009). Without mentioning AMR, they conclude that no generalise standards will help the problems of clinical care for UTI, only careful doctoring. It is not because of AMR, or mobilisations against it, that standardised practices of prescribing antibiotics will not help. It is because standardized, scalable care practices cannot care for everyone.

This is not a moral position against antibiotics. Instead, care practices which go beyond standard uses of antibiotics are important because of the way that care has been so circumscribed by antibiotics, with alternatives confined to the margins, whilst simultaneously antibiotics do not care for everyone. This has happened because antibiotics are a supremely scalable technology, produced industrially and becoming infrastructural to many standardised practices (Landecker, 2016), including that of care as co-ordinated by NICE and UKHSA guidelines nationally. As Tsing says, the difference between scalable (here antibiotic), and non-scalable (here non-antibiotic) practices and projects, is not 'ethical conduct, but that

the latter are more diverse because they are not geared up for expansion' (2015, p.42). Non-scalable ways of being are not normatively preferable to scalable ways of being, but if we can notice them, we can learn different ways of doing a good life. This is useful when we are not sure how to care for something, when we are not sure what good care is. And it's increasingly important because such alternative care practices promise to help a wider group of people as antibiotics come under increasing pressure because of AMR and mobilisations against it.

The drive towards adherence and compliance with evidence based medicine and AMS interventions in primary care has meant that that when guidance runs out, GPs appear to have little wiggle room for inventiveness or creativity. Therefore, to say that good care would happen in the centre does not entail that good care would be centralised and therefore standardised, because such practices, unlike antibiotics, are not geared up for expansion. I have described why I am concerned about this using sociological theory, because of the way that standardised care practices shaped by the scalable, industrial technology of antibiotic therapy constrict room for alternatives, while antibiotics do not care for everyone. But this is also a critique that emanates from within medicine. Senior US ID clinicians Spellberg *et al.* bemoan that guidelines project certainty unwarranted by the evidence they are based on and yet are treated as if 'as if stone tablets descended from the heavens' (2021, p. 1741). They acknowledge that guidelines can be useful to 'provide thoughtful expert input on unsettled questions' but emphasises the need for a desire for standardised care to be 'balanced against the need to humbly admit uncertainty where it exists and avoid mandating incorrect care' (Spellberg *et al.*, 2021, p. 1741).

Clinical knowledge doesn't establish facts first then decide what to do (Mol, 2008, p. 45; Berg, 1992, p.169). The reflection required cannot be separated out from trying to establish in practice what can be done (Mol, 2008, p. 88). This provides a set of tools for working with uncertainty. Spellberg *et al.* recommend that rather than proscribing care via "recommendations", hypothesis-generating data should be summarized in order 'to discuss various care options that can be individualized for patients across diverse care settings' (2021, p. 1741). The emphasis of clinical knowledge is specific, localised in time and space. How would non-standardised care happen and what would it look like?

Shared Doctoring

One answer is that non-standardised care does already happen in practice. To see how things could be done differently in one place, we can look to where they are being done differently. If good care is found in trying out different things, good doctoring means adapting technologies to different situations and circumstances. This entails sharing doctoring with the patient and their specific situations. Mol describes: ‘shared doctoring requires us to take nothing for granted or as given, but to seek what can be done to improve the way in which we live with our diseases’ (Mol, 2008, p. 56). For the same reason that standardised, compliant care is poorly able to care for cases which are not helped by standard uses of antibiotics, care is done differently everywhere. The reason is that difference and multiplicity lies *within*. Therefore, within my analysis of clinical care for urinary symptoms, we can see instances shared doctoring, of HCPs working with multiplicity, taking nothing for granted but trying out different things.

In the end, Nicole’s symptoms resolved. She told me about how she ended up finding care within the clinic:

...you know, with this UTI you go to the toilet a lot and then it makes you feel like you’re not very clean and all that stuff. So, I’d been using a lot of those toilet wipes that you can get, I’d been using those quite a lot and actually, I think it was them that were causing me the issues. They were just drying me out and giving me thrush, and it doesn’t really tell you on the packet that it can do this but my nurse at my local surgery, who’s brilliant, I told her I’d been using those, and she was like no, don’t use those, we tell ladies not to use those, they’re awful things, you know. So, since I stopped using those and I’ve not been washing with soaps, and all of that, and not taking all these antibiotics which give you thrush, I’ve been like way better.

I do not know how Nicole ended up sharing this practice of using vulval wipes with the nurse back home in her local GP surgery. But it was here that the nurse cared for her by suggesting that the care practice Nicole had been doing was less appropriate, less suitable. This is not where Nicole had expected to find care, especially after travelling far from home and spending hundreds of pounds to consult highly specialised doctors. But it is here that she found care, and she started to feel better.

Jules came across my recruitment poster in the toilets of a local pub. They had experienced urinary infection since the age of thirteen and was taken to the doctor's:

They took a sample, they analysed it, of course there's bacteria, whatever, so here are some antibiotics and off you go. And obviously that was painful, but it was something that happened and then you just put it behind you, except it starts happening again and again and again.

Then in their twenties, Jules' tests started to come back negative for UTI and they were diagnosed with IC. But this did not lead to restricted access to antibiotics, as is often feared, and, I do not doubt, does happen⁷. Instead, Jules described how the doctors insisted on antibiotics just in case the analysis was wrong. This is another example, like Nicole's, of a case where diagnosis mediating access to antibiotics was not the problem. Instead, Jules was then in a familiar situation of abandonment and neglect, not feeling well, with antibiotics being the only care on offer:

You don't know what to do, because the antibiotics are obviously not going to help, and not only they are physically not going to help by killing the infection, but you also feel in your mind that, oh, what is this? I don't know what it is, I don't know what to do about it, so you feel really bereft and sort of really at a loss.

I argue that for Jules' GP, like for Sophie, antibiotics represented a (highly understandable) pessimism and a depression about care; there didn't seem to be much else that could be done.

But Jules was not pessimistic about their own chances for care. They went about, like so many patients who find themselves in similar situations, trying to find things that might make them feel better. Online, they found a research paper (FitzGerald *et al.*, 2012) reporting trial data in support of pelvic floor physiotherapy as a beneficial therapy for people with IC. They took this paper to their GP and were referred to a physiotherapist at the local hospital. The physiotherapist, unlike the GP, was not at a loss for practices which might care for Jules. Instead, she recognised what Jules was describing as similar to what other patients described and went about suggesting some things for Jules to try:

She took one look, she said, okay, get undressed, I'm going to touch you, so she touched my belly and then inside my vagina and she said, it's rock hard in there, your muscles are really causing massive issues in there. I'm going to teach you some exercises and see me again in however long, three months or whatever.

⁷ Note that this would also be bad care. If antibiotics make you feel better, then that is good care.

The physiotherapist taught Jules to do vaginal massage using a finger to calm their pelvic muscles, and stretches, to strengthen the surrounding muscles which support the pelvic floor. In this way, Jules found cure through care. They feel frustration but, working with the physiotherapist, they are no longer abandoned, they have things they can do to care for their bladder when it hurts:

The first thought is, not this bullshit again, to be fair, but at least now I don't go into panic mode which I used to, because when you didn't have any tools, you knew you were in for eight hours of pain, and I can't describe the anguish of that, of not only the physical pain, but then the mental anguish that goes with it. These days it's frustration, but at least I know that I will be able to manage it and move on, so yeah, the first feeling is annoyance, but then obviously I have to get on with it.

The key point here is that Jules got to feeling better through a diagnostic category which cared for them; IC. This does not necessarily relay anything about the biological real of Jules' disease. It does not mean that Jules did not have infection. Indeed, Jules' doctor wanted them to continue using antibiotics even while the microbiology was negative for UTI. But it was the category of IC which led Jules to physiotherapy which for them, made them feel better in a way that antibiotics had not. Jules would have had to summon enormous energy to conjure optimism about care. This is the work of chronic living, accepting yourself as an ill person and facing the work you will have to do to care for your bladder. Even now Jules feels this, saying: 'not this bullshit again[...] but then obviously I have to get on with it.'

What would help is if you didn't have to do this alone, if there was someone who would be there with you, not to commiserate, but to sweep you up and face up to the task ahead. To be charged with your problems. We already met Ruth, who was diagnosed with an ESBL colonisation of her bladder. Ruth describes how good care would involve doctor and patient making a plan for living long term with UTI:

A doctor can speak with a person and discuss it with them. And that's necessary. That's part of being a doctor, you have to discuss with the patient [...] So then the doctor and the patient should decide and have a plan in place so that they don't have to beg, they don't have to call on a Saturday night. Have an antibiotic available so that that person can get treatment because they shouldn't have to suffer [...]

The doctor shouldn't avoid people with UTIs because, you know, we care, there should be a treatment plan in place so that you can say, you know what, I am getting it, I drank water, I did...been urinating as much as I can and it's just getting worse and I'm worried it's going

to go to my kidney, or it's just too painful, that's a symptom. Then you say I would like to take the antibiotic and the doctor will give it because they collaborate and the plan is in place. A plan should be in place if somebody has a chronic condition. If you have a chronic condition, it's not something new that you're going to figure out. You should have a plan in place when these symptoms happen, this should be offered for me, that I get urine testing and I can take an antibiotic. Or I should be on Hiprex and let me be on it long term, you know. Or that I need to investigate further maybe long term or maybe phage therapy for those who have clinical trials available or want to go down that path.

This is, like Mol's theorisation of trying something, then adjusting, and improving on it, a description of idealised care. In Ruth's case, it is similar to what she did in fact experience, when her doctor said to her: *'well, here's a case where, what do you want to do? You can definitely get antibiotics or do you want to try to keep it at bay?'* Together, they made a plan.⁸ This idealised care is care which is not scared, or depressed, it does not throw its hands up in despair and discharge the patient from care, but takes on you and your problems with intrepid confidence, it is charged with you. It says come here, let's work on this together and find a way for you to feel better. This is what Mol calls shared doctoring.

Accepting Care and the Psychological

Sandra, who we have already met, was one of the first people I interviewed in this study. She described the onset of her symptoms at the age of fifty. I inexpertly asked her if that coincided with anything in her life, thinking of the onset of menopause. When she began to tell me of a personal disruption in her life, I considered this a great error in my interviewing technique. Whilst I would now more confidently approach the situation in a different way, this experience remains one which has given me great cause for reflection. Sandra responded thus:

Yes it does, unfortunately, it does [...] And I don't want you to think that it's psychological. Because it, it isn't, it really isn't [...] if someone once said it was psychological, I would have jumped off the bridge, I tell you.

Sandra joins others in resisting an idea that symptoms have a psychological underpinning. In chapter one, we saw Liz and Natalie resisting the idea that symptoms were 'in their head.' The story of Ronda, a patient ambassador for ANTRUK, the UK's only dedicated AMR charity, appears on the ANTRUK website thus:

⁸ It is worth noting that Ruth is a patient in the US, where the landscape of care generally but also more specifically for urinary symptoms, is really rather different.

Too often the urinalysis tests come back negative, despite symptoms persisting. Even though it's known the usual dipstick tests is wrong a third of the time, the so-called rapid tests available to doctors haven't progressed in nearly six decades. When you experience a chronic infection, it is all too common for doctors to dismiss the pain and attribute it to one's mental health instead (2021).

Resistance to psychosomatic explanations for pain forms part of an important thread of feminist health mobilisations more broadly, often drawing on analyses of the historical treatment of women within biomedicine. The titles of three popular feminist health books helps us to understand what is at stake in these analyses (Criado-Perez, 2019; Cleghorn, 2021; Jackson, 2021). Jackson's *Pain and Prejudice: How the Medical System Ignores Women—and What We Can Do About It*, as well as Cleghorn's *Unwell Women: Misdiagnosis and Myth in a Man-Made World* share a concern with how women are ignored or disbelieved about the reality of disease, while Criado-Perez's *Invisible Women: Exposing Data Bias in a World Designed for Men* is interested in how technology (itself structured by patriarchy) structures interaction with medicine. To do this, they hold the reality of disease as ontologically stable, central and pre-existing, with women and HCPs looking onto it from different epistemological perspectives. Importantly, although 'the patient perspective' is apparently prized within this model, accounts of difference in the nature of the patient perspective and the doctor's perspective on disease are rarely able to cope with instances where the doctor's perspective leaves the patient in pain. When this happens, feminist interventions in this popular epistemological model often attempt to transgress these boundaries, to challenge where knowledge is produced (Epstein, 1996).

In this approach, where the psyche appears as less 'real' than a disease like endometriosis or a UTI or PCOS, patients participate in maintaining strict boundaries between nature/culture, body/mind, value/fact, psychiatry/uro-gynaecology. Correspondingly, strict boundaries between man/woman, doctor/patient, the well/ the unwell delineate who is able to challenge domination in accessing the reality of disease. As I noted in the literature review, this kind of analysis puts women's health analyses in the anxiety-inducing position of having to hold 'woman' as a coherent and strictly defined entity, held against 'man' as another coherent and strictly defined entity. While Criado-Perez is well known for her trans-exclusionary feminism, Cleghorn's analysis of trans and non-binary health is *necessarily* confined to an

acknowledgement in the introduction, despite attempts to be 'inclusive'. It is quite a task to include trans women and non-binary people in an analysis which relies upon strict boundaries between women and men, just as it relies on strictly upheld boundaries between the body and the mind. It also puts popular mainstream women's health analyses in an uncomfortable position in relation to disability studies and mainstream discourses of mental health, which commonly insist that psychiatric disorders are equally 'real' compared to an injury to any other part of the body. This epistemological analysis of inequality, which sees inequality appearing as a vector of (in)authority in accessing the reality of disease is an analysis I argued against at the end of chapter one. Instead, my analysis sees the problem of poor care as ontological rather than epistemological. Women who seek care for continued urinary symptoms are not ignored and dominated, refused effective treatment on the basis of their epistemic in-authority as a sex class. Instead, people seeking care for continued urinary symptoms who are perceived as women are failed and neglected because, as I argued in chapter one, there is little effective treatment once it becomes clear that antibiotics are unlikely to help and, as clinical care is organised around the question of 'what to do', often no disease to be treated emerges in clinical practice. Diagnoses, just like gender, do not exist 'out there' but emerge relationally, in practice. If this is why people are neglected within medicine, it is also why trans-exclusionary feminists are mistaken about the nature of reality and the 'biological facts' of sex and gender.

Importantly, patients do not maintain these boundaries single-handedly, or even as primary actors (although here I have started from patient narratives). We can all participate or collaborate in maintaining them from different positions. Patients are encouraged to participate in boundary work by the kind of normative ideas about the patient role which are formalised in patient and public involvement in clinical research, preserving biomedical knowledge as the domain of HCPs and asking patients to add in values about the meaning of illness in their lives etc. Moreover, encounters with individual doctors can make it clear to patients that some doctors expect patients to negotiate the lay/professional boundaries with care (Henwood *et al*, 2003, p.605). One of the most obvious and most important ways in which patients are encouraged to maintain a boundary between body and mind is the way in which

historically and currently, a psychiatric diagnosis too often leads to a lack of care, no disease to be treated is enacted and the patient is left neglected in pain.

Furthermore, we can explore the ill-effects of boundary work whilst also recognising its productivity and therefore collaborating in it. Boundaries can be productive, they help us to achieve the organisation of the healthcare system by breaking up the body into different parts and therefore breaking up expertise into specialisms. I myself am here participating in maintaining some of the boundaries explored above in multiple ways. Firstly, I describe people like Liz and Natalie as patients even though they may be a patient sometimes and not others, just as a doctor may also be a patient sometimes and a doctor at other times, and when they seek healthcare themselves, they are unlikely to find it easy to be both at the same time. But there are other reasons to describe people like Liz and Natalie and Sandra as patients. Foremost for me, this is to recognise them as people in need of care. And what of patients as 'them?', in the third person. I could write in the first-person plural, as in 'we patients', we people who are in need of help. I join Cleghorn and Jackson in writing about a health condition which I myself have experienced. I have largely resisted describing or presenting myself in similar terms to Cleghorn who writes of 'unwell women' as an 'unwell woman' herself, because I am invested in the ways that we are all relationally connected to health and ill health (and therefore invested in good care), rather than some of us being healthy people and others being ill. But there are other reasons why it has been productive to distinguish myself from people who have never experienced hard to treat urinary symptoms in rendering explicit the way that my research methods are *part* of the social, help to *create* it and that I could never get outside the social to view it from above and as a whole (Law, 2008, p. 640).

Therefore, boundary work between doctors and patients involves a fraught negotiation of roles. But what Mol talks about when she talks about taking each other's contributions seriously in shared doctoring, and changing whatever it takes, is surrendering defensiveness. The doctor must surrender defensiveness of their certainty in order to allow a caring practice to emerge without an account of the real of disease, as Emily says:

There are really great GPs who are really good at sharing diagnostic uncertainty with patients and explaining options and sort of saying, well we could do this. We could do this. We could

do this [...] But, there's still plenty of you know... I think the prevailing culture in medicine is still that you need to make a diagnosis and offer a treatment, and you don't want to...you don't want to say, I don't know what the diagnosis is, because that means there might not be any treatment effective that we can offer you. And, you know, there's definitely still a reluctance. That is the sort of prevailing culture.

Simultaneously, as a patient, there may be some practices or categories that could care for you (even if you know that a chlamydia swab won't, because you've already tried) and you as the patient will maybe have to be the one to find out about them. But you will need to be open to trying them: Another thing Jules did was use a vibrator:

I think probably, because I have pain in other parts of my body as well, like sometimes I have back pain or whatever, and I use the same vibrator to give myself a massage, and I think it just gets deep into the muscle in a way that perhaps nothing else can, [...] the vibrator's one of those that has a big head, so it's not an insertion one, it's one that you just put...you hold it against you. So the finger would go right in and the vibrator, I guess it does a different job. I guess it touches it from a different angle.

I asked if this was something the physiotherapist taught them to do as well and they told me: 'No, that is something that came quite naturally, because I've used vibrators for sexual purposes for some time, and you just naturally find out, oh, actually that helps that as well.' Thus, Jules found care in knowing what felt good for their body from sex. This mode of trying things and finding that they help is what patients do. But we need to be open to the thought that something might help us, even if it seems very unlikely that it would. To be optimistic about where we might find care.

Part of this might include being open to the idea that something could help you, even if you can't see a clear physiological reason why it would. To be open to what might help you outside of antibiotics, you may find that you need an alternative answer to the questions you have about what is wrong with your body in pain. Taking antibiotics provided you with such an answer: you had an infection. To be open to something else as care might entail opening yourself up to something you don't understand. This is a loss of control. It is a loss of yourself as the healthy person you would be if only you could access antibiotics. And it is a loss of patient choice because patient choice relies upon informed consent; you cannot be informed when you do not know what good care might be.

Therefore, a person in pain needs to be comfortable with uncertainty and vulnerability to be able to accept care, needs to be able to think of themselves in the role of the patient, the student, the child. This ontological analysis, which sees disease as emerging in practice, sits comfortably with insights from disability studies, which is deeply concerned with what disables the person outside of the real of the body.

To take an example, let's reflect on the difference between enacting a UTI and taking antibiotics, and finding that certain stretches help you feel better when you have urinary symptoms, as Jules found. Difference lies between discreetly popping an antibiotic pill because you have a chronic infection (even if that is also stigmatised and difficult) and taking time out of your day to go to a private place, stretch our your pelvic muscles, breath from your diaphragm, caring for what then, because of the answer to the question 'what to do' emerges as something like a chronic pain condition. Caring for a chronic pain condition would involve accepting yourself as an ill person but also the task of confronting what has gone wrong with your body, why your nervous system predicts threat when there is none. Where women's health tends to ask why doctors tell women our pain is in our heads, we could question, drawing on a feminist tradition which emphasises strength in vulnerability, what stops us from being fully open to this being 'real.' There are many answers to this question, not least that often when doctors tell us pain is in our heads, they do not start from symptoms themselves, and do not enact a diagnosis via what to do about symptoms. Often, they enact no disease to be treated.

On the other hand, Jules described a truly clinical diagnosis when the physiotherapist touched their belly and then inside their vagina, found hard muscles and prescribed a treatment of exercises. Touching somewhere- 'does it hurt when I do that?'- 'this is what you need to do about it'. This is a clinical diagnosis of some dysfunction that lies somewhere between the brain, the pelvic floor, the vagina, the urethra, the nervous system. This is very different to being told 'there's nothing wrong with your body, it's all in your head', which maintains a division between mind/body, doctor and patient, just as the patient maintains this split by insisting, from the epistemic position of a patient who knows their own body, that disease is in fact located in the body.

When people resist psychological explanations for pain, they clearly are not feeling cared for by this suggestion. The point here is not to say that everyone who has hard to treat urinary symptoms has a chronic pain condition. It is to say that to be truly ambitious about where we will find care, we ourselves will need to be open to our own discomfort with being ill and in pain and perhaps even more, being ill people.

This ambition in itself may prove important. I spoke with Jilly Bond, a specialist pelvic health physiotherapist. She told me how speculation affects the good:

So, if you have antibiotics and they work really well and they are effective, you are going to feel great about that, you are going to have an expectation that you're going to get better, so you are going to feel better and that is real, it's not fake.

As Jilly says, antibiotics might make you feel better because you've done something about your pain. I have argued throughout that care for urinary symptoms tightly revolves around antibiotics. Here though, antibiotics literally become care; they are there to help you when little else is. Importantly for my argument, this suggests that although we might want to defend practice, what people do to feel better even if it is not evidence-based, and living as an ill person, we may also want to embody an optimism and an ambition about living well, rather than taking on as identity that we are people who cannot drink coffee, or play sport, or whatever 'good' is for you in your life. As I noted above, this involves work. Over the course of writing this thesis, I had many conversations which started with people listing all the things they have cut out to try to avoid infection, or to accommodate a life with unresolved urinary symptoms. Jilly told me what she tells her patients: *'Don't miss out on your life waiting to get better. It's often in doing those things that give you pleasure that you do get better.'* This brings us back to where we started: the practices of care and cure look remarkably similar in practice.

Conclusion

You might not have a doctor who is willing to share doctoring with you- maybe you don't have a plan in place like the one that Ruth talks about. Maybe you do have to beg your GP for antibiotics on a Saturday night in panicked pain and every time you ring up, they treat you like you've never had a UTI before, and you're driven nearly to tears explaining that you don't need a chlamydia swab, or to speak to urology again, because you know there is no care for

you there. Like Flora and Minna in chapter one, maybe you accept antibiotics as a treatment even though you know you will be ringing up again in a couple of weeks.

All over the healthcare system, there will be healthcare practitioners doing inventive things to care for patients and their bladders. It is important that these HCPs are most definitely not just doctors, as we saw in Nicole's nurse and Jules' physiotherapist. But, care for urinary symptoms as it is centrally co-ordinated is not currently inventive, or resourceful. Moreover, it threatens to become even less so as standardised routines of care for UTI are pulled out of urinary symptoms in what is seen as an antimicrobial stewardship interventions. We need to look elsewhere for a clinical sensitivity to difference, for ways of doing things differently.

Where could we find other ways to live with urinary symptoms? Where could we find practices to try that are more diverse than just prescribing antibiotics, even if they use antibiotics in new and innovative ways? Puig de la Bellacasa reminds us that the notion of care is charged with the questions of who will do the work of care, as well as how to do it, and for whom (2011). Following Mol, I have outlined patient participation in the enactment of disease. A common critique of Mol's work in *The Body Multiple* is that it sidelines what patients do. Indeed, in looking for alternative ways of doing things, looking for multiplicity within, Mol confines herself to the clinical practice of HCPs. In the next chapter, following Pols (2013) and hooks (1989), I exhibit examples I have collected of ways people living with long term urinary symptoms have found to do urinary health differently, to live well, or to live better in the radical openness of the margins.

Chapter Four- Crafting a Good Life

In secondary care, we talk of discharge as the moment when a patient leaves the hospital. When we think of discharge, it is important that we think of the moment that HCPs are no longer charged with a patient, rather than the moment they are no longer 'in charge of' the patient. To be charged with is to be loaded up with, to carry, to be burdened. That's part of what care is, being scooped up and someone taking on your problems as their problems. It's a parent saying to a child or a teacher saying to a student: you don't need to worry about that, that's for me to worry about. When you are not cared for, the problem is not that someone is in charge of you, bossing you around and not giving you choice. Instead, it is that no one is charged with your problems, no one is carrying them with you. You must carry them for yourself.

In primary care, we do not talk of discharge because there is intended to be a continuity of care, care embedded within the community. Indeed, patients may be discharged from secondary care back to the GP, who is charged with the long-term care of the patient. But when patients describe (as they did in chapter one) coming to their GP in pain, being prescribed antibiotics and coming back in pain again, only for the routine to be repeated, I argue that the moment when they leave the GP's office prescription in hand is in fact a moment of discharge. There is a lack of care which leaves people dangling, their pain failing to cohere into a disease to be treated, coming back in moments of crisis, to be cared for only when a UTI can be enacted and antibiotics prescribed. In between these moments of crisis, they are discharged from care. When antibiotics cannot be prescribed, care soon runs out of course. This is what happens in the clinic: people who are repeatedly prescribed antibiotics for UTIs struggle to become people who are in need of help living with urinary symptoms. But, importantly, in other spaces, even in every other aspect of life, people who carry their problems for themselves do become people in need of care for urinary symptoms. As I showed in chapter three, sometimes people become UTI patients who seek help for UTI and attempt to make themselves visible as someone who already knows they have a UTI. This is what is happening with the term 'chronic UTI.'

Importantly, is it only patients who can tell us about this because the GP who has discharged the patient is not charged with these experiences of pain. Therefore, this is a reason to speak to patients, they/we can tell about the consequences of what is not enacted in the clinic. Another reason to talk to patients is because, as detailed in chapter one, patients can participate in the process through which they are discharged from care. A person in pain needs to be able to accept care. This is not always easy. Sometimes to be cared for, to have someone else take on your problems as their own, entails a lessening of your choice. You will have to accept how others think is best to approach the problem. Moreover, accepting care means accepting difference; to be cared for by a HCP is to be like the child cared for by the parent and like the student cared for by the teacher. It is not to be an equal with all difference flattened out, but to recognise yourself as someone in need of another's care.

And yet, at the same time, there are no strict divisions between people who are in need of care and people who are not in need of care. Even without relying on my identity as a patient myself, it would nevertheless be important that no strong distinctions be made between patients, doctors, and researchers, in terms of who is ill and who is healthy. If others are reading along with us, they may one day join us as a person in pain or someone close to them might. No-one, including doctors, is immune from the way illness is part of our lives and we are all therefore invested in good care.

Conceptualising and Organising Patient Knowledge

Locating diverse and inventive practices of caring in the practices of people living with urinary symptoms, I draw on interview and visual data generated by participants in a patient role to produce a database. Wahlberg's observation of regulatory efforts to ban CAM rather than improving health (2013) contains the observation that people who feel ill will do things to feel better. This question of what people do when they feel ill has been a guiding principle of the thesis and this same observation leads us to a set of participatory practices. For, people participate, invited or not, in doing things to feel better. On the back of chapter two's recognition of neglected and unruly others, the contribution of this chapter to the thesis is therefore in locating a role for reflective antibiotic-using patients in collective mobilisations on AMR. I therefore move from the collective scales I have considered so far, to the smaller, but still arguably collective, scale of the home in domestic and mundane care practices. Within

this, I pay attention to how caring practices are simultaneously restricted by, but also can flourish within, inequality and precarity. These are useful reflections as clinicians struggle to care amidst similar infrastructural restrictions inside the clinic. Keeping a focus on patient knowledge, and addressing anxieties surrounding what people do outside of biomedicine, I end the chapter with a theoretical account of how to recognise good care outside of the practices of EBM.

A Patient Role: As Recognised by Patients

Patients can tell us about moments of good care for urinary symptoms where they have found them. This includes patients using long-term antibiotics. In chapter two, I addressed the issue of people who identify themselves as targets of existing AMS efforts and mobilise to resist this targeting. Here, I argue that these same people have extremely useful knowledge about how to live with urinary symptoms when antibiotics don't seem to help. In chapter two, I argued both that there is an explicit refusal of engagement with reflective antibiotic- using publics on the part of public health, and that existing patient mobilisations often do not recognise themselves as publics for AMR. Here, I am arguing that these patients should be approached with enthusiasm and encouraged to conceptualise themselves as people for whom antibiotics have not worked, even as it may simultaneously be true that continued antibiotic treatment could be beneficial. I provide a way to approach these patients, through practice. For, coming back to hooks, we might look to the radical openness of the margins to find inventive, creative care, without fetishizing marginality. People who don't use antibiotics, or who do other things alongside antibiotics, or who use antibiotics in new and inventive ways have care practices which range beyond what we already have. Patients who do not choose what they want their doctors to do, because they have no choices left, are neglected and in pain. But they are not passive. They do things.

Pols argues that we can 'turn patient knowledge into science' (Pols, 2013). Studying and observing practices in daily life does not give us understandings of a 'patient perspective', separate from biomedicine, but reveals situations where patients either enact or are restrained from enacting ways of living well with disease, shaped by medical practices and knowledge (Pols, 2005, p. 215). The claim is that 'chronically ill patients and people with disabilities develop knowledge and techniques to interpret, appreciate, and shape their daily lives with

disease in a good way' (Pols, 2013, p. 75) and it is this which is patient knowledge. Thus, daily care practices highlight that good care already exists if we are attentive to it alongside dominant ways of doing care, such as evidence based medicine, (the failure of which is likely to have drawn attention to the condition.) However, empirical care ethics has a political impulse in what must be done otherwise by making clear that between local specificities and wider contexts, it is only in some circumstances that alternative enactments of good care are enabled and prominent practices abandoned (Lindén and Lydahl, 2021).

This is not un-contestable experience, but a practical *knowing in action* from which different *techniques* for living with disease may be derived (Pols, 2013, p. 75). We do not need to normatively establish what 'good care' is, but to listen and observe for where good is done in practice (Mol *et al.*, 2010, p. 13). Indeed, it is not desirable to establish what good care is because as Pols says, 'good here is a matter of tinkering and weighing, of coordinating and translating knowledge, technologies, and advice from various sources, including medical practices and technologies. From an epistemological point view, it is a messy knowledge, involving many different techniques, values and materials' (Pols, 2013, p. 75). This makes this empirical ethics of care different from feminist care ethics (Gilligan, 1982; Kittay, 2011) because it is not prescriptive. This does not mean that the knowledge is not transportable, for this is clearly useful knowledge, but it does mean that general concepts of patient knowledge cannot be built from one case study. Pols suggests building databases of patient knowledge for different conditions (2013) while Kingod *et al.* (2017) argue that the knowhow required to navigate daily life with chronic life is already organised in online peer-to-peer communities such as Facebook groups. Where I noted that behavioural science affords a more accessible and therefore more attractive way to intervene, here we start to see how to access 'the good' while insisting on approaching people through practice. Indeed, the idea of collecting knowledge about how to live well with disease is institutionalised in patient groups and programmes. Benton *et al.*, working in Mozambique, United States and Sierra Leone, found that 'positive living' as a framework for how to live a healthier and more fulfilling life with HIV/AIDS was a constant across all three field sites (2017). Patients who live with hard to treat UTI are not recognised to live with a chronic disease in the same way. But they undoubtedly have knowledge about how to live a good life with both acute and UTI that won't go away.

And crucially in an age of antibiotics under pressure, they have knowledge about how to live well with UTI that is not treated by antimicrobials. These techniques are care, they are how to live well with disease, they are health practices and this is my reason for talking to patients. Using Pol's conceptualisation of patient knowledge, I have here collected some ways people have found to craft a good life with long term urinary symptoms.

Although good care is specific and localised, rather than prescriptive and generalised, we still may use categories that help us to select clusters of care practices which may be relevant to our symptoms and pain. We could call these 'diagnoses', not in that they describe reality, but as durable categories that contain answers to the question of what to do, according to what might be good. They are more like containers than descriptions. Therefore, practices may be transportable, shareable with other people. This is something that was recognised by participants. When I asked about the value of patients coming together, Nicole's answer strongly echoes Pols' theorisation of patient knowledge:

Nicole: I just think patient experience is the greatest knowledge of all. People who are living with this every day of their lives and suffering the same issue as you, they can give you much better advice than somebody who maybe doesn't know as much about it, and that includes a GP or urologist. Um, yeah, I think it's, personal experience is invaluable.

Eleanor: Why do you think they can give you better advice? Like what about it is better?

Nicole: Because they can tell you if they've tried things and it's worked, or they've tried things and it hasn't worked. Not that obviously... someone might have a similar experience to you, but being completely different. So obviously I wouldn't, you know, completely rely on what I'd read on Facebook groups.

Nicole transforms 'patient experience' into the 'greatest knowledge of all' and explains that the utility of this knowledge is predominantly about sharing practices. This knowledge, unlike experience, is contestable: she makes sure to note that she wouldn't rely on what she reads on Facebook. Similarly, Sophie worried about her daughter's future bladder health but explained that she was better equipped by the practices that she as her mother would teach her:

Because I didn't know anyone else that had UTIs, when I first had my one, it, as I said, it took a long time to access treatment and I just really had no idea what I was doing. I didn't know the protocols I should take to prevent a UTI. Obviously, she will know all those things, so I kind of think she's going to be in a stronger position than I was.

As I noted in the methodology chapter, many people who participated in my research identified me as someone who would have been exposed to a lot of different practices and asked me if I had found anything that helped me with my symptoms. Knowing other patients is useful because of what you learn about what you could do in practice. This supports Kingod *et al.*'s (2017) argument that the knowhow required to navigate daily life with chronic life is already organised in online peer-to-peer communities such as Facebook groups.

Producing a Database

As described in the methodology chapter, I asked participants in a patient role to produce a photo of things they 'use to look after their bladder.' I theorised that this method would encourage people to provide me with practice-based accounts of their illness, rather than enrolling them into experiential descriptions of what it is like to live with disease. In the tradition of thick anthropological description, it is possible to read much about people and their experiences through the photos they produced. Social positioning, ranging across gender, location, age, race/ethnicity, class etc., are visible when you ask people to produce a photo of objects they use to achieve intimate practices at home. However, such thick description does not form an important part of my analysis because, following the insights of institutional ethnography (Smith, 2005), I am not studying people but studying care and the production of inequality. This is an important distinction when starting from one person to track the production of inequality. Therefore, rather than going through each photo and analysing the practices done by each named participant, I have organised this section by practice, like a database.

However, I have chosen to include the photos named with pseudonyms which match up to the interview data. This is firstly to demonstrate my method. Secondly, it is to indicate that practices are achievements. Even those health practices which end up not successfully relieving urinary symptoms are an achievement because of the way they cohere and hang together as a practice. A seemingly mundane practice of using a hot water bottle relies upon more-than-human actors, huge infrastructural systems of plumbing and boilers, tiny microbes involved in practices of water sewage works, a paid energy bill, a trip from bed or the sofa to the kettle. Often, participation in these practices must be achieved while in pain. Therefore,

recognising practices as achievements, collaborations in practice of humans and more-than-humans, recognises a role for patients in what they do- they are not passive, dominated by medicine, but active. This is an insight made by Mol in refuting the argument that patients are inactive unless they operate within a logic of choice (Mol, 2008). But this is also a feminist intervention into conceptualisations of gender inequality in healthcare. For, keeping a Black feminist analytic central, this feminist health research pays attention to moments of resistance and community care alongside recognising lacks of centralised and top-down care. In doing so, it does not appeal to a presumably powerful and somewhat un-named decision maker for its theory of change but notices where the good is already being done in practice: here, by patients finding ways to care for their bladders when they haven't been helped in the places they might normally go for help. In this approach of including named photos while insisting on analysing not people, but care, I toe a thin line.

I start by introducing a practice or a cluster of similar practices. Next, I engage in some theoretical discussion of the practice and what it means for how social practice theory could inform our responses to AMR and clinical care for urinary symptoms. An example of a repository of health practices surrounding urinary symptoms is Angela Kilmartin's book of the 1970s and 1980s. These books are often critiqued for the way the emphasis on practices of the self seem to hold women responsible for their symptoms. Indeed, Henwood *et al.* note a reluctance to take the kind of responsibility for self-care suggested by 'informed patient' discourse (2003, p.507). Keeping this critique, as well as how the institutionalisation of encouragements to live well with chronic illness can moralise 'problematic patients' who aren't able to live well (Benton, *et al.*, 2017), I offer not just a repository of practices, but a theorisation of the approach as a whole.

Let's look at the first of the catalogued practices in order to consider how we might theorise care and inequality in practice, without taking people as objects of study.

Temperature Across Scales: From the Infrastructural to the Domestic

I collected twenty-three photos from people who live with long-term urinary symptoms. Nineteen included reference to temperature. Interestingly, both hot and cold appeared. One photo included a flannel which, in the interview, Oliva told me she uses wet with cold water

to cool burning around her urethra. Another photo included a specialist heat pad which could be used hot or cold, with an explanation that they *'mainly used cold therapy.'* Both of these examples are demonstrative of creative tinkering: using domestic items to care for symptoms and switching between hot and cold therapy, trying out which is better depending on the specific circumstances. However, heat and warmth was overwhelming more likely to appear than cold. Many photos included hot water bottles, wheat bags, plug in electric heat blankets or specialist heat pads for uro-gynaecological pain. Online were visible discussions of how to care for *erythema ab igne*, a rash which appears on the skin after prolonged contact with a hot water bottle, demonstrating the range of practices that go into caring for a bladder.

Hot water and references to warm baths were also common across the photos, appearing in three photos through towels and Epsom Salts. Jules describes hot water as a *'life saver'*.



Figure 2- Jules

Alexandra told me how she uses heat: *'When I am get this kind of crisis, I put warm water bottle next to myself, and I also drink something hot.'* But her job in a factory made this impossible:

'Till I didn't bring any letter from doctor they didn't even let me to go, you know, more to the toilet and to mention to them, please to avoid with her the cold area, the freezing area because time to time when they need, they are moving us to the freezing area. Yes, it was very difficult.'

Similarly, Renata told me how when she gets in from work late at night, exhausted and wanting to sleep before starting work again early the next morning, she has to shower with cold water:

Maybe, if you wash yourself using cold water, that's my issue too, not too cold, but still it's not hot enough to wash up. Because, before that, I want to faster go to sleep, and because nobody was using hot water for a long time, so before it's come, cold water is coming cold, cold.

Temperature is a good example to think through what it might mean to approach patients through practice. It is clear that the most effective antimicrobial stewardship and the best clinical care would involve huge infrastructural changes, changing circumstances of living and inequality. This seems to be what approaching patients through practice would constitute, the changing of material conditions. In this example, ensuring that everyone has access to clean and hot running water would require huge changes in the way society is organised, as well as the material infrastructure which delivers water to homes. As I write, in the last days of summer 2022, soaring energy prices threaten to leave many without the means to keep warm. In this context, behavioural approaches which attempt to alter non-reflective cognitive processes can appear attractive in that they offer a means of intervention, by tinkering around the edges of inequality when behavioural change seems hard to provoke. However, when it comes to care, clinicians and patients alike are extremely well practised at providing care amidst huge infrastructural challenges, inequality and neglect in an unequal world and an underfunded healthcare system. Next, I will show how insisting on approaching people through practice can still afford a means of intervention on antibiotic use.

Sleep

Eleven photos included a reference to sleep and/or rest, normally though depicting beds and sofas.



Figure 3-Olivia

It is of course an old and well-known practice that you should rest when you feel unwell. Perhaps especially with infection, many participants referenced the importance of rest in immunity. However, we know that UTI often comes on at night. Indeed, new nocturia is one of three diagnostic signs used by UKHSA/NICE to diagnose UTI (2002b). Many patients I spoke to had stories of trekking to urgent care centres in the middle of the night, and in pain, to urgently access antibiotics, or calling 111 or waiting until 9am when the GP surgery opens. Tanya had been well on a six-month course of daily prophylactic amoxicillin but had had to access repeated courses of nitrofurantoin almost immediately after coming off the amoxicillin. She had just started a six-month course of daily prophylactic nitrofurantoin when I spoke to her. She was really fed up and under a sick review at work. She told me that she would see if money improved during her six months prophylactic course, because she wanted to see a private specialist. I asked her about her symptoms:

They're horrific to be honest, they are absolutely horrible. I don't sleep. So when my urine infection symptoms come on, especially if it comes on in the evening I do not sleep that night at all. I do not get any sleep because I'm getting up and going to the toilet every ten to fifteen minutes. I don't sleep at all.

Within this, ways or techniques or practices of getting a good night's sleep are valuable as an antimicrobial practice and also as a stewardship of antibiotics. Here we are back again at the problem of practice-based approaches: it would take large-scale change for everyone to get a

good night's sleep when paid work and care work are stratified by gender, race, class and global borders. However, inventive ways of facilitating sleep are visible in the practices of people who achieve care for bladders amidst these infrastructural challenges.

Patients in primary care are standardly prescribed 100mg of nitrofurantoin twice daily in a modified release form (NICE, 2018a). However, one patient was prescribed one day of 25mg of nitrofurantoin to be taken four times a day, before finishing the course with the modified release. People seeking care for UTI are often in acute distress and pain, especially if this is repeated problem. Tanya described how she only gets relief from symptoms on commencing antibiotics. Facilitating sleep as a part of care through providing not only rapid access to antibiotics, but rapid access to bioactivity, is, in my theorisation, an antimicrobial stewardship in a way that trying to persuade people to use fewer antibiotics isn't. Again, here is another example of an inventive, experimental and mundane collaborative practice between a HCP and a patient which seeks to limit antibiotic exposure whilst relieving symptoms.

Antibiotics: Inventive Practices

The above is an example of how antibiotics may figure in care, if they make you feel better, regardless of the biological 'real' of your disease. Many of the photos depicted antibiotics (n=12). Overwhelmingly, this was Nitrofurantoin 100mg slow-release (n=7). These probably represent antibiotic prophylaxis, to be taken once daily, as they appeared in Isabella's photos, labelled as 'preventative antibiotics.' However, the same drug appears in Sophie's photos not as prophylaxis but as an acute course of antibiotics to be taken at the onset of symptoms. To avoid confusion, this is what I call 'self-start antibiotics.'



Figure 4-Sophie

Diane describes the process of being prescribed self-start antibiotics:

I've just remembered, it did get to the point one time where I remember my GP saying to me, take this prescription, keep it at home, and the next time, you obviously know when you've got one, and then next time you do get one, you can head it off quicker, here's a prescription for antibiotics but only use it if you need it.

On the other hand, I asked Andrew, an academic GP with a research interest in UTI, if he uses self-start antibiotics in his practice. He responded:

No, I can't think of a single patient or a single time that that has come up in my practice, no. In general, I'm not that keen, same for respiratory infections and so-called rescue packs for people with chronic lung disease. I completely understand that the thinking is, particularly for people with chronic lung disease which is very severe, and you try to prevent what's already quite a severe baseline condition getting worse, which often results in people being hospitalised, I completely understand the rationale but the problem is that people just don't know when to start them. And we don't know what to advise them about when to start them, you know, there's no evidence to support the point at which these treatments should be started. And there are definitely people out there who don't make even vaguely sensible judgements about when they should be started and so they're starting them a lot and then we get requests for repeat top-ups for their rescue packs, type of thing. We know that that happens with people with respiratory infections and I would hate to think of that happening with urinary infections as well.

No recommendation on the use of self-start antibiotics (keeping antibiotics at home) appears in guideline care. This was because no systematic reviews or RCTS were identified on their

use but also because the committee recognised that ‘the use of stand-by antibiotics could potentially lead to inappropriate antibiotic overuse in the absence of medical supervision, which would not reflect the principles of antimicrobial stewardship’ (NICE, 2018c, p.39). Keeping antibiotics at home also appears as a problem for AMS in public health research which expressed concern that individuals with higher educational qualifications were more likely to be doing so (McNulty *et al.*, 2007, p. 736).

However, guidelines do note that people with recurrent UTI who have reached the end of a trial of prophylactic antibiotics should have rapid access to treatment if symptoms reoccur and Andrew is careful to note that access in his surgery is good:

Obviously in some practices people are waiting even a week or two weeks even for a so called urgent appointment, then I can kind of see you’ve got a different set of issues to be dealing with and you might want to then say, okay here’s a prescription that you can keep in your back pocket and use if things are getting worse.

It is worth noting that Diane is a nurse and she described dipping her urine at work in order to confirm infection via the presence of RBC, which potentially altered the nature of the decision to allow her to keep antibiotics at home. Sophie is another patient who told me about being prescribed antibiotics to keep at home. She showed me a letter she had received from her NHS urologist. It read:

Many thanks for referring this lady who I spoke to over the phone today. She has a long history of recurrent urinary tract infection. She tells me that whilst antibiotics work she tended to get reinfection relatively quickly. She tells me, however, that since she was referred she has been commenced on Methenamine by yourself and this has really improved her situation, this is good news and it would seem reasonable for her to continue on the Methenamine. She was concerned about the possibility of breakthrough infections and asked whether self-start antibiotics would be reasonable. She has a good understanding of what symptoms constitute urinary tract infection and would be well motivated, so it would be a reasonable strategy. The last positive urine culture I can see is from September last year which was a fully sensitive E.coli.

As we already saw in chapter one, Sophie has difficulties accessing her GP. Indeed, her decision to ask for self-start antibiotics was precipitated by this. The urologist, however, decides that this would be a reasonable strategy based not on poor access, but because of her good understanding of what symptoms constitute urinary tract infection and good ‘motivation.’ For Sophie’s urologist and for Andrew, poor information, education and

‘motivation’ makes people behave in undesirable ways around antibiotics. For public health workers, people behave in even more undesirable ways the better educated they are. Approaching these problems through practice, we may see that people make reflective decisions about when to use antibiotics, based on factors such as how easily they can access care.



Figure 5- Isabella

Hygiene

In the literature review, I discussed how hygiene appears as an important practice outside of the clinic in guideline care and yet does not emerge as a reason to engage with publics. Nonetheless, animating hygiene practices is a rather obvious reason to speak to people who either don't use antibiotics or don't get lasting symptom relief from antibiotics. Nearly of my participants reported that they were unaware of UTI, and hygiene practices surrounding it, before developing symptoms themselves, as Maddie told me:

No I wouldn't have known, it's definitely something I've learnt from the experience of getting these infections. And now it's like, you kind of, its second nature now in my mind. You make sure you go and pee after you have sex. Whereas if I didn't before, even once, I could get a urine infection.

Associations between hygiene and infection were contentious in interviews, resisted by some participants, and embraced by others. What is of note though, is how they emerge as so important in the clinical care of those who come into the clinic complaining of urinary symptoms, but do not form part of prevention or education efforts at all, with those focusing on non-uses of antibiotics. Again, here is an opportunity for public health to reflect and deliberate on what good care might be with people who already spend a long time doing so.

Alkalinising Agents

Alkalinising agents, such as potassium citrate, sodium citrate and sodium bicarbonate, are preparations which increase the urinary pH. They are commonly sold in chemists and supermarkets and are used by many when experiencing urinary discomfort. Because they are sold over the counter, without a prescription, they form an important part of practices surrounding urinary symptoms outside of the clinic. Indeed, sodium bicarbonate is a common household item as it is also used for other uses, such as baking and cleaning. These agents appeared in only two of the photos produced by participants in my study. Their theoretical mechanism is in reducing burning on urination by decreasing urinary acidity. Therefore, alkalinising agents do not resolve the infection, but alleviate symptoms while leaving the resolution of symptoms to the immune system. I speculate that this is an important reason why they did not appear in many of the photos produced, although they almost certainly constitute an important part of people's practice outside of the clinic; because people for whom urinary symptoms are hugely problematic are the majority in my sample.

Heather was in her 50s when I spoke to her and had experienced UTI since being young. Her photo depicts a hot water bottle, a bed, a bottle of cranberry juice, a bottle of water, pain killers, and an alkalinising agent. Heather's symptoms were truly recurrent in that they always cleared up in between each episode, and she described a lifelong experience of UTI which was inconvenient but not hugely problematic. When I met her online for an interview, she told me she had experienced a water infection the week before, after being symptom free for six

months previously. Overall, this experience of long term but low-level symptoms, including a recent infection, is reflected in her photo: she has fresh cranberry juice and an alkalinising agent to hand but few other specialised objects outside of standard domestic items.



Figure 6- Heather

The NICE guideline recommends that self-care (managing an infection at home) should be encouraged according to the NICE guideline on antimicrobial stewardship: changing risk-related behaviours in the general population (NICE, 2017). Urine alkalinising agents are recorded as self-care options that ‘have been used’ but it is also noted that there is no evidence for their use (NICE, 2018a, p.9). SIGN joins NICE in noting people’s practice outside of the clinic but making no recommendation due to lack of evidence (SIGN, 2020, p.17). Therefore, both SIGN and NICE see the use of alkalinising agents as a potential antimicrobial stewardship, following their recommendation by the British Association of Urological Surgeons, specifically on the basis that they may reduce the need for subsequent antimicrobial treatment (SIGN, 2012, p.17.)

Indeed, Heather described exactly this:

I tend to go off and get the I don't know what it's called, the cystitis relief, which is like the granules that you can make a drink from the pharmacy, and I start off with that and I'll leave it for probably the two days that you would take those for. And if by the next day, so the third, it hasn't cleared up, I would then contact the doctor.

Heather further described her 'self-care' routine the last week when she had symptoms: *'I upped my water intake, I reduced my tea and coffee completely. I didn't have sex. Literally, I sort of have this pattern of behaviour that you know it will go. And then on the third day I got up and thought I actually... I feel alright. I'll leave it till tomorrow. And I'm fine.'*

This is how antimicrobial stewardship is imagined in relation to alkalinising agents, in keeping people managing symptoms at home and therefore not using antibiotics. This is possible for Heather because of the nature of her symptoms and her past experiences, she knows she can manage symptoms at home and she expects full symptom resolution. However, evidence cited in the previous SIGN guideline, SIGN 88, (2012, p.12) shows that increased urinary pH greatly affects the activity of the recommended first line agent for lower UTI, nitrofurantoin (Brumfitt and Percival, 1967). Brumfitt showed that the minimum inhibitory concentration (MIC) for *E.coli* in the presence of nitrofurantoin (the lowest concentration of antibiotic that regularly inhibits growth of the bacterium in vitro) increased twenty fold with a pH from 5.5 to 8.0. The use of alkalinising agents is noted as a practice outside of the clinic, but appears within clinical care only as an opportunity to drive down antibiotic use, seeing that very particular intervention as a pre-dominant AMS intervention. I suggest that as with evidence around hydration, this reflects a missed opportunity to engage with reflective antibiotic-using publics on other kinds of potential antimicrobial stewardships. For, if efficacy of nitrofurantoin against urinary pathogens is reduced in the presence of heightened urinary pH, this may have important unforeseen consequences for AMR. The opportunity to approach these publics through practice, taking collective action and building capacity for future mobilisations is missed. I argue that this is a familiar and unambitiously conservative mode for public health efforts to mobilise on AMR, preferring to drive down antibiotic use and engage only with publics on non-use of antibiotics, rather than engaging with antibiotic-using publics on optimising existing uses of antimicrobials.

Hiprex: Reanimating Forgotten Practices

Methenamine hippurate, methenamine mandelate and hexamethylenetetramine are all examples of urinary antiseptics used during the first half of the twentieth century as pre-antibiotic treatments for UTI. Methenamine is hydrolyzed to ammonia and formaldehyde, which has anti-microbial activity. With the advent of antibiotics in the latter half of the twentieth century, urinary anti-septics fell out of use. In Angela Kilmartin's books on Cystitis published across the 1970s and 1980s, she recalls being prescribed a blue antiseptic pill (most probably methylene blue) alongside antibiotics (Kilmartin, 1986, p. 10). Obayes Al-Khikani suggests that another reason for the decline in use of methenamine salts was controversy over whether they were effective in preventing UTI, due to the low urinary pH needed for bacteriostatic concentrations of formaldehyde to be generated (Obayes Al-Khikani, 2021, p. 247). Indeed, this is noted in the BNF as a barrier to the use of methenamine hippurate in primary care (NICE, 2022, p.8).

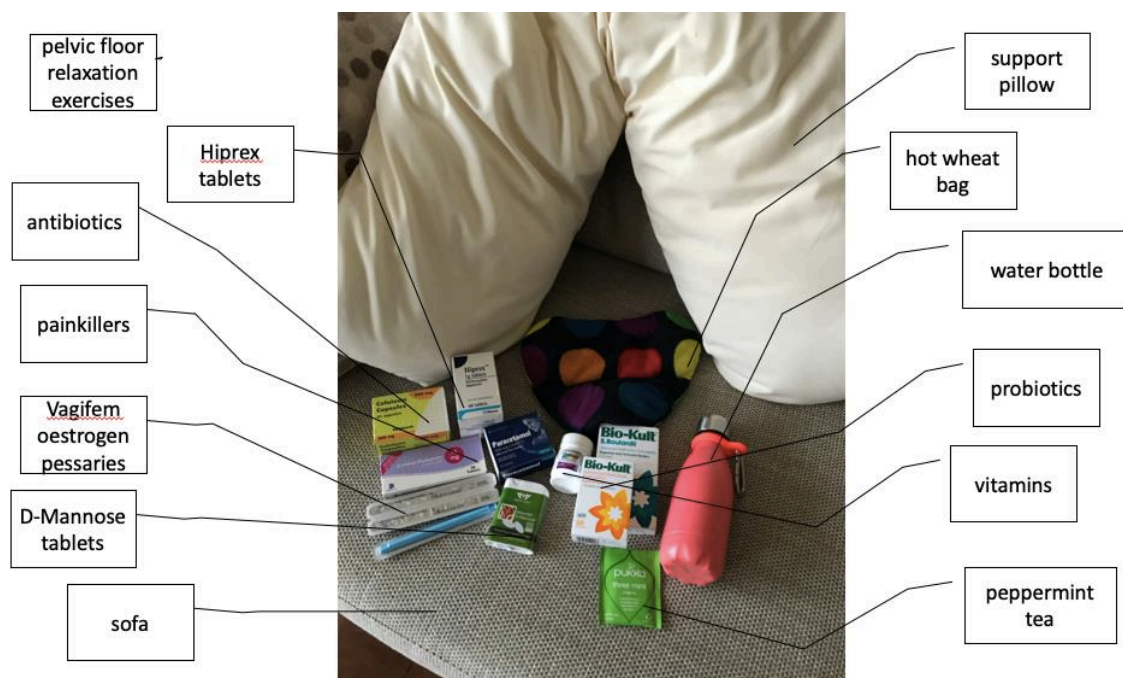


Figure 7- Hannah

Patients for whom initial treatments of antibiotics have not successfully resolved symptoms have been using methenamine alongside or instead of antibiotics for years. Hiprex appeared in eight photos, often alongside antibiotics. In the UK, this practice seems to mainly have followed the introduction of methenamine into treatment protocols in the clinics set up by

James Malone-Lee (Malone-Lee, 2021,p.9), and then shared as a practice amongst patients. Sometimes, this involves the collaboration of HCPs within the NHS. Hiprex is currently listed differently in the formularies of each CCG, listed red or amber in some places, meaning that it cannot be prescribed in primary care, but only under specialist (urology) guidance, and grey listed in other areas, meaning that it is a non-formulary item and advice must be sought from pharmacy teams. This led to a situation where some people could be prescribed Hiprex through asking their primary HCP, and others could not, depending on postcode and of course, the outcome of an interaction which often involved the patient asking the HCP to prescribe a drug they had never heard of.

However, until recently, Hiprex was available over the counter in the UK. In December 2019, the MHRA was unable to retrieve the results of safety reviews and the Commission on Human Medicines advised the Licensing Authority that the Pharmacy legal classification of methenamine containing products was not appropriate. CHM's opinion was stated that:

Methenamine containing products should not be P medicines as the authorised indication for management without medical supervision is clinically inappropriate. Additionally, there is a risk that the availability of this antibiotic as a P medicine could create the wrong message regarding antimicrobial stewardship (MHRA, 2021a)

This decision was provoked by a freedom of information request (FOI 21/084) enquiring about the rationale behind the availability of methenamine products without a prescription. It is not possible to know who made this request, but it certainly confirmed fears and anxieties that increased attention drawn to UTI because of AMR would lead to reductions in care available. I wrote to the MHRA to enquire about the decision and in correspondence CSC 59251 dated 20th September 2021 they concurred that 'methenamine has been inaccurately described as an antibiotic in the report and it would have been more accurate to refer to it as a urinary tract antibacterial agent' (MHRA, 2021b). Although they stated that this inaccuracy affected only the report, not the decision on methenamine as a non-prescription medicine, I suggest that it does reflect a more generalised un-ease with what patients are doing outside of medical supervision, especially around antibiotics. This is unfortunate as it misses opportunities for collective mobilising on AMR, and may have un-intended side effects if people are allowed

to believe that their individual interests are in conflict with the interests of antimicrobial stewardship.

Formaldehyde is a well-known carcinogen (SCHER, 2007) and some patients are understandably reluctant to trial this non-antibiotic option. In this, it joins other patient practices such as the use of azo dyes like phenazopyridine, very commonly used by patients in the US as a bladder analgesic, and purchasable online in the UK, which carry potential safety concerns. For me, this suggests that concerns with what patients are doing outside of the clinic when they find themselves not getting help could helpfully concentrate more explicitly on patient safety, providing safe boundaries for experimentation, rather than attempting to regulate what people do with pharmaceuticals outside of medical supervision.

Recently, results from the ALTAR trial, a multi-centre RCT led by Chris Harding, were published in the BMJ (Harding *et al.*, 2022). This marked one of few major interventions in this topic area of urinary tract infection in the past fifty years, across both diagnostics and treatment. Current NICE guidance runs out of course in patients who continue to experience recurrence or relapse after trials of vaginal oestrogen and antibiotic prophylaxis, and SIGN guidance after antibiotic prophylaxis. The option of using methenamine hippurate, which can be used longer term, therefore represents an additional strategy for patients living with hard-to-treat UTI. As I write in September 2022, NICE has begun an early update of their evidence review for NG112 on recurrent UTI, given the new evidence available from the ALTAR trial (NICE, 2022).

The ALTAR trial design is innovative in the way it conceptualised the patient role. The benefits of non-antibiotic treatment have proved difficult to account for in the methodologies of EBM. In current NICE guidance on recurrent UTI, no recommendation is made on the use of methenamine given evidence that antibiotic prophylaxis with Nitrofurantoin was more effective. In the ALTAR trial, it was the PPI group that defined the non-inferiority margin as one episode of urinary tract infection per person per year. In this, patient involvement in the trial was a way of accounting for what patients and healthcare practitioners collectively do on AMR and UTI inside and outside of the clinic: use antibiotic and non-antibiotic options in

different ways to work towards symptom resolution. Such collective mobilisations on optimum benefit to the individual patient contain AMS within them, there is no suggestion that a patient should forego what is best for them individually in order to conserve antibiotics.

In the same vein, patients who have been using methenamine outside of the clinic have practices which will be very useful if this becomes a more widely adopted approach. For example, many patients encapsulate the tablets by buying encapsulations tabs that are bought on Amazon, in order to protect the stomach from some of the gastro symptoms and burning that patients report. Another example is that, because evidence suggests that most of the formaldehyde generated by methenamine is recovered in urine, these patients are experienced in knowing how to keep urine away from vaginal flora. Methenamine Hippurate tablets are chunky and foul tasting. Learning how to live well with these things is a stewardship.

D-mannose

D-mannose appeared in six photos. D-mannose is a sugar naturally found in various foods, notably including cranberries. D-mannose products contain much more of the sugar than could be gained via eating cranberries. Research suggests that D-mannose in urine can block *E.coli* adhesion to epithelial cells by saturating *E.coli* FimH structures. Guideline care for recurrent UTI (NICE, 2018c, p.11) on 'self-care' notes that 'some women with recurrent UTI may wish to try D-mannose if they are not pregnant.'



Figure 8-Pamela

I spoke with Anna, who set up a company manufacturing and selling D-mannose, which is now one of the most popular companies providing D-mannose to the UK market. Anna had suffered with repeated bladder infections, which often ascended to her kidneys, since childhood. She described how care ran out of course as none of the antibiotics she was being given were helping and she suffered severe damage to her mobility after taking Ciprofloxacin:

'you know they were trying to help me but they couldn't find anything else to give me that was working, so I was at the end of the line.'

She described how what she needed was something else to try:

I literally stood in front, sat in front, of the computer and said. Please help me. And put in bladder infections and mannose research came up and we're talking about, I'd been searching for something for twenty odd years.

Anna imported a kilo of D-mannose to the UK and started giving it to family and friends, before eventually setting up manufacture in the UK.

In uses of D-mannose outside of the clinic, how much D-mannose product to use emerges as a significant concern. This is firstly because D-mannose is currently marketed, sold and

regulated as a food supplement in the UK which means that there is significantly less oversight than products regulated as a medicine. In the company Anna set up, D-mannose is manufactured from fermented birch bark. A strong emphasis on purity in marketing materials and throughout Anna's interview, belies concerns about purity in other D-mannose products: *'we have always focused on is producing something that never could hurt anybody. Probably it's the purest thing you'll ever put in your mouth is our mannose.'*

Secondly, dosing appears as a problem because it varies person to person, 'with some customers finding they need two daily doses and others only need one. The most challenging element of using D-mannose is finding the dosage that works for you, so most people would start higher and reduce down over time' (Sweet Cures, 2002). It is advised that 'a maintenance dosage should be around 2g - 4g and for treatment between 6g - 12g per day for the most success' (Sweet Cures, 2002).

Importantly, this knowledge about how to use D-mannose in practice comes from asking people using it what worked for them:

All the original research that we did was partly based on Doctor Wright in America, who did all the preliminary brilliant research. So we always credit him completely, but it also came through our own research. Feedback from everybody who bought, which is how we learned how to use it most effectively. Literally by doing what you're doing, research and getting feedback from customers, how they'd used it, how it worked the best. And we just drew up a list of suggestions for how it might work the best.

While Anna is careful to credit a Doctor Wright with the development of the technology, the use of the technology in practice depends on patient knowledge, people trying out different things to see what worked best for them.

As of now, a two-arm, individually randomised, double blind placebo controlled, pragmatic trial, MERIT, is underway of D-mannose for prophylaxis of recurrent UTI, based at the University of Oxford. In the trial protocol, the rationale for the trial notes that 'D-mannose is available commercially to the public as a food supplement, and is favoured by many women who have RUTIs, but until recently, there has been little empirical evidence to support its use' (Franssen *et al.*, 2021, p. 2). Therefore, people's practice outside of the clinic is recognised

as important, but specific types of evidence are required to support its incorporation into EBM.

In the trial, the intervention consists of ‘two grams of D-mannose powder to be taken daily for 6 months’ (Franssen *et al.*, 2021, p. 3). It is important to note that no detail is given on how the intervention dosage was decided, nor on the product itself, despite the dosage being on the lower end of what is recommended outside of the clinic.

Water and Hydration

Many photos (n=16) depicted either water or other drinks, or both. Many participants talked about techniques for upping their fluid intake, using bottles or interesting tasting drinks. Indeed, hydration appears as an important self-care practice in guideline care and in existing public health AMS interventions (NHS England, 2022).



Figure 9-Minna

Nicole describes how her urologist told her *'to drink quite a lot of water, which I did. Which makes it worse.'* Nicole's reference to hydration making a UTI worse is a reference to the idea that, 'if you increase your fluid intake you will dilute the large number of anti-infection chemicals that are being produced by the innate immune response of the urinary tract and so too any antibiotic that has been prescribed' (Malone-Lee, 2020). Evidence which supports increased hydration as a protective factor is doubted because it is validated against a positive MSU urine culture which, it is argued, is less sensitive when urine is more dilute (Malone-Lee, 2019).

These discussions about ways to optimise antibiotics used, rather than changing the volume of antibiotics used, is a good example of the types of reflective deliberation about antibiotics that could take place collectively, through practice.

Herbal teas to be consumed hot appeared in nine photos, predominantly peppermint, chamomile and red bush. These were described as helpful for their lack of caffeine, warming heat, and facilitation of increased fluid intake. In my interview with Jennifer, she described how when she has a UTI, she would avoid orange juice, which she normally much enjoyed, because of the high acidity and sugar content. However, she also told me that she would chug cranberry juice 'by the litre.' When asked why she selected practices in this way, this is what she told me:

Now you've said like why would you drink it, like I don't, I honestly don't know why, that seems illogical, 'cos orange juice probably has more sugar in it than cranberry juice to be fair.

Just as behavioural science interventions find themselves grappling with apparently irrational actions, so here too the link between what people do and what people think is complex. Jennifer couldn't really describe why she did certain things and yet every time she gets a UTI she cuts out her orange juice, which she normally enjoys, and goes to the shop to purchase a bottle of cranberry juice. Another participant, Flora, included a bottle of sparkling water in her picture, which she told me she feels is more helpful than still water. If the question here is what to do about painful urinary symptoms, what will make you feel better, an answer for Flora is sparkling water and for Jennifer is cranberry juice. This is unaffected by the lack of RCT data for these interventions.



Figure 10- Flora

Recognising Good Care: Evidence, Practice, Temporality and Futures

How do we recognise what good care is when we come across it? A simple answer is that good care is what makes you feel better. There are obvious objections to this. When I noted that people who are in pain can tell us about ways they have found to feel better, citing Pols (2013), I also noted, citing hooks (1989), that this is not a safe place for these people to be. People who are in pain are often desperate, as I observed many times over the course of my research, and willing to try things, including hugely expensive things, to make them feel better.

This vulnerability is often noted in mobilisations around access to long term antibiotics, drawing on the 'iconic' figure of the 'miracle cure-peddling quack' (Wahlberg, 2007, p.2307).

Some persons crave proffering, breathy advice on how we should live our lives to avoid UTI. Large chunks of this verbiage draw on cherished myth and little substance: drinks buckets of water; fatten up on cranberry juice; wipe from front to back; empty after intercourse; have sex upended; muddle with your hormones; wear calico knickers. Instead, try hiring a shaman to cast spells. If we do not really know, why should we advise? (Malone-Lee, 2021, p.190).

Often, these defences of (rather defenceless) others from quackery revindicate antibiotics as the only effective intervention by revealing the scientific method to the unknowing (MacArtney and Wahlberg, 2014). Meanwhile, social scientific work on alternative health practices shows that they largely supplement rather than substitute biomedicine (MacArtney and Wahlberg, 2014, p.117). But there are important issues of evidence and interest prompting

consideration of what we know and how we know it. Firstly, it is important to bear in mind that we are talking about here is patient knowledge. Although Pols' account of the nature of patient knowledge is not perspectivalist (Mol, 2002, p.12) in that it does not see patients and HCPs having different perspectives on a central and ontologically stable disease, it also does not flatten out difference, recognising that patient knowledge is different to that of biomedical knowledge held by doctors (Pols, 2013). While patient knowledge may be integrated into the healthcare system in order to care for symptoms as embedded in lives, work, sex, relationships, technologies and practices, there is no suggestion that such databases of patient practices such as this should replace RCT data, although I of course argue that it would be beneficial if clinical ways of working could co-exist with the practices of EBM. In the case of D-mannose and Hiprex, we see some interaction between people's practice outside of the clinic and the practices of EBM. However, what is notable is that D-mannose and Hiprex are, like antibiotics, scalable technologies. Therefore, this interaction between EBM and care practices may be more of a co-option than a co-existence. Other care practices, and indeed modes of caring with Hiprex and D-mannose, may struggle significantly more to co-exist with EBM.

A second objection is that the question of what makes you feel better is not clear cut. I have cited the below passage from Tom, a clinical microbiologist, before, drawing attention to the way that clinical work does not need knowledge to be an accurate representation of the reality of disease, but instead to know if a given practice is good for the actors involved. Here, I draw attention to the uncertainty and doubt involved in knowing what is good:

And do you get better with antibiotics? I think the key question for me is, do you get better when you're given antibiotics? And some of them do, and some of them are more convincing than others. And I guess, it is...you know, I make this sound like this works every time. But I think, a lot of the time, it's people just need to be...feel supported in that, and realise...I think, when you show your uncertainty, and say, look, I can't see any bugs here. I don't know what we're treating. I mean, if you're really sure you're getting better with antibiotics, then great.

Here, knowing whether antibiotics are good for a patient or not remains unsure and maintaining uncertainty about what to do remains important. Working within a curative imaginary (Kafer, 2013; Dryden, 2021) as I have argued, patients mobilising around access to long-term high-dose antibiotics often talk about persisting with a treatment regime which

does not make you feel better immediately. If chronicity has a relation to care, as I noted in the previous chapter, it also has a relation to temporality. Being chronically ill means being ill over long periods of time, and never getting better. But as Benton *et al.* note, rhythms of chronic living are punctuated by different interruptions (Benton *et al.*, 2017). Chronic urinary symptoms have specificities for individuals but a temporality common amongst many accounts is that of huge crises amidst longer-term, lower level symptoms. Above, I showed how this is enacted by those using long-term high dose antibiotics, as an anticipation of cure. For those not using antibiotics in this way, I argued in chapter one that people struggle to get help for urinary symptoms unless a UTI to be treated can be enacted and antibiotics prescribed. Care sustains itself because of the way that well-sustained practices of caring for UTI are adequately separate from poorly sustained practices of caring for urinary symptoms. People who aren't helped can always come back next time and be treated as if they were seeking help for the first time. This temporality, of coming to the clinic only when a UTI can be enacted, because that is the only time they get help, mirrors the temporality of recurrent UTI (a series of acute UTIs which may also be thought of as a chronic condition but crucially also enacts a UTI to be treated with antibiotics) and therefore sustains poor care for urinary symptoms. Indeed, this temporality is even visible in policy concerns around the 'medicalisation' of UTI and urinary symptoms more generally (Ghouri *et al.*, 2019). An idea that people come into the clinic, are prescribed tablets (it is not necessarily important that they are antibiotics) and then repeat this routine the next time they feel ill, becomes a concern that 'they would have got better anyway.' Therefore, living with chronic UTI or urinary symptoms in general is characterised by punctuations, or, in the language of patient mobilisations, 'flares' of longer regularity.

Pols tells us to gain familiarity with the good in practice; it matters that antibiotics make people feel better. CUTIC notes on its website that in an observational study of a centre using the long-term high-dose protocol (Swamy *et al.*, 2018), it took on average '383 days of continuous treatment to achieve symptom resolution.' This is explained: 'we do not expect a linear response and should be averse to over-interpreting the natural fluctuations in the healing process. Symptom flares pepper the history of treatment' (Swamy *et al.*, 2018, p.173). In this context, recovery 'involves a series of oscillations of decreasing amplitude' (Swamy *et*

al., 2018, p.174). This is because of the pathophysiology of the disease of CUTI, where antibiotics have to be present for the full cycle of epithelial cell renewal, in order to clear the parasited cells (Swamy *et al.*, 2018). There is therefore a not a straight-forward relation between symptoms resolution (feeling better) and a disease-free state. With regards to CUTI, clinical tools belie the reality not only of disease, but also of recovery.

On the other hand, note how Ruth, attempting to organise patient knowledge of trial and error in the Facebook group she runs, introduces a temporal limit on decisions about what is good:

Do you feel better than you did on your path than you did six months ago, are you healthier, are you feeling better, are your infections less? Check your path and maybe it's time to change if you're not feeling better. You should be improving all the time, not getting worse.

She encourages people to stay much closer to clinical tools in trying to find a way to feel better. A speculative turn in the social sciences has begun to conceptualise temporality in terms of how speculations towards the future shape practices in the present (Wilkie *et al.*, 2019). Antibiotics might be good for a future you even if they don't make you feel better now, a speculative mode engaged in by patients anticipating cure in long-term, high-dose antibiotics. This socio-technical imaginary (Jasanoff and Kim, 2015) and mode of speculation is perhaps less explored than modes of speculation which anticipate an unwanted future (Lemos Dekker, 2021; Svensson, 2021). However, it is certainly not unique to antibiotics and in fact has many parallels with treatments which are unpleasant to experience but facilitate cure: chemotherapy is a clear example. Or, antibiotics might not be good for a future you, even if they make you feel better now, a speculative mode engaged in by policy-makers.

This is speculation, it is uncertain, I offer no answers. But what I do want to insist upon is that the openness of this question about what should be done does not demand a return to the biological real. It is not exclusively in knowing if symptoms reflect an infective disease or not that it will be known if antibiotics will provide good care or not. Different interventions and different practices have different stakes, some are more dangerous than others. It is this question of balancing different speculative futures which may provide a good way forward. Patients do things to feel better outside of medical supervision. But this experimentation needs to be safe and boundaried. Patients living with unresolved urinary symptoms must be

recognised, brought back within the scope of clinical care, and sat with, thinking about what to do next. There are huge infrastructural pressures on this, but negotiating these pressures and speculating on uncertain futures are tasks which HCPs are indeed highly trained and practised in, notwithstanding what I would characterise as a current crisis of self-confidence on UTI and AMR.

Conclusion

This thesis deals with difficult things. There are poor experiences of clinical care that leave people in pain, desperate and vulnerable. A future we contemplate without antibiotics to care for us, in a world where AMR is but one silo of the damaging changes we humans have wrought upon the earth. Moreover, there is racialized, classed and gendered injustice in the distribution of both the perpetration and the effects of climate change, including AMR.

But, despite the difficult and painful matters at hand, in this thesis, where I have located my own standpoint with patients suffering from intractable urinary symptoms, I have refused long expositions of how badly treated we have been, how at risk and vulnerable we are. A major argument of the thesis has been that the way that public health and clinical medicine has so far thought about the future of AMR is both depressed and depressing, facing patients with a defeated exhaustion of what to do outside of antibiotics, and offering only non-reflective roles in not using antibiotics. I have argued that driving down and conserving antibiotic use is seen in public health as the only possible response to AMR. Depression surrounds how best to do this.

But we patients are not depressed. We face the future with openness, ambition, creativity, and deep, careful and slow reflection on where good lies. We notice good care where it flourishes. We are animated to notice the forms of public engagement that are already happening, reflecting on what good is and taking unruly roles outside of the roles offered to us. And we patients are sometimes also doctors, sometimes scientists, sometimes the very same people who do public health work. Although we are all positioned differently in important ways, we all have relational ties to illness and therefore we are all invested in patienthood and good microbial futures.

I have written myself into the story I have offered here, albeit it in specific ways, and I have also exercised some level of control over the stories of others. I have relied on others' stories to make my points. I have aimed for this control to be transparent, rigorous and careful. During the course of writing the thesis, I have found out that I was wrong about many things. For me, this has been a redemptive experience. To realise you are wrong opens up a whole

new world of possibilities, creates space where there was none and refuses to close the issue. This is my story of others' stories. It is one story alongside others but it is a new story, and it is one that I have had much time to think about. Researchers have responsibilities to do more than to simply report on issues as they encounter them. Hence, this story is offered to participate, to discuss, contemplate, challenge, and to open up new ways of thinking. I have therefore emphasised rather than obscured the ways in which this work could participate in constructing different publics (Chilvers and Kearnes, 2020, p.3).

For, there are a multitude of ways of thinking about and meeting the challenge of AMR, letting ways of caring outside of antibiotics bloom and recognising plentiful bounty in difference. There is difference in different roles- sometimes you will be a patient, someone in need of care. You will need to accept vulnerability in yourself in order to be able to accept care as a patient, just as a child from a parent, and a student from a teacher. But it is important that you will not always have this vulnerable role. Other times, you will have a different role and you will care for others. There is difference in all of the different things to do about pain, aside from antibiotics. We can look backwards to reanimate things people used to do before antibiotics came to so dominate our care practices. And we can look forward with anticipation to building a world where care looks different. For, this is certainly not the end of the story. While I have asked how to craft a good life now, regardless of the biological real, elsewhere others are busily working on understanding the biological real, work which has brought about world-making advances in diverse areas of medicine.

There is also difference in the different relations we have to care. Some groups, positioned as they are in specific societies, are accustomed to state level care in biomedicine. Others have greater experience of living without getting help and care. This is important because it illuminates how difference is to be noticed for the way that it contains care, not valorised in itself. It is often because of a lack of care that people have developed alternative ways of caring.

One of the main reasons why it is a good thing to be cared for is because it affords the freedom to be wrong and to do wrong and to still be cared for. To be wrong whilst under the care of

another means you have the space to make your own mistakes. You must take responsibility for your mistakes, but you are not in freefall. You are within a space of experimentation. In research, supervision is one place I learnt about what it means to be under the charge of another, without them being in charge of you. But once I noticed this, I noticed it elsewhere too and it became very important.

Rather than ignoring that people are experimenting with ways to feel better, and focusing on non-uses of antibiotics within a conservationist outlook, new approaches in public health could do more to share moments of collective deliberation, to recognise different publics for AMR, and to set boundaries around experimentation. An overwhelming problem in the experiences of UTI that I have focused on is that you are under no-one's charge, there seems very little space for experimentation, you may feel you are banging up against a brick wall or falling into a black hole. If you are left to be responsible for your own care or you can never accept another's care, there is less room for error and less space for transformation. Noticing the ways in which we can participate in change, including changing ourselves and changing our minds, is a way to create more space, a way to move forward. We must all give up on policing the contours of an issue as we already know it and instead look to where there is experimentation.

Appendix 1

Do you have experience of urinary symptoms including:
Pain around the bladder, needing to go the toilet more often or urgently, pain when you pass urine, can't go to the toilet, or any other symptoms from your bladder?

I am Eleanor Kashouris, a sociology researcher at the University of Sussex. I want to understand more about how people live and work with urinary symptoms. I am not a doctor and this research will not affect your care. I am interested in your experiences.

What would happen?

- We would like you to take a photo of things you use to look after you bladder and to talk with Eleanor about your experiences. We expect this to take one hour, online.
- You will be paid £20 in an online voucher for your time.
- If you would like to take part, but not to do the interview, please get in touch to do the photo only. This will not include any body parts or any people.
- Eleanor will record the interview on a voice recorder, but we will anonymise your words if we use quotes in written work.
- If you change your mind before 6 months after the interview we will delete what we have recorded about you.

How to get involved?
 Contact Eleanor by email (ek403@sussex.ac.uk)





Figure- Recruitment Poster

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