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Illness and healthcare experiences of recent low-income international migrants in a UK city

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OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF
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Summary

Multiple factors account for inequality in health outcomes and in access to healthcare in the UK, including ethnicity and length of residence in the country. This thesis explores the subjective experiences of a group of recent low-income international migrants who live in Brighton and Hove and have used local health services to seek care for a range of illnesses and conditions. The project was formulated in collaboration with Brighton and Hove City Council and the then NHS Brighton and Hove (now Brighton and Hove Clinical Commissioning Group), using local professional knowledge and experience to recruit participants and collect narratives from a 'hard to reach' social group. The theoretical background of this thesis draws on 'lived' experience in the context of illness. Analysis of qualitative interviews, using narrative typologies derived from the work of Frank (1991), revealed both the commonalities across and the specificities of illness experiences, and highlighted a multi-factorial web of bio-psychosocial and economic factors at play. The interviews overwhelmingly fitted with a chronic, 'chaos' typology, in which diagnoses were commonly contested. The particularities of recent migrant status impacted upon participants' illness experiences and healthcare use. Migrants made comparisons with health systems in their countries of origin and managed healthcare through social networks. The findings from the data analysis around patient experience showed that the overall experience was negative, characterised by

disappointment, with communication and access problems as recurrent themes.

These outcomes may be explained by both direct and indirect discrimination.

Direct discrimination and stigma were perceived by many participants in the attitudes and practices of staff, which some participants linked to their own ethnicity, immigration status and faith. From this study it is possible to hypothesise that healthcare practices and policy may give rise to some of the perceptions of discrimination.

Declaration

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.

Signature:.....

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Chapter One: Health and Migrants

Health and illness contour, and are contoured by, human experience (Nettleton, 2006). The reality that there are significant differences in health underpins interdisciplinary interest and points to a crucial link between social injustice and differences in health (Cole, 2007, Mishler, 2005). Health status, health outcomes and access to healthcare are the principle foci of research into health inequality (Scambler, 2012). This thesis takes instruction from Scambler's critical observation of the importance of exploring the social to investigate a less researched group of recent low-income international migrants and in particular their experiences of illness and healthcare.

The epistemological position taken in the thesis is laid out in detail in Chapter Three. To summarise here, constructivism provides the underlying theory in which knowledge is understood to be socially constructed, with subjectivity and lived experiences seen as inherent aspects of reality. This theoretical position also allows a qualitative research project to be undertaken. The methods that are used are a questionnaire and semi-structured interviews, but not as would be the case were a post positivist realist approach to knowledge used. Rather, these methods are seen to provide a cross-sectional glimpse and subjective view of the experiences of a group of recent low income international migrants. These methods are applied reflexively as befits an underlying constructivist

position. It is therefore asserted that lived experiences offer trustworthy representations of constructed realities (Denzin & Lincoln 2011:104-115).

Bearing this theoretical approach in mind; there are several reasons for paying attention to a category called *recent low-income international migrants*¹: First, there is a debate about the degree to which migrants are a vulnerable population. Second, and notably in post-recession United Kingdom (UK), calls for controls on migration have increased and the debates on this matter have increased; whether new migrants have placed an unmanageable strain on welfare budgets and public services, including on health services (Lancet Editorial 2013). Third, health policy has been changed to restrict healthcare to 'overseas visitors'. Fourth, academic interest in migrants as a category has grown and increasingly aims to deconstruct discourses to understand how and why such discourses exist and how they circulate within a wider set of social and economic processes. In contrast, research that gives primacy to the experience of migrants begins by entering these debates, often through alternative sets of categories, such as ethnicity. Nazroo's (1997) research has considered how ethnic minorities and immigrants experience health inequality.

¹ A person who moves from one place to another in order to find work or better living conditions
<http://www.oxforddictionaries.com/definition/english/migrant?q=migrant> (Last accessed 1st November 2013)

Health research on migrants is an alternative, which underscores variations in health status, health outcomes and access to healthcare in general (Acevedo-Garcia and Almeida 2012).

This doctoral research is a case study of recent low-income international migrants resident in the provincial city of Brighton and Hove. They are thus a purposively selected sample within the larger recent migrant population in the UK. Recent low-income migrants are a particularly difficult group to reach, and research on their 'lived experience' of healthcare is scarce. One of the key factors that made this research possible has been the opportunity to draw on the researcher's own health practitioner contacts in Brighton and Hove. Whilst some public discourses about health and migrants pay little attention to the experiences and needs of migrants themselves, the collaborators in this study (Brighton and Hove Council and Brighton and Hove NHS)² have demonstrated a commitment to understanding the lives of new migrants in this city. Lived and 'lay' experiences also relate to the notion of patient satisfaction; therefore, efforts to understand the experience of illness can usefully combine with the intention of health providers to improve the quality of health services

² Brighton and Hove NHS were also known as Brighton and Hove Primary Care Trust. Since 2012, restructuring of the NHS has led to this commissioning organisation being reformulated and it is now called Brighton and Hove Clinical Commissioning Group <http://www.brightonandhoveccg.nhs.uk/> (Last accessed 13th November 2013)

(Department of Health 2013). Consequently, health policy that has the potential to positively impact migrants' should consider the lived experiences of recent migrants. One way to do this is through semi-structured interviews, and to carefully listen to what this group has to say about health care. This thesis seeks to contribute to policy and practice by presenting its findings about this hard-to-reach group of people.

The overriding aim of this thesis is to understand the experiences of recent low-income international migrants through their own narratives of illness experience and healthcare use. The first chapter sets out the central proposition that recent migrants' experience of illness and use of healthcare could be different to those who are not recent migrants. Specifically, this chapter, divided into three sections, provides both context and rationale for the approach taken. First, an overview of current public discussions about migrants and healthcare is given; second, a summary of the various definitions of migrants is considered, alongside some of the current national and local statistics, which together give context for this case study and further underline the need to focus on recent migrants; and third, the thesis questions are presented and the structure of the thesis is mapped.

Migrants and healthcare

Recent migrants are disproportionately concentrated in lower socioeconomic groups; there is considerable evidence that migrants with low socioeconomic status face inequalities in health (Portes et al, 2012), though these relationships are by no means straightforward (Abraido-Lanza et al, 1999). The most cited example of the complexity of interactions in health inequality highlights the exceptions to this general trend as it shows that US Latin American migrants' health outcomes are better than those of other Americans of similar economic status; this paradox has fuelled much research in the US (Palloni and Arias, 2004).

Investigations of health inequality are often concerned with access to healthcare. Access, however, is a highly variable issue and yet it is a term indiscriminately used when referring to different aspects of admittance to, and use of, health services. Dixon-Wood and her colleagues (2006) have reviewed the meaning of access and offered the concept of 'candidacy' to suggest a broad definition of access which conceptually takes account of structural and social factors, rather than focusing only on practical barriers. Chow and colleagues (2009) have included 'access' in their concept of patient satisfaction as the two are seen as overlapping. When conducting research however, it is easier to focus on practical barriers, such as the use of particular health services or the length of waiting times. These are legitimate aspects of access,

and are relatively straightforward factors to measure. However, other factors are also connected to access such as the quality of communication around access (Bhatia and Wallace 2007). Differences between migrants' experiences of access include the particular difficulties of migrants who have a precarious immigration status and as a result encounter more issues with regard to access (Romero-Ortuno, 2004). This has been more recently discussed in the online report Doctors of the World³. One example of practical access problems faced by migrants is the issue of whether they are able to register with a GP in the UK (Kmietowicz, 2001); this is discussed in the online report produced by Global Advocacy Project and others⁴. Even after Kmietowicz raised the issue a

³ Doctors of the World, 2012. Access to healthcare for vulnerable groups in the European Union in 2012 - An overview of the condition of persons excluded from healthcare systems in the EU. London: Doctors of the World. This can be found at:

<http://www.europarl.europa.eu/document/activities/cont/201302/20130208ATT6077620130208ATT60776EN.pdf>. (Last accessed 24th September 2013).

⁴ Global Health Advocacy Project, 2009. Four Years Later: Charging vulnerable adults for NHS Primary medical services can be found at:

http://stillhumanstillhere.files.wordpress.com/2009/01/four_years_later_full_report.pdf

Migrants for primary medical services was found at:

http://www.researchgate.net/publication/236622225_Four_Years_Later_Charging_Vulnerable_Migrants_for_NHS_Primary_Medical_Services_Students_and_junior_doctors_reveal_the_findings_of_an_unpublished_Department_of_Health_consultation. (Last accessed 24th September 2013).

decade earlier, problems of migrants' access to doctors was evident. Some GPs voiced views, some of which can be interpreted as prejudicial, in a recent survey about migrants' access to healthcare conducted by an online magazine for GPs called Pulse 2013⁵. The issue of unequal access for particular groups of migrants has been taken seriously enough that the British Medical Association now offers guidance for asylum seekers (British Medical Association, 2012).

Even while migrants are experiencing practical difficulties in accessing services, they are also sometimes referred to as 'health tourists' within popular discourses (Footnote 6 links to the high profile organisation 'Migration Watch' website⁶). Hanefield and colleagues (2013) reviewed the term 'health tourist', explaining that the original definition was a reference to overseas visitors making trips to other countries *primarily* for healthcare and paying for it – that is,

⁵ <http://www.pulsetoday.co.uk/views/opinion/gps-must-speak-out-against-plans-to-charge-migrants/20004681.article?sm=20004681#.Umd6n3BJOAg>. (Last accessed 22nd October 2013)

⁶ Migrant Watch <http://migrationwatchuk.org/briefing-paper/5.11> (Last accessed 24th September 2013).

as *private* healthcare patients⁷. Instead it has become a derogatory term, implying that people are coming from other countries to the UK to use the National Health Service which is a healthcare system that operates by offering universal access to UK residents. A policy for checking and charging any overseas visitors who might use secondary healthcare (which refers to specialist NHS healthcare and currently incurs no charge for UK residents) has been put in place. The policy has been developed in response to the idea that health tourists are coming to the UK primarily to use the NHS rather than private health care. Such claims of health tourism were challenged on Thursday 12th April 2012 in a letter from a group of migrant rights organisations and academics in *The Independent* newspaper⁸. The issue continues to be debated.

Since 2004, the UK government has been making changes to the health policy referred to above called the Overseas Visitors Healthcare Charging Regulations

⁷ For example, the counter argument to health tourism emerged when research was published that showed medical tourism contributes to the UK economy. <http://www.theguardian.com/society/2013/oct/24/medical-tourism-generates-millions-nhs-health> and in the article

HANEFELD, J., HORSFALL, D., LUNT, N., SMITH, R. 2013. Medical Tourism: A cost or benefit to the NHS? *Public Library of Science One*, 8 e70406.

⁸ Letter in *The Independent* newspaper on Thursday 12th April 2012 was found at: <http://www.independent.co.uk/voices/letters/migrants-are-not-health-tourists-7640155.html>. (Last accessed 24th September 2013).

(OVHCR), which restricts the entitlement of overseas visitors to free secondary healthcare in the UK (Department of Health 2004 revised 2007). During the course of this research there have been two policy reviews and two consultations - the last one closed on 28th August 2013 (Department of Health, 2013) – which have led to the proposal that processes for identifying overseas visitors trying to access services should be more thorough and, when identified, unsuccessful asylum seekers and undocumented migrants should be refused healthcare. In implementing the OVHCR, migrant status would need to be ascertained before secondary healthcare is given. In 2013 further reviews of the OVHCR proposed that a mandatory health levy should be charged to non-EU migrants and visitors. The government's consultation processes have highlighted an uncertain and often contentious use of categorisations of migrants and the erosion of the health professionals' rights and responsibilities to be primarily concerned with patients and not with cost. The next section of this chapter examines the notion of migrant as a categorisation and tries to highlight the limitations of this label. At the same time it will draw attention to some recent statistics pertinent to migration in the UK, in order to provide additional context and to further elucidate local government and health service providers' interest in the subject.

Conceptualisations of the migrant category

The terms 'migrant', 'ethnic minority', 'foreigner', 'foreign-born', and 'immigrant' are used interchangeably and often clarity in their use is lacking. In this section these conceptual difficulties are highlighted. Later some of the useful aspects of statistical data which can provide a picture of migration in the UK are reproduced, the data also illustrates the point that migrants are not a homogenous group and that sub-grouping, along the lines of immigration status or residency, is often required.

Ethnicity is a concept that is frequently used alongside the migrant category. In some health research, the terms 'ethnicity' and 'migrants' are used as discrete categorisations. However, it has been suggested that the category of migrant, like ethnicity, should be approached as a subjective concept (Bradby 2003, Ahmad and Bradby 2007). I argue, then, that ethnicity, at its most useful, would be a self-reported category and at its least useful would be devised as a fixed and closed category where multiple affiliations to different groupings are not permitted. Consequently, disregarding the problematic of these categories, the reality is confusion where policy and popular discourses are concerned; the categories of 'ethnicity' interchange with 'migrants' as well as with other categorisations such as place of birth or nationality do not take note of the conceptual and methodological differences embedded within these terms or categories. Meanwhile governments require data and include ethnicity or other

categorisations as they see fit and on the whole these uses are not debated.

Methodologically, however, the limitations of the category of ethnicity, for example, can cause considerable confusion – to name one problem, Black British or mixed heritage British people are considered within government statistics, for example, to be ‘ethnic minorities’. Furthermore, with regard to migration, sources of data reflect different kinds of migration and can be interpreted and used in misleading ways. The definitional problems highlighted here are addressed by a newly established think tank, the UK Migration Observatory 2013 (see Footnote 9 for link to this discussion⁹).

UK statistical methodologies for migration used by the Office of National Statistics (ONS) have attempted to use two variables: nationality and length of stay (International Labour Organisation 2004:9). The term ‘Long term International Migrants’ (LTIM) was established by the United Nations Population Division to refer to international migrants who intend to reside in a destination country for more than 12 months. The definitions can be found in the

9 The Migration Observatory, 2013, Who counts as a migrant? - Definitions and their

Consequences can be found at:
<http://www.migrationobservatory.ox.ac.uk/briefings/who-counts-migrant-definitions-and-their-consequences>. (Last accessed 24th September 2013)

methodological reports produced by the Office of National Statistics¹⁰ (2010).

People staying for less than 12 months are referred to as 'visitors'.

The three-pronged conceptualisation of an international migrant used by the ONS in 2010 is summarised below, with comments on some of the limitations:

- A person who was born outside the UK, and therefore has migrated to the UK at some point in the past; while some of these people born abroad will have migrated recently, others will have lived in the UK for many years. Moreover, some people born abroad will be UK citizens, either because their parents were UK citizens overseas at the time of their birth, or because they have been granted UK citizenship since arriving.
- A person who holds a non-UK passport (taken to indicate a non-UK national); while some non-UK nationals will have migrated to the UK recently, others will have lived in the UK for many years.
- A person who was usually resident outside the UK one year prior to recent census day, indicating that they have migrated to the UK in the last year up to 27 March 2011: This definition excludes any international migrants who arrived

¹⁰ <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Long-term+Migrants#tab-sum-pub>. This link enters the ONS website and the document dated 25-Feb-2010 called Long-Term International Migration Estimates Methodology Document 1991 onwards. (Last accessed 24th September 2013).

in the UK prior to 28 March 2010 and will include some people who are UK-born or UK nationals (Office of National Statistics 2010).

The UK government uses a variety of surveys to collect statistics on migration. For example, the International Passenger Survey (IPS) asks a sample of arriving *foreign nationals* about the length of time they intend to stay in the country. The limits to the IPS methodology and data were summarised by BBC reporter in 2012 (see Footnote 10 which provides the web link to this article pointing out numerous problems in the IPS data ranging from sampling techniques to the absence of emigration figures of British nationals ¹¹). Wheeler concluded that accuracy of the IPS figures could only be within +/-35,000 people and therefore more work was needed to improve this data.

National Insurance registration numbers (NINOs) are one more tool for counting migrants. Used by the ONS, it aggregates figures of the registration numbers given to newly working people or people intending to get work and who would be eligible for paying tax. NINOs, for example, are given to migrant workers, young British nationals just reaching working age, and returning emigrants. The NINOs of non-UK passport holders is a way of counting new workers in the country. Clearly, further disaggregation of the NINO figure is necessary to avoid

11 BBC News Politics, 15th October 2012: Wheeler, Brian, 2010. <http://www.bbc.co.uk/news/uk-politics-19646459>. (Last accessed 24th September 2013).

misrepresentation. To develop this new approach it would be important to distinguish between migrant workers, UK nationals, part-time workers and foreign nationals who are studying. The aggregated NINo figures have often been strikingly higher than the IPS figures, which has fuelled misunderstanding over which migration figures represent 'real' migration. The Labour Force Survey (LFS) has also been employed and it makes use of an Annual Population Survey. Finally, the decennial National Census data (conducted in 2011) is considered an important source of national and local migration statistics. The first analysis of the census related to migration was released in December 2012 (See the ONS webpage¹²).

Checking on the types of visas issued for entry to the UK is one other way in which distinctions can be made when monitoring migrants. The skills of migrants are used to categorise non-European Union migrants into 'highly skilled', 'skilled', 'unskilled' and 'student' groups, and visas are issued accordingly, which can then be tracked. These numbers fluctuate considerably and change as public policy changes. Visa types, including visas for those fleeing conflict and persecution (in the case of refugees and asylum seekers) further highlight the multiple reasons migrants come to live in the UK. Illegal

12 At the Office of National Statistics release of National Census Data - go to 'view all tables' or: <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Long-term+Migrants#tab-data-tables>. (Last accessed 24th September 2013).

and undocumented migrants are yet another category (Kelly and Sriskandarajah 2005, Kofman et al.2009, Cavanagh and Glennie 2012).

One simple but potent trend statistical data can illuminate is that there was an increase in foreign nationals coming to the UK and intending to stay for more than 12 months between 2004 and 2007 (Office of National Statistics, 2008). A subsequent drop in the rate of migration occurred after the financial crash at the end of 2008 which led to a downturn in economic growth. The ONS report on net international migration to the UK stated the figure for net migration was 215,000 in 2011(see Footnote 12 for the link to ONS table 'LTIM Components and Adjustments 1991-2011'¹³). This data indicates that despite some slowing down of overall migration there has been a steady stream of international migration.

To understand more about recent migration to the UK the 2011 national census provides a valuable source of data. At the beginning of this research, in September 2009, the 2001 census data was seen to have reached the end of its usefulness, particularly in terms of understanding the population figures

¹³ See table on this page called 'LTIM Components and Adjustments 1991-2011' at: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-280889>. (Last accessed 24th September 2013).

about migration in the UK. During the period of analysis and writing up of this research, the 2011 census was conducted and some findings released. This census included most of the questions from the 2001 census (with some variations). Pertinent to this research on migration were the variables of ethnicity, country of birth, length of residency in the UK, passport(s) held and a question on national identity which can be found on the ONS webpage for the Census User Guide¹⁴. However, like the ongoing ONS variables, the national census variables also have limitations. For example, how can variables be equated with one another? How does length of residency or nationality relate to migrant status, and when do migrants stop being migrants? Despite such questions and criticisms of both the census and academic data about migrants, this thesis explores a particular migrant category in an attempt to increase understanding of contemporary societal changes. The following sections summarise some of the national and local census data in order to provide relevant background to this study and to reiterate the importance of recent migrants as a category for the city of Brighton and Hove. The statistics highlight that recent migrants are mixed in terms of ethnicity and residency including giving information about the arrival of foreign nationals to the area over the last ten years.

14 The Census User guide was found at: <http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/2011-census-user-guide/index.html>. (Last accessed 24th September 2013).

Unpacking ‘facts’ about migrants in the UK

Despite some of the limitations of the tools and the data highlighted above, some of the data from the national census merits a critical review (below). The ONS website links to the relevant data tables for each category that may be of interest. The following sections draw attention to key variables that are used to help build an understanding of migration in the national context of England and Wales and then for the local context of Brighton and Hove. Particular attention is paid to four categories: country of birth, residency, ethnicity, and passport ownership as these cumulatively represent key dimensions of migration.

Country of birth

The data generated by local government authorities gives up-to-date statistics for numbers of people who were ‘usual residents’ of England and Wales in 2011 by their country of birth. The Office of National Statistics (ONS) summary report states: 13 per cent (7.5 million) of usual residents of England and Wales were born outside of the UK; in 2001 this was 9 per cent (4.6 million) (See footnote for link to ONS webpage and data¹⁵). Nationally, there has been a change between 2001 and 2011 in the profile of people with a country of birth that was not the UK (that is, foreign-born people) who are living in England and Wales.

¹⁵ ONS key statistics page: <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/index.html>. (Last accessed 24th September 2013).

These data show that there has been a substantial increase of Europeans and most significantly of people from Poland.

Residency

Data on residency are new data not previously collected in the national census and are obtained by asking about the 'date of stay' and 'length of residency' of respondents. Through this data information can be gathered that describes, for example, that in 2011, 6.62 percent of the England and Wales population (totalling 56.1 million people) had been living in England and Wales for less than ten years and 3.8 percent for less than five years. The ONS has concluded from this that 'nationally the resident population of England and Wales has increased by 3.7 million (7 percent) in ten years, with 55 percent (2.1 million) of this increase being due to migration' (see Footnote 14 for the link to data). The indicator used for this statistic was 'date of last arrival' derived from the census question which asked, 'If you were not born in the United Kingdom, when did you most recently arrive to live here?' and it asked respondents *not* to count short stays away from the UK. Clearly this question was open to interpretation and it was unlikely that all respondents applied the same definition of a short stay. Therefore the year of last arrival may not necessarily reflect exactly when respondents became UK residents. Another point to note is the conclusion made by the government that the change in population is due to

migration will include some of the new residents who are returning foreign-born but are also British people.¹⁶

Ethnicity

In the ONS survey in 2011 the number of people who identified themselves as ethnically 'White British' in England and Wales accounted for 80.5% of the total population of 56.1 million (See ONS webpage¹⁷). Those that saw themselves as White-but-not-British accounted for 6 percent; this figure corresponds with country of birth data, showing that the majority of the White-but-not-British group came from European Union nations. Those who classified themselves as not-White (including those who saw themselves as having a 'Mixed' ethnicity) amounted to 14 percent of the England and Wales population. Three ethnicity categories were added in 2011: 'Asian other', 'Gypsy and Traveller' and 'Arab', with 'Chinese' repositioned to the Asian group. Comparability of the Asian group will be possible with care, and changes in the mixed ethnicity figures will be in part due to people choosing the Arab or Asian other groupings (See the

¹⁶ Go to webpage showing the Census prospectus:

<http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/2011-census-prospectus/index.html>.

(Last accessed 24th September 2013).

¹⁷ Go to webpage showing the Census release of 11th December 2012 at <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-ethnicity.html>.

(Last accessed 24th September 2013).

ONS webpage¹⁸). Space was available for people to express ethnicity as 'Any Other'. These figures suggest there has been an increase in ethnic diversity in general which has occurred in the White-but-not British group and notably the mixed ethnicity group.

Passport ownership

The question on passport ownership was asked in the 2011 census for the first time. In the past, the ONS international migration methodology has used the terms 'passport held', 'nationality' and 'citizenship' 'interchangeably' to gather a similar kind of data profile (as for Footnote 16). Of course, some people hold more than one passport and change passports; the concept of citizenship is subjective and cannot be defined by passport ownership alone. Taking these issues into account, the figures were as follows: of those who were usually resident in England and Wales (56.1 million), about 9 percent (4.8 million) had non-UK passports. Of that 4.8 million, 2.3 million were from the European Union and 2.5 million from outside the European Union (See ONS webpage¹⁹). Furthermore, of those without UK passports, the ONS found that 2 million

¹⁸ As for Footnote 9, the Document called 'Long-Term International Migration Estimates Methodology Document 1991 onwards: See Page 13. (Last accessed 24th September 2013).

¹⁹ ONS webpage <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/index.html> and look at Table KS205EW. (Last accessed 24th September 2013).

people from this group usually resided in London. This trend was supported by country of birth data and therefore suggests that it is European Union passport holders who could constitute significant numbers of the recent migrant population.

The Brighton and Hove context

In 2001 the Brighton and Hove resident population was 247,817 and ten years later in 2011 it was 273,369 (ONS webpage²⁰); this amounted to a 9.35 percent increase, which poses a significant challenge for local government planning. Appreciating the number of people who might be recent migrants is useful for understanding this group's importance in relation to service provision. The following sections outline some of the local census data that has been released so far and which is of relevance to this study; it shows that the increase in population in Brighton and Hove is mixed when seen in terms of country of birth and length of residency, with the largest group of new migrants to the city likely to be from the European Union.

²⁰ ONS webpage: <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/index.html>. See Table KS101EW or the webpage Brighton and Hove Local Information Services: <http://www.bhlis.org/dataviews/view?viewId=518>. See the metadata table Brighton and Hove. (Both last accessed 24th September 2013).

Country of birth: Brighton and Hove

In the 2001 census, 11 percent of the Brighton and Hove population had been born outside the UK. In 2011 this had risen to 15.7 percent or 42,918 people. This percentage was in line with figures for the whole of England and Wales (see Footnote 20).

Length of residency: Brighton and Hove

Residency data was collected for the first time in Brighton and Hove, pointing to the fact that 8.4 percent of the 2011 population of 273,369 had arrived in the last ten years and 5.43 percent in the last five years. These figures were proportionately higher than the national England and Wales figures. This local figure goes beyond the national trend of increases in recent migration to show that in Brighton and Hove there has been a substantial increase in residency by recent foreign nationals. Between 2006 and 2011 the number of arrivals of new migrants to Brighton and Hove was higher than it had been between 2001 and 2006. However, this data should be interpreted with some caution because although the question about residency was asked only to foreign nationals and is seen as an accurate estimate of international migrants, it does include the number of international migrants who have moved to Brighton and Hove from other UK cities (that is, internal international migrants). However, based on data up to 2011, it is clear that Brighton and Hove has seen a large growth of international migrants who have come to the UK in the last ten years.

Passport ownership: Brighton and Hove

ONS statistics for Brighton and Hove show that there are 27,060 non-UK passport holders, forming 10 percent of the total population. Of this group it is significant that half (5.3 percent) of this total population had European Union passports. These figures therefore strongly suggest that a large proportion of the 'Black and minority ethnic' (BME) grouping (discussed in more detail below) within the census data are likely to be holders of European passports. In other words, the low number of non-UK passport holders combined with the ethnicity figures below clearly show that a large proportion of the not white population in the area hold British passports.

Ethnicity Statistics: Brighton and Hove

The largest ethnic group in Brighton and Hove in 2011 was those defined as 'White British' but as an overall percentage of the total population this number has fallen. Brighton and Hove council has defined the term 'Black and minority ethnic' (BME) to include *all non-British* white and *British and non-British* ethnic groups not white or 'of colour'. In 2011 this broad ethnic grouping was 19.5 percent, which was an increase from 12 percent in 2001. In 2011 in Brighton and Hove, BME was more narrowly defined as those *not* white, and according to this measurement 10.9 percent of the population fit this description. These differences in definitions where BME can include or exclude white ethnic minorities mean that comparisons with past data should be made with care. In 2001, 5.8 percent of the total Brighton and Hove (247,814) population

categorised themselves as 'White Other' (See Footnote 18 for a link to the ONS website). In the 2011 census, there had been an increase in the number identifying with the 'White Other' group to 7.1 percent of the 273,369 population. The White Other group has increased and now comprises more than a third of the broadly defined Black and Minority Ethnic grouping (See Footnote 21 for webpage link to Brighton and Hove local information service²¹). The White Other ethnicity category most closely reflects the ethnicity designation selected by European migrants and therefore shows an increase in the number of white Europeans and is one of the larger 'ethnic' groups.

There are other points to note about ethnicity. The latest figure of 19.5 percent (53,351) of the total population includes all those who used the new 'Arab' ethnicity category, but in the previous census this group of residents had selected a range of ethnic categories including 'White'. When, in 2011, people were offered the new 'Arab' category they may have simply switched categories. In 2011 the Arab grouping was selected by 0.8 percent of the total Brighton and Hove population (that is, 2,186 people). In Brighton and Hove the people who described themselves as ethnically 'mixed' (one white and one other ethnic parent) has increased greatly to become the highest non-White

²¹ See webpage called Brighton and Hove local information services: <http://www.bhlis.org/profiles/profile?profileId=289&geoTypeId=> (Last accessed 24th September 2013).

ethnic group at 3.8 percent (10,408) of the total 273,369 population. This mixed group is seen as an ethnic minority, raising the question of how ethnicity is formulated and possibly preventing people from expressing ethnicity in the way they would prefer. Footnote 22 provides the link to the ONS webpage²² presenting all of ethnicity data.

Other aspects of the Brighton and Hove context

The participants of this study were all recent residents of Brighton and Hove.

The economy of the city relies on several industries, with two local reports emphasising its strong “creative and knowledge-based industry” (Brighton and Hove Council 2008:2, Oxford Consultants for Social Inclusion 2007a:75).

Brighton is also a university city and as a coastal city in proximity to London, it benefits from regional tourism. In 2007 it was estimated that 43,000 full-time and part-time students were living in the city (See higher education statistics on webpage²³). A local report estimated that about 7,000 students graduated each year and many stayed on in the city after their studies were completed (Oxford

²² ONS webpage: <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-ethnicity.html> See Table KS201EW (Last accessed 24th September 2013).

²³ Higher education statistics at: http://en.wikipedia.org/wiki/List_of_universities_in_the_United_Kingdom_by_enrollment. This page was last modified on 11 September 2013 at 18:24 and was last accessed 24th September 2013.

Consultants for Social Exclusion Ltd 2007a:16). Brighton and Hove appears to be an attractive place to study and live, particularly as London is a feasible destination for work. Local reports have suggested that Brighton has a higher than average working age population (Brighton and Hove Primary Care Trust 2009). Once the ONS releases more of the 2011 census data with data on employment and occupations, these data can be cross-tabulated with ethnicity and hopefully other migration related variables, to offer even more insight into the composition of the migrant population in Brighton and Hove.

A high degree of variation in self-defined sexual orientation is likely to be a unique aspect of Brighton and Hove; local reports have estimated 1 in 6 people in Brighton and Hove would identify as lesbian, gay, bisexual or transgender (LGBT) (Brighton and Hove Primary Care Trust, 2009), though the original source of this statistic is in some dispute. In time, the 2011 census will provide some new local data on civil marriages, household structures and residency which could give greater insight into the sexual orientation figures for Brighton and Hove and may be relevant to the migrant health picture in this area.

In a past local report on deprivation, it was suggested that “migrants are young, in poorer housing and not likely to require healthcare except for alcohol-related problems” (Oxford Consultants for Social Exclusion 2007a:15/48). My own data suggests that this underestimates the healthcare needs of migrants to this area.

In the Oxford Consultants report, only small pockets of deprivation were recorded and these were dispersed *throughout* the city. Local plans concerned with improving health raised concerns about the possible effect of migration on services (Brighton and Hove Primary Care Trust, 2009) but found no sources of quantitative or qualitative data to help identify these concerns. It is now known that a high proportion of foreign born, non-UK passport holders, recently arrived from Europe to live in London (this was shown in the 2011 census when figures were disaggregated and chosen). This also seems to have happened in Brighton and Hove (ONS webpage²⁴). This study aims to shed light on illness experiences and healthcare use of recent low-income migrants who have been shown through census data to consist mainly of European nationals and secondarily a diverse mix of other national groups in Brighton and Hove. Recent migrants are likely to be in low income occupations that form a significant part of the Brighton and Hove economy.

Structure of the thesis

This research was funded by the Economic and Social Research Council of the UK in collaboration with the Brighton and Hove City Council and the then Primary Care Trust (subsequently NHS Brighton). The focus on recent low-

²⁴ ONS webpage link to tables: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-286262>. (Last accessed 24th September 2013).

income international migrants in Brighton and Hove was a new population of interest, and in addition to what was already known about in 2009, the 2011 census data statistics presented in this chapter reaffirmed the need for a more nuanced case study of illness and healthcare among this population group. The approach taken was a purposeful selection of recent migrants, diverse in terms of ethnicity, immigration status, country of birth, nationality, age, gender, educational status, language abilities, and family structures. A focus on low income was pertinent to a study of recent migrants from Brighton and Hove because the service industry that dominates the economy provides work for a large proportion of low waged people in this group. Recent migrants were defined as those who had been resident in the UK between one and six full years, and were currently resident in Brighton and Hove. Finally, all participants had to have experienced health problems at the time of their involvement in the study and/or in the last two years; those who could discuss the health problems of a dependent in detail were also included. The methods used were: a short questionnaire was completed by 46 participants, followed by semi-structured interviews with the aim of collecting narratives. These methods will be outlined fully in Chapters Three and Four. Income was assessed by using a methodology that takes account of household size and calculates an individual

income, which for 'low income' must fall below £402.50 per week in 2011/2012²⁵. These calculations can be found in the government's WebPages and are also summarised in Appendix 1.

The aim of this thesis is to deepen an understanding of illness and healthcare experiences of recent low-income international migrants. The key question that has been asked is this: how does being a recent low-income international migrant affect illness experience and healthcare use?

Four dimensions of this question are examined:

Socioeconomic status and illness: How do social and economic aspects of recent migrants' lives affect their health and how were these aspects important? For example, how did the poverty of recent migrants affect the social patterning of illness?

²⁵ Calculation for low income household was found at:

<https://www.gov.uk/government/organisations/department-for-work-pensions/series/households-below-average-income-hbai--2>.) The report: Households below average income (HBAI): 1994/95 to 2010/11 can be downloaded it has a section on methodology. (Last accessed 24th September 2013). Appendix 1 also summarises the approach taken in this study.

Illness narratives: what kinds of illness narratives did this group of recent migrants have to share?

Patient experiences: what kinds of patient experiences did this group of recent low-income migrants describe?

Were some of the experiences of recent low-income migrants perceived as being related to inequity or discrimination?

In exploring these questions, the thesis is structured as follows: the literature reviewed in Chapter Two shows that there are multiple factors affecting health among migrants (Feldmann et al.2007, Ortega-Alcazar and Dyck 2011) and the relevance of these studies to migrants' experiences is considered. For instance, some of the literature points to the impact of racism on illness among migrants and has become a theme that informs this study and led to an exploration of the concept of discrimination. Another factor identified as important in the literature was the role that language proficiency plays within migrants' experience.

Overall, the literature review suggests migration as a factor in illness experience and urges that nuanced migrant categories could be useful for exploring illness and healthcare use. Therefore differences between migrants emerge; the literature reviewed draws attention to particular immigration statuses, economic status and temporality to show that some groups face more difficulties than others. Similarly, the literature on the use of health services and problems in

access also stimulated this research focus on illness experience and healthcare use.

In Chapter Three, the literature that has directed the theoretical methodology for the research is presented. The merits of adopting a qualitative epistemological position are presented and these theoretical points are used to justify the interest in lived experiences when studying migrant illness and experiences of healthcare. The concepts of lived experiences, illness narratives, patient satisfaction, and patient experience including access issues are reviewed as they are closely aligned to illness experience. The theory of stigmatisation and discrimination is also presented in this chapter as an important concept for enabling an exploration of social factors that may affect the experiences of recent low-income international migrants.

Chapter Four maps out the research design and methods used in more detail. The final sample comprises 46 migrants who had lived predominantly in the Brighton and Hove area since migrating. Particular challenges that arose during the research, ethical issues, and a reflexive account, as well as challenges related to recruitment and interviewing, are also discussed. The thematic coding, analytical methods are summarised and the characteristics of the final sample are explained.

Chapter Five provides the first analysis of the demographic information from the questionnaire which leads to an exploration of the social factors that affected the participants' experiences, such as the significance of ethnicity and immigration status as well as language and faith, which were themes that were commented on by a large number of participants. Other factors such as gender, education, age, and poverty were also highlighted as relevant and indeed revealing aspects of the interviews. The diversity in illness types is presented, in particular the tendency of the majority of the participants to have chronic illnesses.

Chapter Six presents the thematic analysis of the interviews, drawing on illness narrative concepts for the coding. These indicated that the interviews can be treated as illness narratives. The importance of chronology, diagnosis, chronicity and emotion are some of the aspects explored. Four interviews (two refugees, one migrant worker and one undocumented migrant) have been used to highlight the common thematic patterns within the interviews, while also drawing attention to important specific themes emerging from the interviews in which their recent arrival was an important factor.

Chapter Seven examines negative experiences participants have had when trying to access health care services and analyses the interviews, drawing specifically on the concept of patient experience and satisfaction, which are

synthesised into two overall themes: communication and barriers to access.

This chapter also undertakes an analysis of the questionnaire by applying Link and Phelan's concept of stigmatisation and discrimination. This analysis looks at participants' feelings and perceptions about the term "migrant" and also links these personal lived experiences with negative discourses circulating in the wider world. In Chapter Eight the final analysis of this thesis examines the experiences as perceived discrimination which was related to immigration status, ethnicity, faith, and to healthcare practices including poor communication and access. Possible links to the structural or indirect discrimination are raised.

The final chapter draws together the lessons that have been learned through this qualitative study of 46 recent low-income international migrants - most of whom had self-reported as seriously ill and who had experiences of using various health services in Brighton and Hove. The way forward for further research in this area is then presented. This should encompass continued research into these complex issues using the illness narratives of recent migrants of a range of immigration statuses to identify the social and institutional processes that seem to be having the greatest impacts on particular migrant groups and further research that could explore the effect of health policy on migrant health.

Chapter Two: Health Inequality among Migrants – A literature review

Literature which examines variations and inequalities in health and illhealth, between and within groups of individuals, provides the backdrop to this chapter. A second conceptual link reviewed is stigmatisation and discrimination as relevant to recent low-income migrants. Health research is concerned with health from many different angles: the individual, groups and structures, to name some of the perspectives taken. Moreover, a range of epistemological and methodological approaches are taken when investigating health and illness. This thesis is grounded in the concept of the individual, 'lived' experiences and lay health knowledge which are often aligned with qualitative methods. These concepts are reviewed in Chapter Three.

To summarise, this chapter takes the approach of explaining how the term health, health inequality, stigmatisation and discrimination are understood. This is followed by a review of literature relevant to ill migrant healthcare users. Then Chapter Three reviews approaches that inform the epistemology of the thesis which are pertinent to notions of illness experiences and healthcare use.

The conceptualisation of health (both biomedical and lay) puts the absence of disease as central (Dowler and Spencer 2007). Moreover, biomedical and lay concepts overlap with each other; it is argued there are few remaining groups of

people who retain beliefs *not* influenced by the western hegemonic biomedical model (Williams and Calnan 1996:17 in Bury 2005:7). Lay conceptualisations view good health as an inherent part of a person's everyday way of life and lived experience, making it an almost taken-for-granted state (Herzlich, 1973). Blaxter argued that health was ontologically positive, (encompassing fitness and wellbeing (Blaxter, 1990). Both lay and medical concepts of health also show concern with moral norms, and some illnesses are seen as a departure from a given healthy norm and as undesirable for moral and/or social reasons. These moral meanings and judgements are reflected in attitudes towards chronic illness, disability, mental health and HIV (Ezzy 2000, Squire 2010).

Health can therefore be viewed as an 'attribute' - a bounded and individualised concept confined to a biological body, and a 'relational' concept in which, for example, social and environmental relationships are seen to alter health. Social conditions affect how health is perceived. Blaxter highlighted age as an important factor affecting the understanding of health among young people, arguing they were more focused on the functional dimension of health (Blaxter 1990). Sen identified education and cultural frameworks as affecting views of health, arguing that educated people in the USA report poor health while Indians (as a whole) self-report better health. Sen interpreted these differences as emerging from differing belief systems and expectations about health and reflective of differing socio-cultural understandings (Sen, 2002).

Whether health is seen as attribute or relation, healthcare practices will vary and this will also have an effect on health. Zola (1973) argued that fixing on either kind of definition is problematic. A dialectical approach is necessary and must have a social dimension, but this is not to underplay the physical, mental or embodied aspects of health. This multi-dimensional perspective has illuminated this research and led to a methodology which sheds light on the social context and social factors that impact on illness. For example, the relational conceptualisation of mental health work has gained recognition, with social aspects acknowledged largely because service users have challenged the biomedical approach. The tendency by doctors to medicalise troublesome behaviour as a part of asserting control and power over patients has also been challenged (Foucault, 2000, Gutting, 2005, Turner, 1995).

In summary, health is conceptualised as complex and dynamic, varying between people, places and time periods, and changing over the life course. It encompasses biological, social, economic, environmental and political dimensions. As Bury summarises:

Health can be seen as having a multifaceted dimension of human life, and as a 'reserve stock' (Blaxter 2003) of vitality, fitness and strength (whether psychological or physical or both) which individuals can draw upon to pursue

their goals and actions. Health and illness thus “take us to a crucial intersection of biography and history” (Bury 2005:20).

The complexity of health is also defined by the World Health Organisation’s well known and much used definition: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”²⁶.

Bury reiterates a similar view: apart from health being defined by the absence of disease, other dimensions of health should be acknowledged. Further, there are multiple reasons for any one person’s view of health. Achieving and maintaining health is increasingly seen as a human right (Ruiz-Casares 2010:330) and the public in the UK have expressed high expectations in surveys²⁷. Health is, therefore, a subject of major interest when rights are questioned; this is an area that is explored in this thesis by studying migrants who could face restrictions to accessing and using health services.

Having clarified what is understood by health, the next two sections can provide a brief overview of background literature on migrant health inequality and

²⁶ <http://www.who.int/about/definition/en/print.html> (last accessed 21st October 2013)

²⁷ As discussed in the British Social attitudes survey, Chapter on Health in 2012:83 expectations about the NHS and healthcare remain high. (Last accessed 25th September 2013).

discrimination. Both these subjects were considered pertinent to a new study of recent migrants and informed the thesis.

Health inequality

Investigations concerned with inequality try to make sense of differences and disparities both by mapping patterns and looking at effects of a range of conditions or factors on different groups. The principle of health inequality was studied by the UK government (Department of Health 1997, Acheson 1998b, Department of Health, 2009b) as an attempt at reversing the previous government's resistance and to address emerging differences. Despite the embrace of the language of equality by the then new UK government, health inequality is thought to have increased (Wilkinson and Pickett 2009).

In 2010 the first two of the seven principles in the NHS Constitution recognised and addressed health inequalities by acknowledging prejudice based on certain structuring factors which hindered the aim of equal treatment and outlined a health service that should be 'available to all' (Department of Health, 2010a, Department of Health, 2012b). This acknowledgement highlights factors often linked with discrimination:

The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, or belief. It

has a duty to each and every individual that it serves and must respect their human rights ... Access to NHS services is based on clinical need, not on an individual's ability to pay. NHS services are free of charge except in limited circumstances sanctioned by parliament (Department of Health 2010:3).

The principles of equality resonate in other UK health policy including those concerned with lay or patient experience. Some reference to what is considered important in respect to the concept of patient experience (waiting times, the right to make choices about care and a right to information) is made in the NHS constitution (Department of Health 2010:7).

Health inequality is considered a context for this thesis and underscores interest in social and economic aspects of inequality (Wilkinson and Pickett 2009:27). Subramanian and colleagues (2004) considered the relationship between income and health. This complex relationship suggests a link between occupations (and therefore incomes) and morbidity among workers. Marmot and colleagues (1984a) in the Whitehall study referred to 'contextual' and 'confounding' factors between occupation and morbidity between immigrants and others. A lifelong interest from Marmot led to a strategic review of health inequalities in which the link between social inequality and health was substantiated (Marmot, 2010).

Health inequality research uses comparative methods to study countries or groups of people. For example Wilkinson and Pickett's study was also carried out between nations and between different states of the United States of America to show that the pattern *between* countries had not arisen 'spuriously or by chance' and that it also occurred between states within a federal nation (Wilkinson and Pickett 2009:19). They used a mix of indicators they called 'adequate' indicators of health and social wellbeing such as mental illness, obesity, educational performance, birth rates among teenagers, homicides, imprisonment rates, trust and social mobility, combining them into an index of 'Health and Social Problems'. The UNDP's health inequalities index points to a similar trend in the connection between social inequality and illhealth.

Mortality and morbidity are common indicators of health inequality between groups of people with particular foci of interest; such aspects that represent particular social dimensions of health. In the UK the now classic work on health inequality is the Black report (Townsend et al.1997), which argued that socioeconomic inequality was a form of 'health selection' (Annandale 1998:114). The argument has since developed and become a multifactorial hypothesis in which psycho-cultural factors such as behavioural and lifestyle choices have been considered important, and structural aspects are downplayed (Dowler and Spencer 2007). In the next section the notion of discrimination is discussed as another relevant context for understanding difference.

Stigmatisation and discrimination

Literature on stigmatisation, like that which focuses on health inequality, is relevant to a study of recent low-income migrants. Stigma and discrimination are interrelated. Both concepts draw on Erving Goffman's seminal work (Goffman 1963, Gabe and Monaghan 2013), in which stigma was defined as taking place when a person or a group of persons collectively attributed *false* characteristics or negative categorisations of others and acted on these beliefs doing harm (intentionally and unintentionally) to people with those characteristics. Those who stigmatise must also hold false beliefs about themselves and their own status (ibid1963). Goffman was concerned with formation of a 'discredited' or 'discreditable' person, particularly focusing on everyday life as the setting. He referred to three types of stigma. First, physical stigma occurs when visible aspects of people become unacceptable, or are seen as inferior by others; second, when characteristics that were not visible are treated similarly to those which are visible, and considered unacceptable (these characteristics are behaviours and/or actions); third, when stigma is perpetuated through generations, and come to be seen as rational, national and/or ethnic characteristics. Rogers and Pilgrim have summarised the characteristics of stigmatised people as those who have had negative judgments made by others about their intelligibility, competence, and

sometimes aggressiveness: these should be seen as cultural constructs rather than facts (Rogers and Pilgrim 2010:33).

The concept of stigma is therefore grounded in the presentation of an integral self; stigma occurs when that self or identity is spoiled. Identity of course should be regarded as unfixed, in that there are no set roles of 'normal' and 'stigmatised'. Instead, there can be movement between these concepts.

Stigma can be seen as a perspective and a generalised phenomenon.

Goffman's concept also pointed out that stigma was internalised, existing in the behaviour of both the 'discredited' and 'discreditable' – those who were yet to be stigmatised but who anticipated a problem.

Goffman's conceptualisation of stigma gained ground with the related sociological notions of deviance and negative labelling (Scheff 1966). Later critiques of the concept (Gove 1982) found that labelling theory was too quick to put forward a negative perspective and that the effects of labelling were being overstated, thus arguing for sticking with biological arguments and scientific proof for causation. The argument was that whilst positive stereotyping can occur the negative effects of stereotyping have got clearer. Steele and Aronson's study (1995) into the effects of stereotypes, based on intelligence tests with black and white students, is much cited. Rogers and Pilgrim also saw the value and complexity of what became known as 'modified labelling theory',

which emphasised that 'labelling is not about the unidirectional impact of the prejudicial actions of one party on another but an interaction that creates social rejection based on shared acculturated assumptions' (Rogers and Pilgrim 2010:36).

Scambler has furthered Goffman's dramaturgical perspective of stigma with regard to epilepsy (Scambler 1987). Scambler discerned that stigma has forms; it can be 'enacted' and 'felt' (Scambler 2004, Scambler 2009, Gabe and Monaghan 2013). His ideas made the distinction between acts of discreditation and the feelings evoked by it, or the prospect of discreditation. Feelings associated with stigma for the 'discredited' and 'discreditable' are understood to be felt and also 'internalised' as emotions of shame and feeling blamed (Goffman 1963:57). Internalisation was seen as acceptance of stigma, and it can occur in both the stigmatised and non-stigmatised (who become more likely to enact prejudice) (Scambler 2009).

Other studies have examined stigma using particular methodological approaches. Perceived stigma and/or discrimination acknowledge the subjectivity of self-reports. Health research has focused on the effect of stigma, prejudice and discrimination, using a range of methods (Stuber and Meyer 2008, Scambler 2009:447). Others have investigated the possible importance of the difference between enacted, felt and internalised stigma by analysing interviews

and statements (Steward et al.2008) finding all three types of stigma present among HIV-positive people in India and impacting on their mental health. Recognition of the context in social interactions and emotions is important (Scambler 2009).

The concept of stigmatisation 'has translated readily into sociological studies of the meaning and experience of illness both mental and physical' (Gabe and Monaghan 2013:60). The process of stigmatisation was clearer through the study of physical transformations (at birth or later through injury or illness) that are not tolerated on aesthetic or moral grounds -- blindness, epilepsy, schizophrenia and obesity are examples of stigmatised health problems or illnesses. In the case of sexually transmitted diseases including HIV/AIDS, the morality of ill persons becomes questioned. In schizophrenia stigma is associated with what Goffman referred to invisible stigma – noticeable through behaviours. Non-specific illness, for example chronic illnesses which are associated with long-term unemployment, may lead to stigma, with the notion of an unwillingness to work rather than an incapacity to work. Link and colleagues (Link and Streuning 1997, Link and Phelan 2001) have focused on mental illness as an example of stigmatised illness and these studies have shown the link between stigma and psychological problems.

Scambler also reframed Goffman's concept of stigma, challenging colleagues in medical sociology to ask more questions about it (Scambler 2009). For instance, he argued that people experiencing stigma should seek to understand the macro-social and political processes that are at work, including where power is also exercised (ibid: 449). He also suggested that overlapping conditions of class, gender and ethnicity should be better understood when stigma is studied.

Link and Phelan have also framed discrimination as one of five interrelated components of the process of stigmatisation (Link and Phelan 2001:363): The first component involved the identification and labelling of particular individual characteristics. The term 'label' was preferred to 'category' as it made clear that it was constructed, affixed by others and its validity was questionable. Second, individual 'characteristics' become seen as negative attributes and lead to negative stereotyping and labelling. Third, the process of negative labelling becomes more widely established and a loss of status is felt. Fourth, acts were performed against those who were discredited, intentionally and unintentionally, causing harm. This component focused on action which was perceived as discrimination. Fifth, power differences and structures enabled the previously outlined practices or components to continue. These five components -- negative stereotyping, labelling, discrimination and power differences -- were seen as features of the larger negative experience of stigmatisation.

Discrimination overlaps with racism. A nuanced definition of this complex social problem is contained in the footnote below²⁸. Despite laws which support legal challenges to racialised discrimination, it persists and continues to be a sensitive and political matter, yet it receives inadequate attention (Lentin 2008). Goffman made the link between stigma and racism, which he called 'tribal' stigma and used this concept to account for people who were discredited *collectively*. Colonisation can be seen as another part of the process of tribal stigmatisation, where racist belief systems have been created and supported. Thus colonisation should be seen as a paradigm which underscores racism and racial discrimination and which persists in the present day.

Returning to Link and Phelan's framing of stigma and discrimination, another aspect of their conceptualisation is that it has already developed Scambler's challenge to us to note structure and power - and to pay more attention to studying the multiple levels at which stigma operates. Link and Phelan refer to three forms of discrimination:

²⁸ Steve Garner's work on New Racisms provides an excellent overview of the intricate concept of race and a definition of racism. He wrote: 'Racism is a multifaceted social phenomenon, with different levels and overlapping forms. It involves attitudes, actions, processes and unequal power relations and the forms of discrimination that flow from this. Racism is not confined to extreme cases, but is present in a whole continuum of social relations. Specific societies see and do 'race' differently and are organised in different ways' (Garner 2010:18).

Indirect or structural discrimination, which pays attention to institutional policies and practices that enable stigmatisation to occur and aids other forms of discrimination. This may happen without policymakers or practitioners intending or realising it. Alternatively indirect discrimination is sometimes justified by policymakers on the grounds of making savings or efficiencies (Corrigan 2004).

Direct discrimination is observed in individual experiences and accounts of being personally badly treated in various ways. This is also called personal discrimination and links with other terms discussed above, such as perceived discrimination and enacted stigma.

Modified discrimination operates at an individual level referring to the difficulty of classification and subjectivity in the concept. The stigmatised group is aware that they are being stigmatised and discriminated against and they modify their behaviour to compensate, or deny it by withdrawing from certain situations. Also, in incidents of confrontation, when individuals reacted violently to being stigmatised, it has been shown that attempts to challenge do further harm and lead to criminalisation (Dovidio et al. 2008). Other resistance, even with racialised discrimination, can be 'aversive' or implicit and not obviously displayed. Modified discrimination aligns with Goffman's idea of the discreditable and Scambler's notion of felt stigma.

To summarise then, stigma and discrimination have psycho-social elements.

They are political, historicised and therefore dynamic over time. For example,

new and better treatments of both HIV and cancer have led to some reduction in stigma associated with these diseases. Discrimination is studied using a range of methodologies. In the present research, the notion of perceived discrimination is taken up and attention is paid to the different levels at which stigma operates.

Literature on illness and healthcare use among migrants

The first two sections of this review have introduced literature on health inequality and discrimination as relevant to a study of migrants. This section reviews literature relevant to the health of recent international migrants. There is a large corpus of literature on health and illness referring to racialised categories such as ethnic minority populations; many comparative studies have also been conducted. This section will draw attention to some of this literature but then focuses on the literature that relates specifically to migrants and migration and the formulation of research questions.

Ethnicity is a widely used concept in health research and public policy. It is often a category applied to migration statistics, as discussed in Chapter One. It can be seen as a fact rather than a social construct (Ahmad and Bradby 2007). Statistics on both ethnicity and migration are used to make comparisons; in the case of ethnicity this amounts to comparisons between the majority group and

ethnic minorities. Nettleton has identified six reasons why ethnicity and 'race' can be problematic:

First, those studies which have been carried out tend to adopt a biomedical approach in their focus in that they focus on the biological and individual characteristics of different social groups. Second, there has been a tendency to focus on certain conditions, such as sickle cell anaemia, thalassemia and rickets, to the exclusion of more common health problems. Third, 'race' has in some instances come to be treated as an independent variable, which in itself is taken to be a cause of illness. Fourth, the concepts of 'race' and 'ethnicity' are treated as discrete and unproblematic concepts, and the fact that they are socially created categories often goes unacknowledged. Finally, the extent to which 'race' is an indicator of social relations which are shaped by nationalism, colonialism, imperialism and racism tends to go unexplored.' (Nettleton 2006:192).

Despite these reservations Nettleton pragmatically accepts the categories of 'ethnic minority' and uses a framework for understanding ethnic health inequality originally developed by Davey-Smith and colleagues²⁹ (Davey-Smith

²⁹ To explain health inequality among ethnic minorities Davey-Smith and colleagues used 'artefact, biology, socioeconomic difference, cultures and beliefs, racism, access and use of services, and a 'migration mode''. By migration mode, Davey-Smith et al. were referring to migration processes that

et al.2002, Nettleton 2006). The same position is taken in this thesis and Nettleton's and Davey et al.'s framework will be used to organise this review of migrant health. As ethnicity categories are used to highlight differences between ethnic minority groups and/or between an ethnic majority and ethnic minorities, this review highlights factors relevant to migrants and differences between migrants. Often sub-types of migrants (for example based on immigration status or socioeconomic status). Many studies revalidate Nettleton's theoretical point about categories being socially created; moreover, narrowing and combining migrant categories can sometimes increase understanding.

One inference from this literature review is that no single factor or explanation exists for health inequality among migrants and many factors overlap with each other. Where it is possible to generalise, it can be seen that migrants face some inequalities that affect health status and this is understood better when sub- types of migrants are studied. In the following sections five subsections based on Davey et al.'s themes structure the literature: first, literature on

could affect the health status of migrants for better or worse, for example self-selection in terms of fitness to migrate. In this hypothesis some migrants are seen as having good health status for some time after their migration; the converse is also argued about some migrants and that trauma and torture after migration, due to fleeing persecution, means such migrants have more health problems. Therefore making generalisations about migrants would be difficult because the migrant category in and of itself is not a useful research category unless it is specified or combined with other criteria.

biology, culture and racism are looked at together. Second, the aspect of income is examined, including an overview of the extensive literature that links economic status with health inequality. Place is also included in this subsection as literature on migrants and place is used in some studies as a proxy for wealth or deprivation. A third section reviews literature on language proficiency as a factor. Fourth, literature concerned with time since migration and immigration status is reviewed as it helps to illustrate reasons for health inequalities among migrants. Finally, a section on access to services is included to explore literature framed in a various ways which seeks to identify possible barriers experienced by some migrants when using health services.

Biology, culture and racism as factors affecting health inequality of migrants

Studies have shown that ethnic minorities as a whole as well as migrants as a whole, or sometimes other specific groupings of ethnic minorities or migrants, experience lower health status and more constrained access to health care (Modood et al.1997). Many studies of different groupings of ethnic minorities or immigrants have explored links with biological (and genetic differences) factors as explanations for inequality. Some studies have concentrated on mapping disparities and others have gone further, trying to explain some of the patterns seen. For example, Nazroo compared migrants with non-migrants (he defined migrants as those who had arrived in the UK after the age of 11) and found differences in health status (Nazroo, 1997:821).

Identifying biological associations in ethnic minority groupings has led to ethnicity and race being seen as strongly associated with biology. The approach linking biological characteristics to ethnic or 'race' groups often ignores the socially constructed nature of the concept of ethnicity and race - the notion that people living together are influenced by their environment and society (Bloor et al. 1987). The strength of biological explanations and related social factors can be illustrated with increased understanding of sickle cell anaemia. This illness has often been used as an example of a disease having a strong genetic and ethnic basis (Bradby 2013:87) -- studies of prevalence of the disease show patterns with particular ethnic profiles. This biological factor contributing to inequality is undisputed but at the same time is insufficient to explain the disease fully, and sickle cell anaemia is experienced differently according to the social position, psychology, gender, age, culture and income of the individual. The original focus of ethnicity-related research was on biological patterning in unusual and tropical diseases. However, interest has widened to include research into common and chronic illnesses that might occur in different ethnic groups (Modood and Nazroo 1997). In other studies complex ideas about illness, ethnicity and discrimination have been explored: Krieger measured hypertension amongst black American women (combining 'race' with nationality and gender) and investigated experiences of discrimination (Krieger, 1990). In her study of hypertension, which was seen as a proxy indicator of mental distress, perceived discrimination was measured using a questionnaire

(Krieger 1990). Such research combines biological indicators with complex social factors such as ethnicity and discrimination.

Cultural differences also provide some explanation for the illhealth of ethnic minorities and migrants. Once again Marmot and colleagues' work on immigrants to the UK found mortality patterns among 'foreign born' and 'UK-born ethnic minorities' which was seen to be due to 'social and cultural barriers' and 'cultural influences' leading to differentials in mortality (Marmot et al. 1984:1457). They concluded that immigrants were protected from damaging 'cultural practices' but *over time* their health status and mortality rates moved closer to 'English' patterns. The explanation of culture, like biology, objectifies ethnicity and race and treats them as primordial, static characteristics (Lambert and Sevak in Kelleher and Hillier 1997:122). Culture as a concept can be relative; in such a definition culture would exist everywhere, as every person (not only ethnic minorities) and all beliefs and behavioural differences are affected by culture in which the idea of a norm is problematic. Helman explains that culture is ubiquitous and that humans possess more than one culture at the same time; this is often the case for new migrants who indicate the possibilities for occupying several cultures simultaneously, in what Helman terms 'biculturalism and bilingualism' (Helman 2007:3). Helman goes on to note that it 'may be impossible to isolate 'pure' cultural beliefs and behaviour from the social and economic context in which they occur', and to over-attribute to

culture is to ignore important co-existing factors such as poverty or racism (Helman 2007:5).

Ahmad supports Helman's position and links this view of culture with inequality in health by concluding that 'structural factors and racism' should be given more consideration (W. Ahmad 1997:191 in Kelleher and Hillier 1997):

To be of value in explanatory or practical terms 'culture' needed to be recognised as a context, itself flexible and contested, interacting with, shaping and shaped by other social and structural contexts of people's lives. Cultural norms, themselves contested and changing, represent flexible guidelines within which behaviour is negotiated rather than an 'independent variable' which is solely responsible for determining behaviour. (Ahmad 1997:215 in Kelleher and Hillier 1997).

Some studies attempt to explain ethnic inequality in terms of culture or behaviours (where behaviours are regarded cultural practices in action).

Nazroo 1997 accepts this but also cautions linking culture to ethnicity and to 'racial' differences. He argues that it can be problematic for several reasons: too much emphasis on culture can underplay the importance of other social factors, lead to stereotyping of groups of people, and to seeing cultures and behaviours as fixed. One criticism of Nazroo is that he links already broad concepts of social with economic factors when these also overlap with cultural

and behavioural factors. Thus patterns of health inequality may be attributable to a range of factors: cultural, behavioural, psychological and/or social rather than associated directly with biological factors. The focus of this review is expanded to general patient experience as well as a focus on the specific experiences of ethnic minorities and migrants.

There is a large literature exploring the link between racism and health inequality. For example, Paradies reviewed 138 studies about racism, discrimination and self-reported health (Paradies 2006) and concluded that there was a link between poor health and racism seen both in self-reports of illness and those using proxy biological indicators for ill health. Paradies concluded that racism experiences were linked with mental illness in particular in ethnic minorities and immigrants. The link between racism and mental illness is accepted to the extent that the UK government ran a five-year programme on supporting mental health services to achieve race equality in mental health (Department of Health 2005). A study highlighting the association with racism and ethnicity was conducted by Abdulrahim and colleagues (2012), who studied discrimination and psychological distress among Arab-Americans (a group who considered themselves ethnically white) and concluded that both Christian and Muslim Arab-Americans felt discrimination. Their paper also argued that perceived whiteness had some effect on reducing perceptions of discrimination. Psychologists have explored the notion of perceived discrimination. Notable is Steele and Aronson (1995), who looked at what they have called confidence and self-esteem levels among black and white students by using psychological testing. They found black students' confidence and scores lowered when they knew their intelligence was being tested and their levels did drop more than those of white students. Steele and Aronson argued that their work revealed the deeply ingrained nature of inferiority associated with 'race' which was internalised.

Income and place as explanations of health inequality

Migrants obviously do not fall into one particular income bracket. However, recent migrants do tend to be overrepresented amongst lower income groups (Low Pay Commission 2013:23). At the same time the range of pay is great, but migrants as a whole enter high paid work in fewer cases. More patterns can be highlighted with regard to job status, income levels and place when other social factors for example, time since arrival, are taken into account.

Studies have shown that income inequality is related to poor health status among ethnic minorities (Modood and Nazroo 1997), stressing the link between ethnic health inequalities and 'socioeconomic' status. Modood and Nazroo's argument is that socioeconomic status to be an important dimension of health inequality, the complexity of the relationship between income and ethnicity has been made even clearer and a relationship is now accepted (Davey-Smith et al. 2002). Devi has reiterated the strong connection between income, health inequality and ethnicity in the US (Devi 2012:1043); this correlation was found without underestimating the effects of social, environmental and class differences. Farmer compared racialised groups of white and black Americans using income data spanning a 20-year period and showed that aggregated data indicated an association with socioeconomic differences (Farmer, 2005). In another study of black American women it was shown that women of different incomes (and ages) had different health statuses (Kobetza et al.2003).

Furthermore differences in income differences have been shown to partly explain particular health differences, including mental health morbidity, and this has been shown to exist between ethnic groups (Mangalore and Knapp 2012).

Other studies show that between different types of low-income migrants, health inequality exists. A qualitative study of migrant workers showed that the difficult working conditions migrants found themselves in made it hard for them to reach health services (Anderson and Rogaly 2005). Another study of migrants with precarious status (undocumented migrants in the UK) pointed out that their resource constraints were a barrier to health equality. Financial problems made it difficult for some of the undocumented migrants to take care of their health. In another study undocumented migrants were not able to afford over-the-counter medicines or pay for prescriptions if they had seen a doctor (Bloch et al. 2009, Bloch et al. 2011), problems which are very likely to affect health status. A final study focused on the health of low-income migrants and found that among unemployed refugees there was a link with poor mental health (Blight et al. 2006).

Residential location has been explored as a factor in health inequality and this factor clearly intersects with income. For example Fone et al. used council tax banding (which relates mainly to the economic value of a person's home) and looked for an association with morbidity and other health status indicators,

concluding a lower value house was linked to higher frequency of illhealth (Fone et al. 2006). Sundquist and Ahlen (2006) related other proxy indicators of place such as housing quality in Sweden and looked for associations with the use of mental healthcare (in terms of admission rates) and found a correlation that showed admission from wealthier neighbourhoods was lower. Gordon and colleagues (2011) linked poor neighbourhoods, areas they described as 'food deserts', with a high incidence of chronic diseases such as obesity and diabetes. These places also have high numbers of people with low incomes and high ethnic minority populations and it can be therefore inferred that they also have high numbers of migrants.

Nazroo and colleagues' (2007) quantitative comparative study of secondary data of US and UK health surveys also studied the notion that place and migration could affect ethnic and health inequality. They looked for disparities in health among a group of people who were defined as Black Caribbean migrants to different destinations (US and UK) and compared their health status with those who had not migrated. Nazroo and colleagues (ibid.) concluded those who did not migrate had better health than those who did, and that among those who had migrated to the US and UK, social, historical and economic inequalities were explanations for health inequality.

Other studies that focus on place have concluded that there is an association with ethnicity and/or migration. Osypuk and colleagues (2009) found positive and negative comments about places they called 'immigrant enclaves'. Here immigrant respondents felt there were some positive health gains associated with being in particular places, for instance with regard to the availability of food considered healthy, but with respect to healthy activities such as exercise facilities and walking they found their environment limited. Becares and colleagues (2012) examined experiences of racism and mental illness in two neighbourhoods with a high density of ethnic minorities in the US. They found that a higher density of ethnic minorities was linked with fewer experiences of racism. In the case of 'US-based Caribbean' people there was a protective effect that was not indicated in the UK Caribbean group and they concluded that living in ethnically dense areas only sometimes protected health.

Warfaa and colleagues (2006) focused on Somali refugees to explore the effect of forced multiple moves on their mental health. Using a qualitative methodology they found the mental health of these refugees was caused by past trauma but worsened by moving places. Linkages to place with migrants are therefore made using a variety of indicators; some are clearly related to the economic position of ethnic minorities and migrants, such as precise residential locations, housing quality and amenities. Generally, the process of migration itself (a change of residential location which may cross borders) has been

shown to have an unsettling effect on Somali migrants that may have negative repercussions for mental health (Bhui et al. 2012).

Language ability and proficiency

Proficiency in the language of destination may or may not be a challenge for new migrants and may or may not diminish over time. Some may have limited proficiency in English, and others may be highly educated and speak English fluently on arrival. Similarly, long-settled ethnic minorities or migrants may still have limited language proficiency after being resident for considerable periods for various reasons (such as being isolated in child-rearing, having arrived late in life, or other reasons). Language proficiency has been investigated using a range of methods: self-reports, assessments of proficiency, educational qualifications or need for interpreters are all used as ways of measuring ability and investigating the effects on health status.

Karliner and Jacob used the grouping of people with limited language proficiency to investigate the effect language proficiency has on healthcare and noted poorer adherence to treatment, poorer follow-up for chronic illness, decreased comprehension of diagnoses after emergency treatment, decreased satisfaction with healthcare and increased medication complications (Karliner and Jacob 2007:728). Such differences are likely to lead to an overall poor experience, different health status and an observation of inequality in access to

healthcare as broadly described earlier. Another study of interest was that of Abdulrahim and Baker (2009), who conducted a quantitative study to look at perceptions of health among groups categorised by ethnic differences, citizenship, time to explore the effects of varying language proficiencies and among Arabs with and without American citizenship ('US-born Arab Americans') who spoke English and 'Arab immigrants'. The US-born Arab Americans reported better health than the less English-proficient Arab immigrants, who had a negative view of their health (Abdulrahim and Baker 2009). In this study, language proficiency could be seen to contribute to inequality in two ethnically similar groups. Furthermore, differences were found with other studies that postulate that among new Hispanic migrants health status is better than longer settled migrants, showing language proficiency is among a basket of factors. Language proficiency can be linked to migration to some degree and is likely to improve *over time* despite this being a gendered phenomenon. This leads us to the next subsection examining migration as a specific factor and also related differences such as immigration statuses that may affect health status and access to healthcare.

Migration and time

The notion that time is pertinent to migration lies behind many explanations concerning migrants and health. For instance, the belief in a possible 'healthy migrant hypothesis' and a 'Hispanic paradox' has time inherent in their claims.

The reasoning behind the healthy migrant hypothesis was the generalised view that differences were due to new migrants or immigrants being healthier on arrival than long-settled people or other migrants. The 'healthy migrant' proposition was longstanding in the UK literature, notably Marmot and colleagues used mortality to explain differences over time among immigrants (Marmot et al 1984a) and was only later understood to vary when categories were broken down further by ethnicity. In the case of US belief of there being a Hispanic paradox, research initially suggested Hispanics were healthier than white long-settled people or other migrants that also had low socioeconomic statuses (Abraido-Lanza et al.1999, Franzini et al.2001, Abraido-Lanza et al.2006). Some research has suggested that variations in the health among Hispanic migrants do occur over time and a study of Puerto Ricans showed variation in infant mortality rates between these migrants; recent migrants, long settled and non-migrants (Landale et al. 2000). Others have cautioned that the paradox exists among some Hispanics but possibly not among others and that foreign-born Mexicans self-select because they return to their country of origin for treatment and those too ill do not return to the US (Palloni and Arias 2004). Health status has been seen to worsen over time for new migrants; this was suggested as part of the explanation for differences observed by Marmot (Marmot, 1984b) and supported by Modood and Nazroo (Modood and Nazroo 1997). Finch and colleagues (2002) have scrutinised the method of using self-reported health as a measure of health status and found for those 'least

acculturated' it was less of a predictor of mortality; nonetheless their results also supported the healthy migrant hypothesis, which has multiple dimensions.

Franzini and colleagues (2001) helpfully reviewed the literature related to this idea of the healthy migrant and argued the causes should be seen as multi-factorial and contextual.

The healthy migrant hypothesis does not hold in some cases, for example when time or arrival or acculturation concepts are applied to different immigration statuses and ethnic groupings. In the cases of migrants with precarious legal status who have been traumatised by their escape from persecution or by forced migration, poor health is evident quite soon after arrival and is likely to deteriorate further over time. This has been observed in studies both using self-reports of health and clinician assessments. There are few longitudinal studies looking at what happens over time to traumatised migrants; Vaage and colleagues (2010) have shown that mental health among such migrants is affected and is likely to recover slowly, over a long time period.

Acculturation is one concept used in both internal and international migration and can help show how people might acquire the language, customs, attitudes and behaviours of another (host or mainstream) culture over time. The concept assumes movement of people to a new place has occurred and also considers changes over time as a partial explanatory theory for differences in health

status (Hunt et al.2004). Lara and colleagues (2005) have referred to dissonance and concordance with healthcare practitioners who share cultures and Portes has indicated that it is important to take account of the process of 'assimilation' – even to see the process as a segmented rather than a wholesale adoption (Portes et al. 2012). Berry (2005) has recognised that acculturation is not straightforward. There is not always a clear benefit or improvement for migrants or close affinity to places migrated *to* and these can be exaggerated. Berry also argued that 'bi-culturation' is a more accurate description of what is occurring when some cultural aspects from one culture are accepted and others discarded (Berry 1997:11). Acculturation theories suppose that adopting host cultures can lead to poorer health outcomes.

Research as shown by Abdulrahim and Baker (2009) suggested this is not always the case, for example when socioeconomic status is taken into account among Arab immigrants. Read and colleagues (2005) looked at the self-reported health of immigrants who have the same ethnicity to understand these differences further. Arab and white Americans of Arab ethnicity were studied using self-reported health status and differences were found among the Arab-Americans and Arab immigrants, suggesting there is an effect of time and immigration status (ibid: 2005:78). There is further evidence that immigration status can have a negative effect on health status and that other social factors intersect, such as length of settlement and few social ties. These findings

confirm Cwerner's view that time in migration should be seen as 'asynchronous and ruptured' rather than as a linear concept that will have the same effect on all migrants in terms of health or other life outcomes (Cwerner, 2001). To conclude, health status is likely to change for some migrants more than others, and long-settled migrants are likely to exhibit changes over time which are partially addressed in theories of acculturation and time.

Immigration status

Studies of different types of migrants explore links between immigration status and health inequality. Typically interest has been in those with precarious status such as refugees and those seeking asylum. Robjant and colleagues (2009) reviewed 16 studies of detained asylum seekers (as opposed to those given accommodation and permitted to live on some benefits) and concluded that in these specific cases there was a higher incidence of mental illness, notably depression and anxiety disorders. This was linked to the trauma of their migration and to detention in the country where they had sought asylum. The situation for asylum-seeking children who had been detained was highlighted in the UK media as unacceptable and unethical³⁰. The negative labelling of asylum seekers in the media also has damaging effects on the mental health of

³⁰ See webpage 10th February 2010 Hannah Richardson: BBC February 2010 www.news.bbc.co.uk/1/hi/education/8518742.stm. Last accessed 25th September 2013

those individuals (Kelly and Sriskandarajah 2005). Other studies and reports confirm a connection with post-traumatic stress disorder in refugees and asylum seekers (NICE guidelines 2005). In the UK and continental Europe there has been a focus on migrants with precarious legal positions such as undocumented migrants (Sigona and Hughes 2012, Dumper et al. 2006, PICUM, 2007). The Platform for International Cooperation towards Undocumented Migrants (PICUM) has highlighted the effect of policy and found significant variations in treatment of undocumented migrants in health policies of European countries. Restrictions have increased Europe-wide in recent years, which can be linked to events such as the European financial crisis and subsequent recession. The UK is regarded as less restrictive towards undocumented migrants when compared to 11 EU countries (PICUM 2007:3).

The term 'health tourism' was originally used to refer to people travelling for treatment, including wealthy people seeking private cosmetic treatments (Lunt et al. 2013). There has been a growing use of the term in connection to migrants accessing health services. Since 2003 some UK newspapers have reported health tourism with the suggestion that it is occurring on a large scale in the NHS, and implied people were coming to live in the UK for the sole purpose of getting *free* treatment through the NHS. Kelly and Sriskandarajah and later the organisation Doctors of the World have challenged the evidence base for this claim (Kelly and Sriskandarajah 2005:20, Doctors of the World,

2012). Politicians have responded to the media claims, agreeing that ‘health tourism’ such as this is costing the NHS significant amounts of money. There has been a reformulation of the health policy called the Overseas Visitors Hospital Charging Regulations (OVHCR) (Department of Health 2004), which increased restrictions on secondary healthcare by overseas visitors in the UK. The policy created systems whereby hospital administrators were to ask patients questions about their status; whether they were visitors or ‘ordinary residents’ (Department of Health, 2004 (revised 2007), Department of Health, 2012a). Important questions that the policy raised, therefore, include: which patients will be allowed to have secondary healthcare, how are they to be identified and how will they be affected? Clearly the OVHCR policy is linked to migration. Responses to a Department of Health public consultation have argued the policy could be causing inequality in health in various ways by affecting the way health professionals are permitted to practice, different treatments and restricting access to healthcare to some migrants.

Migrants’ differential access to healthcare

Health inequality between majority and minority ethnic groups and between migrants and long-term residents can be conceptualised in terms of differentiated access to services. The notion of access can also be broadened to include utilisation of services, to beliefs, behaviours and practices that

prevent or enable access. Consequently, access can be seen as a broad concept that embraces many aspects of patient experience.

Macintyre and colleagues (2009) presented a theory of access with three dimensions: *availability* (which was linked to the capacity but also the use of services by service users), *affordability* (this related to the full cost of a person or household of travelling services, including the social as well as material costs), and *acceptability* (including a dimension of acceptability between the provider and patient in terms of values and beliefs, attitudes, expert knowledge and lay knowledge). They also suggested that all three of these dimensions interact to produce a broad idea that could be encompassed in the phrase 'accessing' healthcare. Therefore many kinds of research can be included in this conception under the rubric of 'access'. An alternative conceptualisation of access was put forward by Dixon-Woods and colleagues (2006). They recommended the idea of 'candidacy', in which people's eligibility has to be negotiated and is influenced by a number of factors much like the list that was offered by Mechanic (Mechanic, 1978). Goddard built on the idea of candidacy and included the notion of 'navigation' of services and systems and the 'permeability' of services such as physical ease of using services (Goddard, 2009). Access is a broad concept used in different ways and is relevant to the literature on health and migrants.

Jayaweera's review provides an overview of the situation of migrants with regard to health inequality (Jayaweera and Quigley, 2010). These researchers argue that health status, needs, care and barriers to care are issues that are likely to affect international migrants. Benson (2012) also raises the issue of differences in use of services by ethnic minorities. With this in mind the remaining part of this sub-section looks at studies concerned with migrants' use of healthcare and explores the possibility that migrants might use services differently. Particular types of services are reviewed: primary, outpatients and secondary, emergency, and mental health.

Studies focused on primary care have suggested that some migrants have experienced inequality and face problems in not being accepted as patients by GPs who exert their powers by using discretion when accepting new patients into their practices. It has been argued that such policy has created confusion in relation to migrants who are unaware of their rights, and others have felt discrimination (Bhatia and Wallace 2007). The release of guidance on the registration of new patients by the British Medical Association is an acknowledgment of this problem (BMA 2012). The topic was researched by an online magazine for GPs called Pulse Weekly, which surveyed 229 GP readers and revealed that 52 percent felt the rules for migrants were too generous, showing the issue was not merely confusion among migrants or GPs but that

over half of GPs appeared to feel that some migrants were not entitled to healthcare³¹.

The situation of asylum seekers has been raised in several studies. Bhatia and Wallace's study focused on the primary care of refugees and refused asylum seekers reporting that they struggled to get access, were not satisfied with the quality of communication with GPs and perceived stigmatisation (Bhatia and Wallace 2007). Toar and colleagues (2009) conducted a comparative study addressing the question of possible differences between asylum seekers and refugees and found asylum seekers self-reported more mental health problems than refugees. The study concluded that asylum seekers used primary care services more and accessed secondary mental health services less than refugees. Toar et al. could not explain the differential usage and suggested cultural differences as being possible explanations, though they were not suggesting cultural differences were the sole reason.

In relation to primary care and outpatient services among different ethnic groups, Smaje and LeGrande (1997:494) concluded that there was no 'gross' pattern of 'inequity' between ethnic groups and white nationals. Although they identified

³¹ Pulse survey 17th January 2013; <http://www.pulsetoday.co.uk/news/finance-and-practice-life-news/nhs-provision-for-migrants-is-too-generous-say-majority-of-gps/20001524.article#.UkKIhd>. (Last accessed 25th September 2013).

few problems with inequity, they acknowledged inequality among *certain* ethnic minorities. Disaggregation of the ethnic groupings revealed that Chinese people and the sub-group of 'young Pakistani women' under-used GP services compared to the white population and there was a general under-use of outpatient services. This raised questions for other researchers and supports discussions elsewhere about the usefulness of large ethnicity categories (Bradby 2003, Ahmad and Bradby 2008).

Looking at emergency services, Hargreaves and colleagues (2006) conducted a study of international migrants in which countries of origin were used to categorise migrants and explore the issue of access and use of emergency care. Hargreaves et al. (ibid.) concluded that the international migrants had used emergency services arguing that this was likely to be more frequent than for 'non-overseas born' service users. However, importantly, they also addressed the topical question of whether refugee use of emergency services was different from that of international migrants in general and concluded that migrants from 'refugee generating countries' were using hospital services less than those from 'non-refugee generating countries' such as Europe and the Americas.

In terms of secondary or specialist services, other studies have shown that migrants, refugees and asylum seekers face difficulties accessing healthcare (Kelly and Sriskanderajah 2005, Community Care 2007, Feldman, 2006).

Maternal healthcare has been investigated and there were disparities and inequality among vulnerable migrants in use of maternity services and in health outcomes (Bragg 2008). Online research has shown that the state of mental health of child asylum seekers who were detained was of concern. Dorn and colleagues (2011) surveyed undocumented migrants sent to detention centres; many reported difficulty accessing health services when released and gave examples related to lack of help with injuries sustained during and after migration and not knowing about how to access dental services.

The use of mental health services in the UK varies between ethnic groups (Bhui et al. 2003). It is accepted that more ethnic minorities are detained in mental health hospitals whilst community mental health services are underused (Community Care 2007, Rogers and Pilgrim 2010). In the case of migrants the literature connecting mental health needs and usage tends to relate specifically to refugees (Refugee Council 2008 and Department of Health 2005). Reports about migrants have also focused on broader groupings of vulnerable migrant groups such as destitute asylum seekers also raising mental health needs alongside other needs (Dumper et al. 2006). Lindert and colleagues' (2009) review of quantitative studies of mental health compared refugees with 'labour migrants' and concluded that the mental health of refugees was worse than those of working migrants due to the trauma of the migration journey. Robjant and Hassan (2009) reviewed 16 studies on the mental status of asylum seekers

and new refugees; this group were at increased risk of depression and anxiety disorders due to both migration trauma and subsequent post-migration trauma.

Turning to immigration status, increasingly studies are showing that immigration status affects decisions about use of health services, particularly in the case of case of undocumented migrants, asylum seekers and refugees (Romero-Ortuno 2004). Schoevers and colleagues (2010) showed that Asian undocumented migrants appeared to use health services less because of communication difficulties and healthcare practices. There are also studies that suggest vulnerable migrants may become cautious about use, constructing their own barriers and avoiding healthcare. This does not mean that legally resident migrant workers do not also face problems of access. In a qualitative study of migrant workers who were in precarious employment, or in situations where they were forced to continue in contracts they would prefer to end, Anderson and Rogaly (2005) found those migrants in forced labour contracts avoided using health services and were refused by GP practices to register because GPs wanted to see work documents. The hypothesis that there was a lowered use of health services by destitute migrants and asylum seekers was addressed in a government report (Dumper et al. 2006). In this study their use of health services was argued to be lower despite the group's needs being high. Bloch and colleagues' qualitative study of undocumented migrants reiterated these points (Bloch et al. 2011:87).

Conclusion

To summarise this section, a large body of literature indicates that inequality in health status and access to healthcare affects both ethnic minorities and migrants. Research about migrants and health has highlighted health inequality among migrants in general. More specific categorisations of migrants are valuable, such as low income, residency or immigration status, as these can highlight differences between migrant groups.

It is also clear that there are multiple reasons for health inequality and no single factor can claim to be of sole importance. Biological differences, culture and behaviour are significant, as is racism, income and place (which intersect with income). Literature about language proficiency, migration and immigration status show these factors also have an effect on health status and use of different health services. Studies of migration have led researchers towards the concept that new migrants are healthier than long-settled populations but this generalisation has gradually been re-interpreted and been found an insufficient explanation when self-selection and disaggregation of migrant groupings are taken into account. Important factors such as age, gender and social ties provide additional supportive and barrier elements to some migrants being healthy on arrival. Moreover, vulnerable migrants who reside illegally, seeking asylum, or are refugees have more health problems and it is argued access healthcare differently. Again there are multiple reasons given for this; some have identified precarious immigration status, others have argued that the

trauma of migration is as significant. Access to healthcare covers different aspects of health service use including issues that could be related to the quality and satisfaction with services. Language proficiency literature raised concern about communication and the lay-health professional relationship as another factor that may lead to health inequality among migrants.

The idea that inequality and social processes can negatively affect the health of migrants has been explored in this chapter. The concept of stigma and discrimination has also been examined as a valuable and related concept for researching marginalised people such as migrants.

The literature review includes Davey-Smith and colleagues' (et al.2002) method of organising the literature on migrants and social factors such as language proficiency, duration of migration, immigration status, and access issues. The review also makes a strong case for the overlapping nature of these multiple factors. Vertovec (2007) coined the term 'super-diversity' based on his interpretations of the fast-changing nature of British society, which shine new light upon the need to see complexity and multiple factors as interacting. He identified socioeconomic status, class, gender, age as well as ethnicity as important aspects of super-diversity. Moreover, Vertovec contends that certain variables are important to consider when exploring super-diversity: net inflows of people, countries of origin, nationality, languages, religion, immigration

statuses, local space and place and transnationalism. Consequently, Vertovec's ideas about super-diversity support the notion of complexity and the interaction of factors likely to affect illness among migrants. The studies reviewed in this chapter as a whole indicate that layers of inequality and super-diversity exist and point to the need for research on migrants, including on health (Phillimore 2011, Green et al.2014).

The following chapter reviews theories of knowledge that would be appropriate for a study of migrants: lay knowledge, illness experience and patient experience are examined with a view to providing the most suitable methodological approach for studying illness experiences of recent international low-income migrants in Brighton and Hove.

Chapter Three: A Qualitative Approach to Researching the Lived Experience of Recent Migrants

Chapter Three explores the epistemological tools for developing a theoretical framework pertinent to a qualitative study of recent low-income migrants as opposed to a quantitative approach typical of the Nation Health Service in the UK. Theories such as phenomenology, constructivism and narrative are examined as they share a common interest in experience. Illness narrative and the combination of theory and method, is explored for its relevance to this study on illness and healthcare use. Other concepts such as lay knowledge, patient satisfaction and patient experience are explored as theoretical tools and aligned with the study.

The epistemological questions that are asked in research in general relate to the following: is there only one reality or are there multiple representations of reality? What is objectivity and subjectivity? How is knowledge produced? What is the voice and the role of those who gather and produce knowledge? How are values and ethics acted out when constructing knowledge? and do different paradigms sit with one another or are they opposing? (Denzin and Lincoln 2000:158 and 163). These authors refer to paradigms as reflecting individual researchers' epistemological, ontological and methodological premises which are the set of beliefs that guide actions (Denzin and Lincoln 2000:19). In this

thesis it is argued that objectivity is an impossible condition. Again, support for this position can be found from Denzin and Lincoln: 'There are no objective observations, only observations socially situated in the world of and between the observer and the observed' (Denzin and Lincoln 2000:19). This is in part because the ethics and values of an observer or actor influence what can be about the researcher or the researched; therefore the counter-position of subjectivity is considered. Subjectivity is argued to be an unavoidable characteristic of practice and experiences. Noting the intersubjectivity between actors, and between actors and observers, is a necessary part of understanding reality (Dunne et al. 2005).

Theories that relate to lived experiences: phenomenology, constructivism and narrative

Phenomenology and constructivism are concerned with knowledge gained through experience and argue that both everyday and uncommon experiences of the individual are central to making sense of the world. Phenomenology can be traced to Edmond Husserl, who created the concept of the 'lifeworld', seeing more in the taken-for-granted, everyday world which humans tend not to question (Zahavi 2003:130). Alfred Schutz (1977) expanded the concept, considering what can be understood of objectivity through the lifeworld and how it can influence scientific ideas. Berger, a student of Schutz, drew upon Marx and Hegel to describe the connections between the lifeworld, the individual and

society, seeing the lifeworld as comprising *dialectical* processes of 'externalisation, objectification and internalization':

The fundamental dialectic process of society consists of three moments, or steps. These are externalization, objectivation, and internalization ...

Externalization is the ongoing outpouring of human beings into the world, both in the physical and the mental activity of men. Objectivation is the attainment by the products of this activity (again both physical and mental) of a reality that confronts its original producers as a facticity external to and other than themselves. Internalization is the re-appropriation by men of this same reality, transforming it once again from structures of the objective world into structures of the subjective consciousness (Berger 1967).

Phenomenologists therefore support the view that only an approximation of reality can be realised and objectivity cannot be achieved. Husserl's idea of the lifeworld informed others, such as Heidegger, Merleau-Ponty, Sartre, Derrida and Habermas and the idea of individual experiences was theorised further in relation to consciousness, subjectivity and action (Flick 2004:68). The meaning of action (a part of experience) theorised by Schutz differentiated between the purpose of action ('in order to') and the reason behind the action ('the because'). Schutz's theory of 'rational action' was applied by Garfinkel in his approach to ethnomethodology and conversation analysis and in his study of the way action is a part of experience (ibid.:68).

In constructivism, experiences of and between individuals are also important.

This has been theorised by Paul Ricoeur in his conceptualisation of constructivism and 'mimesis' and summarised by Flick (Flick 2004:90)

Phenomenology and constructivism are valuable theories, relevant to this thesis, because of its focus on the experiences of recent low-income migrants.

Furthermore, narrative can be linked to experience; there is a link between experience and narrative by referring to the world of experience being constructed through texts and language that are expressed and interpreted.

These narrated experiences emerge from present or past experiences. Reality is therefore socially constructed and formed from narrated experiences (ibid:90).

Constructivism as a result supports phenomenology and narrative theory as it recognises the importance of lived experiences and reality presented in experience and practices through words. Ferdinand de Saussure's

conceptualisation of narrative as 'signifier' referred to all forms of communication: verbal, gestural, textual, visual shapes, practices and objects (Belsey 2002). He also argued that signifiers did not exist separately from the

world and reality, stating narratives *were* reality, even when words across

languages have different meanings and interpretations that were socially

situated were a reality (ibid. 2002:9). Michel Foucault also saw that we are

connected to each other through language, and discourses are a fundamental part of reality and may challenge or reinforce power relationships (Gutting

2005:62). Following these arguments, various forms of narrative are understood here as being an essential part of the lived experience and collections of narratives enable us to construct a view of what has happened in the present, the recent and distant past.

Narrative theory also focuses on individual experiences, providing a number of advantages as an epistemological tool: narratives can be seen as representations of reality that give rise to social reality, locating the significance of the personal within social structures (Hyden 1997:50). Belsey has argued narratives support observation (Belsey 2002:76). Lawton identifies a number of studies that highlight social construction through narrative for understanding gender in the perception of pain (Bendelow 1993), for showing how social norms affected disability (Ville et al.1994), and for showing that social class plays a role in shaping perceptions of health (d'Houtard and Field 1984, Lawton 2003). Narrative methodology provides a means of hearing and understanding the voices of those who are not heard in mainstream discourses. Finally, through specific narratives less obvious or common cases can be better understood (Yin 2009). This thesis is interested in a form of narrative known as illness narratives conducted through interviews of a particular group (recent low-income migrants). Illness narratives have a distinct context and form and avoid a 'static conception of the world' (Plummer 2000). It is argued in this thesis that

interviews, when conducted using an unstructured or semi-structured approach, can elicit illness narratives. The following section will focus on illness narratives.

From narrative to illness narratives

Narratives of illness can highlight dimensions of illness and healthcare that other approaches would miss. Biomedicine objectifies the patient and views the body primarily as a biological entity which has malfunctioned. Moreover medicine addresses the body and person in isolation from their social and emotional context (Friedson 1988, Illich 1976). The emergence of the concept of illness narratives provided an alternative view of disease, offering detailed representations of lived experiences relating specifically to illness and the patient-doctor relationship. Illness narratives can highlight what is both unique and common in illness and demonstrate connections to the lifeworld not previously understood; through illness narrative patients are seen to be social beings. As Kleinman commented, 'Illness is deeply embedded in the social world and consequently it is inseparable from structures and processes that constitute that world' (Kleinman 1989:186). Many researchers continued to use illness narratives as a way of examining complex health and medical interactions and experiences of subjectivity within these dynamics.

Narratives take us away from an outsider perspective, seen in part in Parson's theory of the 'sick role', in which the acquisition of illness permits a person to be

a patient -- to have a have a new function. It introduced the idea of a personal 'insider perspective' of illness (Lawton 2003:25, Lupton 2003). Bury used illness narratives to theorise illness experience using the case of people with chronic illnesses (Bury 1982). This approach served to draw out the link between lived experience and different dimensions of identity ranging from ethnicity, gender and sexual orientation and the social context of illness such as income, education and social class. This narrative approach has influenced the choice of methodology of this thesis.

Ricoeur underlined the salience of time to illness narratives (Ricoeur 1984). It is a central factor in tracking symptoms (when they appeared, how long they have been present, how they might have changed prior to a medical encounter and how long it took to resolve them or adjust to them). Time is central to deliberations regarding diagnosis among healthcare professionals as well. Narratives of older people are distinctive, coming as they do towards the end of the life course. They may see illness as normal yet disruptive; age leads to different expectations of health and recovery (Sanders 2002).

Bury used the ideas of Giddens on 'critical situations', theorising illness as a 'major type of disruptive experience' (Bury 1982:169). Following his lead, other studies also examined the profound effects of illness. Charmaz (1983), for example, focused on identity and the loss of self. William expanded on the theme of identity and imagination by arguing that illness narratives could be

'reconstructed' and linked the 'individual to society' (William 1984). Similarly, Carricaburu and Pierret (1995) referred to a more dynamic process when they wrote of the 'biographical reinforcement' that could occur in some illnesses over time, such as HIV, in which change was transformative. Subsequently, they contended that too much emphasis was being placed on the notion of disruption in illness when in fact disruption was a common feature of many people's lives even when they are well (Williams et al. 2000).

The expression of emotions, presented in varying degrees of intensity and lucidity, are a feature of illness narratives, and a way of understanding the disruption caused by illness (Thomas-MacLean 2004). Analysis by Lupton (2003) of emotions and illness found the dominant approach to be 'essentialist' or cognitive, in which emotions were inherent and natural, with only minor acknowledgement of the influence of social factors. Other researchers have looked at the construction of emotions (Williams 1996b, Gabe et al. 2004) and found that emotions are also constitutive of the social environment, managed and controlled (or sometimes not controlled) by the individual in his or her interactions with others (Scott 2007).

Goffman made a significant contribution to constructivism in addition to his conceptualisation of stigmatisation and discrimination (these were linked to health inequality in Chapter Two). Here, his contribution to narratives is

highlighted with regard to emotion (in particular shame) in social interactions and through his methodology of narrative (Hall 1990, Goffman 1999)³². Charon (2006) has also built a case for the importance of emotions in illness narratives, seeing shame, guilt and denial as important. Careful interpretation of narratives with regard to emotions is a necessary aspect; moreover, narratives may not explicitly verbalise feelings and they must be inferred.

Typologies of illness narratives

Typologies have developed to summarise the common features seen in illness narratives. Narratives were not recognised as an important part of doctors' practices, and the patient's voice was not accorded much status -- doctors concentrated on clinical understandings and ignored psychological or social dimensions of illness. Illness narratives demonstrate that purely clinical approaches are too narrow and miss useful, even vital sources of new knowledge. Reissman states, 'Narratives of illness can provide a corrective to biomedicine's objectification of the body and help to embody a human subject

³² Goffman's analyses of social interactions in particular in relation to emotion drew on others works by Freud, Elias, Cooley, Adler, Kardiner, Erikson and Horney. Emotion was considered important in the context of illness and embarrassment, shame and pride (seen as the opposite of shame) were of particular interest SCHEFF, T. 2006. *Goffman unbound! A new paradigm for social science*, London, Paradigm. Scheff believed shame was often a hidden emotion; 'the large family of emotions that includes many cognates and variants, most notably embarrassment, guilt, humiliation and related feelings such as shyness, which originate in threats to the social bond' (ibid.).

with agency and voice' (2002:4). Narrative-based medicine has become increasingly recognised by practitioners as a useful way to hear the patient and understand his or her problem (Launer 2002).

Herzlich argued that illness was more than a biomedical construct and developed typologies of illness as destructive, liberating, or as an occupation (Herzlich 1973:105). Another typology was developed by Robinson (1990), who maintained illness narratives were distinctive because they reflected a person's goals and the degree to which these were achieved. Robinson suggested three types of narratives which are centred on the search for a cure or for wellness as a distinctive feature: *progressive*, where goals were achieved, *regressive*, in which there was little or no success, and *stable*, which do not indicate either success or failure (Robinson 1990:1178). Around the same time (Frank 1991) produced his now universally acknowledged typology of illness narratives which resonated with Robinson's work, but which has had a much wider impact and lasting influence.

Frank called the commonest illness narrative type 'restitution', observing that restitution narratives were given frequently by people with acute rather than chronic illness, or among those who knew they could be successfully treated. The hope and expectation of recovery dominates restitution narratives (Frank 1991:80, Whitehead 2006:2238). Restitution is congruent with the objectives of

medical professionals and could occur in contexts where the diagnosis is uncontentious, treatment objectives were more likely to be agreed upon, or the illness was seen as temporary. Alternatively, an illness might be more likely to be tolerated and differences between the doctor and patient accepted. The social and emotional impacts of illness were less evident in restitution narratives; people did not dwell on the idea of disruption or identity changes.

Frank's second narrative category used the concept of chaos to describe the loss of control experienced at different levels when people experience illness.

This was particularly evident in states of health that were not improving, with suffering continuing longer than had been expected. The disruption to the narrator's life was significant; they were unhappy, losing hope of a return to wellness and feeling little prospect that many of their concerns could be resolved (Frank 1991:97, Whitehead 2006:2238). In this type of narrative, the relationship with practitioners had become strained because of treatment not working. This was exacerbated when false expectations had been created, in part by professionals that some relief would come but this did not happen.

Disagreements with practitioners arose for a number of reasons: because the diagnosis had been slow to be made, symptoms were not recognised or their seriousness was not felt to have been understood by practitioners (as in cases of 'medically unexplained symptoms'). Illness narratives of people with chronic

conditions were more likely to be linked with Frank's chaos typology or Robinson's typology of 'a regressive' illness type.

The third and final type of illness narrative in Frank's typology was the 'quest' narrative, in which illness was a journey that was accepted for whatever it was, with or without the likelihood of recovery. This kind of illness narrative was less common. Narration took three possible courses: first, a memoir in which the narrative consisted primarily of the recounting or documenting of events and feelings, providing an autobiographical account of an accepted illness. Second, a 'manifesto' in which truth that is learned is 'prophetic' and leads to social action (Frank 1995) and third, 'auto-mythology' in which the person believed the illness was seen as a destiny providing either atonement or a sense of personal heroism (ibid:120). Robinson had referred to progressive narratives being heroic in character when a battle over the illness was successful (even though this may be spoken about in an understated manner). In this way it was unlike Frank's quest narratives, which were stoical and accepting. In HIV and cancer illness narratives, some have identified a tendency to the quest typology (Carricaburu and Pierret 1995, Whitehead, 2006, Zahavi, 2003, Thomas-MacLean, 2004).

Subsequently Hyden (1997) produced a typology of illness narratives which questioned what illness narratives meant and analysed how they were

constructed. He put forward three types of narratives: first, *illness as narrative* (characteristic of most personal experience narratives); second, *narratives about illness (by health professionals)* and third *narratives by others* (when the ill person lacked the capacity to express their own experiences as in brain and mental disorder, which occurs when 'the person's narratives are inadequate to articulate events and experiences and it is this lack that is the basis for the suffering') (Hyden 1997:55). This typology acknowledges the complex subjectivity and multiple interpretations in narrative, observations that were not being thematically drawn out in Frank's or Robinson's frameworks. Bury theorised narratives according to whom they were directed at and why (Bury 1982). In this paper he suggested there were 'contingent narratives' named as such because they 'address beliefs about the origins of disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life' (Bury 2001:263). Bury also suggested there were 'moral narratives' which linked narratives to wider social identity and which could restore or hinder the formation of moral status. Illness narratives relate to the feelings, opinions, and actions of the individual. In addition, interactions, power dynamics and social relationships are evident and help to convey the social context of illness. Illness narratives as a form are contested by Bury as a narrow approach to understanding illness.

Critiques of illness narratives relate to epistemological questions and are neatly summarised by Thomas (2010). The underlying arguments were seen to be between three protagonists: Frank, Bochner and Atkinson who primarily criticised Kleinman, Frank's and Mishler's approaches to narrative (Kleinman 1989, Frank 1991, Clark and Mishler 1992). Clearly the criticisms stem from epistemological differences about the meaning of narrative, most notably about the voice of the narrator as too subjective and constructed. This thesis argues that these are not problems but realities which apply to health professionals' narratives as well as to empirical studies of patients.

Others have acknowledged this when discussing reflexivity. Charon has argued that stories are narrated sometimes with no reason or motive at a subconscious level yet still capable of contributing to understanding and 'self-discovery' (Charon 2006). Riessman (2002) has suggested caution with this methodological approach but still uses illness narratives, arguing that they should be seen as comprising elements of objectivity and subjectivity but not claim to be 'scientific'. Frank has acknowledged these critiques and warns that reflexivity is an important aspect. In his recent work he argues that illness narratives mirror what has been said in qualitative methodologies in general, and that subjective reality must be interpreted reflexively – but if this is done, narratives are useful tools (Frank 2010a, Frank 2010b). Frank's approach influences this thesis but the approach taken here is different in that the maximum number of participants who could be interviewed within the timeframe available were recruited. For Frank and others doing illness narrative studies, it appears they used fewer interviews and often conducted them longitudinally, similar to a life history approach. In this study, 41 semi-structured interviews lasting up to two hours were carried out. In Chapter Six in particular, the qualitative interviews are analysed using illness narrative typology and with narrative theories and these methodological differences do not appear to be significant.

The next section addresses diagnosis as another typology that is apparent in illness narratives. It is also seen as an important theoretical concept in the study of illness. For this reason it is given a separate subsection.

Diagnosis

Illness narratives often refer to interaction or encounters that patients have with medical professionals. Blaxter (1978) has argued that diagnosis is both central to medical practice and significant in the narratives of patients. Bury (2001) reiterates that the role of diagnosis is central to his conceptualisation of 'contingent narratives' which stress the importance of cause/s of illness. Jutel and Nettleton (2011c) have underscored the importance of diagnosis from the standpoint of constructivism; they contend that diagnosis should be seen as the organising, explanatory, and validating principles behind what is experienced and narrated by patients. Diagnosis is therefore socially mediated.

Diagnosis is a recurring theme in illness narratives, often structuring the story being told. When a diagnosis is offered there is an opportunity for patients to scrutinise this factual development in which illness can feel legitimated and suffering may be understood in a new way. Indeed, the effect of diagnosis (either the presence or absence of it) can have material, psychological and social effects on the patient – effects which will change if the diagnosis changes. The *absence* of a diagnosis can also be profound as it can de-legitimise a patient's experience and diminish the patient's sense of self-belief and worth. Thus when a diagnosis is contested by practitioners the emotions in narratives became amplified, as will be illustrated by some accounts in this thesis.

Jutel and Nettleton (2011c) find that as biomedicine has developed so has the value placed on technical diagnostic tests; doing tests is increasingly sought and seen as more valid than the clinical observations of doctors (or, indeed, the accounts of patients). This highlights the social dimension to technology; diagnosis and testing are technologies of power and may become contentious and emotive in medical practice (Nettleton 2008). Technological developments also provide some opportunities for patients to research their own illnesses. There has always been a tendency for the patient to seek out information from different sources but the availability of the internet has increased attempts to self-diagnose and possibly develop strong views about treatments (Ebeling 2011). Consequently the power of the doctor as diagnostician is under challenge, although since doctors retain the power to determine access to treatment in the UK, their role remains central. The role of power in diagnosis can intersect with issues connected to health inequalities – some groups do not have the means of getting knowledge and become ‘experts’, or, if they do try to get a second opinion on a diagnosis, they may be more likely to be denied this opportunity. These observations are pertinent to this study of recent low-income migrants.

Other dimensions of the concept of diagnosis noted by Jutel and Nettleton include negotiation, investigation and the trial and error nature of the process of

diagnosis (Jutel and Nettleton 2011:796). Doctors and other health professionals may practice differently depending on their patients' characteristics, behaviour or patients' ability to make themselves understood. Doctors may also be put under pressure to modify the process of diagnosis due to policy directives regarding, for example, the length of GP consultations, or in assessing the degree of urgency of a health problem after diagnosis in terms of the need to prioritise patients, which is also of relevance to new policy related to recent migrants. Ideally, reasons for these policy actions should be transparent – for example, whether they are due to limited resources, or, as in other systems, the ability to pay, or if there are issues connected with immigration status. The effects of the policies should also be monitored.

Jutel refers to the *consequences of diagnosis*, in which the politics of diagnosis must be explored (Jutel 2011b). An example of diagnosis determining the utilization of services is ADHD (Attention Deficit Hyperactivity Disorder) in children, where it has been shown that parents will seek and get access to educational resources on the basis of diagnosis. Singh (2011) highlights the consequences of delayed diagnosis in cases of mental illness as the provision of treatment, related therapies and support are then delayed as well. The negative impacts of problems in diagnosis are potentially wide ranging; they can affect the body, emotions, behaviours, relationships, values and beliefs as well as treatment and access. Furthermore, when an illness/diagnosis carries

stigma with it, patients and families become deeply affected and vulnerable and the consequences may be significant. Finally, the importance of diagnosis is central to the shaping of health services, and institutions outside the realm of healthcare, for example insurance companies, educational institutions and political parties.

This thesis uses illness narrative theories in the analysis of the interviews conducted for this project (Bury 1982, Charmaz 1983, Frank 1991, Williams 2003, Bury 2001, Jutel and Nettleton 2011). In addition, important concepts related to the patient's voice are explored – the notion of 'lay' knowledge and then the strength of the idea that patient experience is a valuable source of data.

Lay knowledge: Understanding patient satisfaction and experience

The literature concerned with lay knowledge can be traced to Talcott Parsons' functionalist analysis of the sick role (Scambler 2003:50) which included a theorisation of the experience of patients. For Parsons, the sick role included rights, privileges, and obligations. He argued that the patient has a responsibility to get better, so if they appear not to want to do so, then the patient's motivations should be questioned. This produced a shift towards studying the patient perspective and the subjectivity of illness experience. Mechanic then put forward one of the earlier multi-factorial explanations of illness experience in

which he identified elements such as biology, behaviour, social factors, and power as shaping the experience (Mechanic cited in Scambler 2003:41).

In particular, the power relationship between doctor and patient has been of interest when theorising lay knowledge; the relationship is understood as asymmetric and conflictive (Nettleton 2006:140). Over time health practices have begun to acknowledge the power imbalance reflected this observation and in the shift to the use of the term 'service user' or 'patient expert' instead of 'patient'. Power differences vary in the lay-professional relationship and are reflected in other concepts about communication as well, such as 'paternalistic' and/or 'mutual' communication (Nettleton 2006:145, 152). A more paternalist mode tends to be accepted in the rapid onset of an acute illness, a severe illness, or a terminal illness. Overall, it has been suggested that the dynamic between doctor and patient varies during the course of some illnesses, and is influenced by social and structural factors.

Lay knowledge can be seen as a valuable alternative to professional knowledge (Gabe et al.2004). These authors referred to lay knowledge as having two dimensions:

On the one hand it is a robust empirical approach to the contingencies of everyday life required by people trying to make sense of health and illness in themselves, their families and the wider communities in which they live. On the

other, it displays a search for meaning that goes beyond the straightforwardly empirical, situating personal experiences of health crisis in relation to broader frameworks of morality, politics and cosmology. It represents, in Max Weber's terms, understanding in terms of both cause and meaning (ibid.2004:136).

Other conceptualisations of lay knowledge refer to the active consumer and passive acceptor of a professional's decision for a patient reference. Studies of experiences of illness and healthcare have concentrated on the lay-professional relationship, with the professional role being about giving information, support, reassurance, and subscribing to the collective values and beliefs of a professional doctor (Morgan in Scambler 2003:49, May 2004). The concept of lay knowledge has also emerged out of epistemological concern about what knowledge means. Knowledge should be understood to be created everywhere, formed in part by everyday formal and informal experiences and crises and this approach should also challenge the notion that knowledge is created and owned in particular centres (such as the academy or government). Lay knowledge encompasses practical, everyday knowledge and might focus on action. Consequently, lay beliefs and behaviours might include knowing how to go about accessing a health service, or interacting with health professionals or giving opinions that are expressions of the conscious and unconscious self.

Lay knowledge is gained through experiences in the longer past, recent past and present, and it is affected by time, place and epistemology. Whilst earlier critiques of professional-lay relationships often polarised lay and professional accounts, such as Mishler's characterisation of the voice of medicine versus the 'lifeworld' (Clark and Mishler 1992), more recently there has been an acknowledgement of the complexities of the overlap between the patient as 'expert' and 'lay' knowledge (Reiser 2009). The critique of the doctor-patient relationship has led to the adoption of the term professional-lay to reflect the desire for a less paternalistic dynamic and more balanced mode of power in the relationship.

Furthermore, lay knowledge about illness is influenced by professional knowledge and there is growing acknowledgment of the lay person as the 'expert' on their illness. This is reflected in the increasing weight given to illness narratives (often published within the genre of biography and self-help guides) and in the work of some charities, for example 'Heathtalkonline'. This is an award-winning web-based resource which collects lay persons' knowledge, in the form of illness narratives, which are then grouped by particular illness diagnosis³³. The interest in lay knowledge contours with government and UK

³³ <http://www.healthtalkonline.org/Overview/Research> (Last accessed 2nd October 2013)

health policy development and the NHS Constitution where commitment to lay knowledge has increased (Department of Health 2012b).

In the last few years the shift from lay knowledge to patient expert, as mapped out above, has also accommodated the idea of patient experience. Patient surveys have become mandatory in the NHS; patient experience has become an outcome for assessing quality and standards of healthcare. The government has now made it essential for NHS trusts to regularly undertake questionnaire surveys and the funding of hospitals are tied to these results being satisfactory along with other outcome indicators. Currently the government approach is more quantitative and survey sample sizes have varied between 27,000 and 117,000 patients, depending on types of health services being studied³⁴. The large sample sizes are key aspects of the claim to validity and representativeness made by these surveys. The survey results have been used as evidence of quality by the Care Quality Commission (CQC) and are compiled into summary reports (Department of Health 2008). The NHS patients who are invited to participate in these samples are those patients who have used a health service in the preceding six-month period. The different services are amalgamated as GP and community, inpatient (hospital), outpatient, emergency, ambulance, and mental health services. However, there has been recent

³⁴ <http://www.nhssurveys.org/surveys> (Last accessed 2nd October 2013)

criticism since the inquiry into the failings and low healthcare standards at the mid-Staffordshire NHS Trust, which called the efficacy of large scale questionnaires and monitoring into question (Francis 2013).

Patient experience is concerned with social differences and health outcomes. In the case of gender there is a body of research that has identified different patterns of illness and health status among women and men. For example Scambler (2003a) found that the gender gap in life expectancy in Europe between 1841 and 1998 was decreasing. Mortality initially reduced among women and was lower than male mortality up until the 1980s. The causes of death have changed, with cancer now accounting for more of the deaths in women than it does in men. Other studies of patient experience focus on gender and behaviour. Some suggest women consult doctors more than men; these behavioural claims are qualified by examining differences between women according to other social factors such as illness and life course, and often research concludes that oversimplification is dangerous (ibid.2003a). Differences in the treatment of women by health professionals have been explained in terms of differences in expectations and satisfaction levels for women. A final example are studies which show women have experienced greater medicalisation of their illnesses, particularly with regard to mental ill health (Doyal 1995, Springer 2012, Brown 1995). Arber and Thomas summarise gender differences in patient experience as follows: 'biological,

psychosocial, risk behaviours, occupational and work factors, social roles and relationships, power and resources in the home and social structural differences within society' (Arber and Thomas in Cockerman 2001:94). Such a list reflects explanations for other differences in patient experience among and between groups such as people of different ages, minority ethnic people and migrants (Janevic 2011, Rogers and Pilgrim 2011).

The notion of patient experience places the patient or 'service user' centrally, and can be linked to other ideas such as patient satisfaction and patient choice. These have become prominent discourses in health policy in the last eight years or so (Department of Health 2012/13, Department of Health, 2009a, Department of Health 2006, Department of Health 2009b). Spencer and Dowler attribute this development to the Wanless Report in 2002 (Dowler and Spencer 2007:9) which was to be the first to suggest that service users needed to be more responsible for their health, but Wanless also connected the idea of responsibilities with choice. Dowler and Spencer argued this stance was taken to enable the NHS to take *less* responsibility for the material and structural factors underlying differences in health, thus reducing accountability. More positively, it is the acknowledgement of service user power and rights. A common subject is the dissatisfaction of service users in their interactions with health professionals – a relationship that is perceived as central to good healthcare (Morgan 2003:61). A past and widely quoted study suggested that ill

people failed to remember a lot of information in a consultation (Ley 1979). An improvement in communication in the service user-practitioner interaction is seen as important area of study in patient satisfaction literature. Patients report that their views have not been heard adequately (Barry 2000). Such studies raise questions about the interaction between lay and professional people and about the role played by other possible factors.

The final section in this chapter draws on the recent conceptualisation of patient experience as pertinent and the typologies which were thought to be useful in the analysis of the interviews.

Typologies of patient experience and satisfaction

Patient experience and satisfaction are concepts which are linked to theories of illness narratives and lay knowledge. In qualitative research, patient experience and satisfaction accepts the subjective position of the individual (Williams et al. 1994). Patient experience has surpassed patient satisfaction as the concept of interest to practitioners and policymakers in the NHS (Department of Health 2012d), but the literatures are overlapping. Williams and colleagues (1994) summarise the multiple motivations for tracking patient satisfaction: to better understand patient behaviour and patients' perspectives, to improve compliance with treatments and to evaluate health services for efficiency. Sitzia and Wood (1997) reviewed the literature on this subject and showed how variation in

patient satisfaction is conceived and measured . These different approaches reflect the heterogeneous aspects of healthcare experience, as well as epistemological differences in the way health is studied. Different approaches to patient experience and satisfaction can take account of practical, technical, environmental, social and psychological dimensions (Baker and Streatfield 1995, Williams and Calnan 1991, McIver 1991, Linder-Pelz 1982, Ware et al. 1983). For instance, it has been shown that older patients expressed more gratitude and were more satisfied with their healthcare experiences (Hall and Dornan 1990).

The practitioner-patient relationship (in terms of technical competence and awareness of power) and communication (in terms of empathy) have been emphasised as being key aspects of patient experience (Williams and Calnan 1991). Cooper and colleagues (2006) similarly linked disparities in patient satisfaction to the relationship between the patient and the practitioner, arguing that three aspects of patient satisfaction were important among a group of African-Americans they researched: first, *communication* - patients need to feel they are in a partnership and feel respected. Second, *affiliation* - patients need to know and trust the doctor. Third, *concordance* - a dynamic between patient and doctor in which views and identities are shared. Notably, this study made use of semi-structured interviews to elicit illness narratives and investigate the patients' experiences and subjective healthcare situation.

Williams examined patients' expectations and satisfaction and developed two ideas which should be noted: first, that the patient's views were necessary to professionals (whether drawn from interviews or other methods). Second, that all health professionals had a 'duty' to their patients (seen in terms of perceived obligations and users' rights) to provide a service and a 'culpability' which refers to responsibilities. If one or more of these dimensions are fulfilled, the patient is more likely to be satisfied (Williams et al.1998:1358). Chow and colleagues (2009) also produced a conceptualisation with three components that focus on the 'the background' of patients as shaping 'determinants' and 'characteristics'. Then they suggested a focus on health professionals and proposed three areas to patient satisfaction: *affability*, seen in terms of the communication skills and manners of healthcare staff, which included kindness, empathy and aspects of respect, trust and concordance; *accessibility and availability*, including issues such as waiting times and patients being able to get appointments when they wanted them; and views about the technical *ability* of medical staff which service users might question at any time in either high or low technical medical interventions. Chow and colleagues argued that patient dissatisfaction was primarily a reflection of a lack of affability, accessibility and availability because the ability of health professionals was harder to judge for service users (Chow et al.2009:438).

A useful development of the concept of patient experience and satisfaction has come out of the observation that patient satisfaction is often high. Narrative accounts of experience of patients and carers can go against questionnaire surveys in which opinions are less detailed and less frank about the care received. Various reasons are given including concern for the possible effect of honesty on future care (Le Vois et al.1981, Williams 1994, Edwards et al.2004). In interviews of users of orthopaedic services the process of *transformation in views* by patient was identified by Edwards and colleagues (ibid.2004), who argued that patients could shift from a positive or neutral set of views to negative ones after a process of reflection. Williams (1994) has also argued that even positive experiences were not straightforward expressions. Applying this reasoning, negative experiences are not necessarily expressions of dissatisfaction with healthcare and this may explain high satisfaction rates seen in quantitative surveys (Edwards et al.2004). Patients show variations in their views in what is considered acceptable, some being more accepting than others, tolerating discomfort and delays which may be seen as unavoidable aspects of the experience. Therefore using qualitative methods is important for Edwards and colleagues (2004), who explored the intricacies of patient experience and satisfaction and argued for a conceptualisation that acknowledges 'transformation'. Transformation was most evident when patients were given the opportunity to express themselves outside the constraining format of questionnaires. Such patients 'have a tendency to record consistently positive

responses in questionnaires compared to more nuanced opinion when using qualitative research methods' (Edwards et al.2004:160). Below Edwards and colleagues (2004) outline the many ways participants can under-rate their own views about their experience. The material is reproduced here as it provided useful guidance for this study:

Table 1: The range of ways in which transformation of opinion was put into operation

| |
|--|
| Participants tended to: |
| Be aware of hospital under-staffing in general, so be unwilling to complain about lack of attention; |
| Decide their own concerns were unique to them, rather than common concerns, therefore not worth voicing; |
| Decide that other patients were more deserving of attention so did not complain about lack of attention to their own problems; |
| Class their own concerns as 'little things' so not worth recording; |
| Take part in blaming themselves for a negative event thus reducing the blame attributable elsewhere; |
| Divert blame away from those most closely involved in their own care and thus avoid making a negative assessment of them; |
| Not want to get staff into trouble so prefer not to mention negatively perceived |

| |
|--|
| events; |
| Decide that the poor care received just represented an off day rather than normal standards so was not worth mentioning it; |
| Compare care against low expectations which it exceeded thus appearing relatively good rather than poor in absolute terms; |
| Feel relief at being home so prefer to forget about problems in hospital; |
| Assume staff always put patients' interests first. Any poor care must therefore be humanly unavoidable so no blame can be attributed; |
| Look only to the bottom line i.e. I'm still alive, aren't I? So be prepared to put up with problems on the way if the end is justified ; |
| Feel dependent on the goodwill of staff so prefer to avoid voicing negative comment in case the standard of care is jeopardised; |
| Appreciate that clinicians are only human so can't be criticised for social and even clinical failings on occasions. |

Reproduced from Edwards et al.2004

Edwards and colleagues (2004) highlighted the complexity and difficulty in interpreting patient experiences in the open narrative form as well as questionnaires. Their conceptualisation helped explains some of the difficulties in interpretation in terms of transformation.

Patient experience is seen as an important aspect of patient satisfaction in the recent publication of NHS guidelines on patient experience (Department of Health, 2012d). The focus of the department's literature review contained in the full patient experience guidance was the patient-centred care literature developed by the American organisation the Picker Institute in 1986 and subsequently elaborated upon by Gerteis and colleagues (1993). The National Health Council (2004) and the International Alliance of Patient Organisations (IAPO) further amalgamated their ideas about the meaning of patient experience (IAPO 2007). The Picker Institute has since been commissioned to carry out patient experience work in the UK and adopted a quantitative methodology.

In 2012 a 'Guidelines Development Group' (GDG) was convened for the purposes of developing the National Institute of Clinical Excellence (NICE) guidelines on patient experience. These synthesised the patient experience literature and produce a conceptualisation of good patient experience as being characterised by the following:

| |
|--|
| Dignity and respect; |
| Comfort; |
| Expression of preferences and informed choice; |
| Opportunities to self-manage; |
| Co-ordinated and continued care; |

| |
|--|
| Social, personal and psychological factors taken into account; |
| Sufficient information provided |

(Department of Health 2012:46).

For patients to have these good experiences the Department of Health also identified that related professional attitudes, skills and practices were necessary:

Responding to the patient as an individual;

Good communication skills;

A supportive attitude;

Being able to provide the relevant information.

The guidelines then found the main themes of patient experience (Department of Health 2012:47):

| |
|---|
| Knowing the patient as an individual; |
| Tailoring healthcare services for each patient; |
| Essential requirements of care; |
| Continuity of care and relationships; |
| Enabling patients to actively participate. |

These guidelines are also very similar to the *Patient Experience Framework* in use in the NHS by 2012 (Department of Health 2012c, Department of Health 2012/13). A summary table is reproduced in Appendix 7. Overall, however, both patient experience and satisfaction have the aim of improving quality of healthcare and become main stream in the NHS. The key aspects of good

patient experience are applied in the analysis of the interviews in Chapter Seven.

Conclusion

This chapter appraises qualitative approaches to conducting qualitative research. It began with a consideration of the methods, rooted in phenomenology. The discussion examined theories related to narratives and illness narratives offering a valuable approach to qualitative interviews of illness: 'Telling a story, enacting one or listening to one is a constructive process, grounded in a specific cultural setting, interaction and history. Text, context and meaning are intertwined' (Garro and Mattingly 2000:22). Qualitative interviews are seen as an important methodology for identifying themes and reflecting on the constructed interpretation of illness. Since Parsons' scrutiny of patient experience, a patient-centred focus has become a mainstream concern in healthcare. In the UK, this has generated obligations for the NHS to conduct regular surveys of patient experience. Such surveys often based their legitimacy on quantitative data and contrast with qualitative methodologies which were more open to identifying experiences taking in a wider range of social characteristics. In this thesis the experiences of recent migrants, by using a qualitative approach, was considered most feasible. The methods that were used are presented in the next chapter.

Chapter Four: Methods

The previous two chapters have mapped the theoretical journey necessary for locating the methodology of this thesis. Chapter Two presented literature which points to the likelihood of health inequality and perceived discrimination faced by migrant groups. Chapter Three made a case for qualitative interviews being able to evoke lay knowledge of illness as an appropriate method for exploring patient experiences and perceptions of stigmatisation. This chapter is concerned with the methods that were finally utilised.

The choice of methods for this research emerged from the ontological position that multiple representations and subjectivities exist. This position is appropriate for a study of recent low-income migrants and illness for reasons that will be outlined below. Furthermore, in this chapter, the key problems that were encountered when using the preferred methods are discussed, and finally some personal reflections about my involvement in this study are offered.

Research design

This research focused on recent low-income international migrants who had been ill at the time of interview between November 2009 and June 2010.

Recent migrants were defined as migrants who had been resident in the UK for between one and six years, meaning that they had arrived in the UK between 2004 and 2010. Low income was defined according to the UK government's definition of low-income households as those with an income below 60% of the

median income (the calculation for this can be found in Appendix 1). Illness was self-defined by perceived seriousness in a questionnaire using a Likert scale (the questionnaire is presented in full in Appendix 4). Originally, a comparative study was considered in which migrant experience would be compared with a 'control group' of non-migrants; however, it was concluded that there were too many potential problems with this type of design when the groups, including a mix in service use, were not sufficiently distinct (Flyvberg 2004). Instead a single case study approach was taken.

The advantages and feasibility of developing a qualitative or quantitative approach to data-gathering was weighed up. The preferred design was qualitative and is a contrast to the mainstream focus on researching patient experience which uses quantitative methods (Graham and Maccormick 2012 , Jenkinson et al. 2002). An exploration of illness and healthcare use by migrants could favourably be achieved by using an open and in-depth participant-led approach and produce insights that could not be generated through structured questionnaires alone. Moreover, in building the research population itself, difficulty was anticipated in locating and recruiting large numbers of willing recent migrants as there was no accessible and up-to-date data based on residency and nationality; and therefore no way of contacting such a population. Furthermore, conducting a large sample survey of recent migrants over a wide geographical area would also have been time-consuming for one researcher. Attempting to contact such a research group by post would mostly likely have

produced a low response rate. Lastly, a postal questionnaire would have needed respondents to have a reasonable degree of literacy to complete the questionnaires without additional help.

The approach most appropriate to the epistemology and the research questions was to carry out a face-to-face questionnaire with participants for gathering contextual information (see Appendix 4), followed by semi-structured interviews for gathering illness narratives (see Appendix 5). Interviews conducted with a maximum number of individuals in the time available was preferred over conducting second or third interviews with a fewer number of individuals. It was expected that some recent migrants would have low proficiency in spoken and written English. Language was therefore expected to be a potential difficulty in communication as one researcher could not span the many languages that would be required in order to interview participants in their first language. Low educational levels and writing proficiency was considered to be another possible barrier to communication with some recent low-income migrants -- although many migrants have been shown to have high levels of qualifications (Anderson et al. 2006 Zietsma, 2010). Overall, an approach that relied on verbal communication, allowing for the use of professional interpreters, was therefore preferred over methods requiring writing skills.

Community projects were the main means of finding participants. The participants were recruited from outside of the NHS settings for a number of reasons: the literature suggested such an approach would enable participants

to speak more freely to a researcher who was not associated with the NHS, in part because this would reduce any concerns that treatment could be affected or delayed because of their participation. Recruiting in this way also had the potential for including people who had felt ill but had not used, or had hardly used, health services. In addition to these reasons, recruiting from the NHS requires approval acquired through an extensive ethics procedure and there would have been no guarantee that after a long application process that permission would have been granted. NHS recruitment may have also required access to some patient information considered confidential. An ethnographic study of migrants using one or two specialist health services would have been an interesting approach but carried the connected risk of staff feeling evaluated by the presence of an outsider/researcher and thus affecting practices. Specific specialist services and illness associated with these were considered and rejected because such an approach would have made it hard for participants to remain anonymous in terms of the health staff treating them and this may have created worry. The design finally chosen was to conduct qualitative interviews with users of many different health services who were recruited from *outside* the health services setting.

Interviews were conducted between December 2009 and July 2010. At this time the connection between migrants and healthcare was not significant in the news media whereas in the last six months of 2013 the issue of health tourism has been widely discussed. These negative discourses about migrants may

have affected participants' willingness to join the study. Community organisations were used to locate recent low-income international migrants. I expected to face some difficulties in finding participants and therefore contacts and some snowball sampling methods were vital to help expand my network. I used a variety of contacts to increase the chances of reaching people of diverse backgrounds. This will be discussed further in the section on recruitment.

The first stage of the research data-gathering process was the development and administration of a questionnaire, which included both closed and open-ended questions. The preferred method of investigation was to meet participants, once to gain consent and conduct the questionnaire and then a second time for the semi-structured interview. However, the two tasks could be amalgamated into one interview if participants did not want to meet twice. It took approximately eight months to complete in-depth interviews with 41 participants. It was felt to be sufficient to focus on patient experiences of low-income migrants, a marginal group who are presently under-researched.

Foreign nationality, as discussed in Chapter One, is one criterion for identifying individuals as migrants. However, this study takes less account of nationality and considers residency and duration of migration as defining factors and explores the significance of these in shaping illness and patient experiences. Relevant, therefore, was the UK government's definition of a migrant as including a minimum residency requirement as it refers to persons who intend or have been resident for at least 12 months. Acculturation theories and the

healthy migrant hypothesis, discussed in Chapter Two, also argue that time is an important dimension of understanding migration. There is no one reason for the effect of duration of migration on the health of migrants; nonetheless, the duration of migration has been claimed to affect health status (Abraido-Lanza et al.1999) and continues to be a topic of interest (Lara et al.2005) and an area warranting further study. In order to avoid the ambiguities in the migrant category discussed in the introduction, a definition of recent migration was necessary. Recent migrants were defined, therefore, as people who had been resident in the UK for at least one *year but less than six full years*.

Despite identifying categorisations as important to the design of the study, some flexibility in sampling was necessary. This reflects both the qualitative methodological approach taken and most importantly the difficulty in recruitment. For instance, the income criterion was simple (changing incomes, changing rents and wealth could not be taken into account in the questionnaire as it would have become too long and intrusive). Also, only later in recruitment did it become apparent that migrant workers were hard to recruit and were more likely to drop out at the stage of the second interview because of heavy work commitments. Therefore during recruitment the residency criterion was treated flexibly in two migrant worker cases; one was resident for 11 months, joining family who were also recent migrants, and one had been resident for seven years. A flexible application of the criteria was therefore used because it was hard to recruit migrant workers willing to be interviewed. Consequently, the

small difference in sample sizes between the questionnaire and the semi-structured interviews reflects the hard to reach nature of the group being researched in this thesis and do not alter the findings. The final number of questionnaires was 46 and the number of semi-structured interviews conducted was 41 (see Appendix 7). The following section highlights more of the issues that related to recruitment.

Recruitment

Participants were recruited using a variety of methods. In order to reduce the risk of selection bias inherent in snowball or network sampling, a variety of initial contact points were used. Key informants from different organisations were contacted by drawing on my own local knowledge and professional contacts. I am a former community mental health worker and through this role I had contacts in different community organisations. In addition, the research topic had attracted interest from the City Council and Primary Health Care Trust (now known as the Joint Commissioning Service). Some of the informants in these organisations knew of or were working directly with migrants, and they acted as gatekeepers as well as helping to find potential participants. Through email, phone or face-to-face meetings, these key informants from community organisations initiated meetings with prospective participants. In total, key informants from 15 different organisations met to discuss involvement in the research as initial contact points for sampling. These included an open-access

walk-in health clinic operated by a privately owned company for the NHS; two voluntary sector community organisations offering services to migrants and refugees; four community educational projects (providing English classes in separate locations); three private sector workplaces; a community alcohol drug rehabilitation project; two places of worship; one children's centre; and an unemployed family centre.

A poster-leaflet was designed and prepared with generous assistance from an officer at the council (see Appendix 2). The poster information was circulated to the above mentioned organisations. It was also sent to the local interpreting service for translation into the most frequently requested foreign languages by health service users. The interpreting service also circulated the information to their interpreters asking them to mention the project to clients.

These initial meetings were crucial to recruitment yet even though the aims of the research were clearly presented verbally and with translated written information, some community service managers did not want to expose their service users to any research or disturb their programme of activities.

I decided to offer those completing both the questionnaire and the semi-structured interview an expenses voucher. The reason for doing this was primarily to value the time and effort given by participants to the project, particularly when most of the participants recruited to the study would be low paid workers or unemployed. This intention was mentioned in the information sheet about the project (see Appendix 3) and briefly when discussing the

project to potential participants. However the value of the voucher was not mentioned and the researcher was careful not to over-emphasise this aspect. This cautious approach aimed to counter possible criticism that the expenses were an incentive to participants which could have affected recruitment. Reflecting on this possibility, I concluded that none of the respondents appeared to be participating to receive the research expenses. For instance, there was one English language teacher in one of the classes who emphasised the expenses when introducing the project but this conspicuous introduction did not lead to more participation from this particular class of students. The possibility of expenses affecting recruitment was reflected on continuously during analysis and the conclusion drawn was that participants had not been unduly influenced, but instead that many had needed encouragement to come forward and the expenses had helped. The possible stress of participating in this research as a recent low-income migrant was acknowledged and valued in this method. Many participants had shown surprise and pleasure at the end of the interview when offered the £25 voucher.

In part, the success of the recruitment sites rested on the ethical stance taken by managers as they were acting as gatekeepers and their responses to the project varied. Private workplaces were difficult to gain access to; the collaborators and my academic supervisor both used their connections to companies to help gain access. Even so, some companies were too busy to take on the additional task of talking to a researcher and their workers about a

project. Most gave response to the project information sent by email to named managers. Fortunately, of the companies that were approached one large workplace did respond and was happy to allow me to meet their staff at the end of their shift. This workplace led to several recent working migrants participating.

Another approach taken to diversify the initial sample was to present the project to a city-wide meeting of adult language training providers; this again made use of one of the research collaborators' contacts. Two of these organisations responded positively to the research and provided opportunities to introduce the project to their clients at five different venues. In this way 15 classes were visited to recruit for the project. The teachers of these classes showed different degrees of interest in the research but all gave the researcher a few minutes to talk to the participants who were attending their classes. There was a wide range of English proficiency. Some teachers who showed more enthusiasm for the project did so because they saw the research and outsider contact as a worthwhile experience individuals in their class.

Refugees were well represented in the sample and were not difficult to recruit from the community organisations they attended. The type of migrant that was harder to recruit were working economic migrants; their workplaces proved to be the most effective place through which to make contact, though snowballing also led to interviews. Asylum seekers were also hard to recruit -- possibly also a reflection of the lower numbers in Brighton and Hove. More common were

refugees who had recently been granted refugee status and so they could talk about recent experiences as both asylum seekers and as refugees.

Some participants were not sure about participating for a range of reasons.

One reason for their uncertainty appeared to be related to their confidence in speaking English and/or a lack of awareness of or experience with using an interpreter. In some cases it took two telephone conversations for participants to understand the purpose of the study and agree to a meeting with an interpreter and the researcher. This process suggested a lack of confidence as well as fear about confidentiality and anonymity in relation to participation.

During recruitment and while gaining consent, the option of withdrawal from the project at any time was reiterated (the consent form is included in Appendix 3).

However, interpreters were not available at this initial stage of recruitment and this posed a challenge as there were some participants who struggled to understand the research objectives at first contact. In such cases the researcher made several careful phone calls or returned to the point of contact to get assistance from a potential participant's friend who would interpret and ensure the participant understood the objectives of the study and terms of participation. Each potential participant was asked if they had a preference for using an interpreter and while some participants did know about interpreters there were several people who learned about the existence of the interpreting service for the first time as a result of receiving information about the project.

There were some who used interpreters in some situations but decided they did

not want to use an interpreter for the study and this decision appeared out of step in a few cases with my perception of the participant's language ability. I checked this decision again before commencing with interviews and if maintained the preference was accepted; the issue of interpretation is discussed later in this chapter and in the analysis chapters. The appointment time for the interview was arranged with a professional interpreter present. In these cases, project information was repeated with the interpreter present to ensure full comprehension with regard to consent and to clarify that the aims and scope of the project were understood. There were other reasons for participants finding it hard to commit to the study such as childcare and work commitments. The physical and mental health of some participants created anxiety and uncertainty about talking about illness; this will be discussed in the section about ethics.

Access to service users at an NHS walk-in clinic was given after a meeting was set up with the manager (the clinic was run by a private company that was commissioned by the local Primary Care Trust). One of my supervisors and local collaborators in the research also attended and the outcome was for the manager to give permission for me to try to recruit participants who might be waiting in the clinic. However it proved difficult to approach users of the clinic who were waiting for their appointments for various reasons. In some cases people approached were not recent international migrants, others were students who were very new migrants (and were still considered visitors by the

governmental definition) or some faced only very mild, temporary illnesses that would not have given them sufficient experience of using healthcare services. Finally, the majority of patients in this clinic were not migrants. One suitable participant who was recruited in this way withdrew later, giving work reasons for not meeting with me further.

Two community organisations gave access to their drop-in services which would have potentially been for all ethnic minority persons and one was specifically for migrants. In these organisations I could chat on a one-to-one basis with potential participants and these proved to be good places to gather extra information and recruit participants. In another place, information was distributed to potential participants after a church service. The remaining organisations took the information and mentioned the work to clients themselves or left the posters in their reception areas; however, only in a few cases did this method lead to participation from their service users. After being interviewed, several participants were able to recommend people they knew, so some effective snowball sampling also took place.

Following these gradual successes at developing networks to recruit participants, people in public places were no longer approached. This method had been left as a last resort as it felt inappropriate for a purposive sample methodology and unlikely to yield positive results. I also felt personally uncomfortable about approaching people in this way in order to talk about health. Finally, I was also concerned that the interaction leading to the selection

of recent migrants, if observed, risked reinforcing negative discourses about migrants receiving excessive attention and resources.

The interviewing process

Potential participants were introduced to the project in a five-minute presentation and a poster/flyer that had been translated into nine languages (see Appendix 2 for English version). The choice of languages for translation of the information sheet was based on advice from the interpreting service which monitors the most commonly requested languages³⁵. The translated information sheets were helpful in communication and gave credibility to the project. This first meeting with potential participants involved some purposive selection based on asking people about their length of residency and whether they had experiences of illness. If participants fitted the criteria of recent migrant and illness experience the project aims were discussed further, often on a one-to-one basis to ascertain interest in participating. Potential candidates were offered interpreters and especially for those with less fluency in English another discussion with an interpreter was necessary to gain consent. For those who did not want or need to use an interpreter, contact details were taken and an interview time and place set up without any additional problems. For those using interpreters, setting up the interview was a much harder process

³⁵ The project information was translated into Arabic, French, Portuguese, Farsi, Polish, Oromifa and Mandarin.

and miscommunication was guarded against. At the beginning of the interview the project aims were explained again, written consent obtained (see Appendix 3) and the demographic questionnaire answers were recording by hand by the researcher and after the first few, the questionnaire responses were also tape-recorded.

Interviews were the principal technique being used and it was considered important that full use of the data gathered was made possible and so the interviews were tape recorded. According to Denzin and Lincoln the criteria for achieving quality in interviews (and qualitative research in general) include 'trustworthiness, credibility, dependability, transferability and confirmability' (Denzin and Lincoln 2000:21). They advise that these criteria for doing research should be the measure for quality rather than the positivist concepts of validity, reliability and objectivity. This study used recorded semi-structured interviews in order to collect credible, transferable and dependable narratives. Open-ended questions enable an empathetic approach to interviewing which allows the participants to express their views in the order they prefer, and is a less directed approach suitable for developing knowledge within new areas of research. The approach also creates a relaxed and less demanding atmosphere within the interview, making it suitable for gaining the trust of vulnerable participants. In this research, the target number of semi-structured interviews in order to achieve reliability was set at between 40 and 50 and the former target was achieved.

In addition to the epistemological questions surrounding narrative inquiry which have been discussed in Chapter Three, the aim of collecting narratives from people who would not be speaking in their first language was an additional aspect to consider when conducting a study involving recent migrants. The fundamental problem here is the inevitable differences between my own language proficiency and those of some of the participants. If the categorisation of recent low-income migrants was to remain, then my best strategy for addressing the issues was to use professional interpreters, thus providing a means for me as the researcher (albeit an imperfect one) to communicate with recent migrants who spoke a range of languages. Professional interpreters were offered to *a//*the potential participants and 18 of those who participated chose to use an interpreter.

The questionnaire was structured and short, with approximately 50 questions which were mostly closed-ended questions. Three questions about health status used a Likert scale which deliberately followed the questions in the 2011 census about health status. In particular, the questionnaire asked about age, gender, migration types, nationality, ethnicity, illness diagnosis (if known), work, income, household size, education, reasons for leaving their country of origin, immigration status and nationality, and language ability. A total of 46 participants answered the questionnaire and from these several dropped out due to work commitments or misunderstandings about the health-illness focus of the project.

The cost of using professional interpreters was budgeted into the project. The decision to use an interpreter was based on the participants' wishes and once interest was expressed a booking was made for a particular place, time and length of session – logistics which both enabled and constrained the research process. Costs were incurred for any late starts or cancellations to the interview – there were some cases when participants were not on time (and in a few instances the interpreters were late due to difficulties finding the home or interview location). Both situations were stressful for the researcher. The aim was to spend 15 minutes briefing the interpreter about the project before the interview; however, lateness or meeting on a busy street sometimes affected my ability to carry out this task and/or the quality of the briefing.

The consent process took varying periods of time to be explained and agreed upon, with more time taken up by participants using interpreters. When participants consented they were asked to split the meeting and have two meetings: one for the questionnaire schedule and a second for the semi-structured interview. This request reflected the researcher's preference, as I saw an advantage to meeting twice to build better rapport with participants and to giving them additional time to reflect on the questionnaire information.

However, even though a choice was offered it became quickly apparent that most participants preferred to combine both tasks. All participants agreed to the interviews being taped, although some expressed initial reluctance.

A choice was offered to participants with regard to the venue for the interview. Specifically, homes, workplaces, community organisations, the Primary Care Trust office, council offices and cafes were all offered and used by participants in the study. Upon reflection, more was learned when invited into a participant's home in terms of understanding participants' living environments. However, it was not clear if participants were more relaxed at home as many of these interviews were conducted with small children present and in these circumstances it was often necessary to break off the interview. This was stressful for the researcher and affected the flow of the narrative. On the other hand, on some occasions these enforced pauses were helpful as they provided time to reflect on what was being said and to re-frame a question. Undoubtedly, interviews with children present were hard for the participant as they tired more quickly from concentrating on their child and the interview and this continued distraction also tended to result in the participant offering briefer answers. In one example, during an interview a participant's toddler cut her finger when out of sight because the participant had not been able to keep an eye on the child whilst being interviewed. This was a disturbing consequence of the interview but fortunately the cut was not serious.

Interviews arranged in the centre of town created some problems; some participants had problems finding the venue, especially when it was necessary to give them directions over the phone. Interviewing in offices produced formality. For instance, the Primary Care Trust kindly offered their meeting

rooms, and these were comfortable and centrally located but could have led to participants connecting the research to the government, which may have been an unsettling association for some. However, this concern was not apparent, and in fact a few participants appeared to enjoy the change and the formality of a busy working office and in one case a participant revealed he had once worked in the office as a cleaner.

There were some limitations to using semi-structured interviews. On occasions I found myself using closed questions when intending to ask open questions and I was concerned that this could have shaped some of the responses given. This was mainly due to my nervousness in interviewing and this got better over time. My concerns were also overcome by having taped a good number of interviews which enabled a process of verification of the data and its utility within the analytical process. Taping also enabled more sensitivity to the possible vulnerabilities of the participants as note-taking was not necessary, which reduced the formality of the interviewing process. Reflecting on the process of interviewing, the pressure of time was very strong; as mentioned already, children were often present or participants wanted to give or had only a limited amount of time. Semi-structured interviewing provided some prompts which were useful for consistency and shaping the narratives which aided interpretation. The questionnaire presented a large number of questions in a closed-ended format which produced shorter responses and was a conscious strategy. The goal was to collect key demographic information and it reflected

awareness that participants would experience time constraints. Being able to re-read full transcripts of the semi-structured interviews allowed me to make full use of interviews and complemented the open approach sought. Both methods (questionnaire and semi-structured interviews) had limitations but together they complemented each other: Finally, the method of semi-structured interviewing still encouraged and enabled narratives of experiences of illness and use of healthcare to emerge.

Ethical issues

The University of Sussex has a procedure for research ethics which requires the ethical implications of a study to be fully considered before full approval to start a project can be given. This was applied for and granted between August and October 2009. In the application it was stated that potential participants in this study would be assumed to be vulnerable persons in terms of their mental, physical health and financial status. Therefore various measures were taken by the researcher to protect participants. Every effort was made to anticipate potential participants' uncertainty and concerns about the project, and in recruitment efforts the aim was to not be too persuasive when recruiting. Again, research participants were informed about the nature of the research and asked for consent before the start of interviews (Appendix 3) and participants were told they had the right to withdraw from the project at any time.

Additional ethical issues raised in designing the research project are also noteworthy. For example, the NHS could have been used as the initial point of contact with potential research participants but it was felt that talking to patients whilst they were on-site using health services would raise larger ethical issues about approaching patients whilst unwell and suffering. In addition, more NHS permission at various levels and operational staff co-operation would have been needed and this could have met with resistance. In comparison, accessing community organisations raised fewer ethical issues than if the study had been located on health service premises. Even so, each community organisation took its own ethical position about granting the researcher access to potential participants. From the point of view of the participants' vulnerabilities, approaching individuals in the community setting was a little easier in the sense that it was outside of the NHS and this enabled individuals to recount their stories without fearing any consequences in relation to health care servicing. The managers of the community organisations approached were gatekeepers; they considered the ethics of allowing access to their service users. Some spoke of concerns about whether they should allow me to approach potential participants about issues that were unrelated to service users' reasons for being in the service. In many cases the managers set conditions on when, what and for how long potential participants could be approached. One organisation refused access because the manager perceived no direct benefit for service users who were seen as vulnerable. This organisation had developed a policy

that restricted access to participants for research unless there was some component that involved skill development for the users. This was not known about during the design stage of this project and the offer of research expenses did not compensate for the absence of this educational element in this research project. Managers of community organisations, therefore, acted as 'gatekeepers' whose views on the benefits of this research to their services users varied and as a result access to them also fluctuated. Promotion of the project by the staff of community organisations enhanced the credibility of the project. Overall, attention was paid to where participants had been recruited from and the organisations that had done the referring. Both investigations showed that many participants used diverse community organisations (and included those from where access had been denied) and therefore participants were likely to have heard about the project from diverse sources.

The ethical implications of offering participants a monetary gift was also considered. Participants were offered expenses for travel (the equivalent of the daily bus fare) and a voucher for participation worth £25 in recognition of a number of factors: most participants were on a low income, many had complicated work schedules, and some may have sacrificed work to participate.

The project information sheet in Appendix 3 mentioned the offer of research expenses and the voucher was available to all of those who completed the semi-structured interviews. I considered the possibility that giving expenses could be a factor driving participation. At the same time, I felt it was the more

ethical approach to offer expenses as some recompense for involvement. I was convinced of this when I evaluated the mixture of responses when giving the gift. Three of the participants refused them and many more were surprised and most very pleased to receive the voucher at the end of the interview. This confirmed to me that most participants had not realised they would get a voucher for two possible reasons -- I had not emphasised it in recruitment or they had forgotten about it. For whichever reason, it seemed that most had participated because they wanted to talk about their illness and healthcare experiences. The three participants who did not accept the voucher were male refugees and it was clear in these cases that they were making a point; they did not accept a voucher because they wanted to use participation in the project as way of showing their gratitude for being granted refugee status in the UK, to feel less shame about being unemployed, and to give their own self-esteem a boost. The issue of vulnerability was alluded to at the beginning of this subsection and was a key ethical consideration within this study. For example, before starting the research an assessment of the likely vulnerability of the participants was made. As people who had been recently ill, including with mental health problems, care would be necessary when explaining the project and informing participants about the various dimensions of voluntary consent. When discussing the project with potential participants, the researcher made assurances to retain confidentiality which was reinforced by the interpreting services confidentiality policy. During interviews care was also taken to be

sensitive to the emotional vulnerabilities of the participants. To illustrate, when some of the participants cried or looked upset during their interviews, further questions were not asked on the topic and participants only continued if they wished. Reasons for migration were often sensitive issues and there was considerable variation in the detail given. In one case the participant said she was able to give her narrative only once because it was too draining for her to discuss the past.

Analytical methods

This section looks at the basis upon which interviews were analysed and how in some chapters particular interviews were selected for in-depth study. The thesis uses a simple form of narrative analysis. Some approaches to this type of analysis are very structured. For example, Labov and Waletzky's early work is cited for its framework for analysis that includes the following steps: orientation, abstraction, complicating action, resolution, evaluation and coda (Labov and Waletzky (1967) cited in Whitehead 2006:2237). On the other hand Mautner (2009) recommends curbing the use of rigid approaches to narrative analysis and suggests the method should reflect what is necessary and manageable (Mautner 2009:123-144). In the study 41 interviews between 60 and 90 minutes in length were transcribed in full, to gather all of the audible aspects of the interview. This data was then linked with notes I kept which captured, among other things, salient points about the setting. A two-pronged

approach made maximal use of the interviews, multiple readings of each transcript allowed the researcher to become very familiar with the interviews (which would not have been possible in a larger research project). Several analyses of each transcript were conducted. All the interviews were taped and could be listened to again and again. The on the spot interpretation by the interpreters formed the basis of the transcripts in English because there was no budget or time to produce a second translation of the taped interview. To make the most of the interviews, including those in which interpreters were used, a full verbatim transcript was made. This was also seen as a way of getting to know each interview in detail, to extract the fullest possible meaning from each interviews and this was especially useful for the interviews using interpreters.

Mayring (2004) conceptualised a simple method for narrative analysis that has become known as content analysis in which 'coding units' and 'contextualising units' are identified and analysed; these coding units can be equated with themes and form the main approach used in this thesis. Transcripts were read five or six times and thematic codes were produced (Flick, 2006; see Figure 1). These themes also reflect some of the questions asked in the semi-structured interview, such as perceptions of discrimination, social relationships, and emotions.

Figure 1: First thematic analysis codes

| <i>Thematic analysis codes:</i> |
|--|
| Migration experience and references to immigration status |
| Language issues. |
| Material deprivation and comments about work. |
| Suggestions that the knowledge of participants or education affected the interviews. |
| Comments about family life and networks, life course, and gender. |
| Communication issues, rapport and feelings about staff. |
| Perceptions of discrimination. |

The second analysis is presented in Chapter Six and for this a second set of thematic codes were created which were derived from further reading of the transcripts and from relevant theories about illness narratives. In addition, some of the most common features of illness narratives discussed in Chapter Three, such as diagnosis, loss of function, disruption and the emotional distress of being ill (and most often chronically ill), were taken as codes (see Figure 3).

Figure 2: Second thematic analysis codes

| <i>Second thematic analysis codes:</i> |
|--|
| Functional and emotional disruption |
| Time –emplotment and chronology |
| Chronic nature of illness |
| Frank's typology (Frank 1991) of chaos narratives |
| Diagnosis and treatment–contestation or acceptance |

In this thesis four of the 41 interviews have been selected to explore the significance of illness narrative theory and to consider what aspects, if any, demarcate them as being indicative of recent low-income migrants. In particular, the issues taken into account in the four interviews presented in Chapter Six were numerous and included variation in immigration status (refugees, European Union migrants and undocumented migrants), age, gender, and issues of ‘reliability, validity, objectivity’ (Flick 2006:376). The third point – issues of ‘reliability, validity and objectivity’ – led to considerations of the interviews in the following ways (see Figure 3):

Figure 3: Additional criteria used for selection for Chapter Six

| |
|---|
| <p>Additional criteria used to assist selection of four narratives for Chapter Six</p> <p>Use of interpreters</p> <p>Rapport with participants - number of contacts with researcher</p> <p>Perceived high satisfaction with interpreter</p> <p>Different location of the interviews</p> |
|---|

The possibility that differences between interviews were related to the use of a variety of professional interpreters or the use of the interpretation dialogue led to the decision to make full transcriptions of all 41 semi-structured interviews. A mixture of participants who had both used, and had not used interpreters, was deliberately presented.

Rapport between the researcher and participants (and in some cases also with interpreters) was considered an important aspect of the interviews. Interviews where the participant had met with the researcher on several occasions were regarded as particularly valuable, as through multiple contacts a stronger rapport was achieved. The researcher had encouraged all participants to meet twice, once for the questionnaire and the other for the semi-structured interviews, but most participants preferred to combine the two interviews into one longer interview. In one case, in order to conduct the interview the researcher had several meetings with the participant who was ultimately selected for Chapter Six to reflect that the experience of interpreting and being interviewed varied between participants. Similarly, the way the interpreter listened and became the voice of the participant was one aspect of rapport (and also a limitation in the method); one example of such tentative judgments was when the length of translated questions or responses was different to untranslated questions or answers. Finally, rapport was felt by the researcher in many cases but moreso when there had been hospitality from participants such as offering drinks or snacks at the interview, though it is also acknowledged this may have been a standard way of treating any guest for these participants.

The research processes described in this chapter have produced analyses of the data that will be presented in Chapters Five, Six, Seven, and Eight of this thesis, as each chapter uses a different analytical approach and together present a range of related findings. Specifically, Chapter Five explores the

social context of participants and participants' responses to the questionnaire; this is supported by comments from the interviews. For example, immigration status, ethnicity and language proficiency are some of the issues examined as important social contexts of illness for this study. The analysis in Chapter Six applies illness narrative theory to the interviews showing they contain both common characteristics and others unique to them as those of recent migrants. Chapter Seven uses a patient experience framework of communication and access issues. The analysis in Chapter Seven also presents responses to the questionnaire with regard to the term 'migrant'. These are linked to the concept of stigmatisation and discrimination (Link and Phelan 2006) and I argue that perceptions of both existed among participants. Finally Chapter Eight focuses on where the interviews support the argument that discrimination was perceived and finds that the experiences were likely to have a negative impact upon migrant healthcare experiences.

Intersubjectivity and positionality

Subjectivity refers to the subject's interpretation of the world. Denzin has argued that the researcher is like a 'bricoleur' - a type of do-it-yourself person who can do many different things with the tools available (Denzin and Lincoln 2000:4-6). In research, he argues that one aim of the bricoleur is to make sense of oneself whilst trying to make sense of others. As a researcher-bricoleur I kept a diary during the period in which I met and interviewed

participants. This section draws on this data to examine the development of intersubjectivity whilst undertaking research.

Intersubjectivity between researcher and participant permeates the interview encounter (Kvale, 2009) and is also at play within informal encounters with participants, creating interesting and noteworthy moments to also reflect upon. In some organisations with a drop-in format of support, it was possible to have conversations with many potential participants over a series of weeks. These conversations that occurred outside of the interview setting also offered insights into participant's experiences. For instance, one migrant confirmed what had been said elsewhere about how being stuck in the asylum process and having asylum status for so long made him feel like a new migrant after many years. Another recent migrant in a conversation at a drop-in centre discussed his dislike of the city and his desire to leave to be nearer his one relative. There was also a relationship between research participant and researcher created by the formulation of questions which shaped the responses that could and were given by participants. The questionnaire needed to be kept simple so that it could be easily understood and translated given that English was a second language for all the participants. In contrast, the interview encouraged subjectivity by providing the opportunity to speak freely; when questions were put to participants they were framed so as to be open and to encourage detailed responses and for people to feel invited to express their views. As more interviews were carried out, this became easier to do as a researcher and the

semi-structured approach meant it was less important to replicate the same questions in each interview.

Another question that should be addressed with regard to subjectivity is the effect of using interpreters within interviews. Did using interpreters and working across languages create a significant loss in meaning and understanding? Did the presence of the interpreter change the openness in respondents? Such limitations are present in this research design as the overarching goal was to obtain a breadth of participation from a range of migrants. Furthermore, 22 of the 41 narrative interviews were conducted without interpreters, showing that a large number of migrants interviewed were confident in their English language ability and/or preferred not to use interpreters.

The experience of communicating using an interpreter as discussed in the section on analysis was reflected upon in field notes. The presence of an interpreter changed the dynamic in the interview. Indeed, the interpreter as someone from the same ethnic group as the participant introduced a variety of issues for the participants, which related to ethnicity, class and gender as well as other social factors. Some participants discussed fears about interpreting and of confidentiality being lost when an interpreter was involved. Having an interpreter involved in the interview changed the relationship between the individual and their doctor with the result that many expressed a desire to manage without an interpreter when they felt this was possible. One participant was ambiguous in her views as she expressed appreciation to the interpreter

present but also described a preference for using a friend for crucial meetings with a specialist, suggesting she wanted an advocate present at times.

Conversely, some other participants who had struggled without an interpreter were seen to enjoy the interview, feeling empowered by having an interpreter to aid communication. Yet other participants recounted variable experiences: being unaware of the option of having interpreters when accessing primary care and thinking that interpreters were only available when they were referred to hospital. For those participants who discussed how much they valued their relationship with interpreters, in the majority of cases the same interpreters were requested for the research project to meet the stated preference of, and create a familiar atmosphere for, the participant.

Reflecting on the project, some interviews seemed to go better than others. In some cases I felt that this was connected to the relationship with the interpreter and participant. Some clearly had a positive impact on the interview, in other cases the effect appeared to be neutral, and in a few cases participants seemed unforthcoming and appeared concerned by both the presence of an interpreter and the research process. Just under half of the participants using interpreters did not know the interpreter who was requested to conduct the interview.

One discussion with an interpreter confirmed that the issue of confidentiality affected her client group's use of interpreting and emphasised a fear of loss of privacy and suspicion which was seen to inhibit use by this ethnic group (to which the interpreter also belonged). She suggested this was a cultural

attribute which was a powerful comment coming from a person of the same ethnic group (though appearing to have a different economic and class position).

The comment here highlights how explanations were sought by interpreters for behaviours that might appear to have risked worse health. One participant talked at length about other factors of importance to him, such as the importance of precision in interpretation and becoming familiar with an interpreter which for him had happened over a period of time.

The power dynamic between the participant and the interpreter (and also the researcher) was reflected upon. For example, the participant sometimes sought the opinion of the interpreter and I had to make clear that it was the participant's view that was of interest. Sometimes class differences were also apparent in these interactions. One interpreter had a strong personality and on several occasions could not resist correcting me when I found myself using the third person (he/she) to refer to the research participant instead of the second person (you) in the interview. The same interpreter also could not withhold giving her own views about ethnicity.

Participants showed hospitality in different ways and I reflected on the possible meanings of these acts of kindness on the interviewing process. On one occasion when I went to a participant's house, she had gone to considerable trouble preparing homemade sweets whilst separately revealing she had been feeling very ill the last few days. Yet the participant showed a great deal of pleasure at being able to be hospitable, particularly to the accompanying

interpreter who had previously attended appointments with the participant and who was coming to her house for the first time as a result of the research project. The interpreter took care in accepting the hospitality but did not become too familiar, thus trying to maintain her professional position and possibly status. The participant remained friendly to the interpreter but I wondered if she was disappointed with this formal approach. In contrast, in another interview when I went alone to the house of a participant, a similar level of hospitality was experienced (with handmade biscuits and tea). I was moved by the generosity shown towards me, a stranger, and by the pride in the homemade biscuits which clearly reproduced traditions of her country of origin. In both cases the participants had produced the sweets despite being on benefits and therefore having very limited incomes.

A narrative is subjective in the sense that it is an attempt at representing one or many personal experiences. A narrative may vary each time it is told.

Moreover, it can be interpreted in many ways. The interviews were also subjective in the sense that participants were expressing feelings about their experiences. Understanding the emotions in the interviews was difficult and demanded sensitivity and interpretation. At times I was moved as I heard descriptions of migration, participants' longing for their country of origin and their distant families, their experiences of unemployment, and the day to day struggle of bringing up a family in the UK on a low income. On some occasions such sharing led to intersubjective exchange as I felt it appropriate to share

some of my own subjective experiences. This intersubjectivity was played out for many reasons including a wish to show understanding, empathy, and respect and to shift the power balance inherent in the researcher-participant relationship.

The researcher's position is also a part of the research; certainly, my views have changed over time. During the course of this study, patient experience has been a regular topic discussed in the news media. My views and position on these subjects has been influenced by what I have heard in relation to patient experience, the discourses that have developed around 'health tourism' in the NHS (as discussed in Chapter One) and the challenges to universal health care were of interest to me. Hearing the migrant narratives of illness also prompted personal memories and reflections.

One example of a personal link made by me whilst doing this research related to my father's experience of being an economic migrant. Another was that when hearing participants' experiences, I was reminded of occasions when I have felt like an outsider; in my childhood, adulthood and recently when using health services. These reflections are discussed in the final section of this methodology chapter on positionality. Like the interviewees who were being scrutinised for their views and positions, I look to my own viewpoints, or 'positionality' in this section. These standpoints are related to what I think about social conditions, how I feel about (and choose to remember) past experiences; and how experiences have accumulated to inform my current opinions. Clearly,

the process of research is affected by the attitudes and experiences of the researcher both prior to and during the research , making the concept of reflexivity a valuable tool for pointing out the importance of making these connections mindfully (Kvale, 2009).

As humans we hold and express views and take positions in conscious and subconscious ways. These forms of felt, expressed and interpreted positions are relevant to the knowledge production process. In positivist theories of knowledge, one's positionality is not relevant or at the very least should be kept out of research and in qualitative research it is recognised as unavoidable. Rather, positionality is a part of processes of interaction and interpretation and therefore should be acknowledged in research. Moreover, a worthy interpretation of others' behaviours should come from an awareness of one's own social and psychological 'baggage'. Therefore, I would argue that reflecting on and acknowledging one's own subjectivity is essential when interpreting the accounts of others. With this aim in mind, I kept reflective notes during the period of making contact with participants, including when I felt resonance between the research and my past experiences and what was happening in my personal life at that time.

It is part of the methodology to acknowledge that the interest in both recent migrants and long-settled migrants is of personal interest. My parents' and my own experience of migration have at times resonated with the experiences of some of the participants. I am the daughter of an economic migrant who arrived

in the UK from Delhi in 1962. My father came with very few resources - a quilt on his back and some distant family contacts – and when he realised he could not complete his studies, could not tolerate working so hard, or to be alone any longer, my mother sailed to join him (over four years later) with five children. He had never met his by then three-year-old and youngest son who was born only after he had left India. There are many aspects of my personal narrative that are connected to the migration experience – my parents’ story of migration, my upbringing and identity. Questions also arise as to whether I am a migrant. Is the notion of second generation migrant a valid concept and at what point does a person cease being a migrant? Is this a personal, subjective matter and/or should distinctions be made clearer between government’s definition of migrants and other definitions? In adulthood I have undertaken my own migrations for work to different places (India, Ethiopia, and Nepal) and for personal reasons to explore my own background. Migration and identity are closely related but not exclusively so. Others’ perceptions can affect how one feels; for instance on the telephone I am often aware that I am heard as an English person and I sense the listener’s surprise when I give my Indian name; this reveals a new aspect of identity that many of the listeners did not expect. Thus, for many of the reasons mentioned previously, in face-to-face encounters with health professionals I am aware of how professionals are required to make judgements and may begin when they initially see me; here is a person of colour, probably Indian, and then how any preliminary judgements they have

made have to shift as we converse and my language fluency and accent is registered and new judgements must be made.

It is common to have an awareness of people who might appear to have had similar experiences. For the reasons given above it is interesting to me personally to explore what ethnicity and racism mean, alongside many other social aspects of the lifeworld of migrants. Additionally, I have children and they have dark skin and may not necessarily appear to be of mixed heritage. They could even appear to be genetically fully Indian, even though they have a father who has a white European ancestry. Their experiences of living in the UK, as young people with mixed heritages, has shaped their views; yet having a skin colour that could align them with recent migrants has added another layer to my own personal awareness and experience of the subjectivity of ethnicity.

The illness narratives I gathered resonated with the literature, media and also with my own experiences of using the NHS. I experienced a kind of 'other-ing' in a recent NHS appointment when my name was called out in a very clumsy way in the waiting room. It was clearly a foreign name for the nurse and she made little attempt to pronounce it. On other occasions my field notes reflected on waiting times and my feeling as a patient that my health problem was minor and I should really just ignore it – in other words, that I was being a nuisance.

Then there is the pressure to express one's suffering and illness clearly in eight minutes to the GP, an arrangement that has always felt rushed and difficult for me. In my field notes I reflect on my own position with regard to biomedicine, in

particular my tendency to put the possibility of biological causes for illnesses over psychological ones. I did this recently when experiencing symptoms which could have been stress-related. I was keen for investigations for a hormonal problem to be done, but fortunately my GP was willing to take the same approach and offered blood tests which led to a diagnosis of having an iron deficiency. I reflected on how it would feel not to get this response from the GP; this experience resonated with many of the narratives.

I also reflected in my notes on how my GP was making judgements about who I am. In my case I felt concordance with my GP in terms of social and biological matching of certain characteristics (Armstrong et al.2007, Blanchard et al.2007, Cooper et al.1999). I felt there was some connection between us as both being long-settled ethnic minority persons, women, and having the same class position despite some differences. I have become aware that medical specialists have attempted to place me and my children in terms of class, which has occurred by asking me about my occupation. My GP now recalls that my work is related to studying illness when we meet.

Finally I come back to doing research having long left the world of higher education except for some Open University modules some 20 years previously when I completed a Master of Science in nutrition soon after an undergraduate medical science degree. Doctoral study has led to me learn about social science methods for the first time as has my completion of a Master of Science in comparative and social research methods. The studentship I hold is intended

to bring a person who had been working outside the academy to a topic of interest to them and in this sense I think it has achieved one of its purposes. My working life has been varied. It has led me to being an economic migrant myself, after training to be a nutritionist, then returning to the UK to work for local government as a health promotion specialist, and later to work for several community organisations as a mental health worker and support worker for vulnerable people. I have found the academic style of writing necessarily challenging and in this respect I have found affinity with the international students who struggle to write in English which is often their second language. This chapter has laid bare some of the issues that have led to the selection and use of this research methodology. Some of my research experiences are described as well as thoughts on the risks and limitations of the chosen methods. Subsequently, personal reflections of doing research and my position with regard to the project have been raised. The following four chapters present the findings generated from the data gathered using the questionnaire and interviews. Chapter Five will show the importance of the social context of a group of recent low-income migrants. Chapter Six will discern aspects of the interviews as illness narratives. Chapter Seven discusses the negative experiences raised in the narratives. The final chapter, Chapter Eight, first discusses one health policy to explore whether policy can be instrumental with regard to indirect discrimination and then examines participants' perceptions of direct discrimination in their treatment.

Chapter Five: Contextualising illness and healthcare use

The central aim of this thesis is to understand the health experiences of recent low-income international migrants. The focus of this first analytical chapter is to present contextual information pertaining to the social factors affecting the illness experience of migrants. The data provides some empirical support to the concept of health inequality which is one theoretical framework upon which this thesis is constructed. The literature review in Chapter Two suggested that social and economic factors affect the health of migrants and this argument is explored using the data gathered. Specifically, this chapter presents an analysis of both the questionnaires to provide descriptive statistics and uses extracts from the interviews. The coding themes for the semi-structured interviews related to issues such as migration experiences, language, material deprivation, education, social networks, gender, communication and perceived discrimination. The questionnaire responses were analysed with regard to the presence of the themes identified above.

Therefore this chapter begins by addressing the characteristics of migrants as a group such as residency, nationality, ethnicity, visa statuses and language proficiency. In this research, these characteristics also situate the migrants' interviews and comments from the interviews illustrate how these issues were important in the experiences of illness and pathways of healthcare accessed by

research participants. The significance of faith is also discussed in this section, raising the issue of faith being a neglected but important characteristic of migrants' experiences. Subsequently, other contextual material is analysed, namely income, occupation, education, social networks, age and gender as they were significant factors for the group studied. In the last part of this chapter an overview of the specific types of illness faced by the respondents is offered and explored, variations and types of illness are significant dimensions which are invisible if illness is seen as a homogeneous factor across the group. In each section the demographic data are presented as tables and are supported with extracts from the interviews. Appendix 7 summarises individual participants' names and demographic data which may be useful for reference purposes when reading individuals' quotes.

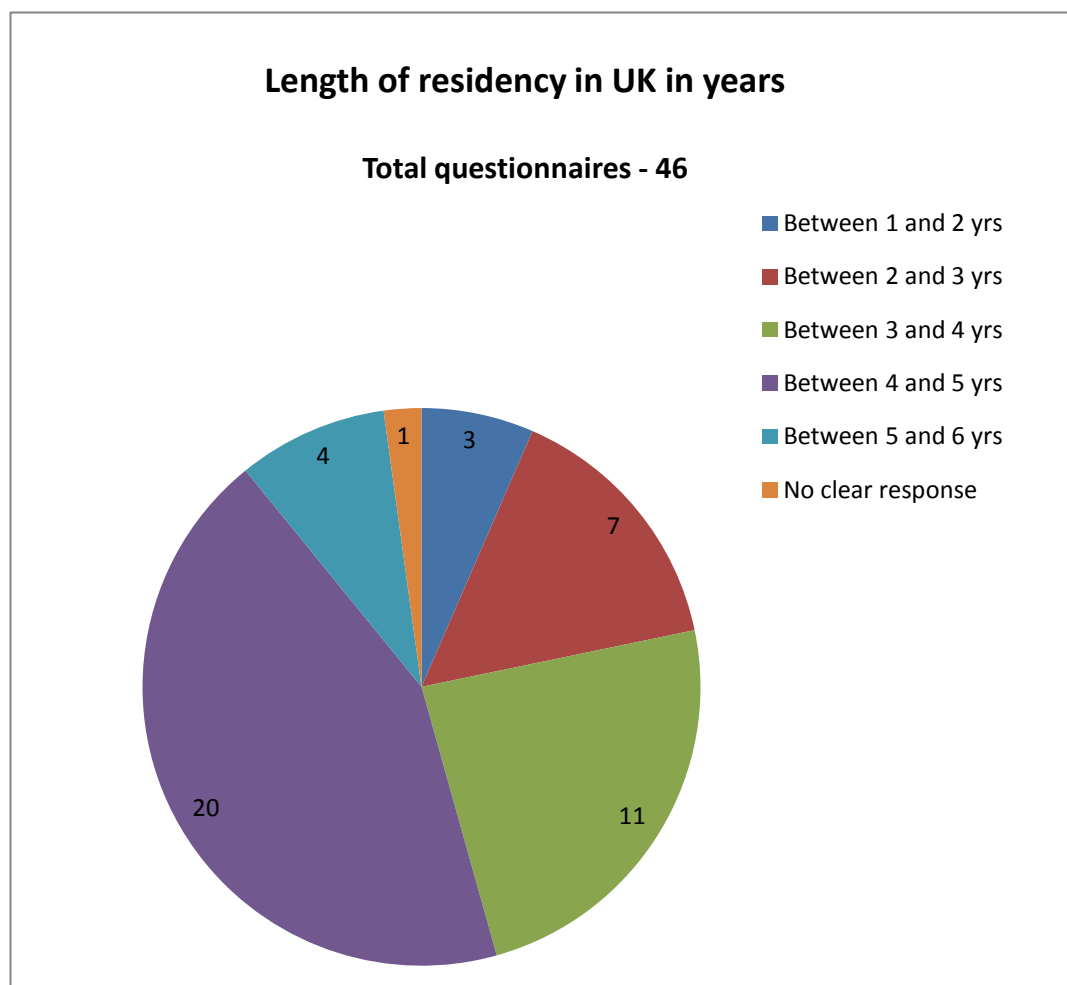
Situating participants within migrant categorisations

Understanding the effect of migration on the lives of recent low-income migrants who have been ill is central to this study. The respondents self-defined as migrants from two main lines of questioning in the questionnaire; first they were asked if they had come from another country to reside and if so, from where. Participants were also asked about nationality and some volunteered the information that their nationality was different from their country of birth. The second line of questioning investigated residency, namely how long participants had been resident in the UK. This information was used to confirm that

participants were recent migrants and had been resident in the UK for between one and six full years.

The group of participants who were subsequently interviewed were diverse in terms of length of residency, immigration statuses and nationality as is shown in Figures 4 and 5 and Tables 2 and 3. Of those interviewed, the majority fell in the middle of the residency range as most of the group had been resident for over three years and under six years. The idea of being a migrant and participants' specific views pertaining to residency (gathered through these questions) are explored in more detail in Chapter Seven.

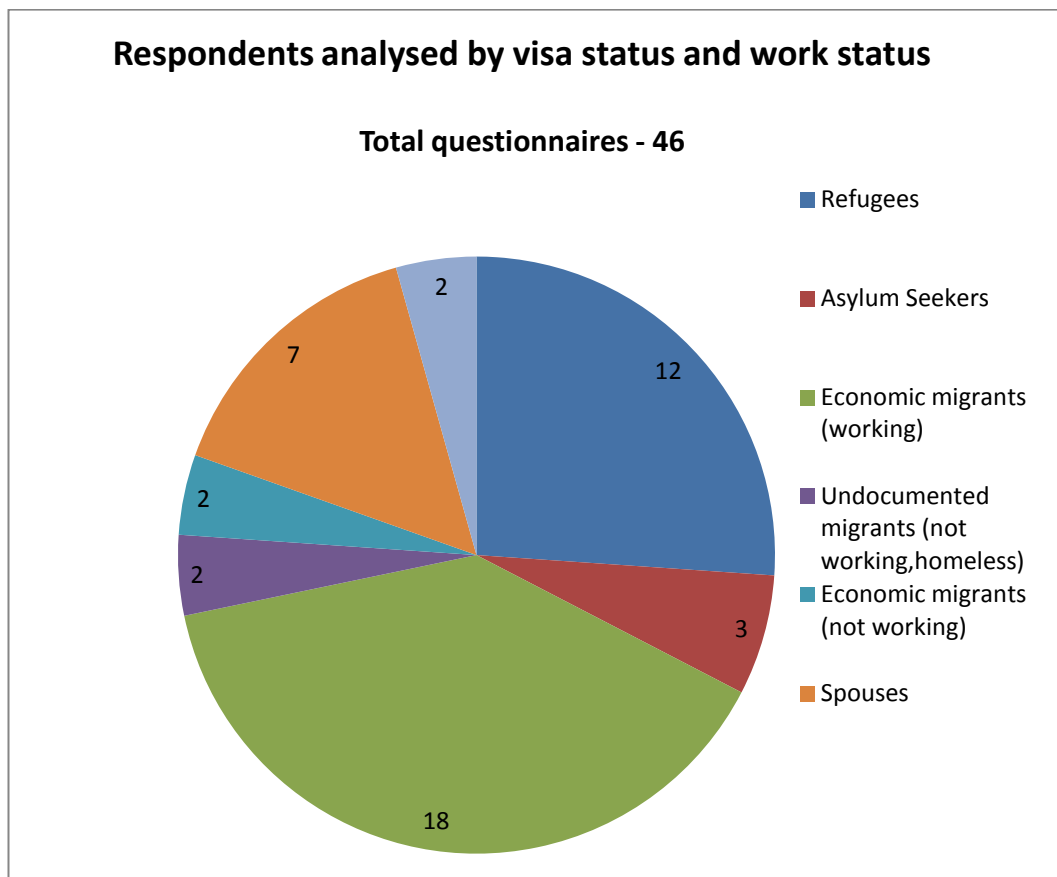
Figure 4: Length of residency in the UK of respondents



The participants were also asked for information about their immigration status and the answers presented in Figure 6 below indicate that the sample was approximately equal between economic migrants and refugees/asylum seekers/spouses. Spouses could be formulated as group comprising people who were married to refugees, working economic migrants and non-migrants. This constructed category of 'spouse' was valuable as it highlighted an intersection between immigration status and gender and also pointed to another nuanced finding which was that spouses were likely to have different experiences based on the opportunities available to them

In this study, another large sub-group were working economic migrants; 18 out of the 24 economic migrants who were in employment at the time of the study. Interestingly, what was seen in the case of refugees was that 11 out of the 12 refugees interviewed were not working. Differences in immigration status (between refugees and asylums seekers) are particularly clear and this is an important factor as asylum seekers are officially prevented from taking any paid work, whereas refugees have the the right to work. Only one refugee participant out of 12 was in paid work at the time of the interview. Work issues will be discussed in more depth in the income and occupation section of this chapter. Importantly, and regardless of work status, these depictions could not account for variations in the caring responsibilities many participants had or whether they were in full- or part-time work.

Figure 5: Types of visa statuses of respondents



Spouses formed a larger number than had been expected: two of a total of seven spouses were married to UK nationals, five were joining refugee partners, and one respondent was a spouse within a family soon to become British nationals. Spouses have different rights to work and mostly had caring responsibilities. There were two other individuals who had started out as economic migrants and had later lost their jobs and become homeless and undocumented by the time of the interview. Two participants were self-identified as students – a status choice based on their different rights to work as well as feelings about their identity. Both participants had been studying full-

time and one had recently completed her studies --- both were working part-time.

Nationality, as this study confirms, is a fluid concept. In several cases respondents first said they had EU nationality but then stated that they were born outside of the EU. It was not clear if this description meant they held on to their nationality in their country of birth; however, this practice was most commonly spoken about by those born in South America who claimed, via historical heritage, a right to ancestral citizenship within a European country. In these cases Italy and Spain was mentioned, though other European countries are also referred to in this way. Many respondents reported that they were either in the process of applying for or expressed their intention to become British citizens. Others still referred to themselves as EU nationals but inferring from the non-EU languages spoken it seemed likely that they had heritage, ties or were born in other countries outside the EU. Overall, it was clear that nationality would change over time and as a category in this research it is shown to be limited in its scope and ability to define participants. Significantly, these observations made in my own research also reflect the data showing changes in the UK population between the 2001 and 2011 UK census data on nationality, issues which were highlighted in the introductory chapter.

Table 2: Nationalities of respondents to the questionnaire

| Nationalities | Regional nationality | Total 46 |
|-----------------|---------------------------|-------------|
| Polish | EU | 8 |
| Czech | EU | 2 |
| German | EU | 1 |
| Latvian | EU | 3 |
| Lithuanian | EU | 2 |
| Hungarian | EU | 1 |
| Romanian | EU | 1 |
| Greek | EU | 1 |
| Peruvian | South America* | 1 |
| Brazilian | South America* | 1 |
| Turkish/Kurdish | Eastern Europe/non EU* | 1 |
| Turkish | Eastern Europe/non EU | 1 |
| Ethiopian | East Africa | 5 |
| Sudanese | Central Africa | 3 |
| Gambian | Central Africa | 1 |
| Egyptian | North Africa | 3 |
| Libyan | North Africa | 1 |
| Palestinian | Middle East | 2 |
| Iranian | West Asia | 3 |
| Indian | South Asia | 2 |
| Sri Lankan | South Asia | 1 |
| Afghani | West Asia | 1 |
| Chinese | East Asia | 1 |

*refers to participants who also informed the researcher they changed nationalities and to those who referred to dual citizenship

Table 3: Regions of birth of respondents

| Nationality European Union (includes changes *) | Nationality Outside European Union | Total |
|---|--|-------|
| 22 | 24 | 46 |

Information about ethnicity was also collected in the questionnaire. This was done using three ethnicity classifications which reflect conceptual critiques of subjectivity of ethnicity, the complex public discourses and my subjective views about the limitations of ethnicity classifications. The first ethnicity classification used was identical to the 2011 national census, the second was derived from a tool being used by the Brighton and Hove NHS Walk-in clinic in 2010 (the company delivering this was privately owned) and the third was an option to self-define one's own ethnicity. The question was framed using a definition of ethnicity as being about traditions, cultures, nationality and place, as some interpreters found the concept difficult to interpret. There also appeared to be a tendency to equate ethnicity with nationality and place. Furthermore, many of the responses indicated the choices offered in the census and walk-in clinic were unsatisfactory and respondents preferred to define their ethnicity without constraints.

Figure 6: Ethnicity using the 2011 census classification

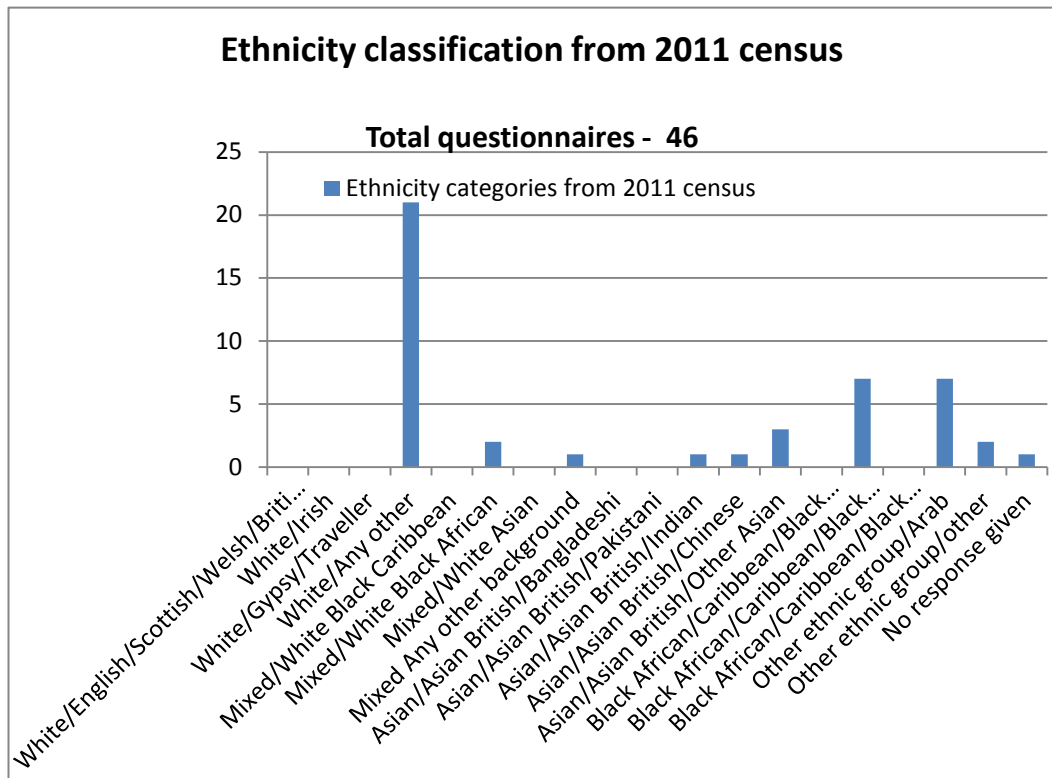


Figure 7: Ethnicity using the NHS Walk-In classification

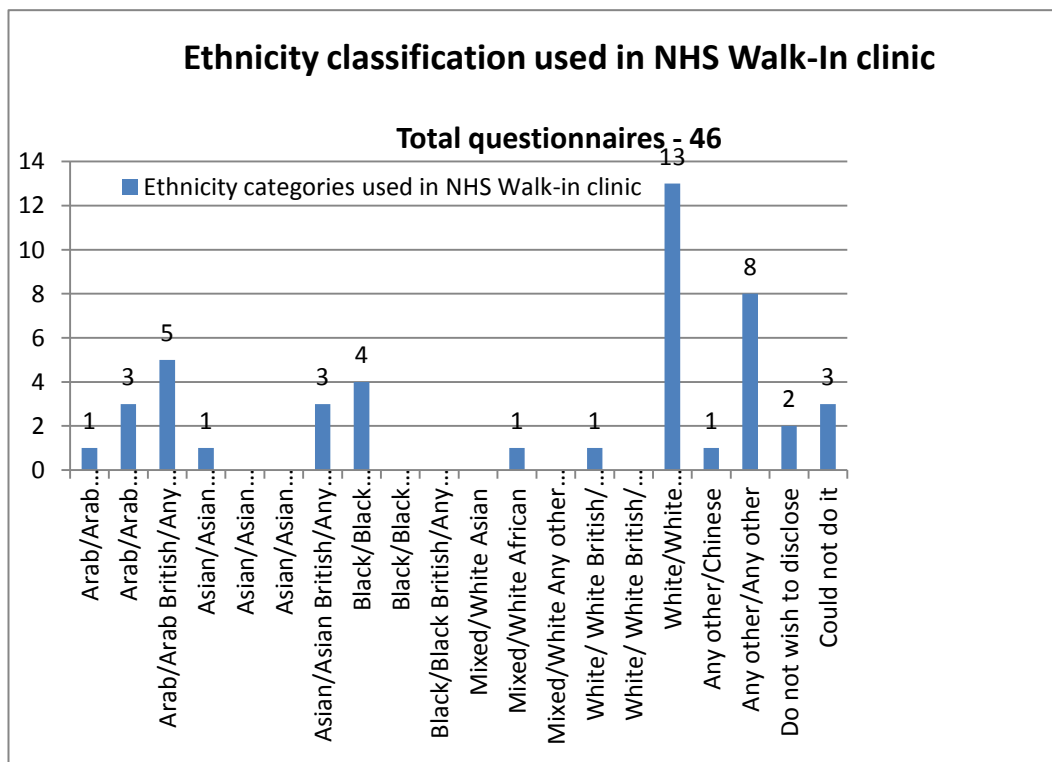
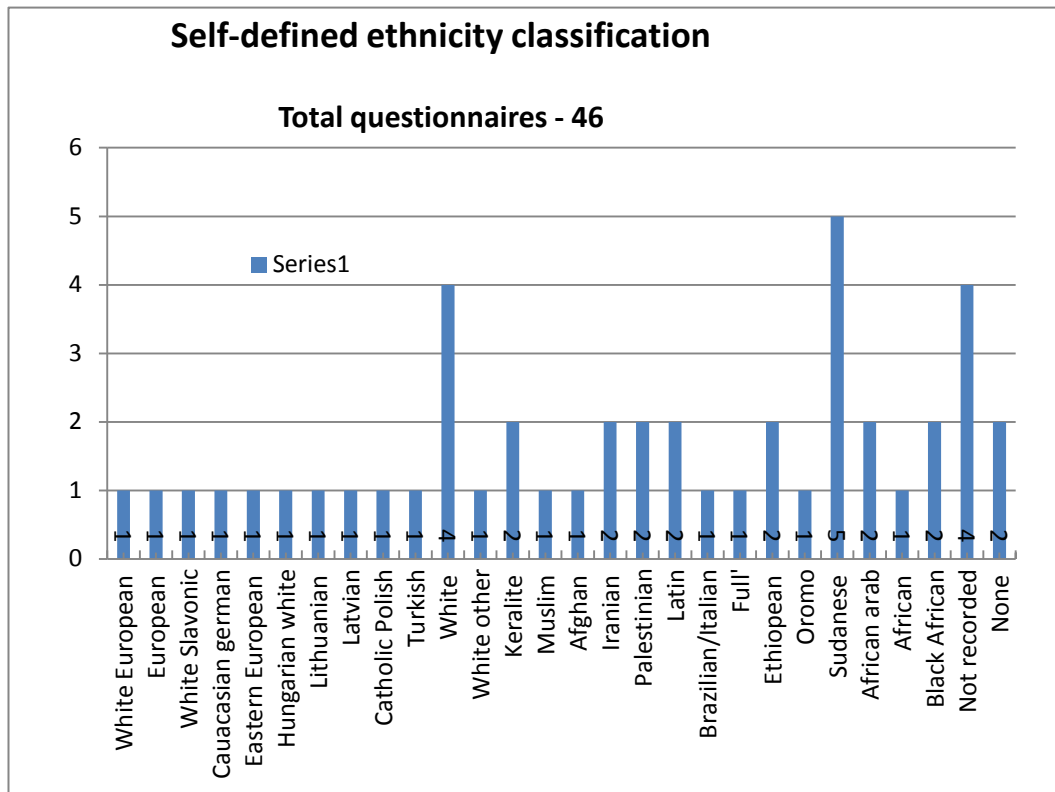


Figure 8: Self-defined ethnicity



Accepting the limitations of classifications Figures 7-9 shows the participants interviewed were ethnically diverse. However, these findings also show a lack of correspondence between official categories used, as well as with the self-defined classifications generated. For example, the largest group of participants (21 out of 46) defined themselves as 'white other' when using the 2011 census classification. The largest group from the NHS walk-in clinic classification was 'Eastern European' and then 'Any Other', once again showing the subjectivity of ethnic categorisation. As expected, the self-defined ethnicity classification led to greater diversity. The opportunity was welcomed and was easier to complete by research participants. It can be inferred from the self-defined classification that ethnicity was connected to a number of identity markers including skin colour, nationality, and in one case faith. In the Walk-in

clinic classification, an Arab category existed which was split into three sub-groups: Middle Eastern, North African and 'Other Arab'. Nine people chose this ethnic group, which was nearly one quarter of the total group questioned, suggesting the Arab grouping was clearly a welcome addition to the classification matrix. Some participants volunteered their comments about how they had previously used 'White other' or 'Other', in order to describe themselves but had changed when seeing this option. This Arab ethnicity profile reflects what has been seen in the new Arab grouping in the 2011 census data for Brighton and Hove.

In sum, ethnicity, country of birth, and nationality are distinct categories and the questionnaire was able to highlight the differences between and limitations of these classificatory systems. The group was diverse in all of the variables and as such the questionnaire also asked about language proficiency and faith – which also reflected important aspects of migrant identity. In the section that follows, the classification data about ethnicity presented above is elaborated upon using extracts from the interviews and is used to provide additional information about participants' own sense of their ethnicity and immigration statuses.

Ethnicity and immigration status

Ethnicity and migration status affected the experiences of illness and healthcare for the people who participated in this research. In this section I draw from some specific participants' experiences to reinforce this point. For example, a participant I will refer to as Jahander was an asylum seeker fluent in English; he chose to identify himself using the national census classification as 'Asian other'. He had recently claimed asylum and has suffered from severe asthma attacks since childhood but he currently associated his attacks with the stress of the court hearings he went through when he first arrived, with the new environments he lived in and travelling to and from London for court hearings. Jahander's interview was extremely detailed, covering experiences of primary and secondary care. In primary care he developed a good relationship with his GP whom had been recommended by people who had befriended him when he first arrived in Brighton. Jahander recognised that this GP was attentive to his asylum story and the effects of leaving his family on his mental health and showed empathy and referred him for therapy. He felt very fortunate to have found a supportive GP, indicating he saw the recommendation from his new friend as good fortune. He had frequently needed emergency treatment when his asthma was out of control and he had a lot to say about experiences of emergency departments in London and locally when he was not known to health professionals. In general, Jahander felt the attitude of emergency staff towards him changed when his immigration status became known. He also

offered some other interpretations for these experiences but then returned to the ethnicity and immigration status as the key factor:

Jahander: In case of that...a feeling for asylum seeker is very difficult in the hospital, it is very difficult. They start checking you - if you have full refugee status in this country ...but as an asylum seeker...you don't think it would be good to argue with the staff.

Jahander considered the healthcare he received was related in part to him being an asthma patient but also to attitudes of staff to his ethnicity and immigration status – these experiences he perceived as 'racism'. Again, Jahander acknowledged other possible structural factors such as the NHS understaffing emergency departments so that care for patients became inadequate and medical protocols such as triage leading to the de-prioritisation of asthma when other urgent cases come to the department leading to a greater likelihood of neglect. However, after making these alternative points Jahander returned to his original interpretation of racism based on ethnicity, recalling images of being judged; in the eyes of the staff he perceived dislike. These experiences confirmed for him that ethnicity was an important structural factor that could not be omitted from his narrative.

Jahander: Sometimes I would say...racism...it happens everywhere. It depends on individual thoughts. If a person is racist he or she is racist, they will apply it even if they are in a hospital or official place. I would better say sometimes, it felt a bit like.... I will face a problem. This is the feeling every migrant or asylum

seeker will have in this country. If it is getting longer and you see the people are coming after you and they are going in and you are still waiting...what is the situation? But still I can make sense that an emergency patient should be taken first to see the nurse. Yes, sometimes it is a racialised feeling. I try to avoid a person who I feel is bad, who is racist, because I get very angry and grumpy. Maybe it is good or bad manners or habit. If a person tells me something wrong, I answer that person just right there. I don't keep it. Otherwise after that I feel a bit annoyed – why I didn't answer that person, she was too rude to me and I kept silent. When I am in that situation I try to keep myself silent. I feel if I answer them they will not want to give me the services. They will say he argued he was too rude...like that we can't give you the treatment. In this case I am trying to protect. I see it, I feel it... if a person is racist. The eyes tell me, hey I am a racist I am not going to help you...like this. But then I think I need help I have to suffer this person; I have to tolerate this person ...

Clearly Jahander saw attitudes toward his ethnicity and immigration status as significant aspects of his experience. His behaviour was affected by the experiences; for instance Jahander felt he became a 'silent' and passive patient at times though countered this with a comment about trying to be assertive and vacillating back to admitting he was usually in a state of fear about having treatment withheld and this led him to not complain.

Jahander: If I face a bad person...it is a very bad word to use but anyway I will...if a person is racist...this situation is happening, I need to be calmed down

and I need to save myself, because if I argue I will go into a greater problem.

They are members and their office will defend that person even if it is a racist - this person not me. You don't understand my situation...And I need help...even if they do anything to me, I need to get help and so I have to keep myself silent...

In this informative interview, Jahander also described the emotions that were evoked by his interactions. His way of coping with his feelings was to control his anger and to remain passive. It can also be inferred from the extract that such harmful effects were likely to compound both the asthma and affect his mental health. Other extracts from the interview illustrate the effect of negative experience on the mental health of the participants.

In another respondent's case, Zola had recently become a refugee, having been an asylum seeker along with her family. She spoke English fluently. Having expressed her view that her immigration status was important, she was asked to reflect on her original comments about being a 'foreigner':

KR: Do you feel that being a woman has affected the way you are treated by the doctor.....and you have mentioned being a 'foreigner'? Are there other reasons (like this) for the way you are treated?

Zola: My personal feeling...because we are foreigners and we are sick. We will cost the government more money that is why...maybe...They are English

people: 'These foreigners they come to our country they uses each....our money.' This is my personal feeling. But regarding the Dr W, he is really respectful. I feel happy to deal with him...but for the others...?

In this case, Zola was a refugee who had only recently been granted refugee status, and she felt that there was a link between her being a 'foreigner' and her healthcare. I argue here that Zola linked her experiences to her immigration status, and she stated it was significant to how health professionals treated her, though she also acknowledged there were variations between GPs in their treatment (including some positive experiences). Her mention of the government's attitude to money and pervasive discourses about foreigners also suggested a lot of awareness about what was happening in the socio-political context around her. Zola's comments also indicate awareness of differences between individual practitioners, suggesting that other social factors such as social class, political orientations and values lay behind the actions and behaviours of individual practitioners with whom she was interacting within the healthcare sector.

To offer yet another set of illustrations, excerpts from an interview with Saidah are offered here. Due to the richness of this interview, it is also referenced in greater detail in the next chapter. Once again, this person's experience underscores that it is a pertinent argument that immigration status affects illness experience. Saidah's narrative confirms that treatment could lack respect and

this was connected to how he was seen by staff. Saidah explains it as a difference among people -- 'every person is not the same' -- and describes being resigned to being seen by practitioners 'in a different way', alluding to the influence of his ethnicity and immigration status on his treatment. This reference to discrimination is taken up again in Chapter Eight but is used here to show awareness of social factors:

KR: Would you say in the last year that you have any negative kind of feelings from the staff...in any of the services you have used? Are they showing respect and patience?

Saidah: Yes...every person is not the same. In hospital as well, you see some people are respectful, some of them you see there is not...there is ...what I can say....like seeing people differently...in a different way... When you ask them for help they ignore you...sometimes; they show you that in hospital... sometimes. Not all people, but some, some... there is some good persons... some of them show ... discrimination ...

Saidah felt that on occasions he had experienced discrimination but did not want to over-generalise and so pointed out variability in attitude and treatment.

During some other interviews, a few positive references to ethnicity were made in the sense that some refugees felt there was a degree of recognition of their different needs, such as those connected with an increased likelihood of post-

traumatic stress disorder. Zatkik was a refugee. In this case the recognition of ethnic difference relating to diet was discussed and Zatkik recalled how his GP had offered telephone contact with a GP from his country of origin in case he could give some additional advice about diabetes. This was a gesture Zatkik appreciated greatly.

Ethnicity played a role in the choices some participants made with regard to which GP practices to join. Some refugees had registered with particular GPs where there was similarity or 'concordance' with regard to doctors' ethnicity or their apparent knowledge of the migrant's country of origin (Cooper et al.1999). In several cases this was commented on as a positive occurrence, though not always. For instance, Rosana felt she had concordance with one GP but this worked against her as it was assumed by reception staff that she would only want to see this particular GP (who spoke the same language and therefore did not require the practice to provide an interpreter). So she waited a long time for her appointments when sometimes she preferred to have an appointment quickly with an interpreter accompanying. Rosana also suggested the same GP did not see her chronic problems as serious. Another refugee recalled a positive experience he had when meeting a specialist who spoke Arabic. This was a very pleasant surprise and had helped the quality of the consultation. Similarly, one asylum seeker noted how his GP did not have the same ethnic background but took extra time to understand any factors relevant to his cultural

background and ethnicity. She also showed sympathy with regard to his asylum story, which led to a better consultation experience. Three migrant workers who had consulted with their GP also spoke about finding GPs with similar continental European or eastern European backgrounds and were pleased about this experience. Another migrant worker was impressed by a locum GP who did not have the same background but spoke sympathetically about her country of origin, commenting that he had worked in her country of origin a long time ago. His approach was appreciated.

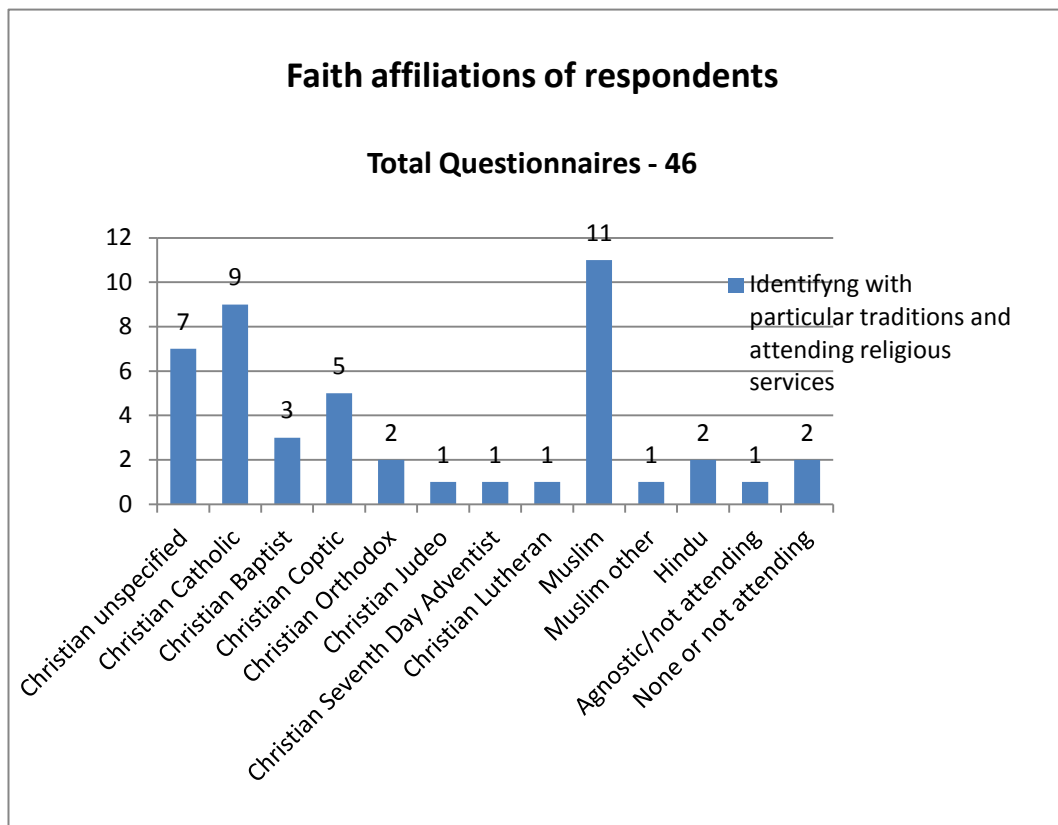
When read together, these extracts show the overlapping nature of ethnicity and migration status with illness. Ethnicity and migration status affected experiences of illness and healthcare use with comments reflecting their sadness about their health problems; this was particularly evident among the asylum seekers and refugees, who appeared very affected. Many migrants found it hard to separate ethnicity from migration status in their predominantly negative experiences.

The next section summarises the information and comments made about faith in the questionnaire and in the interview which show that faith should also be considered an important factor when studying migrants.

Faith as a valuable contextual factor for recent migrants

Respondents answered questions about their faith identity in the questionnaire, showing that having a faith was common among most of the participants - 42 responded out of the total of 46 respondents to the question regarding faith allegiance. The diversity of religions to which participants felt affiliation was also evident, suggesting that religion should be understood as social factor of significance to migrants' experiences. Many volunteered information on the specific denominations of Christianity to which they had allegiance. Nine respondents did not say to which Christian denomination they belonged but the most frequent references were to Christianity (Catholicism, Coptic or Orthodox Christianity) and reflect demographic data released in the 2011 census for the city. Muslims did not mention particular sectarian affiliations but it could be inferred from preferences for attending certain mosques that such differences did exist and were significant to migrants' experiences. This observation was further supported by the diversity of places of worship attended by respondents both for worship and for support.

Figure 9: Self-reported faith allegiances among the participants



In response to questions about faith, some participants volunteered information about the degree of regularity of their visits while others gave reasons for their preferences for certain places of worship. Some spoke about the difficulty of attending their preferred place because of time or travel costs. This was mentioned by some Muslims and Lutheran Christians who expressed preferences for going to places of worship outside of Brighton and Hove.

Some respondents commented on how their lives were affected by their faith. For example; some Christians commented they found it difficult to attend church as often as they wanted because of work schedules, tiredness from work, and lack of money for transport. Some women expressed a desire to go to mosque

more than they could but did not explain why they found it so difficult. Some Muslims and Lutheran Christians suggested they would prefer to go to a particular mosque and church further away but did not have the resources to do so.

In terms of faith affecting participants' experiences of illness, four Muslim (men and women) participants spoke about how being a Muslim directly affected their illness experiences. In the cases of the two women, they felt that wearing a hijab identified them as Muslims and this visibility had led to unfriendliness, being ignored and perceiving discrimination. Their narrative interviews switched to ethnicity as well as faith, being seen as complementary factors that could explain their marginalisation. For example, Idra spoke about the negative experience of medical treatment during his wife's stay in hospital and concluded that the doctor's attitude was linked to them being Muslims:

KR: If you were to put your finger on the attitude of that doctor, what do you think it was about?

Idra: I told him: 'You are racist of us because we are Muslim'. I told him. I saw him in the same time...we had a meeting with them...They treat British people by being kind and laughing and smiling with them and treating in a very nice way - I saw him. In the same time he treats us by a different (pause) in a

different way. I told him 'You are racist of us and you treat us because we are Muslim ... or because we are not English people.'

Idra's words were very clear and powerful in describing what he felt about his interactions with a specialist. He used the term 'racist' twice and then switched to ethnicity to describe this doctor's attitude when treating his wife. His conclusions were based on observations of the doctor in interaction with him and his wife as compared to other patients whom he saw as British.

In an interview with Bahar, who used an interpreter, she focused on recounting three childbirth stories to which she attributed present chronic health problems. She described her experience in childbirth tearfully, referring to being left alone and indicating she felt this was neglectful and related to her being Muslim. At the end of the interview this suggestion was checked by adding some other possible associations such as gender, cultural differences and then asking about religion. Bahar confirmed that she felt it was her faith that had affected her treatment and recounted another incident on a bus where she also felt sure wearing a Hijab had led to abuse:

KR: So...are there other aspects of your life that are affecting you mentally...your family background, things to do with your culture or religion...or being a woman? Any of these things...how are they affecting you?

Bahar: Yes, to my memory...[her child became unsettled again]...I remember I was pregnant with my first child on the bus in England...when one woman just

pushed me. I fell over and she never said sorry or nothing. I felt it was because of my scarf and because of my religion. So yes, my religion has affected me. These extracts support the idea that Islamophobia was perceived by Muslims in the group and that for them, faith was a factor that was linked to ethnicity. However, those who saw themselves as ethnically white were less likely to speak about ethnicity as a social force or structure. These participants appeared to prefer to shift the focus onto language as a means of understanding what had happened to them. Davis and Nencel (2011) produced an auto-ethnography that highlighted how they had only gradually become aware of subtle differences in the ways they were treated and they proposed that it was their language proficiency and accent which marked them out as migrants in the Netherlands. They argued that this had led to some of the exclusionary behaviour from others. The next section illustrates this phenomenon.

English language ability

Questions about language proficiency were related to the premise that language was likely to be an important social context for this group. The questionnaire asked participants to identify their spoken and written English proficiency using a Likert scale and this is presented in Figure 10 and 11 below. Clearly, this was a subjective exercise. Nonetheless, the researcher's

perception of fluency in English fitted with participants' self-assessments and often with the decision of participants to use or not use an interpreter.

Figure 10: English language proficiency (Speaking)

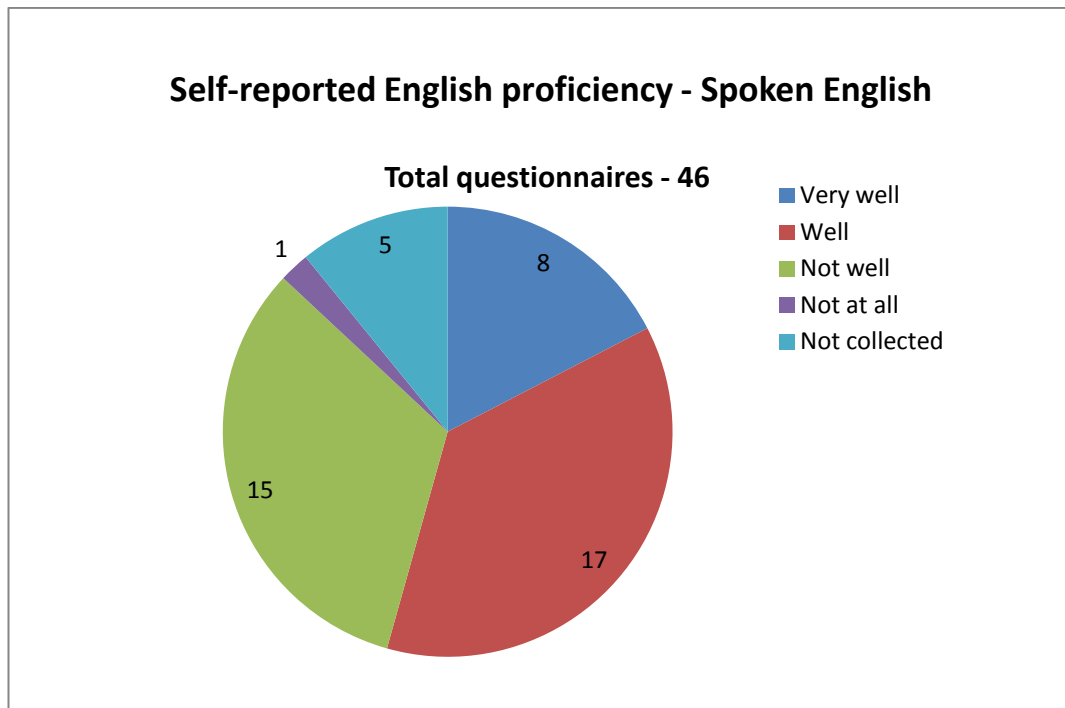
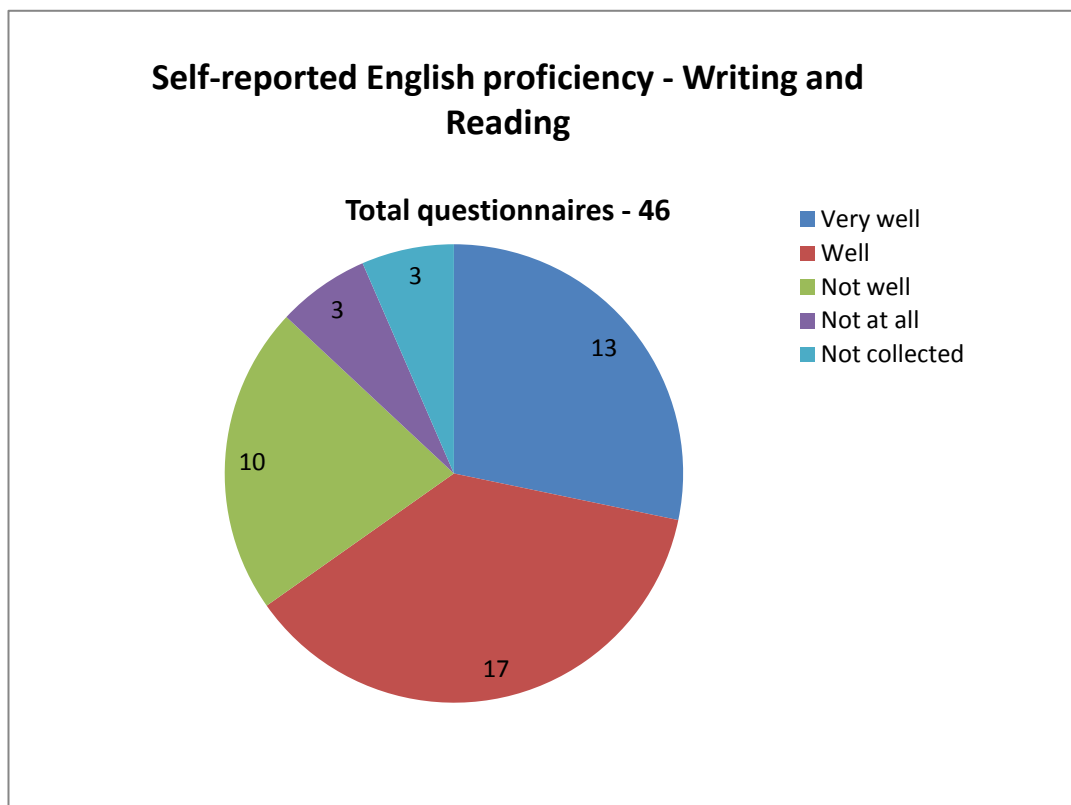


Figure 11: English Language Proficiency (Writing and Reading)



Interpreters were used in 19 out of 41 semi-structured interviews. This number coincides with the self-assessment of the participants, 15 of whom said they felt they did not speak English at all or not well enough. This group readily asked for an interpreter in this study. Language was a common topic in many of the interviews; the specific issue of being understood as a part of the patient experience is taken up in Chapter 7.

Language was seen as a significant barrier or difficulty which was not surmountable for some. Proficiency in English was mentioned in the interviews of those with fluency whereby they reflected on those who did not have it as well as by those who did not have fluency themselves. Often constraints in communication were observed and yet did not lead to use of a professional interpreter. There were considerable differences as well between the desire to use and actual use of interpreters in the healthcare setting. Some participants did not know about interpreting and were very pleased to learn about the services and their entitlement to them, while others had hardly used the service. Finally, there were some who appeared not to want to use interpreters, even though in the researcher's view these participants were likely to have communicated with considerable difficulty in consultations without assistance.

The reasons for not using an interpreter were numerous. For example, some participants felt their GP did not offer interpretation services. Several had been unaware of the service and came to realise it was available only through referral to secondary care. These participants were still confused about when they could ask for interpreting services. Three respondents only learned about interpreting services by participating in the research project. Several participants said they knew interpreters were available in primary care but admitted they found it hard to request one, explaining this was because they were concerned about the cost of interpreting for the GP practice rather than it being their own preference not to use an interpreter. In a few cases the decision not to use an interpreter was a personal choice because these respondents wanted to try to manage the consultation using their own language skills and hoped in this way to build a stronger relationship with their GP. There was also a desire for confidentiality, with participants feeling more exposed when an interpreter was present. All of these factors were being weighed up by individual participants. The extracts below illustrate some of these points, showing that language proficiency was an important factor affecting migrants' experiences.

In an interview with one female migrant worker who self-identified as ethnically white, Lara explained that she was a single parent who had claimed European citizenship but was born in South America. Her spoken English ability was very

limited to the extent that it had been necessary to get help to set up the time and date of the interview with her friend. An interpreter was used for the interview. The subject of language was a key part of her narrative. Lara had been offered interpreters on a number of occasions since becoming acutely ill, particularly when using secondary healthcare and she had also asked her friend for help with interpreting. In Lara's case she felt a lack of respect from the GP and the specialist and connected this attitude to her lack of language skills. Trying to clarify this view, Lara said she felt that if she had a language in common with the doctors the interactions would have gone better. However, she also felt this was not only reason for her poor experience. When asked if ethnicity was a factor she answered that she perceived language to be more relevant than ethnicity. In addition, the way the doctors spoke without respect and 'patience' was mentioned and these types of issues also affected Lara's experience. English proficiency was an issue but not the only issue; however, when using an interpreter Lara felt judged and said the GP did not like having to use interpreters.

Lara: The lady GP is not nice. She is not patient. The man is patient. And if he is not respectful at least in front of us he is very respectful, in my opinion. I don't know if the lady doctor is like this to another person but in my opinion, maybe because we go with an interpreter, maybe the doctor doesn't like it...maybe...but in my opinion it is this.

Lara wanted to emphasise the importance of language in her narrative; she said it was language that connected her to others, her means to communicate and understand in the UK. The use of the word 'respect' by Lara suggested that the effect of her not feeling respected for attending with an interpreter was similar to the disrespect expressed by others but attributed to their ethnicity. In this case, Lara was a white migrant who did not consider her ethnicity to be a factor. She was optimistic that when she got better at speaking and understanding English many of her problems would be reduced.

The importance of language was a theme for another participant, Catalena, who was a migrant worker and who defined ethnicity using the census category 'white other.' Also a single mother, Catalena had joined her own mother, after separating from her husband, and her mother was already working in the UK. Catalena framed her experiences around her difficulty in communicating and the doctor's attitude to the health problems with which she presented. She knew about the existence of interpreters and had used them on a few occasions in secondary healthcare. Interpreters had been offered but Catalena did not feel she could request interpreters in primary care herself. She was pleased when offered an interpreter on a second specialist appointment having struggled with a little help from her mother during the first visit. Catalena's interview centred on the idea of not being properly understood by her GP and she was concerned particularly when the consultation was for her children.

Catalena also mentioned that she used her children to interpret. When asked why she could not ask her GP for an interpreter she said the GP faced extra costs in asking for an interpreter. Catalena, like Lara, lamented her limited English ability and spoke about how difficult it was for her to fit in English classes when she was working as a cleaner and caring for her two children and her grandmother.

KR: Why do you not ask for an interpreter for the GP?

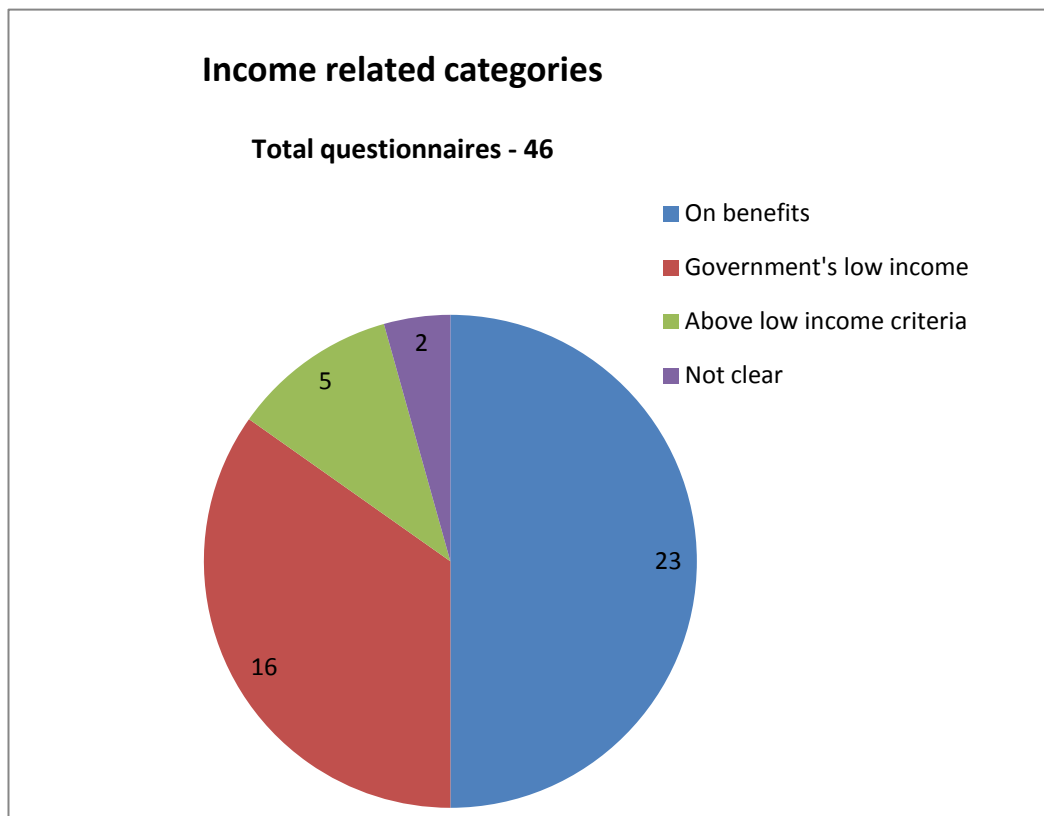
Catalena: [Sighs] Of course it is also important...I kind of manage to communicate, sometimes the doctor uses easy or less difficult words and we manage to communicate like that. I understand that the interpreting services cost money and if I think I can manage to communicate I will not ask for an interpreter...It is of course another country, another language and my little one is talking quite a lot of English now and my son also used to study English in X and now he is in English school, in English, so they are doing well. But the problem is that it is most difficult for me and my mother and my grandmother. Of course my grandmother is sick, so she is always at home but I have to go to work and I have to communicate with people and that is the reason I am not studying English, and my mother is also stopped studying English.

Language proficiency affected the healthcare experiences of a large number of participants; this was articulated strongly by some of the migrant workers and seemed to be the most prominent explanations given by economic migrants for

whom a precarious immigration status, visible ethnicity or affiliation to Islam did not apply. Comments about language were also evident in remarks about the quality of communication and perceptions of a lack of respect from staff; this is a theme taken up in more detail in Chapter Seven. Similarly, using interpreters brought up other issues such as problems of access and entitlement to health care services.

Low income and occupation

Low income and type of occupation appeared to be linked to stress during illness and concurrently illness was affected by working participants' ability to continue earning an income. Research participants were asked about their income in the questionnaire to establish whether they were on a low income. Self-reported income was equalised for size of the household; the definition for low income was 60 percent of the national median income in 2010 (Appendix 1 and www.statistics.dwp.gov.uk/asd/hbai.asp). All the participants were recent migrants. Thirty-nine of the 46 respondents completed the questionnaire and fitted the categorisation of being likely to have a low income. Seven of the 46 possibly had an income just above the low categorisation because the income question was deliberately kept simple (for instance, changes over time and wealth were not measured due to the time needed for additional questions and concerns about intrusiveness). The final total for the questionnaires was 46. The number of semi-structured interviews was 41.

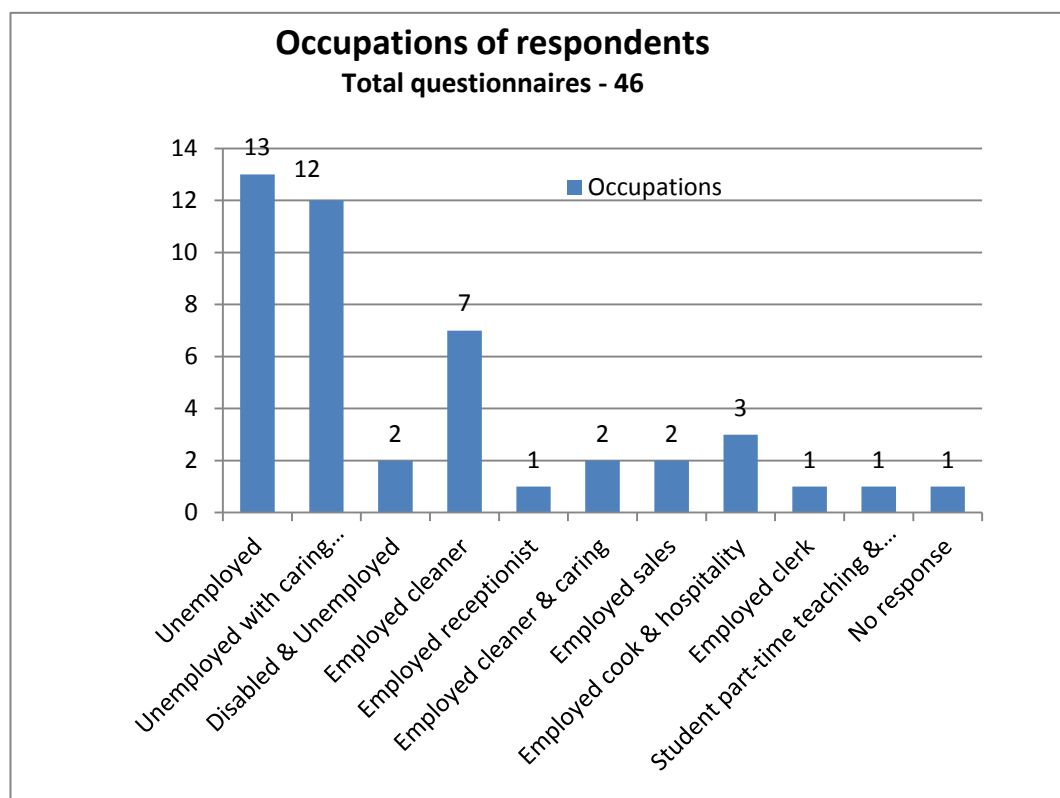
Figure 12: Respondents grouped by income related categories

Some questions were asked about how participants spent their income with regard to the social networks in their countries of origin in order to explore whether there were additional financial pressures on this group. Of the 46 completing the questionnaire, 34 wished they were able to send money to family abroad but could not, and many expressed sadness about this. A few participants were able to save money occasionally from their income and send small amounts, mainly for festivals or special occasions. Finally there were a number of working participants who said they had to save and send money to their country of origin to support their dependents, usually their own children left with other family members. Others mentioned the need to pay back a loan.

Overall, there was a strong suggestion that some of the migrant workers had some additional financial commitments that added pressure to their income.

Figure 13 below shows the type of work the employed participants were doing. Of the 45 out of 46 who responded to this question, 18 were working and 27 said they were unemployed (and were on welfare benefits) and 13 of these also had significant caring responsibilities which affected their ability to work. Those who were working were in jobs that would have been low paid, typically office and hotel cleaning and catering, while a few others worked in areas such as food delivery, a sales job, an administrator/caretaker and teaching work (which although better paid on an hourly basis was only available part-time).

Figure 13: Occupations of respondents



Respondents mentioned work and income in various contexts. Firstly, a high proportion of participants, seven out of the 16 who were employed, were working as cleaners. Most of those working spoke about their work being an important factor in their illness experiences. Many referred to the effect of strenuous work on their bodies. Some of the working participants pointed out their GPs lack of appreciation of the necessity to continue working despite illness. Several participants recalled that their current or past illness had caused a drop in income due to time taken from work. A few described receiving sickness benefit (Statutory Sick Pay) which did not meet their ongoing financial commitments such as rent and servicing debts. There were also some working participants who were unaware of housing benefits. One working participant connected his future work options to his housing costs; he calculated that the cost of the private rental sector was so high that this prevented him from working in another job which might be less well paid but would be more satisfying and beneficial in the long term. This was because he knew he would not get enough housing allowance.

The situation for those participants who were unemployed appeared different: Some discussed their feelings specifically with regard to being unemployed. Among those who were workless there were many who expressed a strong desire to work. Respondents' feelings of sadness and shame were connected to not being able to work and a desire for the respect that comes from doing

paid work. Among refugees there was a reluctance to appear critical or ungrateful and this seemed to be connected to their immigration status and being granted refugee status. Conversely it was also evident that illness could legitimate the unhappy situation of being on benefits, particularly for men. This did not change their situation but it did allow them to cope.

A number of participants with children admitted how difficult they found being unemployed and spoke about not being able to do basic things such as travel on public transport for leisure, including worship, and not having enough resources to support their children's basic needs (these points were raised in the narratives of Saidah, Zola, Morayu, Idra and Samiya). Clearly, for these participants (and others) material poverty was impacting on their quality of life, physical health and mental health as well as on the health and wellbeing of their dependants.

The importance of work was raised by those with precarious immigration status and unable to work legally, such as asylum seekers. For them immigration status and employment, not working and healthcare, were connected. Jahander expressed his view that many undocumented migrants in general chose to work over accessing health and claiming asylum; they did this in order to 'save the lives' of their dependents abroad.

Two undocumented migrants in the study were male and homeless. They were only recently receiving benefits and had been working migrants before becoming destitute. In their interviews, these two men reflected on their past working lives; they were both nostalgic and regretful about how their situation had changed. They both saw work as their future and expressed a hope about returning to work at the same time as wanting to deal with their alcohol dependency. The degree of connection between these two points was not clearly made, nor was it explicitly attributed to background stresses generated by their migrant experiences.

To illustrate the effect of low income on the health of other participants: In some cases poverty that resulted from low income was perceived by participants as of little significance to the health professionals. For instance, Beata, a low-income EU migrant worker, felt her GP did not show enough care towards her including understanding the precarious financial situation she was in once she fell ill. Beata described how she found it hard to pay her rent, utility bills and send back money to her son and parents to help them care for him. These commitments took so much of her income that she often skipped meals to save money. Consequently when she became suddenly ill her poverty rapidly worsened and so did her ability to cope, which she did only with the help of friends and going back to work sooner than she should have done. She visited her GP several times for help. In her narrative, Beata said she had very

little time to understand the benefits system to which she might be entitled.

When asked if the GP was aware of her struggle financially Beata said the following:

KR: Did the doctor ask you if you were living on your own or how you were managing?

Beata: Nothing, nothing. Even if I told I couldn't afford to stay at home. I have nothing...I couldn't eat if I don't have money. What should I do? Who will be helping? Not even one accessory to help me to walk. If I am laying on the floor what will people think, maybe she is drunk or something. And one day I went to the supermarket...I wanted to pay at the cashier to the woman I said 'I am not feel very well and I fallen down in front of her'. The men were waking me up and asked me if they should call an emergency service or something. I have been before this and I think my sugar level had gone down, after I drink and eat I walking back home.

Clearly, Beata's illness was affected by her poverty and vice versa. In addition she found the GP's attitude to her health problem unsympathetic; when she could not walk at all she could not understand why he did not help her get an 'accessory' for walking.

A similar experience was reported by Klaudia. The strenuousness of cleaning work in a hotel led her to lose a lot of weight, which she did not mind at first.

However Klaudia sustained an injury at work within the first six months, followed by a second. Klaudia focused on the first injury and described several visits to her GP in which she was given a diagnosis of arthritis. She found herself needing to return again to insist that the GP investigate her continuing pain. Klaudia was sent for an x-ray and got the diagnosis of a fracture. She felt she got no sympathy or action from the first GP and had to go back to see another GP and to 'beg' him for the problem to be investigated. Klaudia also felt the doctors did not appreciate that she had to continue to work despite her injury and that the lack of care of her injury affected others as well, as she is a single mother supporting two children, one living with her.

Klaudia: She just took a look at my foot and she said is it swollen but it was not swollen but it is not red enough. 'Inflammatory arthritis', no explanation, nothing, I had just three, four maximum, minutes in her study...I went back after 7 days or 10 days and I said I need medical help because I have pain in my foot. She said 'Go to another doctor'. The first was an English woman; the other was a Spanish guy. He said let's have a blood test. I had to wait for ten or 14 days to have a blood test ...'Doctor why still my foot is still swollen the pain has changed...'I don't know what it may be so I need an x-ray?' 'Why do you need an x-ray?' 'Maybe there is something broken or something?' 'No, no, no, I don't think so'....I begged him to give me an x-ray. Okay, I had to wait weeks to get this invitation for x-ray...Immediately the doctor said there is a bone fracture.

This participant illustrates a perception of the GP, which could not be explained only by language skills, as Klaudia and Beata, for example, were articulate. The situation of these participants suggests overlap with many other social factors, such as medical systems which did not allow time for the GP consultation, participants' perceptions of illness, and poor communication (particularly when they felt their pain and suffering had gone on a long time) – this will be focused on in Chapters Six, Seven and Eight.

The general stress and the link to low income in this case referred to the initial period of being a migrant. Daina was a female migrant worker fluent in English. She, her husband and three children faced poverty when they had first arrived in the UK and she recounted memories of trying to find a job, maintain a job, and the strain of the work as she began to feel increasingly unwell. After blood tests Daina was diagnosed with pernicious anaemia by her GP. This diagnosis was a relief after a long period of not knowing what her problem could be. The memories of the hardship faced at that time brought Daina to tears in the interview but she did not discuss the stress of their financial situation with her GP. Clearly stress during illness was exacerbated by a drop in income, having no savings to cushion themselves, and often the need to continue to make debts repayments caused additional stress. Lara, Aneta, Carlota and Pedro also shared examples of this kind. Pedro was aware of his chronic illness

(Hepatitis C) and knew the situation was likely to get worse in the future and he reflected on how he would not be able to work at all.

Work as a factor overlapped with other social conditions, such as gender.

Gender will be explored in more detail in the next section where the interplay in the interviews between masculinity, unemployment and illness will be discussed.

To discuss the aspect of work and single parent workers here briefly, the cases of Lara and Catalena were striking as it was evident that they were working extremely hard. As single mothers, when they had fallen ill their descriptions of the precariousness of their financial situation formed a large part of their interviews. Clearly these single parent participants were unprepared for the additional problem of illness, and the challenges that they might encounter when seeking medical help in the NHS. This made it necessary for Lara and Catalena to rely on other resources including their social and cultural capital to facilitate borrowing money, as well as to find emotional and practical support.

In these interviews with new working migrants, they described their jobs as strenuous, precarious and stressful, and linked illnesses to work and work injuries. Read together, these kinds of experiences call into question overemphasis on a 'healthy migrant effect' as discussed in the literature review in Chapter Three. This literature suggested migrants represent a group whose health status remains good in the early stages of migration. But the present

study confirms findings that distinctions made according to type of work and income are important. Moreover patients struggled to share information about their financial and social circumstances with their GPs, and the doctor-patient relationship did not allow time for such factors to be shared, nor be considered in treatment. In fact, from many of these patients' perspectives, there was limited interest shown by health service providers in non-medical factors. Both for those in low-paid jobs and those not working but on benefits, falling ill with a condition that became chronic led to emotions which were frequently articulated; about how they managed at the time and how they would manage in a future characterised by continuing worklessness and/or low-paid work.

Gender

Gender and health are socially constructed and changing (Annandale, 2009), and intersect with factors such as age (Charles, 1998) and work status. Of the 46 respondents to the questionnaire, 31 were women and 15 men (Table 4) and 12 of the 15 men were refugees and asylum seekers.

Table 4: Gender of respondents

| Immigration status | Women | Men | Total Questionnaires |
|-------------------------------|-------|-----|----------------------|
| Whole group – Recent migrants | 31 | 15 | 46 |
| Refugees | 7 | 7 | - |
| Asylum seekers/undocumented | 0 | 4 | - |
| Economic migrants | 24 | 4 | - |

In this study there was greater willingness among women to come forward to participate in a discussion about illness. For example, women tried to participate by rescheduling some of their caring duties and shiftwork patterns. Also, the unemployed men in this study were more amenable to participation than the men who were employed. In this study it was found, as elsewhere (Arber, 2001), that women and men had distinctive morbidities and patterns in health service use. In the past this has been attributed to biological gender differences, and social factors have gradually been accepted as nuanced explanations for gender differences. In this study, for instance, gynaecological and obstetric morbidity was interpreted as an indication of socially mediated differentials as well as being attributable to biological gender differences.

Males were hard to interview. Many who were approached were unwilling due to work commitments - only five of the 20 economic migrant interviewees were men and two of the five men were not working at the time of interview. Table Three shows the gender of the participants according to immigration status. In addition men appeared less comfortable talking about illness (Evans, 2011).

An indication of this difference was seen on several occasions, for instance during recruitment, when men suggested that their partners or a female family member join the study rather than getting involved themselves. In one case, towards the end of her interview one participant reiterated how she felt her husband did not take care of his health. She felt he had health problems but

was reluctant to talk about them. This tendency for men to avoid discussion of illness is supported in wider research (Brown, 2001, O'Brien, 2005).

Preferences for male or female GPs was another topic in which gender had an impact on the decisions being made. Although this was not an issue that was commonly articulated in the interviews, it was striking when gender did get explicitly mentioned by several participants. Some of the women chose women GPs for health problems that were likely to involve physical examinations. Interestingly three women respondents also considered it noteworthy that they had come to prefer their male GP in their practice over the female GP whom they had found to be less caring and patient.

The significant impact of caring responsibilities in the female interviews on mental health was apparent. Respondents included four single-parent mothers who were under a lot of pressure, as discussed earlier. The mental health of women and women as patients has been studied as a significant issue (Werner, 2003). In addition the mental health of migrant participants was affected by difficulties which hinged on a breakdown of family life. Several men and women participants spoke about the strain of living apart from the partners and children and many were coming to terms with leaving their families (including children) behind. Some did this to flee persecution, while others left after a marriage breakdown, increasing the push to earn money. More of the male participants

who had fled persecution were separated from their families for longer periods.

Caring for child dependents was a big part of the lives of many participants irrespective of whether this was with or without partners. The centrality of children was evident when trying to arrange the interviews; caring responsibilities affected the ability of some female participants to concentrate - eight interviews were conducted with pre-school children present.

Two interviews with women raised domestic abuse as a health issue, one implicitly and one explicitly. In the implicit description, one participant described her need to use a refuge and the chronic gynaecological problems she endured, suggesting a link with abuse and not only childbirth. The other participant explicitly described physical and sexual violence having succeeded in fleeing the abusive relationship. This interview saw the overlap of gender with language as factors as the participant explained that her ex-husband had deliberately prevented her from using professional interpreters and had acted as her interpreter to hide the domestic abuse.

The reliance on male partners and wider family support during labour or an acute illness was illustrated in Bella's narrative. Bella had limited English; in labour she had found it very difficult to express herself, which increased her dependence on her husband. She was disappointed in his support during labour,

which was clearly unconnected to his language proficiency because he had English as his first language.

Bella: He was not very...I said to my husband you have to tell them something and my husband...we have to follow the doctors' instructions. He had been trying for two days...he had been trying to tell the doctor for me, to have something done but they were not listening...it was very difficult. And in the moment B came out they didn't hold him, they didn't hold his head and he came out and he came out on the bed and it was so hard he fell, he hit his head quite strong and for two months he had a crooked neck. I tore really badly, I had loads of stitches and from then I have the consequences of that...is my pain and discomfort.

Bella's mother was present during the labour but like Bella had little English language ability. This participant was unaware of her right to use an interpreter and had only come to learn about it through participation in the research. Bella was one of the few participants whose income was outside the low-income categorisation but participated because she wanted to give her story and to have the experience of using a professional interpreter.

Gender was not visible to many participants but it permeated the interviews as shown above. In this case a male spouse cared for his very disabled wife and children. The disabled wife said she hardly thought about gender, but saw her

situation as 'dependence', which was her reference to her disability and the gender division being her norm.

Samiya: With my husband's presence, I really don't give it much care - I really depend on my husband.

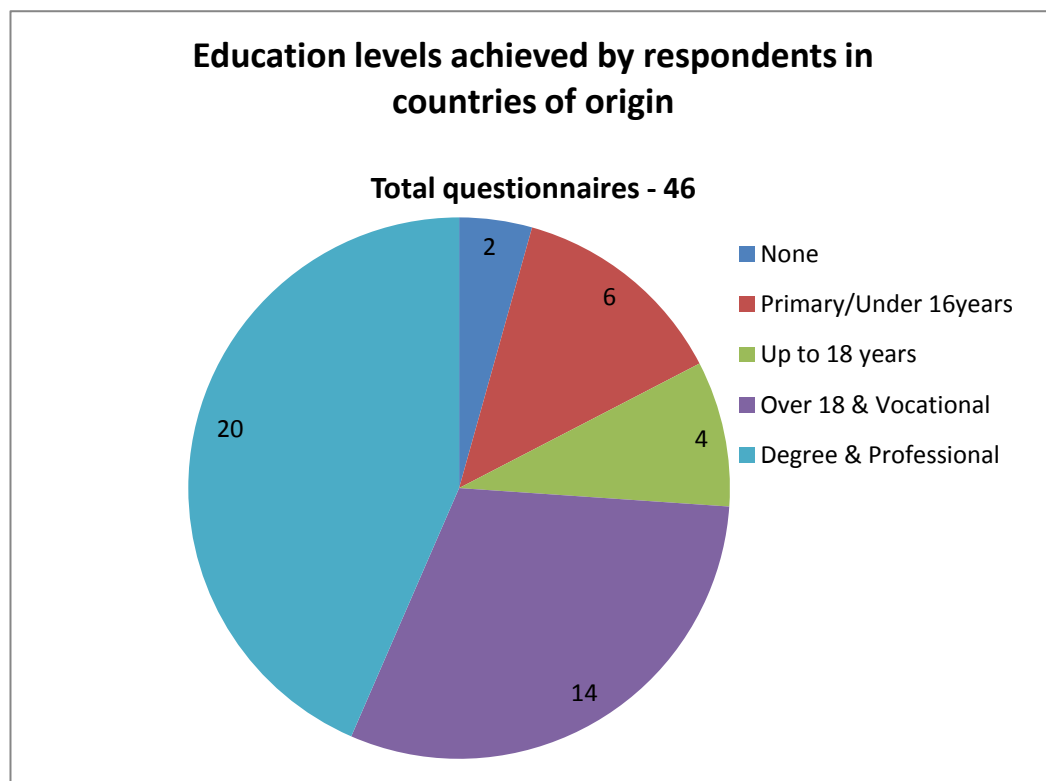
There was a strong suggestion language and gender overlapped and that the women who had a weak command of English were additionally exposed to vulnerability, particularly when ill. Language issues have been discussed in the subsection above. In other cases women with low English proficiency (who may have had high status in their countries of origin, having educational qualifications of value there) felt they lost status in the UK. They noticed this when using public services, such as health services. This leads us to the effect of education and other status indicators inherent in social networks on participants. These are considered in the following section.

Education and social effects on illness experiences

The educational qualifications held by the participants were diverse and many participants had reached a high level of education: of the total of 46 respondents to the questionnaire, 34 answered that they had a degree or college-level vocational qualification from their country of origin. Only eight participants had very little education and had left school before the age of 16.

However, participants felt that educational qualifications from their countries did not have the same value as in the UK. There appeared a disjuncture between past educational achievements and the present occupations of the participants, even moreso when the educational achievements were examined in greater detail. Language proficiency and education interacted, with more of those who were highly educated having a reasonable command of English on which they were able to build.

Figure 14: Education levels of respondents



Social networks

Illness can have a negative impact on important social networks as has been shown in the case of mental illness (Scambler, 2003c, Rogers and Pilgrim 2010). Migrants draw on social networks to varying degrees, for a range of

purposes and in ways that are also contingent upon their (often changing) immigration status (Menjivar, 2002, Collyer, 2005, Williams, 2006). In this study, recent migrants who could not travel back and forth to their countries of origin described how hard it was to form new social contacts and maintain those from the past. The refugees and asylum seekers who participated sought new social networks. For them being unemployed suggested their social networks were limited with regard to the prospect of finding work. Faith, places of worship and various community organisations (including educational institutions) were places of support for the majority of the participants in this study. Participants also spoke about being able to maintain contact with distant family members through free internet access and using cheap phone cards. In a number of interviews this mechanism was mentioned as a source of health information and advice about health-related concerns, as well as providing other forms of psychological support. Economic migrants who were able to make visits to their countries of origin -- several respondents described going to see doctors for advice and diagnostic tests during these visits -- and this finding is taken up further in Chapter Six.

It has been argued that social networks protect people from perceiving discrimination and racism in a variety of ways as discussed in Chapter Two (Heim, 2011). This study found that social networks supported many participants in coping with their illnesses, suggesting that participants with weak

social capital were likely to be more vulnerable to social isolation during illness episodes. This was more evident during acute episodes when some participants had few people to call upon for help. With chronic illnesses participants got used to being ill and became more prepared, for example by setting up ways of getting help when they could not cope. Conversely there were also indications that for some participants their social resources were slowly being exhausted or they felt embarrassment to continue asking for assistance. Finally, this study showed that social resources were used selectively by participants.

When the social networks of friends and family were mentioned, they were often with reference to the roles these people adopted as advocates or interpreters as well as in providing transportation or childcare during illness. Other sources of help were financial, such as an informal loan during illness when work was not possible or when participants could not cover debt payments. In this study these networks were often, but not always, based on ethnic ties – a more general phenomenon also shown in the literature by researchers. Morasanu (2012), for example, points to this trend while also highlighting the crossing of ethnic ties, and these traverses were also seen to be occurring for the people in my study. The interpreting service provided important additional social connections, and several respondents valued the support they received from interpreters, who they saw as coming from less close social networks. There

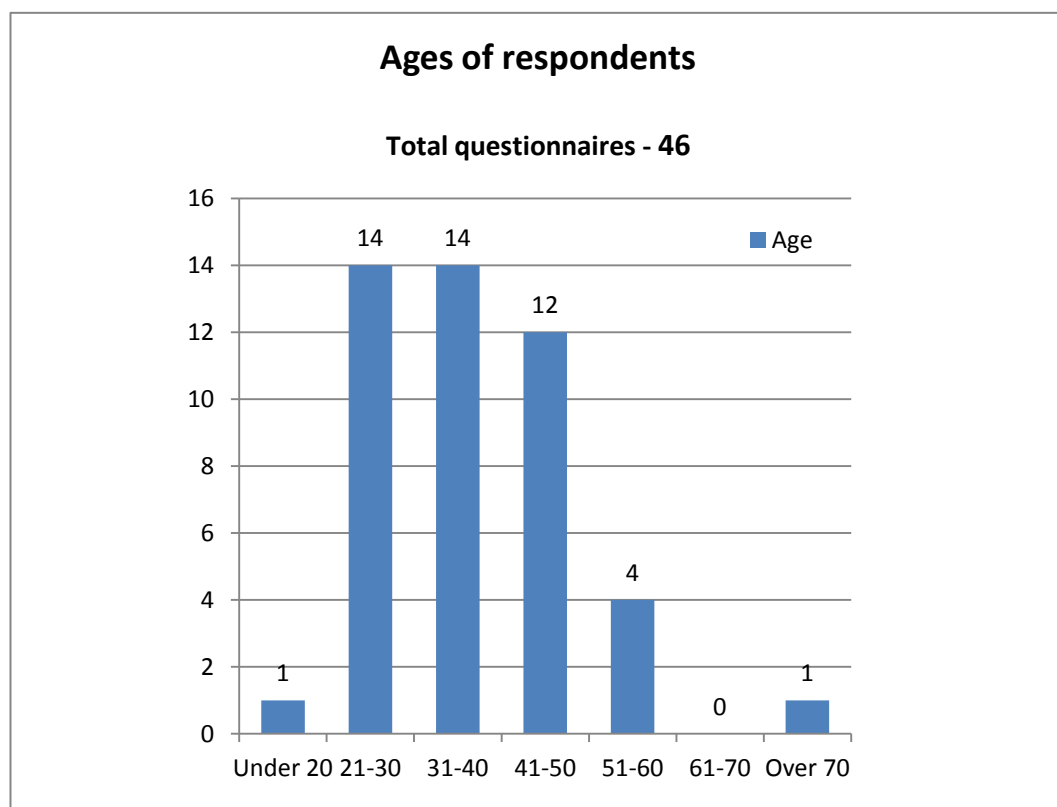
are several examples of social networks making illness more bearable in this research. These include Zola's interview about her workplace friends who advised her when she was shocked and upset by receptionists in a GPs practice. Daina offered a narrative about colleagues who gave advice when she had been refused treatment by her GP. When she took their advice she obtained treatment from a new practice, as soon as she had informed her old GP practice she was leaving. Idra and Samiya were interviewed separately; however, both spoke about an incident in which they got help from Idra's brother who was long settled in the UK and who also helped them get to many medical appointments. In one incident the brother's help was essential to Samiya's release from police custody. Finally, Jahander described making friends on arrival in the UK and the subsequent assistance they offered him when he was seeking accommodation, finding a GP, making trips to Accident and Emergency departments during acute asthma attacks, and when identifying supports when applying and subsequently fighting for asylum. The importance of social networks in ameliorating illness experiences was clear in all these interviews.

Age

The ages of the participants ranged between 20 and over 70 years of age (Figure 15). The majority of participants fell within the age range of 21 to 50, meaning more participants were of working age. Age as a factor appeared to

overlap with illness; more of the younger working age participants presented with acute illness, maternity related issues and their children's illnesses. Older participants presented with chronic illnesses. Only one participant over the age of 41 gave an interview about an acute episode of illness that was later diagnosed as a stomach ulcer. Age was not explicitly spoken about; rather, once again it could be inferred to be an important factor through an analysis of the distress caused by severe injuries that took a long time to treat. For example, both Alicja and Jana had back and knee injuries and referred to their age when describing their problems. Age was also referred to indirectly when speaking about the chronic and/or life-long nature of a problem. Age as a factor, therefore, overlapped with conditions of work and illness.

Figure 15: Ages of respondents

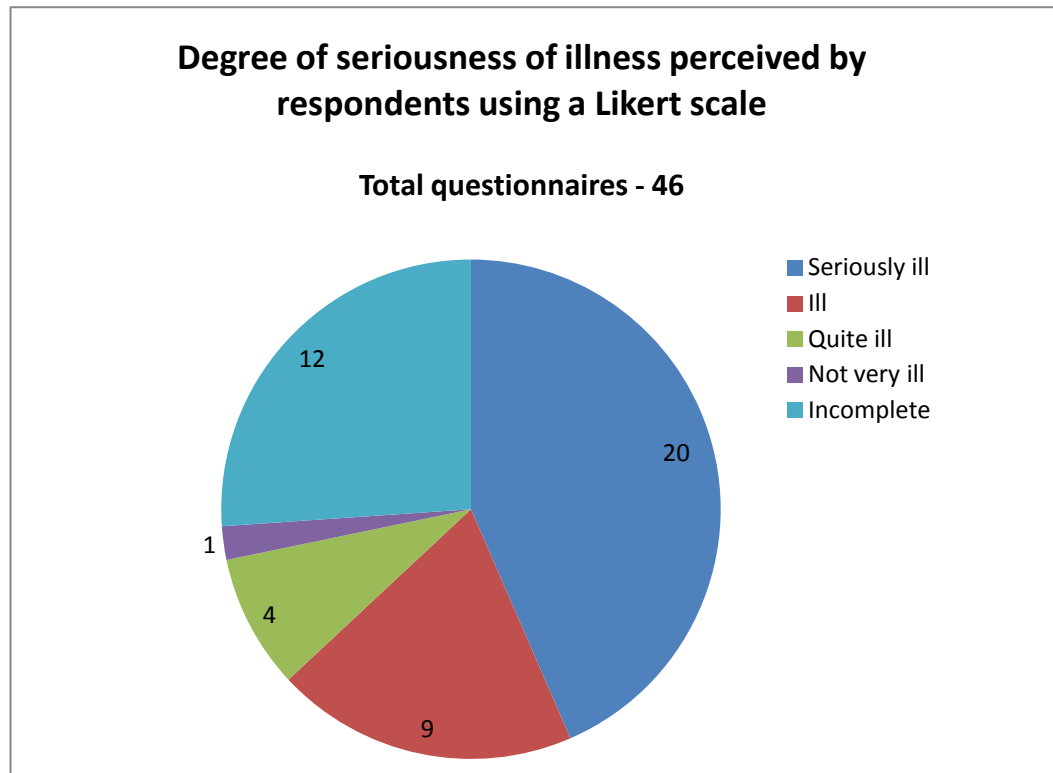


Illness

One of the aims of this study was to interview *recent* low-income migrants who had experienced illness. Therefore during recruitment all potential participants were asked if they had been ill in the last two years and particularly in the last six months. They were also asked about their arrival and on the basis of their responses were invited to participate in the questionnaire, which gives rise to the descriptive statistics discussed in this chapter. Initial questions were asked about illness experience without pre-empting what would be raised in even more detail in the semi-structured interviews. Specifically, there were two questions that were asked in the questionnaire: these were soliciting self-reports of the degree of seriousness illness perceived by participants and self-reported health status. Both questions employed a Likert scale (Bryman, 2012) which is a commonly used tool within health surveys. Participants were asked to give a diagnosis of their condition only if they could do so without difficulty. As expected this was not straightforward for many of the participants, especially those who had chronic health problems. Also there were some who contested their diagnosis or had medically unexplained conditions (MUS) or conditions that had been difficult to diagnose. Participants were encouraged to do the best in making a difficult judgement about their diagnosis for the purposes of the questionnaire but in the case of 12 participants they found it difficult to answer and in these cases the researcher did not persist as qualitative interviews would elicit detailed reasons later. These two questions relating to self-reporting of

health status have been shown in health research to be a reliable measure of clinical judgements of health (Finch et al.2002). Figure 17 is presented as illness perceived. The majority of respondents perceived themselves to be 'seriously ill' or 'ill'.

Figure 16: Self-reported seriousness of illnesses perceived by respondents

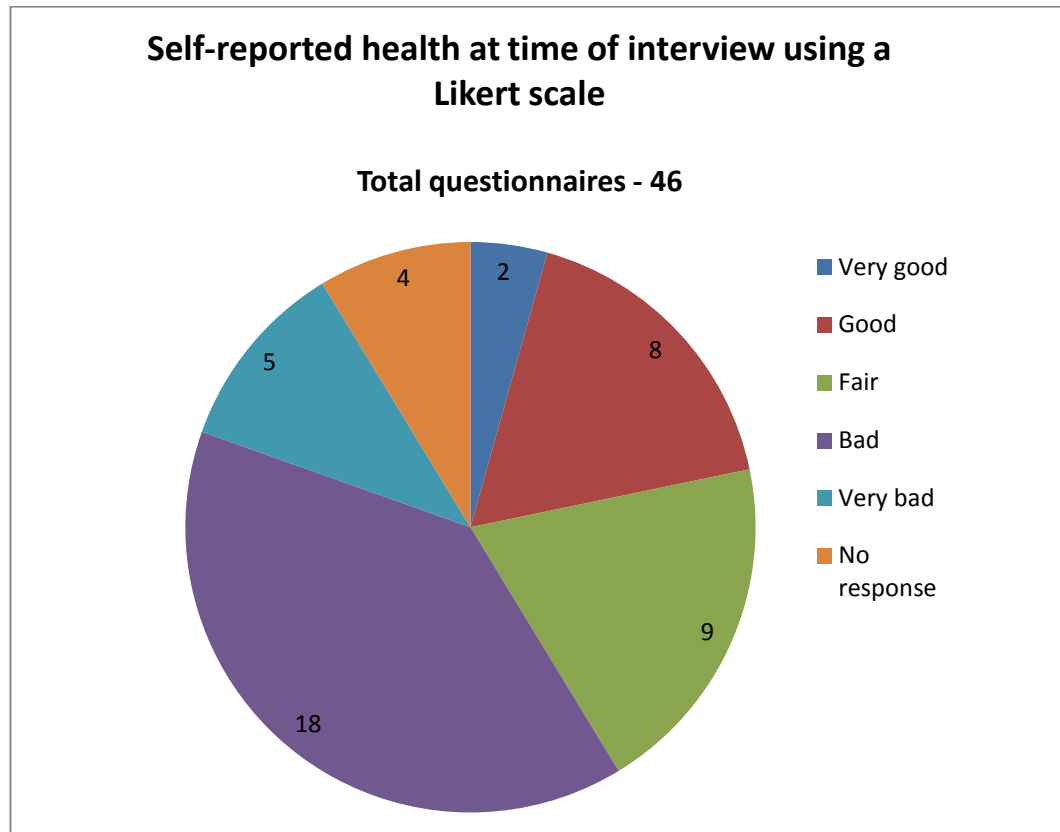


The second question about health status, also put to all the participants, was almost identical to the question proposed in the 2011 national census with a slight modification being made after a pilot interview suggested a timeframe was needed for it to be understood fully by respondents. Consequently two timeframes were added: participants were asked about their health at the present time (clarified as the week leading up to the interview) and the second question was the state of the participant's health in last three to six months.

About half of the group in the study, 23 out of 42 of the participants, considered

their *present* health status to be bad or very bad. The remaining 19 participants were able to say about themselves, or a child dependent (as in one case), that they had fair, good, or very good health at the time of the interview.

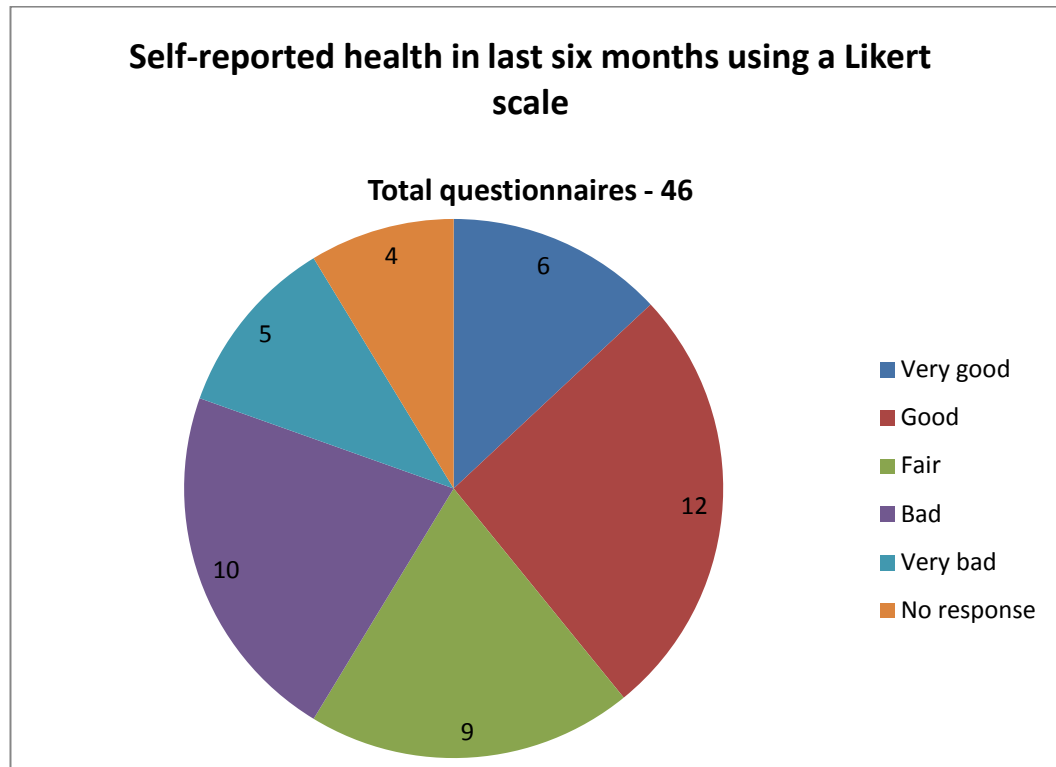
Figure 17: Self-reported health of respondents at the time of interview



When participants were asked to comment on their state of health in the last *three to six months*, the responses were more positive, with only 15 out of the 42 respondents who answered this question saying that their health had been very bad or bad. The remaining 27 had said they felt their health had been fair, good or very good in the previous three to six months. This shows that the sample was drawn from a group of recent migrants who were feeling ill at the time of interview. The group can also be shown to have fluctuating health status with more participants stating a slightly better picture in the last three

months than in the two weeks prior to the interview. These questions about health status confirm that the effect of illness was significant and recent for the group in the study.

Figure 18: Self-reported health of respondents three to six months prior to interview

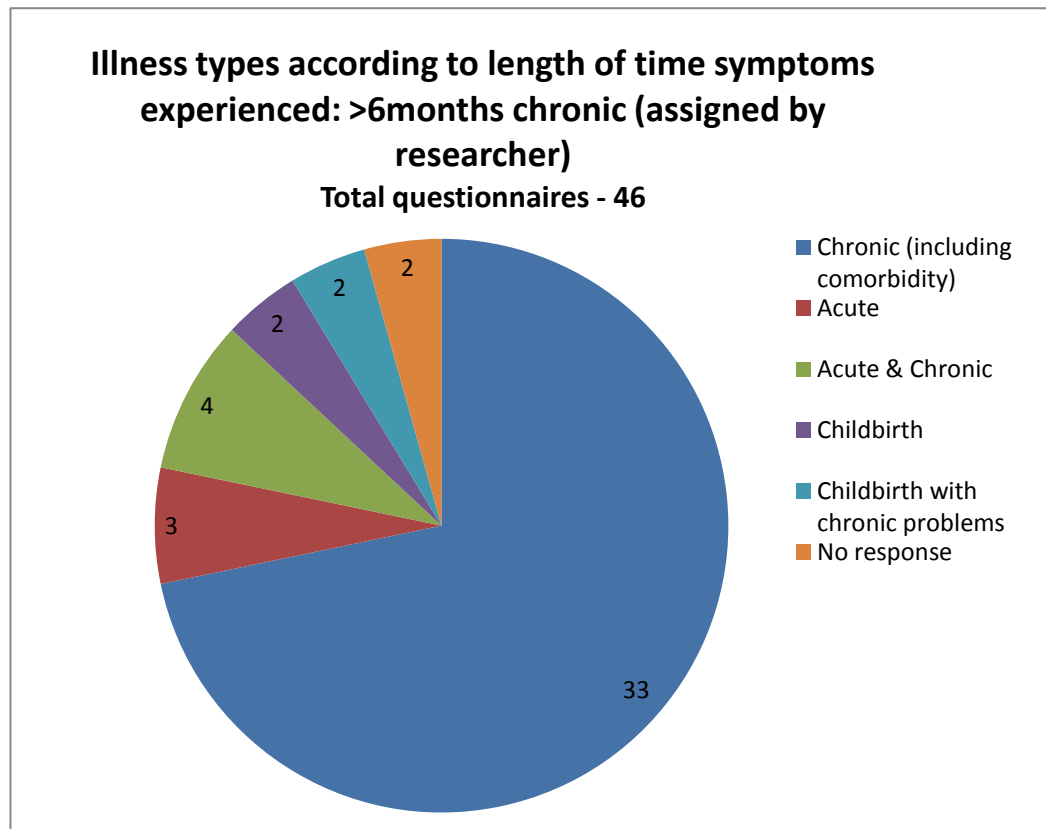


Some participants asked for clarification about what was meant by health, and particularly if what was meant included mental as well as physical health. The responses suggest that the impact of being ill on participants' emotions and mental health was likely to be great as so many chose the description of 'bad' and 'very bad'. Some participants were so affected by their illnesses that they found simplifying the descriptions of their health in this way was difficult and unsatisfactory.

Participants were not asked directly in the questionnaire how long their illness had gone on; instead, an interpretation of the duration of illness was made from

the interviews. Figure 19 below categorises illness by their approximate duration. Chronic illness is a complex notion related to disability, and definitions can refer to impairment, limitations to executing activities, and restrictions on the ability to participate (Scambler 2003:84). Here chronic illness was defined by participants as loss of function and length of time. Indications that it had gone on for more than six months were categorised by the researcher as chronic. The application of this definition suggested a large number of the interviews, 33 out of 44, were about chronic illnesses. Moreover, many of the narratives referred to multiple illnesses, suggesting co-morbidity. The high proportion of chronic illnesses explains why a strong feature of the interviews was the tendency to discuss a range of experiences of chronic illness that had affected them on many levels.

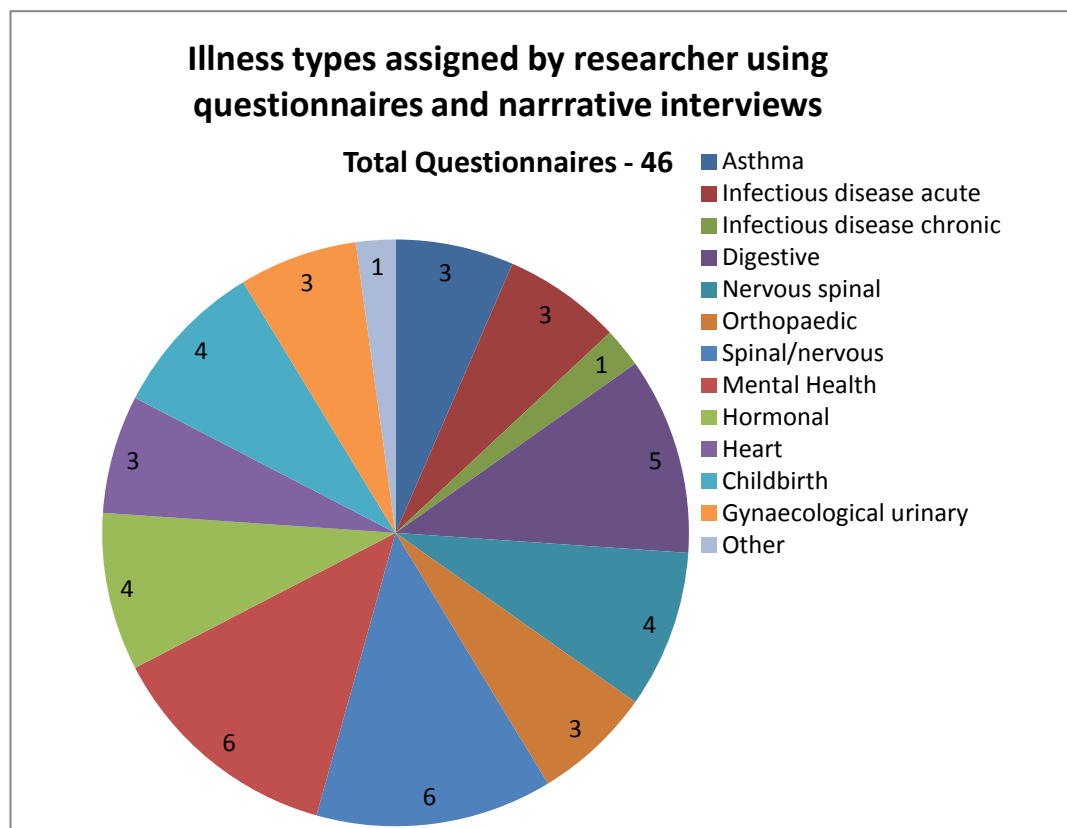
Figure 19: Illness types according to length of symptoms experienced (categorised by the researcher)



A few of the interviews were specifically about childbirth, though two of these overlapped with the chronic illness grouping as the participants perceived childbirth was the cause of subsequent chronic gynaecological conditions. Both the questionnaires and narrative interviews were used to group the participants into people suffering from particular types of illnesses and are presented in Figure 20. Spinal, nervous and orthopaedic problems were placed together as one group, and interestingly several interviews showed that the diagnoses changed between these three types of illness. Mental distress overlaps with many social factors and mental instability could be discerned from many of the comments made in the interviews. Incidence of mental illness among participants' surfaced in 6 out of 41 interviews but this was based on the

number of participants who were using mental health services at the time of interview. This is argued to be an underestimate because such a figure does not include some very vulnerable people who were clearly suffering but not using services. For instance, two participants who were undocumented migrants with serious alcohol dependency problems were left out of the calculation. Similarly, other participants who faced other problems indicated they felt emotional and distressed but were not included in the narrow definition of having mental illness if they were not accessing mental health services. Therefore mental distress was an important feature for many participants and will be discussed in the next section.

Figure 20: Illness categories (assigned by the researcher)



As mentioned earlier a large number of the illnesses were perceived as serious and the diversity in types of illness was further supported by an analysis of the range of health services used by the participants. The questionnaire attempted to collect a list of health service used, which was cross-checked with the interviews that followed. Again for those with a number of problems the list was not precise. Most participants had used both primary and secondary services, with the latter for diagnostic services. In the interviews, the diversity in the health services used may also reflect the chronicity and the long process of reaching a diagnosis rather than long-term use of specialist services. Most participants had started by using primary care before accessing any other services.

Twelve of the participants could be classified as having health problems that were acute and led to the use of Accident and Emergency services, with three of these participants speaking about emergency services at length in their interviews. The remaining participants who mentioned emergency services were categorised in Figure 20 as having chronic illnesses or childbirth interviews. The reasons that were given for using emergency services in almost all of these interviews appeared appropriate in the researcher's view as participants' comments were related to acute episodes of illness or injuries. There was no suggestion of a widespread tendency for participants to use emergency services without perceiving a need for urgent medical care.

However, several interviewees expressed confusion about making the choice between primary and emergency and for others the experience of going to emergency services was fraught. The comments raised a range of issues: being shocked by the waiting times being so long, advice being given that seemed to be inadequate, feeling prematurely discharged without being offered diagnostic tests, scans or x-rays and having to return to hospital for tests as non-urgent cases by their GP. Whilst it is accepted similar experiences are likely to be found among non-migrant and long-settled people, the risk was that other social factors such as poor communication with recent migrants could also jeopardise satisfactory health outcomes.

The two of the 12 interviews that discussed emergency services could be interpreted as being inappropriate attempts at use of the emergency service; one was an EU migrant who recounted telephoning the emergency services and being questioned by the call centre about her illness and being re-directed to her GP. Another case was recounted in which an EU migrant (who was a nurse by training) saying herself she had used Accident and Emergency at the weekend as she felt her GP would not have given her antibiotics and she wanted to try to get them from emergency services. Consequently, in these 12 interviews a range of views and experiences about emergency services were evident.

Mental distress

A large number of the participants referred to their mental and emotional state during their interviews. I argue the interviews support the idea that this group of participants, who held mixed immigration statuses, were vulnerable to mental illness. However, it could be seen that those who were particularly vulnerable to mental distress were refugees and asylum seekers and these examples are discussed. Social/contextual issues such as low income were linked to mental strain, as discussed earlier. There was also a gender element in that several male interviewees discussed their mental distress in relation to being workless. In some of these cases medicalization of mental distress as mental illness appeared to provide a helpful explanation for the strain of long-term unemployment. Mental distress could also be linked to the perception of low status of the migrant category - this will be explored in Chapter Seven. Some participants made the link between mental distress and chronic illness. Chronic illness will be discussed further in Chapter Six.

In the interviews of refugees, asylum seekers, and undocumented migrants mental distress was evident and could be connected with the claim that the trauma of migration is an important factor that affects health. Thus the data supports the literature reviewed in Chapter Two. In several cases, for example, memories of persecution in countries of origin, traumatic migration journeys and homesickness were raised as causes of mental distress and illness. Two

interviews mentioned the specific stress of going through the asylum process, and several others who had been accepted as refugees recalled the distress of going through the process.

The interviews of refugees reflected considerable forbearance and acceptance of their current situation relative to their past. Some participants even felt better off in some respects. Many comments suggested a dilemma for participants, who did not want to sound ungrateful about their current situation as they had been granted refugee status and this translated into a desire to accept the healthcare received without complaint. In some cases, again particularly among refugees and asylum seekers, relative to past experiences of healthcare in countries of origin, healthcare in the UK was perceived as better. In such cases it could be argued that some internalisation of distress occurred and was often a silent burden.

In other cases the refugee participants received a mental illness diagnosis. Many of these participants expressed some relief that their migration history was seen as a factor affecting their mental health, and felt some vindication for their traumatic personal histories. In four of the 15 refugees and asylum-seeker interviews GPs had diagnosed symptoms of Post Traumatic Stress Disorder (PTSD) and made referrals to mental health services, so these individuals were now being treated. One interview was striking in this regard as a female

refugee was eventually diagnosed with a mental illness after childbirth.

However the diagnosis of PTSD was reached only after an initial diagnosis of post-natal depression by the midwife and following a suicide attempt.

In other interviews the situation was more nuanced, and participants felt the GP focused on mental distress when the participant did not perceive mental issues to be the problem. Two participants (one woman – with the immigration status of a spouse and a man – with refugee status) expressed dissatisfaction with their doctors' references to mental distress, showing that in some cases there was a preference for a diagnosis which focused on the physical problem rather than mental illness. Both of these participants felt their physical symptoms were being ignored and the problem was being diagnosed as psychological at the expense of physical investigations. Despite a mental illness diagnosis being suggested neither was offered psychological therapies to explore the GP's diagnosis. Kismet's story illustrates the complex overlap between felt stigma of mental illness, gender and chronic illness which was enacted in the research interview.

KR: What do you think is getting in the way...this kind of relationship and the way they are treating you. What do you think are the reasons?

Kismet: I believe that is affecting because every time I go to the doctors he would say to me 'oh you have some family problems and you have got some...psychological issue that is the problem, that is the issue'. But I don't

believe that is the thing. If I have got a family problem would it hurt my stomach inside my groin area or my problem? I don't put all the blood in my eyes myself it is there physically. I need to see someone... I go there and they would treat me as if I have got no problem whatsoever. They want me to go away because it is all psychological and they don't believe me in that sense. I don't do things on purpose to make...why would I go to the doctors for that reason? And my main problem is my left arm gets numb all the time and my leg, my right leg. My biggest problem is in the groin area and I don't do this on purpose. If there is a family problem it wouldn't hurt me physically in my stomach. I wanted to know why.

Similar comments were made by economic migrants about physical and mental symptoms. As illustrated above there were other cases where it was felt doctors were seeing a somatisation of illness and did not offer treatment for the physical symptoms. These participants felt the stress of contesting the diagnosis or not being offered a referral, and this disagreement was seen as the source of the mental stress. What they felt as physical distress was found to lead to additional mental problems, exemplifying that the mind-body dichotomy can be a problematic division in medical practice and not seen by patients. The complexity of mental distress can be seen again when several of the economic migrants also suggested that they held back from discussing mental health issues with their GP. This also supports the view held that stress was being

experienced stigma associated with mental illness was an additional factor.

The stigma of mental illness was enacted in practices: as patients accepted doctors' lack of exploration of causes, were reluctant to discuss issues related to mental distress, and when some participants wanted services which were perceived as addressing physical symptoms.

Conclusion

This analysis of the social context of participants shows the diversity among a group of 46 recent low-income international migrants and confirms that an understanding of the multiplicity of factors is necessary. Ethnicity, immigration status, and low English language proficiency were perceived by many respondents as being negative factors in their experiences. Faith, on the other hand, was discussed as a valuable social factor, primarily as a positive source of social support. Islam was the exception here in that it was discussed both positively and negatively; several Muslim participants connected being Muslim with negative experiences of healthcare, supporting the discourse of felt 'Islamophobia'.

Education and social networks were contextual factors of importance. Some of the participants had high levels of education and social networks of relatives and friends. These networks engendered work opportunities and helped these participants navigate the healthcare system. This could include being

recommended to a good GP. For other participants social networks appeared limited, both opportunities to make new networks and maintain those within and outside their ethnic group. Gender also overlapped with many of these social factors, albeit often subtly. For example, less educated women participants with fewer social networks possibly developed the view that their health was worse and referred to feeling that it would be less so if they had had more support. Moreover the whole group saw the impact of work on illness and illness on work, with clear and significant implications for their income.

Finally, some details about illness as a vital characteristic of the group under study were presented in this chapter, showing the diversity of illness among those included in the study. The choice of healthcare services by participants could be interpreted as appropriate. Chronic poor health was common. Mental distress was a factor contributing to illness among the group and overlapped with the social context. Income, gender and migration trauma led to contestation of illness and felt stigma. In the following chapter the interviews are analysed according to narrative theories reviewed in Chapter Three and a thematic analysis of the interviews as illness narratives is undertaken. This is done by looking for the five key themes which characterise illness narratives in the interviews and then look for differences which might suggest the narratives are specific to recent low-income international migrants.

Chapter Six: An Exploration of Four Illness Narratives

In the previous chapter the social context and factors that were significant to the participants were discussed by drawing on the questionnaire and interviews. In this chapter the concept of illness narratives is applied to the interviews. The themes used for the analysis are drawn from the illness narrative literature reviewed in Chapter Three. Such an approach reveals the detailed representations of lived illness experiences, in which narratives derived from these interviews are subjective, yet can be considered trustworthy. The method of deriving themes was discussed in the analysis section of the methods chapter (Chapter Four).

The five **themes** are: **time and chronology** (Ezzy, 2000, Ricoeur, 1984, Frankenburgh, 1992, Frank, 1991); **chronic illness** (Charmaz, 1983, Kelly, 1997, Kleinman, 1989, Rogers, 2011); **disruption and loss of self** (Bury, 1982, Carricaburu, 1995, Taghizadeh Larsson, 2012); **diagnosis** (Zola, 1993, Jutel, 2009, Jutel, 2011c, Jutel, 2011b, Nettleton, 2008); and **emotions** evoked by illness (Williams and Bendelow 1996, Williams and Bendelow 1996, Bendelow 2009).

Several **typologies** for illness narratives were also reviewed in Chapter Three and were found to be helpful in framing the analysis; (Frank, 1991, Whitehead,

2006, Nosek, 2012, Robinson, 1990). Of this array of work, Frank's typology remains particularly accessible as he depicted four patterns in illness narratives: 1. 'restitution', which reflects a narrative of desire for health: 2. 'chaos', referring to the frustration related to slowness in diagnosis and long periods of suffering; 3. contention and 4. quest as representing a less questioning and more accepting approach to the illness including acceptance of outcomes (good and bad) and the care given.

This chapter uses four cases from the 41 interviews to exemplify the above themes of illness narratives; many of the 41 interviews contained all of the five themes, though to varying degrees. The vast majority of the participants in this study (37 out of 46 questionnaire responses) spoke about illnesses, in terms of duration (which I have categorised as being chronic when interviews indicated illness experiences had gone on for more than six months). Diagnosis was a common feature of the interviews. Often there was an overlap between chronic illness and contested diagnoses. The emotions which were both articulated and inherent related to contestation of the diagnosis, desire for an end to pain and suffering, despair, anxiety, sadness and/or shame. Disruption and loss of self were less explicit in many of the interviews. Finally, applying Frank's typology of illness narratives, many of the interviews suggested the characteristics of a chaos type, or moved between other types often returning to a chaos type. The four cases therefore provide examples of the five themes common in illness

narratives. Saidah and Alicja's interviews present the themes of chronology and diagnosis. Beata's narrative contained elements of all the themes but noteworthy was the emotionality of her interview in terms of despair and pain. Peta's case exemplifies the frequently present chaotic typology but he showed less concern than others about diagnosis and did not contest it. Moreover, for Peta, chronology was less important in his interview, though it was present to some degree in his description of his day-to-day street homelessness.

In addition to using the themes for analysis, this chapter also searches for evidence that the illness experiences of these recent international migrants were specific in some respects were made and these specificities are also illustrated with the four interviews as cases. The aspect that surfaced repeatedly related to the participants making frequent comparisons between healthcare systems in general, and the practices of individual health practitioners. This tendency appeared to occur irrespective of immigration status: refugees, asylum seekers, migrant workers and the undocumented migrants made comparisons. The two undocumented migrants in this study, however, were less concerned with healthcare. They expressed the feeling that they had no entitlement to healthcare and appeared less inclined to reflect on what would have happened in their country of origin. These interviews

supported the view that migrants with this immigration status had a tendency to avoid health services (Bloch et al.2011).

The selection of the four illness narratives for this thematic analysis included some additional criteria: one, variations in immigration status among the interviewees (that is; refugees, European Union migrants and an undocumented migrant). Two, the selection took account of gender and included both men and women. Three, some account of variation in interview quality was taken into account, as raised in detail in Chapter Four (Denzin and Lincoln 2000:21)

The cases that follow are presented in a similar format: first a short summary of the interview is given in a text box; second, interpretations are made using the five themes, signifying the interviews to be illness narratives, with references to themes highlighted with bold formatting; and third, another interpretive section, which focuses on issues that are specific to the narratives of recent international migrants.

Narrative One: Saidah

Saidah's narrative in context

Saidah preferred to meet in a community organisation in the centre of town that

he knew well. Saidah said he

found it difficult to leave his house

for the interview but Saidah had

chosen a Friday so that he could

also get to the mosque for prayers

and later meet friends, thus making

the most of the travel expenses.

He also decided that he wanted to

attend one research interview,

preferring to combine the

questionnaire with the semi-

structured interview because he

thought he would find two outings

difficult.

Saidah had been granted refugee

status soon after arrival in the UK with his wife and two children, but he had not

been able to find work and this he attributed to the illness which he proceeded

to describe. He mentioned that he had studied in a sub-Saharan African

country until he was 18 years old and graded his level of spoken and written

Box 1:

Summary of the medical aspects of his narrative

HIV positive diagnosis - statement of wellness on arrival in UK.

Breathlessness worsens over several months. GP prescribed inhaler.

HIV team prescribed anti-viral medication.

Breathlessness worsens and a different inhaler prescribed.

Continued breathlessness and third type of inhaler prescribed.

Over the next two months other symptoms appear and worry increases. These were investigated with blood tests. Diabetes and raised cholesterol found.

GP referred Saidah to HIV team. HIV team refers Saidah back to GP.

Collapse and hospitalisation.

Diagnosis in hospital - side effects from the inhaler or interaction between asthma and anti-viral medication.

Discharged from hospital after three weeks.

Second collapse after several days.

Re-hospitalised and diagnosis of diverticular thrombosis given.

Slow recovery.

New thrombosis one year later.

Continued slow recovery; will remain on warfarin.

English as 'well'. Saidah still felt like a newcomer after over four years and identified himself as a refugee. He had initially attended a language course but became too ill to study and to search for work. In the last year Saidah had been able to resume doing some studies (maths and English) and had completed some English tests soon after arrival and before getting too ill to study, as well as other courses (health and safety, painting and decorating). He also found the question about self-reported assessment of health the week preceding the interview difficult because he felt his health varied a lot from day to day. Generalising about the last six months he reported his health as 'bad'. The interview was a retrospective and chronological account of his illness experience.

Interpretations of Saidah's narrative

This narrative could be framed using Jutel's conceptualisation of **diagnosis** in narrative. It opened with Saidah stating his diagnosis of being HIV positive and qualifying this statement by adding he was in good health on arrival at which time he was referred to the HIV team. He spoke about new symptoms of breathlessness that had appeared a few months after his arrival and how this had led to the diagnosis of asthma from his GP and a prescription for inhalers. Persistent symptoms led to two new prescriptions and later when symptoms worsened and more diagnostic investigations were made by the GP, she diagnosed Saidah with diabetes and raised cholesterol. At this point in the Saidah said that he had not accepted these diagnoses but it was not clear how

much he had strongly disagreed at the time. It is also possible this reflection about diagnosis indicated disagreement which he had not challenged at the time and was expressed in the interview only with the benefit of hindsight. The GP referred Saidah back to the HIV team but they were not worried by the new symptoms as HIV-related or the test results and they referred him back to the GP.

At this point Saidah's comments showed his **emotions**; mainly indicating anger at what had happened; '*...they [the doctors] played games to me*'. This view was reiterated later when he was asked to say once more what happened: 'I think this is careless working. When they work - not caring about people, if they care about people they used to have to communicate between two doctors, because if I have two doctors they have to discuss what they give me and what is the right thing for me, and if they give me this one. Because they know every medication has side effects, they know, they have the knowledge... They have knowledge and they have studied, they know every single medication, some medication has interrupted or side effect they know that. But this is, for me, this is like careless. They don't care about the life of people that is why'.

Both quotes capture Saidah's view that the doctors missed opportunities, did not try hard enough to make a correct **diagnosis** of his problem, and repeatedly were '*careless*'. Clearly he blamed the doctors for the deterioration in his health and described the moment he became critically ill and was hospitalised:

‘.....my face big, my body big, my legs become dead, like paralysed, and my stomach gets big, and my body start to stretch everywhere, and after that my neck as well, very swollen. My body is shaking, and every day, I can’t walk, a lot of things going on’.

The revelatory moment when Saidah finally got the correct diagnosis was recalled in detail, including the names of doctors and the act of throwing away the inhaler. He was able to tell his story and show his gratitude to the student doctors who made the diagnosis by seeing a link between the inhaler and the antiviral medication. This brief moment of positivity was followed by Saidah recalling that by that time he was so ill, distressed (and possibly hallucinating) that he ‘attempted suicide’ with needles. This was a shocking and powerful comment that highlighted the seriousness of his health and the degree of suffering Saidah had endured.

Saidah discussed his experience **chronologically**. He was discharged from hospital after about 16 days but he said this was against his wishes at the time – he recalled pleading with the doctor to be allowed to stay longer as he still felt so unwell and he was kept in hospital another two days. However after two days at home Saidah experienced his leg swelling up. Feeling very ill again, he got himself to the HIV unit and was rapidly diagnosed with diverticular thrombosis and re-admitted to hospital.

The contentious and **disruptive** nature of his illness was described:

'....she [was] working at the X, a registrar, immediately she tried to help me.

She sends for a scan, immediately they bring an ambulance to go [to] the hospital and send me to the scan, immediately when they see a blood clot in my [leg] as well. It is very dangerous situation. If I wait the next day I am dying in the street from a heart attack'.

Saidah came to know the diverticular thrombosis happened because he had not been given anticoagulants whilst bedridden (he learned later this should have been routine treatment). Once again disappointed and feeling that the staff were slow to diagnose, and treat, Saidah perceived them to be culpable in this respect. This was evident in these words:

'They know they should give me before (this injection), but they never give me the injection, they just wait until I get the blood clot. This is another mistake that happened again to me, because for everyone they give [the] injection, even for one hour staying in hospital they give an injection. For me they do not give an injection - I stayed 18 days.'

This shows that Saidah felt the **disruption** and chaotic nature of his experience, he identified mistakes on the part of the health practitioners, which were avoidable and missed warfarin injections that he believed should have been given routinely had not been given.

While diagnosis was a strong feature, once again **chronological time** could be seen to structure and plot his narrative, providing credible detail and adding reliability. For example, he gave the exact date of his collapse and the lengths

of time spent inside hospital and outside. Also time is used to describe the build-up to the collapse:

‘After that, every day, every day my health situation starts to change. After two months I am a completely different person because my body starts swelling very big....’

Throughout the narrative Saidah tried to be precise about time, the frequency of treatment and appointments, and his final mention of time was to add that he now faced another lifelong chronic illness.

The despair and **disruptiveness** of the illness was evident in this quote:

‘...the steroid gone from my body first to my leg, I can’t walk and after that [it] is going to my head and started to make me crazy and at night I am not sleeping. My leg, stretching in the middle of the night I can’t open it. I am crying at night because my legs are tingling and I can’t move them back. The hands, it is the same thing. I am very confused and crazy and pressured, I never laugh or talk in my house I am always angry - because this situation made me angry. My situation has changed, like someone crazy...’

Saidah used the word ‘crazy’ several times signifying his **emotions** of confusion and despair at critical moments. The quote above relayed a gamut of emotions: confusion, pressure, never laughing, crying, speechlessness, anger and sadness. Saidah also described the emotion of fear; clearly he felt it on the morning of his collapse, which caused him to call his support worker: ‘I am worried for myself; [I] call my social worker to help at home because I don’t

know what has happened to me'. He recalled saying to her that morning:

"Please look after my family, today I am worried for myself because my head is not correct. I never sleep; my head is not correct, look after them". The critical moment was captured in these emotional comments. Saidah showed this by saying the social worker also cried. He reflected on his state of mind at that time:

'I think I am strong but I am not strong, I am weak, I am dying'.

Saidah was describing significant worry about his health at the time and admitting he was hiding these feelings. Gender was being indirectly mentioned as a factor when he said that as the male head of family, he felt he had to appear strong.

A sense of shame and guilt about being HIV positive was inferred in this narrative, particularly from his opening claim that his HIV was an illness under control and the problems he would recount related to other illnesses.

Using Frank's typology of illness narratives (Frank 1991) this account also fitted initially with Frank's notion of the **chaos typology** and then also with a contested narrative. In the description of the severity of symptoms Saidah was able to describe his pain and later he was able to indicate that he tried to be strong, he thought he was strong but in retrospect he realised he had been close to dying. The length of time Saidah suffered; the repeated attempts to get help and the contested diagnoses he was given created a chaos type of narrative. Saidah found it hard to envisage a full recovery according to Frank's typology of 'restitution narratives' and predicted he faced life-long health problems. With

irony he commented on being healthy on arrival whilst referencing past hardships of living in a refugee camp. Saidah did attempt to end his narrative by being a little positive, talking about the improvements in his symptoms in the last few weeks and saying he felt emotionally a bit stronger, and that he had noticed an improvement in his ability to build friendships again and to be a bit more involved in his family. Saidah measured this by the new feeling of wanting to socialise again and being involved in community events. Thus it is at the very end of his story that an attempt was made to give a restitution narrative. He added that the main improvement to his healthcare was that his patient records had alerts or tags on them so that all health services and pharmacies he used were aware of the side effects he had experienced. Saidah had also changed GPs to one he felt was more knowledgeable about HIV, although he did not mention how he made the decision to change doctors.

Specificity in Saidah's narrative

Saidah's narrative illustrates that as a recent migrant he made comparisons, implicitly, which also reflected his vulnerability, confusion about using a new healthcare system, and expectation that the system would be better than his past experiences. His narrative showed he was unfamiliar with the NHS in a number of ways; for instance he was unclear he could contact the HIV unit without a referral from the GP once he was already a patient. He also showed reluctance in using Accident and Emergency. At times his narrative indicated he was not assertive and these behaviours may have affected his treatment. However, at

other times he said he had to 'plead' with his GP. This can be interpreted as showing assertiveness and desperation after silence and much suffering.

Although Saidah was receiving some support from a community organisation for refugees, clearly this support did not prevent his suffering and slow diagnosis.

Later in the narrative, Saidah averted heart failure after feeling very unwell – the second time he had learned from his first experience and went directly to the HIV department from where a doctor sent him straight to Accident and Emergency where he was diagnosed with thrombosis.

The initial misdiagnosis that Saidah experienced could be interpreted at the very least as bad luck, but Saidah did not accept this explanation and criticised the GP and HIV team for not spotting the interaction between medications. He tried to understand the failures in healthcare alongside the number of times he had asked for help. The initial problems Saidah faced were a likely reflection of his misunderstanding the role of the HIV team in importance above that of his GP. The second oversight, not being offered Warfarin whilst being bedridden in hospital, had near-fatal consequences. This event can also be understood in terms of Saidah's vulnerability as a new migrant who lacked social networks which could have supported him in the hospital.

Saidah describes a chaos typology for much of his narrative but ends with elements of restitution and quest. Despite Saidah articulating some contestation I would argue that Saidah's narrative also suggests a situation that

exists among new migrants – acceptance of their healthcare situation – and it is possible that this factor overlaps with the influence of religious beliefs.

Narrative Two: Alicja

Alicja's narrative in context

Alicja was fluent in English; she had studied to a post graduate degree level and became a teacher. She spoke with clarity, confidence and possessed an authoritative manner. She was comfortable about being involved in a research project, mentioning that she had started a PhD herself at one point in her teaching career.

Alicja said her main reason

for leaving her country of

origin was losing her job. She had left Eastern Europe before the accession of eight more countries to the EU in 2004. She had got a job in the Channel

Islands and worked there for two years before her onward move to the UK in

Box 2:

Summary of the medical aspects of her narrative

Diagnosis of anaemia as a teenager.

Prognosis of thyroid deficiency at age 21.

In England Alicja treated for anaemia for over a year. Made repeated requests for a thyroid function test to be carried out - the test showed thyroxine deficiency.

Alicja was treated for thyroxine deficiency by her GP.

Treatment becomes contested, referral made.

Consultation with a specialist and the dose of hormone was doubled.

Alicja's symptoms improved for six months, then a routine thyroid function test showed no thyroxine deficiency. Alicja was taken off thyroxine and prescribed iron.

Symptoms reappeared. The GP made a new referral.

The second referral took a long time, symptoms worsened.

Alicja went to X and consulted a doctor there. Alicja got a slightly different diagnosis of Hashimoto (still a thyroid deficiency) and was given a scan.

Alicja went to the appointment with the UK specialist. Alicja talked about the other opinion and showed the scan from X.

The specialist said there was no treatment they could give her and referred her back to the GP. The last blood test had not indicated thyroxine deficiency. Alicja was once again prescribed iron instead of hormones.

2005 because she had become bored with where she was living. At the time of the interview Alicja had been in England for five years.

Interpretations of Alicja's narrative

Diagnosis directed this narrative as it opened with Alicja's statement of a diagnosis of anaemia in her country of origin. This was later followed by a prognosis of thyroid problems when she went for a routine check-up for another matter - she was told she had the appearance of somebody who, in the future, would have an underactive thyroid as well as anaemia.

Alicja described her symptoms as gradually worsening and she implied that this had happened over a long period. She was not clear if her symptoms had started when she lived in her country of origin but certainly she felt they had progressed since her move to the UK. She had blood tests and scans taken periodically on going back to her country of origin. It appeared that Alicja was deeply affected by the prognosis of thyroid deficiency given by the doctor in her country of origin – in the questionnaire she said she had symptoms for 18 years (here she could have been referring to anaemia) and later she said the thyroid illness began in 2008, referring to the NHS diagnosis given in the UK. Alicja did not describe in detail the build-up to seeking help but suggested a gradual beginning in 2006 after her arrival in England. She was treated for anaemia for at least a year before any further tests were offered. Alicja explained she was disappointed with her treatment and had wanted to have a blood test for thyroid function sooner. Her view was that diagnosis took longer than it should have

done. Finally the test was done in 2008, confirming what the doctor in her country of origin had predicted. Alicja presented these moments of medical diagnosis as punctuating points in her illness, even though she had been experiencing symptoms for longer.

Alicja's view was that the symptoms of underactive thyroid were confused and she **contested** the diagnosis of iron deficiency, producing a **chaotic** typology of **chronic** illness. She repeatedly requested to see a specialist and she felt that she would have been tested in her country of origin sooner. The treatment for thyroid deficiency was thyroxin and the GP decided to prescribe it, as opposed to referring Alicja to a specialist. The dosage of the hormone also became contested - Alicja described the GP's cautious approach with regard to the dosage and she felt her symptoms worsened and remained longer because of the reluctance to increase the dose. Alicja was frustrated and wrote a letter to the GP practice as means of trying to persuade them to change their approach. She also saw different GPs to see if they had a different approach to medication. On one such visit to the practice Alicja saw a locum, who she described as '*an old GP*' and the first GP '*who took an interest in me*'. To her relief he offered a referral to a specialist and agreed that it was not the GP's role to try to prescribe thyroxin.

When Alicja met with the specialist the dose of thyroid hormone was immediately doubled. She described the meeting as fast and involving no physical contact from the doctor which surprised her but she was satisfied with

the medication and over the course of six months she gradually became well and active again. For this period the amount of hormone was not a contested issue but when she was asked to return to her GP for a blood test to monitor thyroxin levels the result showed no deficiency of thyroxin in her blood, and so Alicja was told she would no longer be prescribed thyroxin. She challenged the GP's rationale for stopping the hormone and made requests for another referral to the specialist but this was not made. It was only after subsequent visits, when Alicja repeatedly complained about her symptoms returning, that she was given another referral. Alicja recalled the long process of diagnosis and then battling for the hormone:

'In 2006 I started going to see a doctor but he said no, just anaemia just anaemia, but "it might be something with thyroid?" "No, no". So I was just taking iron most of the time in 2007...But he said he didn't want to take any blood to check hormones. I don't understand why, for anaemia, yes. But I asked him for something like six months or so to take samples for blood to check. "Okay, okay, let's do it"'.

Alicja felt getting the second referral to a specialist from the GP had once again taken too much effort on her part. The contestation over the treatment resumed as a result of the monitoring of the thyroxin levels.

In desperation for a speedier diagnosis, Alicja went back to her country of origin to seek out another opinion. The doctor there diagnosed her on first sight, telling her she had '*Hashimoto*' (an illness related to hypothyroidism caused by

an inflammation of the thyroid gland), which she said was later confirmed by a scan. Alicja was therefore critical about being able to get diagnostic scans in England saying they *'did not exist'*. Eventually she met with a second specialist in the UK and in this consultation Alicja discussed the diagnosis from the doctor in her country of origin. She also showed the specialist the scan but felt the specialist was unsympathetic and said, without explanation, that *'we cannot do anything for you'*.

Alicja displayed certainty about her (lay) medical knowledge and the ideas about the cause of her problems at various points in her narrative, for example when she admitted she knew her symptoms of iron deficiency were similar to deficiency in thyroid hormone. She also showed a strong interest in a biological explanation for the illness, not liking the suggestion of there being psychological causes. Alicja was comfortable and fluent in using medical terminology and was keen to use technology to diagnose her condition. When she did not get diagnostic tests she attributed delays to a lack of skills of the UK doctors:

'I was told recently, well, I listened to X television, and they did some research there. They said they have the best medical equipment here in Britain, but the worse doctors. So, look that is [it] the education.'

The biomedical-technological approach that Alicja sought was later used in a way that she did not like. When she was called back for a blood test after six months of being on thyroxin, this result led to stopping the thyroxin prescription. She was upset by this and said to the specialist she could provide 'proof' she

still had a condition that warranted the continued, not erratic, prescription of hormones:

‘So, when I went here [in the UK] to see a doctor I just told her, “I suffer from Hashimoto” She said “No, you suffer from underactive thyroid, not Hashimoto”. But she doesn’t have any proof of it. I am good because I have got a scan, I have got like this. [The doctor said] “No”’.

It can be inferred from Alicja talking in this way and her mention of sending letters to GPs that she preferred the diagnosis she had received in her country of origin. It was also possible that she had antagonised some of the GPs and also the specialist with her assertions and the use of second opinions. The specialist relied on one blood test result to decide to stop treatment, which was interpreted as her hormone deficiency being resolved. Any current symptoms and fears she was experiencing were ignored; according to the GPs, they were caused by iron deficiency. Several interpretations of the approach taken by the specialist are possible; one could be that technology held more weight over the patient’s historical scans and experiences of illness. Alicja’s wishes for continued prescriptions were ignored, and she did not feel well informed about the specialist doctor’s reasoning.

‘.... “we are not going to give you more hormones and I am not going to help you anymore and you will have to be in contact with your GP”. She sent a letter to the GP, I got a copy that said “Alicja was apparently very unhappy with the

last visit but I can't do anything for her". So, I am still in the hands of the GP, who treats me with iron'.

Another example of the importance of technology on this participant's illness experience occurred when Alicja described another major illness experience related to a chronic knee problem. For this problem Alicja's health seeking led to her eventually being given a referral and treatment. This time diagnosis was not contested. Alicja recounted waiting for the appointment a long time because the diagnostic tests were not received, with some results being delayed and others lost. Later Alicja described the post-operative experiences as mixed; her stay in hospital for the operation was good, but later physiotherapy and the consultation with the specialist were less good.

Alicja's narrative was **emotional**, ending in expressions of uncertainty and despair about what to do next. She was in turmoil when she could not be prescribed the hormone anymore. She felt both fearful and certain that in time her symptoms would return strongly and the thought of having to experience this again was very upsetting.

Alicja was asked about the emotional effect of the illness on her relationships.

Alicja answered by speaking about the physical effect of the illness on her sexual relationships because intercourse was no longer pleasurable. Alicja also said she was finding it difficult to maintain relationships, which was a cause of concern. Alicja talked about the effect of the illness by using the word depressed:

'Depressed, depressed but this illness makes me depressed...Just something deeply in there, I observe myself very well, but not being ill makes me, just the issue, oh yea God I am ill, because I was always someone to try to do things to assure myself to be active, as much as I can. Just it is, something deeply in there, I am more resigned than before. I am losing my optimism'.

Alicja's description of thyroid deficiency symptoms also revealed her emotional state indicating anxiety and despair:

'I was very bad because I started to lose my hair. I lost a lot of weight in just a month and then the totally opposite, [I] was gaining weight without eating. I mean of course I ate but I always take care what I eat and I used to go three times a week to gym, so I kept healthy. And constipation started and everything was rubbish, then my heart, finally.'

Time and chronological plot was evocatively and effectively used by Alicja in her narrative. She referred to how old she was when she was diagnosed with anaemia and when she was given the prognosis of hypothyroidism. Her comments were chronological when she described the contested diagnosis, referrals, and treatment despite ambiguity about the start of the illness. Using time in this way Alicja was able to strengthen her narrative, and showed she felt she had waited too long for her diagnosis. A second narrative about a knee injury was told similarly, with the cause, diagnosis and treatment being the key markers of the story.

When she spoke about not getting hormones it was clear she feared returning to the same state of **disruption** and chaos. Here Alicja articulated that the illness had changed her sense of self and who she felt she was - to somebody who was not active or motivated – and her future felt bleak. This narrative fitted Frank's chaos type of narrative. Alicja also wanted restitution or a resolution; this was apparent in her persistence to be diagnosed and in her seeking treatment by a specialist. Finally, because the narrative included contestations over treatment being withdrawn, it also indicated a sense of chaos. By the end of the narrative Alicja was feeling powerless and unclear about what she should do next. She mentioned she would now try alternative complementary medicines and therapy, hoping that this could provide some relief.

The length of time that Alicja had felt unwell since the diagnosis in the UK was at least two years. The illness was a chronic debilitating illness and the length of suffering had seriously affected her emotions. Alicja was also recovering from a knee operation at the time of interview having experienced over-vigorous physiotherapy sessions in which the stitches were broken. She had found the specialist unsympathetic about this experience and unwilling to see her for further follow-up.

Alicja desired restitution and she was prepared to deny negative feelings in the hope this would help her return to better health:

‘.....someone to try to do things, to assure myself, to be active’.

But Alicja returned to a chaos narrative and reflected stoically that the effects on her were not necessarily due to the medical condition but were due to the chronic nature of her illness:

‘...it is lifelong illness, maybe I will not find, until the end’.

Alicja’s had started her narrative by showing a preference for a biomedical approach. She showed her disappointment at the doctors in the UK, seeing the management of her treatment as showing a lack of expertise and ending with reflections on the experience of having a chronic condition that was difficult to treat.

Specificity in Alicja’s narrative

This migrant worker’s narrative illustrated some dilemmas that were common to the other recent migrants’ narratives. Alicja had a condition that pre-dated her migration and she wanted and needed treatment when symptoms got worse, which occurred soon after arrival in the UK. Alicja did not appear to know about UK health policy towards migrants or any conditions of entitlement to health care services. In the narrative there was little awareness that when trying to access both primary and secondary care she could have also be perceived as a health tourist rather than a resident trying to get information she wanted by showing additional diagnostic information and scans from her country of origin.

Alicja’s self-labelling is indicated in her description of herself as a person expecting to get ill, having had a prognosis, seeking treatment when her

symptoms worsened and not recognising she might be perceived as lacking entitlement. Alicja reflected on an additional question the researcher posed about whether doctors in the UK might expect her to use healthcare services in her country of origin. Alicja replied that there was no option for her but to be treated in the UK and it was not her preference. While she was able to go to her country of origin and get a faster diagnosis, treatment was not an option because she was a UK taxpayer and was no longer eligible for free treatment in her country of origin. She also added that it was not practical for her to get hormones regularly from her country of origin due to the cost of going back and forth and because of additional monitoring needed in the UK. Alicja also seemed unaware that her entitlement to secondary healthcare may have been scrutinised in the first year of arrival in England and that it was possible that the initial reluctance to test by the GP could have been because of a policy which deterred GPs referring new migrants to a specialist for a year. Alicja did question whether the problems she had faced were particular to her condition of hypothyroidism; perhaps long-settled people experienced similar practices. But at the same time Alicja was dissatisfied with other aspects of healthcare she had received.

As a recent migrant worker Alicja made a lot of comparisons between diagnoses, referral mechanisms and treatment in the health services of her country of origin and the UK. Moreover, as an EU migrant she was able to travel back and get seen by a doctor for a second opinion when the treatment

she had received for six months was withdrawn, but this did not help her get her treatment reinstated in the UK when a referral did come through. Alicja had access to information and in this way was able to be in touch with different medical systems such as in her country of origin. There was variation in participants' experiences in the material and social capital that they had to draw upon. Alicja had moved from chaos to restitution and back to chaos and perhaps ended on a quest motif, sounding resigned to a life-long health problem.

Narrative Three: Beata

Beata's narrative in context

Beata was a 38-year-old migrant worker who had been in the UK since the middle of 2005. She had left Europe because of financial and relationship problems, leaving her teenage son in the care of family. Beata had a diploma in nursing and social work and worked with elderly people but decided she had to leave because her earnings were too low. However, she could not use her skills and get care work in the UK. Beata was quite fluent in English and used her

Box 3:

Summary of medical aspects of her narrative

Beata developed flu-like symptoms on return from a trip back to see family.

Beata went to her GP after a week and was given painkillers.

Additional symptoms of severe muscular pain and a swollen knee appeared and she returned to her GP and was given anti-inflammatory medication.

In severe pain in the middle of the night she went to hospital. Beata was referred back to her GP. The doctor in emergency suggested an HIV test be done.

GP did blood tests. A referral was made for the swollen knee. Beata was helped to apply for sickness benefit.

Beata collapsed in a supermarket. Beata returned to some of her cleaning work whilst still feeling ill in order to be able to pay rent. It took Beata two and half months to recover. Referral to clinic came through. After three months Beata was offered a steroid injection for a remaining swelling in knee which she declined.

English language skills to help translate for her friend when she needed to see a GP.

Beata supported her son by sending back money and going back regularly to see him and her family. In the last few months Beata had travelled home to see her father who was seriously ill and subsequently died. She had moved accommodation several times and after the bereavement had decided to move to live with a friend. Even though it was more expensive, she decided it was a warmer, friendlier place for her to live.

Beata had mostly worked as a cleaner and she described that the 'worst and hardest job she had ever done was being a room attendant in a big hotel. She had also worked in a café and despite liking this work she had been laid off.

Beata had gone back to being a hotel room attendant in a small hotel and had been working in this cleaning job since January 2008. Beata recalled needing to do three jobs in one day to earn enough to pay her rent, live, send money to her son and see him regularly. She was finding it very difficult to manage financially. At the time of interview, she was not able to send any money back as she needed to furnish her new accommodation, in particular needing a bed for her room. Beata had heard about housing benefit and child benefit but did not have the time or know how to apply for them. Beata was interviewed in familiar surroundings in one of her workplaces. She had not understood that she would get some expenses for giving her time to participate and at the end of the interview when offered expenses she was very happy. She said the

voucher would enable her to eat properly as often she skipped a meal to save money.

This interview had been rearranged once before because of Beata's work schedule. Other interviews with migrant workers in the same company had also been cancelled because of their busy work schedules. It would have been good to have asked Beata to talk more about her present state of health. For instance, she was not feeling healthy at the time of the interview but had not said why, and it would have been useful to have known more about her personal circumstances. However the interview was conducted at a fast pace, with Beata telling her illness story with little prompting. Towards the end of the interview the researcher tried to introduce some questions but it became clear Beata was tired, having come straight from a cleaning shift and she wanted to finish the interview and prepare herself for her next job.

Interpretations of Beata's narrative:

The illness episode had occurred nearly two years ago but Beata was keen to recount the story, suggesting it had been a significant life experience:

‘I have never been like this sick, never in my life.’

Time clearly drove this narrative but unlike the previous narratives, this was seen to be related to an acute condition as opposed to the two previous chronic conditions. Beata tried to give a chronological account from the time the symptoms first appeared and the key events which followed.

Seeking a **diagnosis** and appropriate healthcare framed this narrative about acute illness. Beata described how the illness had started, with common symptoms at first, and then with additional symptoms which became more worrying. After a week of feeling unwell with flu symptoms, Beata went to her GP and where she was prescribed something for pain and inflammation in her throat. More symptoms appeared -- all-over muscular pain and most worryingly a sudden swelling of her knee. Beata returned to her GP but was disappointed with the response she got:

‘He gave me, but it wasn’t antibioticum, I am not remembering what, it was mainly just painkillers. Every four hours I needed to repeat. It wasn’t any proper medicine. This was not good. I am not feeling any change, it was still painful, everywhere. I said what about my knee and he just say “some inflammation”. In my country I am straight away getting paper to go to a specialist, the next day I would go to hospital and do an x-ray or whatever. To take the inflammation injection or something but in here nothing! But just send me home; even if I couldn’t move nearly, it was ridiculous how I felt. Not even any helping accessories like for walking, nothing!’

Beata felt she did not get a diagnosis or sufficient treatments such as antibiotics, an urgent referral to investigate her swollen knee, or practical aids to manage her disability. Her symptoms worsened and became more distressing:

‘...it was under my skin, everywhere, everywhere, just paining!’

Beata's **emotions** were expressed through the raised tone of voice and in repeated use of the word '*pain*' or '*paining*' (the word appeared 26 times in the interview). The word pain, repeated, signified a number of emotions such as worry, despair, frustration and anger. For example, when Beata described the pain she was in and the response she got from the GP that she could only have painkillers and nothing else, there was a suggestion of anger and despair, Beata felt alone at that time and uncared for. Another emotion was blame at what she felt was the inadequate investigation of both her health problems. Then she referred to the fear and intense pain she felt that led her to go to Accident and Emergency. Beata said she had never felt so seriously sick: 'I just feel I can't live like this, I need to go... I had very big pain...some pain I could manage but this one was just un- (I don't know this word), I felt I will go there and I was crying about the pain.'

One night soon after the GP consultation, Beata became so distressed and frightened she went to Accident and Emergency on her own. In hospital she was disappointed by the response to her pain. She felt she should have been given something, and she felt some tests could have been done whilst she was there.

'I thought they put some injection in me straight away to get away the paining but nothing, nothing!'

When asked more about the hospital incident Beata reiterated her view about the seriousness of her symptoms:

'...I hadn't sleep, I couldn't move my arm. I feel some under my skin like a small vegetable and it was hurting....It was like everywhere; if I touched my skin I jumped. I couldn't sleep I couldn't move I couldn't do anything.'

At the point when she saw the emergency doctor, Beata was in such a bad state that she noted:

'He was so scared, what could be my problem, why I am crying, and he got some translator.'

Beata's interview fitted Frank's **chaos typology**, with a key characteristic of **contestation**. This was evident in a number of Beata's comments with regard to the GP. Similarly, in the emergency department, with the suggestion of an HIV test; Beata was irritated by this and then again later, by the GP's responses. Beata was given a blood test and she thought this had included a test for HIV without her consent. There was stigma both with regard to the possibility of being HIV positive and disagreement based on her sexual inactivity. For much of the narrative Beata regarded her symptoms as being unexplained by the doctors. Much later in the narrative Beata said the GP had diagnosed her with arthritis and a referral had been made but it was not clear on what basis this diagnosis had been reached. However, Beata was preoccupied with a lack of a satisfactory diagnosis and other possibilities for the cause of her illness. The researcher asked Beata if she had agreed with the diagnosis of arthritis and she said:

Beata: 'It could be, but it wasn't just that thing, it was more things underneath.

You know what I am thinking it was that virus, do you remember?

KR: There was a flu virus, a swine flu virus?

Beata: You know, I think I have that one as well.'

In the last month of Beata's illness an outbreak of swine flu had occurred, which had been widely reported in the media. Since that time some critiques about the way the media and department of health gave disproportionate coverage to the possibility of swine flu emerged, in which it was argued that the warnings were out of proportion to the scale of the outbreak. Beata regarded this as a possibility:

'I don't know about the blood test but it didn't told about something very bad. I think they could find out; something was inside me, some serious thing, some serious thing was there. And my joint fluid and inflammation was there. But I still don't know what was it.'

It was also clear that about two years after the illness the belief in an infectious disease was still strong in Beata's expression of fear of getting a similar illness again. She hoped she had developed some immunity and found herself watching other people, how they moved and remarked that a lot of people suffered from '*bad legs*'. She also mentioned her knee had given her some problem that winter. This recurrence had led her to only partially accept that some arthritis or injury may exist:

'...this time, every year at this time, I felt it hurting. Not like another one again, but I feel the bone is not in the right place or something. I don't know what it was from, how I don't know'.

Beata could not agree with the diagnosis she was given. She felt the illness had been caused by a virus and she reluctantly accepted that she may have arthritis.

This was seen as a possible additional problem.

Beata explained that her illness had been worse because of poverty and her social context:

'I think the whole thing, the whole illness, is affected by that poor, not proper heating, that circumstance is not what it should be. It was very cold, I haven't too much money, [I couldn't] eat properly, take proper vitamin and fluids and it was connect to that I think. If I am good and hot, be warm and eat properly I think I am not getting this badly down. I am not sure but I think, I think.'

Beata felt that poor living conditions and a low single-person household income had weakened her ability to cope and exacerbated her illness. She explained how she could not heat her room sufficiently and had needed to keep a window open for ventilation if the heater was on. In describing the episode when she fainted in the supermarket and returned to her room to be alone, Beata highlighted her vulnerability as a person living alone and having few people to take care of her when she was seriously ill. She felt the GP had not cared enough. Even though Beata had not felt well enough to go to work she went back to work sooner than she should have liked because being without savings

meant she needed to earn in order to pay her rent. Beata mentioned she did not know how to apply for any benefits.

This illness narrative developed from chaos type to reflect some elements of a restitution type by discussing immunity she should now have from similar pathogens. Beata also discussed how changes in her social context had affected her positively, such as better accommodation she had moved to recently, living with a supportive friend, and lastly she felt that she had found a GP she trusted who was *'more patient and more helpful'*. She was planning to register with this GP soon, for herself and in preparation for her son who she hoped would be coming to join her in the summer. Her illness had been very significant and brought chaos to her life; the intolerable symptoms and the time it had gone on was something Beata feared living through again.

Specificity in Beata's narrative

Beata's vulnerability was discussed in the section above. Here I point out the specificity which relates to low income being linked to migrant status. Beata lacked a financial cushion, and had a need to work continuously. This is a position that is common for such migrant workers. Beata had received some sickness benefit but this did not help her with her mounting rent and she did not know if she was entitled to get help. Beata was therefore unaware of the full extent of the help available to her when she was ill. She was also unaware that she was entitled to seek a second medical opinion. Beata clearly felt the

accommodation she had at the time was of a poor standard; she voiced concerns about the gas heater being below the safety level, and this indicated the vulnerability and overlap with poor housing for low-income migrants.

Overall Beata felt her GP had not been attentive to her vulnerability as a poor migrant and her unfamiliarity with the health and benefits systems affected her illness experience.

Beata's narrative indicated that there was psychological stress associated with being a recent migrant which was linked to social networks. After separating from her partner, she had left behind her son to be cared for by her family in her country of origin, in order that she would find work. She needed to earn enough money for herself to send back for her son's upkeep and to save in order to visit her son regularly. Beata talked about her social networks being essential when she was ill yet insufficient. A friend tried to help her as much as possible when Beata was very ill and housebound. When Beata hadn't been able to get to work by public transport she had managed to get help through friends and acquaintances to get a lift to her job.

Beata made comparisons; she referred to her past knowledge of the health service in her country of origin. She showed how being a migrant affected what she expected from the UK health system which related to her past experiences. For example, her view was that she was not given adequate diagnostic testing for her swollen knee, fast enough specialist referrals or sufficient willingness to prescribe antibiotics. She indicated she would have been offered these

treatments in her country of origin. Beata's expectations were therefore not met and this affected her attitude towards the GPs she met when acutely ill, as well as when her illness became prolonged and her experiences cumulated. Beata therefore sought biological explanations for her illness and biomedical interventions based on her use of other health systems.

Narrative Four: Peta

Peta's narrative in context

Peta was fluent and proud of his knowledge of the English language. 'My

English is good enough to get a job you know, properly - I used to work in a customer service for six years, that is another thing, you know'. He was keen to demonstrate his English ability and later he also chose English as his main spoken language (above that of his country of birth).

Box 4:

Summary of the medical aspects of his narrative

Peta stated he was an alcoholic. He described his condition and the problems that arose from it. Peta gave reasons for his dependency on alcohol. He described his use of health services and his hope that he would be eligible for rehabilitation. He gave more reasons why he had become homeless. Peta talked about his worries about being homeless and drunk, the tendency to hurt himself and his approach to being with others who were homeless and needed to drink.

Peta was without official documents at the time of the interview because they had been stolen from him, although he still had a National Insurance Number and some '*home office papers*'. At times Peta's narrative changed on certain details which suggested confusion or fear that by revealing his nationality and/or visa status, he would be revealing his identity and making himself vulnerable.

Clearly he was mistrustful of the researcher and pointed out he was wary of all 'official' people. Implicit in this was the sense that Peta was trying to protect himself from any possible risks of deportation to his country of origin. Peta's multilingual ability (which included Russian) made his immigration status appear ambiguous. Peta said he possessed a Polish passport and was therefore an EU migrant, perhaps from near the border with Russia. It is also possible that he was a non-EU migrant who had overstayed his visa. Peta said he had had a venturesome and difficult life. He said he had been robbed of his passport in the UK. This aspect of his narrative was not queried further as the researcher thought it would have damaged rapport. Peta was unfamiliar with the office of the alcohol rehabilitation service where the interview took place, despite receiving considerable support from them since arriving in the city. Clearly he had experienced this support as an outreach service. Peta preferred to be asked questions rather than telling his story unprompted. This was difficult but once he started he gave a flowing account.

The interview took place in the morning and he appeared to be under the influence of alcohol. The researcher was sensitive to the fact that Peta was both physically and emotionally fragile, being street homeless. All questions were asked carefully and lightly.

Additional ethical issues arose from this interview regarding giving expenses which would probably be spent on alcohol. This issue was discussed with the support worker and her manager and it was decided Peta should be treated like

the other participants. Peta and another interviewee were both undocumented and homeless. Despite his obvious destitution, the tone of the interview suggested that participation by Peta was not driven by material gain and he had other reasons for participation -- a desire to speak English and to tell his story, despite perceiving risks and having reservations about the research process.

Interpretations of Peta's narrative

Peta started his narrative with a statement of his **diagnosis**, thus establishing a biomedical view of his situation. This also suggested a wish to legitimise his condition, reduce feelings of blame and stigma. He therefore interpreted the question about his problem in a broad sense.

'Once I left London I became an alcoholic and that is a disease. And most of all I became an alcoholic. If I am not drinking, if I haven't got any tablets at all, I became epileptic. I am having epileptic fits'.

Peta used the term '*epileptic*' to describe his fits and it was his view that he had such fits if he stopped drinking so this gave him the desired justification to continue drinking.

In Peta's use of the phrase 'became an alcoholic' there was a sense that alcohol dependency had been a major **disruption**, it had affected his identity and his sense of self. Peta described how his behaviour was affected by alcohol: 'No, actually I was fighting yesterday, no, it wasn't a fight you know, I did have bump you know, to a guy who insulted me. It wasn't actually really bad,

normally I would actually walk away but once you are drunk - I just couldn't actually stop myself, that is another thing.'

Peta didn't like his behaviour and felt he had not behaved as he 'normally' would.

Peta's narrative used **time** less precisely and coherently, a reflection of having been on the street all night. It suited Peta not to be too precise and reflected his chaotic lifestyle.

When Peta was asked about his experiences of using health services in the UK, he focused on emergency services, from which it could be inferred that in recent times this had been the route he had taken into healthcare. He identified the situation of having '*epileptic*' fits as being the main reason for using Accident and Emergency services. These encounters had been positive but he also made clear he tried to get away as soon as possible and overall he avoided using health services. The reason he gave for this was that he said that he did not like doctors, though he felt they were nice to him, and he did not like to stay in medical services very long. Other medical episodes were managed by St. John Ambulance, with whom he also had helpful encounters following minor accidents. This had saved him going to Accident and Emergency at a hospital. Peta was also positive about help he was receiving from the community alcohol support team. There was some suggestion of a restitution narrative developing in the way he spoke about looking forward to a better future: He had also recently registered with primary healthcare with help, was helped to get a new

passport issued, and hoped for rehabilitation. Peta was able to sound both hopeful and apprehensive of a future that could lead him towards changing his behaviour:

‘Next week if they are going to give me my passport back I want to stop to drink, and I can’t do it just like that you know, snap of my fingers you know, coz even the doctors told me that. I just can’t, I just can’t, I need the tablets. I need valium or something like that. Anyway it is called – somehow - I don’t know [the word] - I think I will need it. And I want to stop to drink, believe me I do.’

However, there was some contestation in his narrative about what triggered Peta’s epilepsy; he insisted there had not been a link with excessive alcohol consumption. Peta also put forward several social explanations for his alcohol dependency which showed he did not fully accept a biological explanation for what could be seen as a health problem. Clearly he saw that there were social links between alcoholism and his past difficulties. Later Peta described a difficult youth and he admitted to mental health problems, stealing and taking up drinking from an early age.

‘To be honest with you...I am psychiatric and I had a breakdown. I will tell you how it started. Nicking things, doing things I don’t like. I did this before, always I was getting drunk. I am getting better you know, well to be honest with you, it is not getting better. I am just getting aggressive and then I am just fighting people, you know.’

Peta also linked his alcohol dependency to his migration and separation from his family:

'Well, I have lost my family, I have only got my sister back in X you know who is actually now sick - really, really seriously sick. In my life she is having an impact as well because she has two children, I love them both. But the thing is that it is not the way for me to come in this condition you know, over there. It might be actually that is part of a reason... Well, I lost my mother whilst I was here. She passed away about two years ago. I was without a passport at the time as well and the X consulate couldn't even give me a one-way ticket. That is another thing you know. I was pissed off at the time'.

Another reason Peta mentioned for becoming alcohol-dependent was the breakdown of a personal relationship:

'I lost my girlfriend, you know. Anyway, now I have sent her back home cause she was doing, you know she was finishing her university. Actually, two of them, we were living together. But her visa was actually expiring so that was the thing, so I have sent her back home. She didn't want to actually go, she wanted to stay. Anyway, I said I am not going to mess up your life, you know. So I dropped her off at Heathrow airport and that is it. That might be actually one of the reasons because everything, actually you get it together you know, it makes, you know, end up somewhere, and it does end up actually at the bottom of a bad hole.'

Peta alluded to having a child with his girlfriend but we did not dwell on this obviously upsetting aspect of his situation. He alluded to feelings of loss and a desire for more contact with faraway family and loved ones and clearly felt shame with regard to his alcohol dependency and general situation. Finally, Peta discussed the connection between alcoholism and losing his job. He had helped to set up a business which had gone wrong eventually, and this, he reflected, was because he had employed friends who did not work well who also drank alcohol. Peta presented a complex account of social issues and events and presented numerous reasons that had led to alcohol dependency. He ended poignantly, concluding that it had all ended with him being 'at the bottom of a bad hole'. Peta also made the point about not wanting to 'mess up' his girlfriend's life by living with someone with his many problems. This indicated Peta considered his current situation undesirable and that he had experienced better times.

The **emotional** aspects of Peta's narrative emerged when he talked about his family. For instance, Peta carried regret and guilt regarding his seriously ill sister, feeling that as a brother he was not supporting her or her children through her major illness. He was also deeply sad about not being able to see his mother when she was dying. Therefore shame featured in the stories of family crises. Finally, Peta conveyed a sense of loss caused by ending a close relationship. Alluding to this briefly appeared too painful and sensitive a topic for him to discuss further. Peta wanted to protect his family and reduce the shame

he felt. He thought he could achieve this by not telling them about his real situation or not returning until he was better:

‘.....it is not the way for me to come [back], in this condition you know, over there - it might be actually that is part of a reason.’

Peta’s narrative indicated a **chaos typology** in which drinking alcohol led to loss of control and anti-social behaviour. His condition had been going on for a long time, it had steadily become more disruptive and his behaviour had led to destitution and homelessness. There was recently a new opportunity to overcome his alcohol dependency through rehabilitation and Peta showed some recognition of a future in which he might get better, thus taking on a restitution narrative. The starting point of this process, he felt, was getting a new passport the following week. He thought this development would enable him to get a job again and then, giving himself a reality check, he added that he knew this was only possible if he also started an alcohol rehabilitation programme.

Peta ended his narrative by returning to his immediate concerns for the day ahead: his homeless life. This revealed some of the anxiety and daily stress of being homeless -- how he would spend the night, where he would stay, and the importance of having a social group to be with on the street. His narrative showed the connection between his social network and his health as his friends could prevent him from having alcohol-related fits by helping to moderate his

drinking and prevent accidents, and this would not happen if he was alone on the street.

Specificity in Peta's narrative

Peta's narrative showed connections between immigration status and health behaviour. There was avoidance of health services which was linked to a fear of his immigration status being found out and this was couched in comments about unlikely medical situations and officials. Peta registered with a GP in Brighton and Hove only with the encouragement of the outreach team, indicating he was unfamiliar and not keen to be in touch with services whilst being an undocumented migrant. His immigration status was an additional factor in this illness narrative, causing some mental distress and affecting health behaviour.

Peta preferred not to go back to his country of origin, an element of his complex illness narrative of why he had become alcoholic. He indicated he felt a strong degree of shame about his alcoholism and the state of his affairs. He had many sad memories he had yet to reconcile. The felt stigma of being alcohol-dependent and becoming destitute prevented him from contacting his family or social networks in his country of origin which he missed greatly. The pain of migration in the sense of missing loved ones interacted with his alcohol dependency. Peta's few social networks in the UK were important to his health; his friends were of similar ethnicity and migrant status. Peta referred to his friends as helpers in preventing accidents, anti-social behaviour and moderating

his drinking. Peta had few demands or expectations of the health systems. He assumed a lack of entitlement to healthcare, even in emergency situations, and was fearful of deportation as an undocumented migrant. He was pleased and accepting of the primary health care services he had been given access to by the alcohol rehabilitation team, as well as the prospect of specialist care.

Chapter conclusion

The four interviews analysed in depth in this chapter highlighted both significant and common characteristics of theories of illness narratives, showing that the interviews could be understood both as general illness narratives and yet specific to narratives of migrants. The themes common to all four narratives were the centrality of diagnosis, the importance of time, the concept of disruption, typologies such as 'chaos' and chronicity, the contestation of illness and emotions. The narratives also revealed some distinct characteristics which support the idea that migration should be seen as a significant factor in illness and healthcare experiences. These related to migrants having past experiences of other health systems which affected current experiences and use of healthcare services in the UK. A second feature was a lack of social networks and at the same time the high value placed on them by participants. The importance of time and plot to interviewees was evident from the frequent attempts made at giving chronological accounts. Time, in relation to the length of the illness or chronicity of illness featured repeatedly in participants' accounts.

The notion of illness being a serious disruption also emerged. A chaos illness narrative typology was commonly seen, and chronicity of illness experience had similar deep-seated negative effects on many participants. Many of the participants felt they waited a long time for referrals to specialists by GPs and this appeared to be a gauge of perceived quality of health services and experience. In the narratives variations on the theme of chaos emerged: new referrals or treatments were often sought, relapses were experienced, and changes made by GPs were described. In summary, many narratives changed and attempted an optimistic or stoical point about the future, suggesting a shift to a restitution narrative.

Misdiagnosis and contestation of diagnosis were frequently articulated problems. Often there was dissatisfaction with the perceived underuse of diagnostic technology. Some participants felt they were left with medically unexplained symptoms (MUS), a situation which they found unsatisfactory. In most of the narratives it could be inferred that there was a strong expectation for a biomedical approach to illness to be taken and there was a common preference for technology to be offered (Jutel, 2011a). There were also cases where patients and doctors contested treatments and so dissatisfaction arose from these situations as well.

The case studies appeared as complex conduits of emotionality, which were contextual and varied. For example, despair, sadness, anger, and shame were expressed in the four cases presented. Stress and mental instability were

common and seen to have developed for a variety of reasons. For instance, mental distress was heightened when illnesses became chronic conditions and gave rise to further social problems of material poverty.

The case studies highlighted the specificity of the interviews which could be related to nature of narratives of recent low-income migrants; expectations, and health-related practices suggested tentative and fearful approaches to health services among those with precarious immigration statuses and seen in other work, such as Bloch et al. (2011). Peta clearly stated his aim of avoiding using health services; as an undocumented migrant he used emergency service only when he had a fit or accident. In Saidah's case, as a refugee he was so keen to use the health services appropriately that he did so at risk to his own health; he became critically ill and went to the GP practice instead of hospital and collapsed on the way. Some links were seen between emotional stress, trauma and migration. However, avoidance of health services was evident even among those with less precarious immigration statuses, for whom it seemed unsatisfactory earlier experiences led to avoidance later. Overall, the interviews did not substantiate the discourses circulating that a high proportion of migrants seek out emergency healthcare.

The interviews as narratives further pointed to migrant status being relevant to illness and healthcare use in other ways. Understanding the way of accessing health services (primary, secondary and emergency) was considered confusing and difficult in many recent migrants' narratives. The narratives also indicated

that participants often wanted better access to secondary health services such as getting timely referrals and checking the progress of the referrals made. A high value was placed on having social networks, which provided crucial support during serious illness and help in accessing healthcare. The participants also showed the importance of networks when they consulted specific professional health networks (those that had such contacts). The narratives were also characteristic of recent migrant experience in the sense that they made comparisons with (and use of) health systems in their countries of origin. Past experiences, based on other health systems, affected participants' practices, with some recent migrants backing up or doubling up their use of the NHS with knowledge and tests from their countries of origin. Once again, these can be related to how recent migrants behaved as health service users, with their narratives suggesting that as new migrants there was acceptance of the healthcare received at the time and yet on occasions supplementary action was also taken by using services available in their countries of origin.

The views of participants about their experience and healthcare use will be explored further in Chapters Seven and Eight using two frameworks: patient experience and discrimination.

Chapter Seven: Encountering obstacles - negative patient experiences

Chapter Seven returns to the main question of this thesis: what are the everyday lived experiences of recent low-income migrants when they are ill and trying to access NHS health services? The previous chapter highlighted some of the common characteristics of illness narratives. In particular it raised the issue of diagnosis, which was frequently contested; the emotional and physical disruption caused by illness, and the frequent presence of Frank's 'chaos' narrative type (Frank, 1991). Moreover, Chapter Six demonstrated that many of the narratives shared characteristics which seem to be specific to the illness narratives of *recent migrants*. In particular, in their descriptions there was a strong tendency for participants to make comparisons with previous healthcare experiences from their countries of origin, making this a distinctive element of their narratives. Building on these observations, Chapter Seven analyses the interviews collected using the concept of *patient experience* in order to explore why many of the participants negatively described the healthcare they had received. The analysis references the main themes of patient experience taken from the UK Department of Health guidance (Department of Health, 2012d) and adapts them to take account of additional concepts which relate to two key aspects of the participants' experiences: communication and access.

This chapter reveals reasons for negative patient experiences among participants and these are highlighted in an analysis of practices, which link to patient experience. The chapter also explores what was said by participants about the term 'migrant' and 'recent migrant'. My analysis shows that the views expressed by a significant number of participants indicated that status loss and perceived stigma play a role in the construction of their experiences. These phenomena are linked to both wider negative public discourses and lived experiences in the social world, including the memories participants have of the prejudicial actions of others. I argue that migrants' knowledge, feelings and experiences of migration are likely to impact on illness and healthcare experiences.

The analysis in this chapter is also informed by some of the components of stigmatisation described within Link and Phelan's concept of stigmatisation and discrimination, concepts that were reviewed in Chapter Three. The final analytical chapter, Chapter Eight, will extend the analysis to examine if the remaining components of Link and Phelan's concept of discrimination pertain to the interviews. Chapter Eight makes use of the interviews to provide examples of perceived discrimination that are specific to the healthcare context; some of these comments are understood to be direct forms of discrimination and others indirect discrimination. Therefore the question is whether some of the

discrimination can be connected back to the role health policy plays in shaping the illness experiences of patients, and particularly those of recent migrants.

Patient experience

The concept of patient experience can be traced back to Gerteis and colleagues (1993), who examined what constitutes a positive patient experience. They referred to a number of aspects that were important to patients, paying initial attention to the patient-health professional relationship and highlighting three key aims for the practitioner to strive to embody in these relationships: first, to show respect; second, to show understanding about the impact of the illness; and third; to provide some emotional support to patients. Research on other aspects of patient experience takes account of the structure of health services, which includes waiting times as a part of patient experiences.

Fluctuations in the views of patients and variations in satisfaction are also recognised in the concept of 'transformation' (Edwards et al.2004). This concept was discussed in the methodology chapter and is noted in the analysis when specific participants presented a range of views.

The concept of patient experience has been assembled with reference to the meta-theory of lived experience (Pascal et al.2011) and other related concepts such as patient satisfaction (Sitzia and Wood 1997). Patient experience is a

concept that is currently employed by the NHS and appears in a guidance document produced by the Department of Health summarising the concept's origins and the approaches advocated by the NHS intended to be used to help improve practice within the service (Department of Health, 2012d). Four key aspects of good practice by health professionals are highlighted to assure a positive patient experience: the first is to respond to the patient as an individual; the second to use good communication skills; the third to take a supportive attitude towards patients; and fourth to provide relevant information to the patient (Department of Health 2012c:47).

The NHS themes of 'knowing the patient as an individual', 'tailoring healthcare services for each patient', and 'enabling patients to actively participate' are aligned with a wider body of literature that focuses on the doctor-patient encounter and the importance of good communication. In addition to the literature which looks closely at the service user-practitioner relationship, a fifth key aspect of patient experience is noted and this is the 'essential requirements of care'. In the approach taken in this thesis, I understand this theme overlaps with the concept of access which was reviewed in methodology in Chapter Three (Chow et al.2009, Williams et al.1998). Both the concept of access and the 'essential requirements of care' are similarly concerned with practical issues such as 'comfort, nutrition, safety, and pain management' (Department of Health 2012c:47). Chow et al.'s concept of access also acknowledges some of

the psychological issues requiring consideration during treatment. This analysis interprets access simply, mainly in terms of the practical concerns of getting care.

To advance the analysis of patient experience, this chapter explores two overall themes: communication and access. Most of the interviews in this study raised issues that relate to both themes. Communication was a frequently discussed problem which participants linked to both language difficulties and the dynamics within exchanges with healthcare providers. Some examples of this were evident in the comments about staff such as an absence of a caring attitude, feeling there was a lack of respect, not feeling listened to, not feeling a discussion was possible, not being offered adequate explanations, not being offered choices in treatment, and feeling trust had diminished. The second theme adopted in analysis of the interviews indicated access was seen as a problem in several areas of care such as waiting for diagnoses and treatment, not being given referrals to secondary care when requested, and a lack of continuity in care when an illness was prolonged. Not surprisingly, the issues relating to communication and access often overlapped; for example, when problems in waiting times occurred they could be intertwined with the attitudes of staff described in the narrative. This chapter reports on the key findings of an analysis conducted on all 41 interview transcripts exploring issues of access and communication and their link to negative patient experiences.

Problems related to communication

In the interviews, communication between health professionals and administrative staff was frequently referred to as unsatisfactory by participants and was one of the most significant factors identified in accounts in which, overall, participants' illness and healthcare experiences were negative. Six cases that illustrate these issues are presented below. Appendix Seven provides useful additional demographic information about the immigration status and origins of each participant.

Garai recounted his wife's experience of maternity services, recalling the disagreement he had with the doctors on how far her labour had progressed. He felt that both he and his wife knew that she would deliver soon because she had been through three previous labours. Several members of staff maintained, however, that she would continue in labour for as much as two days. Garai and his wife protested and were finally admitted. Subsequently, staff left them alone in the labour room and his wife, with Garai's assistance, delivered the baby without any medical aid very soon after admission:

Garai: When we took her to hospital all the doctors come and check it. 'Oh she can't birth today maybe the baby will come after two days' they told us, they said. 'No', she said 'I know myself. I have had three children before this. I am now nearly'... I am carrying that baby in my hand, then I try to call them. They ran and came. 'The baby is due!' They say: 'This is our mistake, oh, you can

accuse us, oh you can claim'. We said 'No, now she is okay'. We don't make any accusation, we just left the hospital. They are not helpful sometimes... the next day we go home...we feel bad on that day.

Garai showed dissatisfaction with the maternity unit's lack of communication with the patient and what the patient knew about his child's imminent birth, which became an unattended birth in a hospital (therefore with some associated risks). In this participant's view this additional risk at the birth would have been avoidable if the medical staff had listened.

The theme of not being listened to within medical encounters was also shared by Kismet, who had come to the UK to join her husband who left his country of birth as an asylum seeker and eventually became a refugee. After a long absence from each other they were reunited. Through an interpreter Kismet explained that she was not happy about the interactions she had had with her GP. She stated, for example, that his manner was brusque. In addition, Kismet felt that her GP did not listen to her or take what she said seriously and did not like the way she brought more than one problem at a time into a consultation. She also commented on the difficulty of getting GP appointments which were given so far away from the time when she had requested them, so that by the time she had her consultation her symptoms had subsided. She felt this devalued her pain, her illness and, by inference, herself, and described that the

poor communication she had with her GP led her to not trust the doctor. The issue of poor communication also raises the issue of the roles and responsibilities of GPs to make an effort to get to know what the patient has been experiencing:

Kismet: I wouldn't say that I trust him so much, because every time I go there I am trying to talk about one thing he would just say to me - you can only talk about one problem. 'Just go away and come back again'. When I feel ill and I phone them up and they give me an appointment a week later maybe, and by the time I get to them I won't have the problem. They will write me little medication and say go away and when you are feeling ill come back.

Communication was a theme that not only ran through narratives of trying to access care prior or during a health event but was also raised as an issue within efforts to access post-operative care, as illustrated in the narrative of Lara, a migrant worker with a chronic bladder problem. She was referred to a specialist, assessed and an operation was offered. However, Lara's interview focused on the post-operative care she had received just prior to the interview. During the interview Lara was in visible pain which had been severe and continuous for the week since the operation. She raised concerns about communication with the specialist and recounted his defensive manner when she had asked questions, leaving her to feel that her questions were seen by the consultant as an

accusation. In response to these encounters Lara felt she was not listened to and was upset by this, feeling that there was a lack of concern for her pain. She went on to talk about the absence of continuity of care in relation to her premature discharge from the care of the specialist and the reluctance to refer her directly to another specialist and she was then told to go back to her GP for a new referral. It was only with vital help from a friend who spoke English that Lara secured an appointment with the GP and he made a referral. She found she could not get an appointment with her GP immediately, despite being in intense pain, and waited several days for an appointment. This experience covers many issues related to communication including a lack of continuity of care and creating an overall feeling that she has not having a good patient experience:

Lara: He cuts me short; he tries to not let me explain. What he is trying to say is 'it is not my fault...my operation went fine'. I am trying to ask him why I am feeling in so much pain and he is not letting me speak. I feel he is smiling but when I ask him why I am in so much pain then he stops smiling at me. He doesn't see the funny side any more.

Describing a similar set of circumstances, Beata shared a poor patient experience, saying her GP did not listen to her or treat her as an individual. She felt there was a lack of interest in her precarious circumstances of living alone on a low income. Beata tried another GP in the same practice but found

little difference and resolved to go to the practice as little as possible in the future, admitting she had been called for cervical screening and she did not want to go. Recently, she had helped a friend in her consultation with a GP and this experience had surprised her in the quality of attention her friend had received; it changed Beata's expectations of how GPs might respond and she promised herself she would change her GP practice. Her friend's GP had shown Beata that 'she really wants to help' and was 'clear in everything'; these comments were aligned with a good patient experience which includes trying to get to know your patient, tailoring care to each patient, and providing enough information to the patient:

Beata: I went with a different one because after he didn't, I didn't find him so good, I am not satisfied, I changed...I found a very, very proper GP now because my friend has a problem - she is bleeding all the time and they can't do anything with her. And I went to her once. Somebody didn't come for their appointment so we get free time to go. She is a very good GP. I think I will move because it is near to my place. If I bring my son then definitely I want to get her because I feel I trust her. Because I help to my friend to translate and found one who really wants to help and she clear in everything. Even when we finished the appointment after a few weeks she sent a letter to her, if she wants to do this thing or that thing. She wrote the letter, she was watchful and very reliable and everything. I trust her – not so young. I think I will move. And I

have told her, since I am here, I have found only you to be a very good doctor because my opinion in England, the whole hospital and everything how it is.

The experience of Rosana mirrors some of the themes in the last interview but also identifies the consequences of changing communication dynamics across a consultation pathway. Rosana has a chronic spinal condition which causes her constant pain. In this case she appreciated her GP's quick referral after showing him an old MRI scan she had carried with her from her country of origin. After the first consultation with the specialist her spinal condition was confirmed and she was told that surgery was an option (she had been told this in her country of origin as well) but that this could be delayed. Rosana decided to wait for approximately a year, until the pain finally became intolerable, and she then went back to her GP and he referred her to a second specialist. Rosana found this experience disconcerting, and she was left feeling this specialist was reluctant to communicate well:

Rosana: 'And they send me, my GP, send me to polyclinic, [to] another consultant neurologist. He was very calm, this consultant, and he said your MRI shows what you have just told me, that is what it is. He didn't show me in any way how I would get better, he was very ignorant to say "well that is what it is, what it says in your MRI".

KR: Did he advise you what to do?

Rosana: He sent me for a muscle test. But it didn't show anything. The muscle test didn't show any signs, they said it is fine, but my arm got worse and I knew it was the nerve in my arms, [they] go numb so I had to, I decided to phone my consultant in my country of origin, on the phone. I am very surprised because this is supposed to be the best in the world apparently, but it is not. I am really surprised why do they not go through things properly and they don't know that for somebody like myself I have two children and especially my daughter, I have to support her'.

This second consultation Rosana had damaged her confidence in the specialist and she extrapolated from this to the NHS in general. Rosana found him unwilling to communicate with her and he did not show a supportive attitude which would have helped Rosanna to have a good patient experience. She did not know what she should do next so she telephoned the specialist in her country of origin. The impact of Rosana's illness on her family was of concern. A second interview I conducted to hear Rosana's views about the third specialist indicated a much better experience than the previous two, suggesting the communication practices between specialists varied considerably and was significant:

Rosana: 'The second one, very bad, I think the second one didn't have the patience even to listen to me, even what I was talking about'.

Communication aspects were central to Josef's interview. He expressed diminishing trust for two GPs and then two specialists in secondary care. Josef did not feel his concerns or illness were understood. Josef's narrative started with the story of persecution in his country of origin and how he was eventually forced to leave his job. To cope, Josef took comfort from time to time in drinking alcohol, even though it was illegal. He described what happened one night in a bar in 2004 after he was sold adulterated alcohol. He was left comatose for several months. The scale of this event was huge; 75 people who had drunk at the same establishment that night died of alcohol poisoning. Josef said he survived only because he had drunk just a little, having tasted something strange about the alcohol. Everything became too much when his wife also experienced harassment and so they fled with their children to seek asylum in the UK and the family was given refugee status. Josef was ill from arrival and sought help for his poor health which he linked to the alcohol poisoning. However, Josef perceived prejudice related to early experiences with two GPs with whom he had registered. One GP said that since he had been granted refugee status he should be looking for work. Josef felt the GPs believed he was exaggerating his symptoms. Josef left this GP and registered with a second GP who did eventually give him a referral to an eye specialist. He recalled that he had been told in that consultation that he would be invited for a second appointment but after four months he had not received a follow-up and he never understood or was told why. Josef was eventually given a second

referral to a specialist by his GP, this time to a neurologist but this specialist did not make a diagnosis nor offer him any treatment. This was very disappointing for Josef and he once again felt his symptoms were being doubted. Clearly problems in communication with health professionals over a long period of time were a feature of this narrative. Josef's trust in staff diminished as he experienced a series of unsatisfactory treatments or even a complete lack of treatment. Josef felt the attempts to treat him as an individual were few and he received little emotional support:

Josef: 'The fact they said I am okay and there is nothing wrong with me. Why would I lie to them and things and I feel these symptoms. You can't answer them back because they are specialists, they know what they are doing - so I didn't say anything. Nevertheless I am in a limbo because I am having these symptoms, because nobody helped me or gave me the medication towards it.'

On the eventual third referral to a specialist Josef was offered treatment and finally felt some affirmation of his illness. At the time of interview Josef reported that the latest medication had begun to alleviate some of his pain. For the first time Josef felt alcohol poisoning was accepted as the cause of health problems. He explained aspects of communication he had liked in the interaction with his current GP (the third); this comment summarised the kind of communication he had hoped for from the beginning but had not received:

Josef: 'You feel that he gives you all his attention. He takes his time, he tried to find out exactly what you are suffering from and he doesn't just try to brush you aside quickly, that is exactly it.'

The six interviews highlighted here illustrate that poor patient experiences hinged around issues of communication. This theme was present in many interviews, with a large number focusing on the patient-doctor interactions which they found unsatisfactory. A failure in care was frequently pinpointed as originating with a GP or specialist and participants found their experiences could not be solely explained by language difficulties. Many felt they were not being treated as individuals, their views were not being adequately taken into account, and doctors' explanations and actions were not satisfactory. Continuity of care and treatment was also found to be lacking by participants. These issues arose in the full range of service settings included in this study: primary, maternity, specialist and secondary care.

Problems in accessing services

The term 'access' or 'accessibility' was reviewed in Chapter Three and was shown to have multiple meanings (Dixon-Wood et al.2006, Chow et al.2009). In the NHS patient experience guidance, the 'essential requirements of healthcare' is a theme that most speaks to the concept of access. Importantly, access can also be linked to organisational or structural issues in the NHS. Referrals made

by GPs to secondary care put them in the position of being gatekeepers to specialist services (an issue which was also identified in the interviews). In contrast to a nationally provided health care system, when healthcare is privately provided by systems in which patients have health insurance policies or pay directly for services, they do not face the issue of a professional gatekeeper. In such systems, patients may feel they can determine to a greater extent when and what services they access. The comments made in this study underscore the importance and relevance of the theme of obstacles to access including delays in diagnosis, referrals, treatments, and waiting times. These were all commonly recounted.

The following subsections highlight negative patient experiences that relate to the issue of access, they separate the notion of seeking diagnosis and treatment from other examples of access such as waiting. Three cases are drawn upon to illustrate different kinds of access issues that arose and how they affected patient experience negatively.

Diagnosis and treatment

In a large number of the interviews, the time and energy taken to get a referral reoccurred as a theme; I argue that these were key underlying reasons for experiences being perceived as negative by participants. Many of the participants attributed their experience to their GP not adequately taking their

wishes into account. While this was framed as a communication issue, in other cases the issue of access and not getting the outcome of a faster referral to a specialist were specifically discussed. The explanations given for delays experienced varied in detail. Some participants did not give a view as to why their GP did not make a referral but instead expressed their unease, dissatisfaction, distress and a subsequent lack of respect they felt had occurred. Some other participants said they had not known after they left a check-up if a referral had been made for them and had waited a long time to find an error had been made. Yet others described the long delays in getting the results of investigative tests or even lost test results, both of which delayed the start of treatment. Individual narratives are used to illustrate these points.

Access problems are illustrated by the following participant in her inability to access tests she felt she needed. Adele was fluent in English, having come to the UK to study. She had been diagnosed with epilepsy in childhood. Her preferences for tests and participation in her ongoing condition were not taken into account by the GP. In Germany, her country of origin, Adele had been advised to have six-monthly electro-encephalograms (EEG) to monitor her condition but in the UK her GP was not willing to send her for an EEG. Adele felt she was not being offered individual care and that the decision not to be allowed the test was connected to the fact she had been diagnosed in Germany. The refusal of her GP to offer these reassuring tests tainted her

relationship and later consultations about back pain, which also did not result in an investigation or treatment. This affected her overall opinion. Adele felt the GP was unsupportive, even 'useless', with 'never a conclusion':

Adele: I applied for, or the GP applied for a referral to a neurologist but their response was that I didn't need an EEG which then again shocked me because they don't know anything about me, why would they say that?..I asked the GP to see if I could see a specialist so he emailed them describing my situation but they said because I didn't have any abnormalities then I don't need to have a test...because my epilepsy was discovered not in England, rather it was discovered in Germany and because I have had a GP and doctor there. Because my tests have been done there that I feel it might be less of a main problem for them. Whereas I know of some people who have illness and they were discovered here and they take things more seriously...the email about the neurologist it stated that the original GP in X could do the EEG if she really needed one. It was all a bit interesting. I wasn't quite satisfied with that, yeh...I feel like every time I see the GP I have to retell my medical history which I told quite a few times to him. Then he goes 'Oh yes I remember now', but little aspects like that don't feel he knows me well enough or even I know him well, despite me having seen him about five times. Because I haven't got anything out of seeing him, I have found recently it is quite useless going to see him because there was never a conclusion that was satisfactory.

The above quote illustrates that Adele needed more reassurance that her illness was under control and central to feeling this was the EEG that the GP was unwilling to offer. Furthermore, she had problems which could be interpreted as access or communication issues, where Adele felt the GP's responses on other matters she consulted him about were also inadequate and these different experiences led her to conclude there was no individualised care available and little point in going for help.

Waiting for care

Waiting times are often used in evaluations of the quality of healthcare and are seen as an aspect of access (Department of Health 2009a, Department of Health 2012b) with penalties placed on hospitals and other specialist waiting times for not achieving targets. Criticisms about long waiting times are regularly made in public discourses about the NHS, showing this to be an important aspect of patient experience and quality monitoring. In particular there have been both local and national concerns about hospitals not meeting national targets for waiting times. The nationwide debate in the media was reported as a crisis in many Accident and Emergency departments and noted in the

footnote below³⁶. This controversial issue was taken up by politicians who have defended long emergency waiting times as being an inevitable consequence of rising demand and expectations of patients. What is more, politicians have argued the increasing costs associated with bringing down waiting times are impossible to meet. Of course it is natural to have expectations about health services; patients will enter health services with their individual expectations about how much time they should be waiting. To avoid a mismatch of expectations with what is possible to deliver in terms of services, it is now common practice that patients are explained their rights by posters and leaflets about waiting time targets. An example of this kind of information campaign can be found on the NHS website³⁷.

In this study some participants expressed their awareness of the busyness of healthcare staff and in the research interviews there was clear acknowledgement that staff shortages were possible explanations for their poor patient experience. However, several participants with acute problems said they still felt that the waiting time in emergency services or secondary services

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http://www.theargus.co.uk/news/10467123.Damning_report_into_Brighton_hospital_s_accident_and_emergency

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<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/Waitingtimes/Pages/Guide%20to%20waiting%20times.aspx>.

was unacceptably long. Two users of the Accident and Emergency services experienced waits longer than what was regarded as acceptable in the national guidelines. These participants' interviews reflected the distress caused by waiting times.

Christina was a migrant worker who recounted an experience she had in Accident and Emergency in 2009. She could not understand how a woman on her own with three children could be left waiting for over six hours and this experience marred her view of the NHS. Christina described how she had suspected her baby had broken a limb in the park earlier in the day. During her wait, she felt ignored by staff and found the experience very upsetting. Later she described how the experience had affected her decision to use emergency and hospital services six months later when her baby was ill again with gastroenteritis symptoms that had worsened. Christina was very worried but did elect to go to hospital a second time, even though the memories of the first time made her apprehensive. This time she prepared herself for another long wait. However, in this second incident Christina found she was admitted to the children's hospital and she did not have to wait long to see a doctor. This time she was pleased with the way she was treated by all the staff. She also recalled that her own manner had been more assertive and she asked to be seen as she and the baby were distressed. But questions remained for Christina with regards to the first experience of waiting. She ended her interview

questioning why she had not been treated as an urgent case when she had presented with an injured baby the first time. Christina felt her first treatment involved a distressing wait and a lack of compassion:

Christina: I don't think it is broken, no. I went to hospital it was around 7pm. We was waiting a long time and coming one doctor, a lady. I was explaining how it had happened and she done a scan. I take all my children you know. The big one was sleeping in the buggy, because I come home about 1am, everybody was tired. My husband was working until 11pm and he is calling to me, 'how, how, how'? I am so upset because I need to wait, no one to speak with me. All the time I am going, turning, saying look he (my other child) is crying he wants to eat, he wants to drink.

In Christina's interview she pointed to other negative experience where she perceived treatment was not easily accessible. The interview included comments about her children in primary care and another account related to her concern about one child possibly having anaemia.

Christina: If I want to check myself now I need to pay money because I am living here and I don't pay tax for my country of origin. For children it is okay, under 16, I think, I am not sure now but she [the doctor in X] always helps...I went with the children, she says, he has got anaemia. Exactly, I go to check

blood and it, exactly, it was, I bought some syrup for this. Now I don't know how because she said you need to drink three months and my son really don't want you know. He is crying he don't like the medicine...I panic to go to X now, but I don't know when soon and I am going to check the blood because I can't check here...how this stupid here don't do this at this age, maybe later six or seven maybe yes but he is three years I can't see...If my child is sick or not very well I don't want to go to the hospital, you know I give some tea or better I call in X for my family Dr and I ask what I need to do...I am not going too often to the GP I am trying to treat my children at home. If I go to a GP and I don't understand something he just tries to explain to me in different words. What I don't like: 'Blah blah blah, oh paracetamol', it is nothing this paracetamol, I can give him at home paracetamol. But if a kid is coughing, before Christmas I go with my son to the GP and I was asking for antibiotics and he didn't want to give me antibiotics. I said 'Please because I can't listen to him because he is coughing like, do you know. If I am sleeping and he is in the house coughing and it is like he is sick and he drunk the antibiotics and it not help you know. I say to people I give steam. Or put salt on his neck and steam to help...I don't want to ask any more because I know antibiotics are not good for children but...It is different here. I can see some children with running noses and coughing very badly and mothers taking them around...Not head covered I am not saying everybody but some English people don't care. Some babies you should put a warm jacket on them without socks or something. It is like crazy.

Christina felt she got no help from her GP in the UK and felt she must consult a doctor in her country of origin when she visited. There a test was readily offered which led to a diagnosis of anaemia. Since then she did not feel her views were listened to by the GP adequately, she decided to get second opinions from doctors in her country of origin, particularly for her children. Christina sometimes did this before or sometimes after seeing her GP in the UK. This interview pointed to differences in practices and behaviours among participants' lay cultures, knowledge and beliefs relating to illness which could influence poor patient experience. Clearly Christina had found it hard to access emergency services but also struggled with primary healthcare and this influenced her healthcare-seeking practices.

A further example of problems of access or essential care concerned childbirth. Bella came to the UK as a spouse of a British national. Her interview started with a description of the birth of her first and only child several years ago which she felt was the root cause of her current health problems. Bella told the labour story in detail and was clearly deeply affected by this experience. She felt she was denied access to hospital twice when she wanted to go. Her waters had broken and by that time she was having painful contractions. Bella was sent back home twice. On arrival the third time her husband refused to return home and they were admitted to hospital. Bella was dissatisfied with the care she received for two reasons: first, she had a strong recollection of being left

unattended for long periods and secondly, she was concerned about the care she would receive at the eventual arrival of the baby as her newborn had been allowed to fall on to its head on a hard mattress at the moment of delivery. Bella attributed the baby's crooked neck to this event and was dissatisfied with what she thought was inadequate advice for her baby's subsequent neck position. She was so worried that she went back to her country of origin to access treatment and there she was told that staff had been 'negligent' at the time of delivery. Bella also recalled another problem she had in pregnancy related to a perceived delay in treatment for ongoing vomiting in the first trimester. She concluded that the degree of suffering that staff regarded as acceptable before action was taken by them was excessive. This example is placed here under the category of waiting times, but a number of issues related to communication were also clearly present. The long-term effects of this experience were serious in that Bella was hesitant to have a second child.

Bella: In my experience when I was pregnant with B I used to vomit a lot...when I went to the midwives they said 'it is normal'...After that I got really dehydrated and then I went to the GP...I am in really bad shape and I needed to be admitted. They wait until the last minute when you are really bad to resolve your problems.

Many other cases raised questions about waiting and these were mixed with comments about diagnoses, referrals and often with comments about communication. Many of the participants in this study felt they experienced unusual delays in referral, or with their GP's diagnosis of their problem, or delays with the treatment being offered and slowness in changing approach when treatment was not successful. The common opinion among many of the participants was that referrals could have been made sooner. Some saw the role of the GP as problematic as many took a predominantly 'wait and see approach', which for many participants stalled progress. These practices were not seen as intentional but many participants connected it to the worsening of their health and to more suffering. Demographic literature about migrants has shown that although generalising about a culturally diverse group is problematic, there are indications that some migrant experience leads to greater morbidity and mortality in this population. This analysis of a group of ill recent low-income migrants suggest experiences of poor communication with staff, problems in access and protracted waiting times supports the argument that there could be an effect on participants' overall health.

Reasons for poor patient experience among the participants

The following analysis focuses on how the categorisation of migrant was perceived and can be related to wider negative discourses about migrants and how these views were linked to effect patient experiences. Using the concepts

of stigmatisation and discrimination (Phelan et al.2008, Link and Phelan 2006) to analyse their responses, the participants were asked about the acceptability of being described as migrants or recent migrants. Approximately one third of the participants did not like the term, showing they perceived it to be a negative label and part of negative discourses about newcomers which surrounded them. I therefore argue that the term migrant was often perceived as stigmatising as it led to feelings of status loss and negative stereotyping. Together such negative feelings were likely to have an impact on participants' healthcare experiences.

Examples of participants' views about being a migrant

The analysis of answers to two questions in the questionnaire about the migrant 'label' are presented in this section. The first question asked whether participants 'considered themselves to be a migrant', and a second queried whether participants 'considered themselves to be a recent migrant'. The majority of participants did not expand on the question beyond accepting the term migrant as a category. This was probably because the question was closed. However, 11 of the participants clarified their opinion, accepting the term migrant even though they saw the term in a negative light. The participants who provided additional views constituted nearly a quarter of the group, and primarily questioned the category of migrant and preferred that some qualifications to the term be made. The 11 respondents who addressed this point had reasonable to good English language ability; four were very fluent

English speakers and seven were reasonably fluent. The reasons expressed for not liking the migrant category were:

The word carried a negative meaning being taken from negative public discourses.

The word applied to those who don't speak English well.

The term didn't apply to those who were forced to migrate, as was the case for refugees, and inadequately reflected what this group had faced.

It shouldn't apply for those who have become British citizens.

To one respondent the word migrant suggested a greater feeling of being settled than she felt and felt it ignored her strong emotional tie to the family she left behind.

Clearly these participants were referring to negative discourses about migrants and were reporting their experiences and impressions that the term migrant was often being used in a derogatory way. Their objections to the term clearly could be linked to perception of a low status. Some explained in detail why the term was perceived negatively:

Klaudia: Actually many people have asked me this question, do you feel as a migrant? And actually for me this word has a kind of negative meaning. But I don't feel like a migrant because, maybe it is because of my, how to say it, my teacher self-esteem...I don't feel like a migrant... we kind of feel that a migrant is

a person who comes into my country and doesn't want to use our language, he doesn't want to follow our traditions. So, how to say, has no respect to local people. But I have come here, I myself, I don't want to, how to say, to follow so much my way of life because I have to integrate into this environment. Everything is in English, I have English people around or people from other countries who also use English and it is kind of...I don't feel bad about this word migrant worker.

The above quote illustrates Klaudia's view of the term was her own but was in response to the negative view she felt others had. She was frustrated at being lumped into a group called migrants which was negatively labelled and stereotyped. She concluded on a positive note that her strategy was to mix with diverse types of people and to try to not let these wider negative discourses affect her mentally. Other participants were in agreement with Klaudia's well-articulated sentiment that the term was a shorthand term for people who had not 'adjusted' to life in the host country.

Pedro referred to the low status inherent in the term migrant, and expressed his dislike for what he also saw as a stereotype of a migrant being from a poor country, and that it was also associated with notions of laziness – all were suggested as derogatory ideas about migrants:

Pedro: I don't like the term migrant. It is like I come from a very poor country to stay here and I will make excuses. People don't see you very good. It is not very good words.

Aneta's comments showed her view of migrants was affected by public discourses, how others spoke about themselves or others. Although she did not elaborate on her understanding it could be inferred that Aneta felt it was meant as an insult. The next quote links the term with the stereotype of poverty and foreign-ness but as the respondent points out, these labels do not reflect her economic situation, which was getting better. For Kirsty the term also evoked an association with belonging:

Kirsty: I don't feel as some sort of immigrant because we live quite well here and all the people around are nice and apart from the home sickness it is fine.

Gizela's understanding of the term was that it reminded her of her foreign-ness. She sensed it was a label used by others to alienate or exclude her, and this was not how she felt about herself. The implication was that Gizela minded the term:

Gizela: I think of myself as a foreigner, which is rather that is how English people see me, not how I feel.

A second respondent made a similar observation, seeing two aspects to being a migrant: one was lack of ability in the host language and the other was the cultural differences between migrants and settled residents:

Beata: It is not easy, at first it was hard; another culture so many things are different. The language was the main problem, even if I learn the language.

The following three respondents made similar points; that there were relative differences between the terms migrant, refugee and asylum seeker. For Rosana the term migrant was too simple and it missed a vital aspect of her experience which was that she was forced to migrate. For Jahander it was the lesser of two negative statuses

Jahander: Personally yes, I am a migrant; I have been treated worse than that.

This point was not restricted to refugees, however. As one migrant worker said, her choice was limited; she was forced to migrate because of the breakdown of her marriage due to domestic violence which led to joining her mother in the UK. Therefore, the idea that migration was a negative experience was strong; it was spoken about as an undesirable necessity by refugees and migrant workers:

Catalena: In my country my life was good. I have a job; my life was good and normal. I married X but [pause] my daughter was afraid of him. My mother lives in England, for four years she helped me to come. My grandmother is also here now, since June.

Several students dissociated themselves from the term. For Carlota the difference between herself and people who were migrants was related to being 'un-free' or free because, for her, a migrant had fewer choices. She had not made any decisions about staying in the UK for a long period and this suggested that the period of time spent in the country was significant and a part of her understanding of the term. Carlota knew she would leave the UK and therefore she felt she was a visitor even though she had been resident for more than a year. There was also a suggestion that other factors were influencing her view such as her relative wealth and the perception that migrants were poor.

Carlota: I could be somewhere else; I don't feel like an un-free person. I could go from country to country. I don't want to stay here forever.

Adele was also a student and held a similar view to Carlota, she stressed that she did not feel like a migrant because she found migration easy. She had had few struggles to adjusting to life in the UK, from which it could be inferred she

felt that other migrants made difficult journeys and found life less easy than she did:

Adele: This is interesting one, not really, personally I have a history of being 'an expat', it never crossed my mind 'recent' is a term I can embrace more than migrant. I feel so comfortable in this country. I kind of adapt immediately.

Both these participants showed a preference for the term student over migrant. A third student from outside of the EU had less problem embracing the term for herself, she commented that her migration for study had required a big effort and she had needed to adapt to life in the UK, which she saw as different. She imagined some of her experiences were similar to other temporary or new migrants:

Brona: I consider myself a migrant because you are adapting to the life here, you don't think you are going to move at some point, or you don't plan while doing a degree, you cannot plan. I am a migrant, I packed all my stuff at home put them in boxes in the corner and I came here and lead all the problems of a migrant who comes here to settle for all his life would lead.

For some respondents the question produced comments about citizenship or plans to change. One participant of Kurdish ethnicity asserted she had

changed her nationality and another east European worker mentioned her intention to get British nationality. The implication was that the term British gave higher status and the desire or hope that it would be possible to disconnect from the migrant categorisation:

Kismet: I used to see myself as migrant but now I am British, so I am not.

Another participant (Lara) linked the term to foreignness and citizenship. She expressed her keenness to be seen as English as soon as possible, even though she had migrated less than two years ago, implying strongly that she saw the term as exclusionary and undesirable:

Lara: I am a migrant - it is logic, okay. I came from X but my heart is already English.

This was seen in another respondent's answer in which she reflected on belonging and identification. For her the term migrant made invisible the aspect that was still painful; it brought up feelings of loss and longing for her extended family, place and cultures and by inference, the place she still felt was 'home':

Layla: Well, what do I think? I have mixed feelings about it. Sometimes I feel good about it, and sometimes [pause] that I miss home.

Adwoa spoke through an interpreter said she did not understand the term; she wanted to be seen 'as a person'. Later in this respondent's interview she also wanted to express gratitude for the safety and security she felt for being granted refugee status:

Adwoa: I think of myself, not about the immigration order, or I am not thinking about being a refugee. So, I think of myself as a person who is living in this country.

This section shows that a third of the participants had observed and experienced the term migrant to be a negative label and stereotype. Refugees made some distinction between their forced migration and that of economic migrants, whereas some of the migrant workers still perceived their migration to lack agency as well as being a negative label. Two students did not identify with the term, their comments suggesting some dissociation because they perceived they had more agency. These findings support other views found in the literature (Papademetriou et al.2010, Cavanagh and Glennie 2012) and also media searches conducted on migrants and health that found discourses about migrants were often negative. I argue that these views signalled negative labelling which in turn was likely to have adverse mental and physical health consequences for participants. The next section shows similar barriers for

participants in the degree to which they felt welcome or able to integrate. Again it is argued that these feelings could also have an impact on health status and experiences within the UK healthcare system.

Examples of participants' views about being a 'recent migrant'

The second question in the questionnaire was a follow-on question from the first one analysed above, asking if respondents considered themselves to be *recent* migrants. In total 21 out of the 46 interviewees expressed the view that they did not feel like recent migrants any more, while 18 said they still did. Of those who said that they still felt like recent migrants, 10 had been in the UK for less than three years. Eight said they did not feel like new migrants and they had been resident for similar lengths of time, some longer than five years. This question raises the issue of subjectivity in the notion of 'migrant' and particularly *recent* migrant not being only about residency; some respondents who had been resident for short periods of time said they felt settled whilst others who had been resident for six years or more said they did not feel settled. Three participants who were not included in the final sample said that despite being UK residents for longer than the project's criteria of seven years, they still felt like newcomers.

Numerous reasons were given by respondents for continuing to feel like a recent migrant. These were about the difficult lived experiences of being a

migrant, including not being able to master English quickly enough, finding many systems and procedures in the UK difficult to understand and navigate, not knowing long-settled people, feeling like they had a heavy burden of caring responsibilities that restricted their ability to integrate, being in contact with and missing friends and family in their country of origin, perceiving discrimination and racism, and experiencing continued visa difficulties. For example, Idra at first referred to language proficiency as an issue, despite being fluent and having spent four and half years in the UK, as the main reason for feeling like a recent migrant. When he expanded on these thoughts he added other reasons such as feelings of isolation due to being the main carer for his disabled wife and children. Elsewhere, too, this respondent reflected on how his situation would have been managed differently in his country of origin, where he would have got a lot more help from social networks of family and friends:

Idra: Yes, some things are new and I find it difficult to do some things. My language is not very good and it is difficult to do a lot of things, to get the help we need... because my wife is a lot unwell and I can't go anywhere by myself. If I want to go anywhere for some reason, I can't leave her for a long time (resident for 4.5 years).

Another respondent referred to her living in the UK being a necessity and became nostalgic about her family and the passing of time being slow. Her experience of belonging was attached to longing, and missing friends:

Jana: I wish I could go back home. I have many friends, 3.5 years feels like a long time. I don't feel like it is recent. For some of my husband's friends it is five years –oh my god (resident for 3.5 years).

One participant who had lived in another European country for 17 years but had come to the UK four years previously still felt like a new migrant:

Rehan: I didn't come directly from X, I was in Germany for 17 years but I am a new migrant here (resident for 4.5 years).

Some participants referred to the racist experiences and harassment that made it difficult not to feel like an outsider:

Bahar: Yes, I feel new here. I was moved to a women's refuge [to escape domestic violence] for eight months. Then I lived in a flat with people knocking on the door. The police had to come. A lady had a dog and it attacked my son and she pushed me (resident for 4 years).

In contrast, there were several other respondents who commented on aspects that had helped them feel settled as migrants. For Parveen it was when she and her family were happy and had positive interactions that they began feeling that they could enjoy living in the UK and second, it was when she met long-settled people and was able to build new relationships and networks that she felt settled herself. These respondents sought and valued new social networks, particularly with local people, and these helped them feel a part of the place where they had come to live. This, they accepted, was an ongoing and lengthy process, perhaps something to aspire to over time. Similarly for Alicja the passing of time was a metaphor for the gradual building up of positive experiences and this had helped her to stop feeling like a recent migrant:

Parveen: I feel quite settled, as if I am going to continue living here, so we are not isolated in any way and I am quite familiar with the local community (resident for 5 years).

This section has argued that some lived experiences of participants have been negative and that these broader social experiences have impacted on participants' experiences of healthcare. From the analyses about the term migrant and recent migrant it can be inferred that many participants were aware of negative public and media views regarding recent migrants. This was evident when some participants commented that there was a connection

between experiences which they viewed as racist and continuing to feel like a recent migrant. Other reasons were also given for not liking the term 'recent migrant' – the general feelings of exclusion and confusion it prompted. I contend that such awareness implies that experiences of healthcare that were perceived as negative were affected in part by a wider social phenomenon of stigmatisation.

Communication and access to healthcare were specific themes explored within the first part of this chapter, both pertaining to the notion of patient experiences; the second analysis in the chapter was able to show that these were likely to be linked to everyday migrant experiences. I argue the general and specific contexts support one another.

Conclusion

In the first analysis chapter, Chapter Four, it was argued that immigration status was one of many contextual factors in illness and healthcare experience. In Chapter Five illness narratives were examined and it was found that participants made distinctive comparisons about the healthcare received in the UK and their countries of origin. In this chapter, the concept of patient experience was used to focus on problems commonly discussed by patients, and these were framed using the broad themes of communication and access. Many patient experiences were expressed in a negative way when examined through the

lenses of communication and access problems. The second analysis of the general views of participants about the terms 'migrant' and 'recent migrant' suggests that participants perceived stereotyping and status loss. The next chapter continues this train of thought with a further analysis of the comments that referred to perceiving discrimination in healthcare encounters. These comments are analysed using Link and Phelan's notion of discrimination.

Chapter Eight: Perceived discrimination

In keeping with the aim of this collaborative project, the voices of a group who are not often heard in health research in the UK have been researched. This final empirical chapter looks at where deviations in illness experiences among these recent low-income international migrants occurred which were perceived as discrimination.

A variety of quantitative and qualitative methods have been used to study perceived discrimination (Stuber and Meyer 2008, Williams and Mohammed 2009). In the present qualitative study the focus is on the comments in interviews which described discrimination, both felt and enacted, according to Scambler's distinction discussed in Chapter Two. The interviews provide insights into experiences, practices and policies from the service user's perspective, including the moral implications of practices (Bury 2001, Ross 2012). In the first part of the analysis in Chapter Seven, negative healthcare experiences were shown to be widespread and often appeared to occur in situations that could also be construed as being experienced by non-migrants. In the second part of the previous chapter, the analysis of the questionnaire uncovered participants' views about low status, their feelings about being labelled a migrant and pointed to the likelihood that the negative views of the term 'migrant' were linked to felt stigma and wider negative discourses. These

experiences affected migrants' everyday lives. In this final analytical chapter, Link and Phelan's concept of discrimination is used to examine situations in which discrimination was perceived by participants which could affect the health and healthcare experiences of participants (Link and Phelan 2001, Link and Phelan 2006). At the same time, and as discussed in Chapter Two, the qualitative approach taken here relies on the notion of perceived discrimination as a way of detecting discrimination. Perceived discrimination is therefore the coding theme that directs this chapter (Mayring 2004).

This analysis indicates that discrimination was a significant concern for many of the participants. Discrimination has been associated with the experience of a strong dissatisfaction with healthcare practices and procedures which were seen by patients as unfair. These views can stem prejudicial ideas and a misuse of power (Garner 2010). Perceived discrimination as a concept has been explored in Chapter Two. Such perceptions emerged in the interviews and are analysed in this chapter and presented as indirect and direct discrimination by applying Link and Phelan's (2006) framework. The comments concerned with practices and structures (for instance, those related to procedures for admission to hospital, lack of referrals, and treatment) are organised in a section on indirect discrimination. Experiences named by participants as discrimination are organised in a section on direct discrimination. Ethnicity,

immigration status, and in some cases the Muslim faith, were named as reasons for perceiving discrimination, suggesting a partly racialised experience.

Perceived indirect discrimination

This section on perceived discrimination which is regarded as indirect discrimination is organised into three subsections. The comments made in the interviews strongly suggested that practices and policies were associated with discrimination. This is illustrated using a total of ten interviews.

The experience of being asked questions

The interview excerpts included below suggest that perceived discrimination affected participants' experiences. They spoke spontaneously about being asked many questions by hospital staff in both secondary and emergency services. Other participants expressed their concern by talking about their entitlement to healthcare and the fact that they paid taxes, suggesting that they felt their entitlement had been questioned. One participant clearly stated that he knew he was entitled from his arrival because his illness was infectious.

Many more participants alluded to their entitlement being questioned irrespective of their residency. In several interviews, the experience of being asked an excessive number of questions when participants were in distress and receiving emergency services was seen as insensitive and unethical. These kinds of incidents led to feelings of discrimination. Perceived discrimination was mentioned by different migrants with varied immigration statuses including

asylum seekers, refugees and one migrant worker. Three cases illustrate these points:

Jahander made a clear point about his view of the practice in emergency services of asking questions and said he found it was an approach that lacked compassion and was discriminatory. This train of thought prompted Jahander to talk about what he had observed among acquaintances who were undocumented migrants, which was that they generally avoided health services. As an asthmatic in need of Accident and Emergency care, he felt he had to tolerate the system but felt that by now there should be a clear record of his immigration status which should have minimised the repetitive questioning he experienced.

Jahander: In the case of that...a feeling of asylum seeker, it is very difficult in the hospital it is very difficult. They start checking you, if you have full refugee status in this country, but as an asylum seeker, you don't think it would be good to argue with the staff. Even if you are right they will make you false and put you in trouble.

The view of Saidah, a refugee who was quite fluent in English, also conveys unease. In this interview he referred to his wife being 'disturbed' by being asked questions by staff in order to confirm her immigration status before she

was given treatment. This occurred repeatedly. Eventually Saidah said he took the action of photocopying all of her immigration papers and sent them to the hospital in an attempt to stop them asking her for information:

Saidah:...but they used to disturb my wife, they ask to have your identification to prove who you are so many times. After that I make a copy. I make copy the third time they send me a letter from the hospital to know who is she, which situation she stay, is she a student or living in the UK. After that I make for them her travel document and 'indefinite' paper, everything, and I make for them a copy and I send it. After that they stopped.

Another example of the perceptions of discrimination that arose from questioning was evident from Carlota's narrative (Carlota was a migrant worker fluent in English). She recalled the occasion when she tried to call an ambulance due to a sudden injury to her knee and was struck by the extent of questioning by the ambulance staff. Her narrative reflected on the additional cost of sending out an emergency car prior to the ambulance which was an emergency service she knew was necessary in that instance. She was confused by the questions and it created doubts for her about her entitlement:

Carlota: They asked me a million of questions. Really, they shouldn't ask me so many. Maybe they needed it for general information or I don't know for general

opinion, but it was really lots of it. There was a man who came by car and then he called the paramedic unit. Maybe that is the system, first somebody come and check the situation and just decide if I need paramedic unit or not. But he really saw me in a really bad, bad situation. About these questions, it wasn't necessary to ask me so many questions. The strange thing is I expected them to ask me, for example, if I have an NHS number. That one they didn't ask me, they ask me if I work or not but they didn't ask me for that one because in the situation, I don't know, if I am unemployed if I am able to get help from the paramedical health unit?

Later in Carlota's narrative she expressed other concerns about delays in her treatment and she felt that her particular experience was shaped by being a migrant. The above extracts from the interviews support the policy analysis that raised concerns about the process of questioning a person's status and shows that the process itself could be perceived in various ways by the patient. In these examples it was at best confusing, in other cases demeaning and irrelevant and overall led to perceptions of discrimination.

Delays in referrals and treatment

Perceived discrimination often related to experiences of secondary care. This section argues that experiences with specialist doctors was one context where this was often felt. Four cases illustrate this point, which also relates to the outcome of delays in treatment (because specialists were seen to prioritise

some patients based on being long-settled residents or not being immigrants and this was perceived as discrimination by some participants: Klaudia felt that the consultant not coming and instead sending a student doctor after a long wait implied that she lacked entitlement. It was also under these circumstances that she felt the consultant offered a lower standard of care:

Klaudia: Because why do I have to wait for everything so long...I will go and tell to my surgery. I feel pain, I have a pain, and at the clinic - I say it is so painful. It gives me lots of problems, yes. You have to wait, I understand but I cannot understand, I work hard, I pay taxes everything. They withdraw tax very, very quickly without asking me anything but when I just want to get, how to say, immediate help, when I have bone fracture nothing happens, I have to wait. I cannot understand why.

Another example of a specialist in secondary care assessing urgency was evident in Garai's interview. He was a male refugee who was not very fluent in English but preferred to conduct the interview himself. His comments were about the specialist he saw for chronic back and leg problems that had forced him to leave his cleaning job after he did not get better. Garai hoped that the referral to a specialist (after trying a lot of different pain relief medication from his GP) would lead to a better treatment. However, during the specialist consultation he perceived rudeness and an uncaring attitude. Garai was struck

by the medical students present at the time asking the consultant why he did not do more tests. The consultant answered by saying the problem was 'an African problem'. Garai had reflected on this comment and in the interview said he felt this specialist showed little inclination to give him treatment. When asked to explain what he thought had happened he said the interaction with the consultant had felt like 'hate' and therefore Garai had certainly felt stigma and discrimination. The implication here is that Garai's status as a possible overseas visitor was being questioned and he was not given priority for a longstanding problem:

Garai: I told you I went to the clinic with my specialist doctor, Dr A, even I asked him many times. He told: 'He doesn't have any problem'. He doesn't need even to exam [examine me or] anything. That time there is a student [present], they are doing research, a girl and a boy - two students from the university. Those students they said 'Why don't you check it'? He said 'Oh I know, I know African problems' he said. 'They have African problems, they have poverty, they have TB, but they don't have any problem if they come here'. He talked many things. Then he was angry and he sends me for an x-ray at that time. Also, he got that result he said, 'This is from before this leg, before it is not straight, the bone is not straight but for now he doesn't have any problem'. Then he said 'Oh, I saw your problem, go, go and I will write the letter to your GP doctor'. He told me, yeh, that is why I was not happy with him.

KR: Pause, that interaction, are you saying you, it didn't feel respectful or...?

Garai: No.

KR: How else would you describe that interaction, explain what it was about the way he behaved?

Garai: I think he showed me like, hate. Because he said 'Go, go, go'!

Alicja's interview provides an example about the issue of delay in treatment being related to GPs preventing access to specialists. Alicja was a migrant worker and very fluent in English; her narrative was striking in that it was about a long struggle of trying to get a referral to a specialist doctor for an endocrinal problem. Alicja wanted to see a specialist as well as a GP but the GPs in her practice would not refer her. Her condition deteriorated further until by chance she saw a semi-retired locum GP for the first time. Alicja felt this doctor was different in that he showed more interest in her condition and immediately gave a referral to a specialist. At this point Alicja spoke about her entitlement as a taxpayer and questioned it in the context of her being able to access treatment, suggesting she saw a problem that was specific to her being a migrant and for this reason perceived discrimination:

Alicja: It is because you didn't have to change four GPs, to be referred to a consultant (who actually didn't help) but to be seen by a professional. So you,

well I am here yes, I am working here and I am going to be, so why shouldn't I use the NHS? Why should I go and be treated in X? I pay taxes here.

In the following extract the speed of specialist referral received was connected to the urgency of treatment: Idra's wife (Samiya) became critically ill as she was preparing to join Idra (after he was granted refugee status). In their country of origin Samiya had been diagnosed as having a brain tumour. She had been assisted through social networks to leave the country with her three children and to join her husband as soon as possible. Samiya was hospitalised on arrival to the UK and the diagnosis was confirmed. After further tests and approximately a month in intensive care in London, Idra's wife was rediagnosed with a less critical problem – a neurological disorder. Samiya was clearly a recent migrant, specifically a spouse of a refugee who had been seriously ill on arrival in the UK. After some weeks Samiya was moved to a hospital in Sussex and with the new diagnosis and prognosis of a neurological disease, Idra perceived she was treated differently. Idra identified problematic elements in the interaction he had with the specialists. He found them to be unfriendly and very keen to get them out of hospital. His comments in the following quotation are interpreted as indicating structural problems which led to a perception of indirect discrimination. Idra's experiences are taken up again in the following section, where subsequent quotes suggested that direct discrimination was also perceived.

Idra: When we were in the hospital my wife wasn't very well and she couldn't walk or use her arms properly. She was there just one month and the doctor told me he would like to discharge her from the hospital. I told him: 'Why do you want to discharge Y from the hospital and you know about her situation, she can't do anything and I can't cope, the house is not suitable any more for her, she can't walk and she can't go up the stairs to sleep, and there is not space down for her'. And he told me 'We will decide and that is final, that is final'...I complained and then they gave her some time to make physiotherapy and she started to improve.

At least eight other participants felt that their GPs were controlling access to specialists and others found that the specialists they eventually saw were reluctant to treat them. The extracts below focus on cases that refer to communication problems which underscore perceived discrimination.

Insufficient healthcare and a lack of quality in the interactions with health professionals in maternity care were spoken about by participants. Two out of the four childbirth narratives indicated the women felt they were left alone for long periods during their labour and regarded this as being linked to discrimination. For example, Bahar felt that later chronic health problems were related to her experiences of childbirth when she had been left alone for long

periods. She got very emotional telling her story and later in the interview Bahar was asked to clarify if what she had said was connected to being a migrant. She agreed:

KR: Do you think being a migrant and a foreign national affects some of the story that you have told me, about your pregnancies and your other health problems?

Bahar: Truthfully, yes I do feel that way.

KR: Which thing in your mind and your memory makes you feel that?

Bahar: When I gave birth to my first baby I felt they left me alone...they didn't come and see me. They put me in a room and they left me there. Nobody was there to ask me how I feel. (Tearfully) I really hate it when my mind goes to this.

The above examples sought to demonstrate that the discrimination perceived by participants was likely to be a result of indirect discrimination, with the contexts showing a likely link with structural factors (practices and procedures).

The second section of this chapter identifies more cases of perceived discrimination which are strongly linked to immigration status or ethnicity.

These illustrations suggest experiences that reflect direct discrimination.

Perceived direct discrimination

In the previous section dissatisfaction with the time and effort involved in getting referrals to a specialist and other aspects of waiting were linked by some participants to indirect discrimination. In this part of the analysis, the examples show a strong connection to an identity perceived to be stigmatising. Often this was immigration status or ethnicity and sometimes faith. The three interviews below interpret some participants' views of perceived discrimination as an indication of direct discrimination. This was felt to be based on interactions with healthcare workers who were holding prejudiced views.

Morayu was a refugee who was able to describe in English how she felt about her first GP and her inability to get a referral from him. She felt her abdominal pain warranted tests and further investigation. The lack of a referral and the suggestion she had to keep asking for a referral was demeaning and was perceived as discrimination:

Morayu: I wanted to see a gynaecologist for my womb. For five times...they give me paracetamol but I wanted to know what is going on - I need a professional not like [a GP]...But at that time I had a social worker. [I said] 'Please, like do something'...She said 'they need pushing...you have to go every day'. I don't want to, if I am not feeling okay...sometimes I don't want to go...if I am ill...nothing... She [the social worker] would say 'You are ill – go'. I said 'I

don't want to go, when I go they give me paracetamol, I have paracetamol at home'. It is my...I can't say...every day...to beg...I couldn't do that. At last...they didn't send me...for anything...the pregnancy came. After that, when I was pregnant I saw in the scan. They said 'You have fibroids'. That is why I wanted to know what is going. It was painful, I couldn't move. That is what I needed.

Another example of not being given referrals was seen in Josef's interview. He was also a new refugee and less fluent in speaking English. Josef said he generally requested an interpreter to help him express himself better in healthcare situations. His comments were detailed about both communication and referrals. He eventually felt he had to change GPs so that further investigations were done, but he did this after two years of expecting more tests. He interpreted the lack of referral as discrimination:

Josef: The German, the first GP, he was insistent, or keen for me to work. I said I have no objection to work but at the time I had just arrived from X, I am not in a position to work. I feel everything what happened in X is still fresh in my mind. He was insisting 'I am right and you should start working as soon as possible'. There I had to leave him. The other one was a lady doctor, initially she was alright she met me alright and she was alright...I felt something as well, she was treating me differently...I feel that people come after, they see her first

rather than my appointment, I don't know, if I was right or wrong but that is what I felt. And she did not refer me to any specialist. Several times I told her I feel so and so and I suffer from a lot of things but she did not refer me to any specialist whatsoever. I remained with this lady doctor for two years but I didn't benefit from her anything...I was not referred to any specialist at all. I think she would just give me some medication; the medication would make me feel like I wanted to sleep all the day. And I didn't like that at all. Therefore I left this GP...I was recommended by somebody else, this other one; they said this is a good doctor and things and so I registered. I have been with this GP for one year and half now. I am not saying that I am getting 100% alright but I feel some progress with him and maybe I will be alright.

In Jahander's interview he spoke about getting healthcare from emergency services in London and Brighton and Hove. He showed sensitivity to the busyness of the emergency services. He was even aware that as an asthma patient perhaps he was an 'odd' type of patient, but he maintained that on occasions when he was left to wait too long it led him to feel he was being treated differently. He perceived this was connected to being an asylum seeker.

Jahander: There is stress, there is loads of work and many people come to the emergency section. I felt like, I am an asthmatic patient, or an odd patient. They need to be treated soon. They just take them in and have a place to take

them in directly. As I wait I get more panicky and then I get more...Last time I went to the emergency lady, I gave my details and they were just busy with the computer. 'If you get bad and worse just knock on the nurse door they will get you in'. I have to wait until that? Until I say 'I am dying? I can't breathe anymore?' Then they will run and pick me up and take me inside. So, after one hour I was called, my name and I went there they started checking my blood pressure, heart beat and the oxygen level and these things.

Problems related to communication

The final sub-section focuses on extracts from interviews which demonstrate that some participants felt discrimination based on poor communication with health professionals. As in Chapter Seven, communication frames patient experience; the difference in the following quotes from the interviews is that negative experiences were linked to immigration status. Two cases are used to further illustrate perceived direct discrimination in the primary care setting:

Klaudia, a migrant worker who had been an English teacher, eloquently explained her feelings. Klaudia was able to register with a GP practice but faced problems when interacting with the GPs and she perceived that they saw her as just 'one more migrant worker':

Klaudia: I think it was more about my ethnicity because I am not English, because she was very, very negative and no politeness, nothing. I couldn't see any politeness in her attitude. 'Ah one more', for her, 'one more migrant worker has come here'. I could feel that because she wasn't friendly, no smile no, no she wasn't, she was really nasty I would say - I decided to go to another doctor [in the same practice].

Interestingly, Klaudia was one of a few white migrant workers in the sample. She explicitly referred to herself as a migrant in her narrative and saw her migrant status and later her ethnicity as reasons for discrimination. In the case of Zola, who was also fluent in English, she and her family had recently been through the asylum process and become refugees, and had then moved house and GP practice. In the new practice Zola felt a difference in how she was treated by the reception staff; she articulated this as being uncivil towards her and her husband on a number of occasions. This led her to conclude she was experiencing discrimination. Zola described the communication with staff being loud, aggressive, and a kind of telling-off, for example, regarding how she was filling out her prescription form. On other occasions staff did not respond to her greetings but clearly did to other patients, and another example was when an appointment for a blood test in the practice was withdrawn and Zola was told to go across the city for it. Zola's husband was reluctant to go to the surgery as he found it unfriendly. Zola's narrative distinguished between doctors, staff and

reception staff. She had come to prefer certain GPs, a male over the female one. Zola's perception was that her experience of poor communication was connected to her being a 'foreigner'. I would further argue that this perception could be related to Zola being a recent migrant:

Zola: For the reception there, they are very bad. Really, they are very, very bad. The reception for the surgery, my god, each time I went for the prescription for my children.

KR: What do you think the reason is for this behaviour?

Zola: Because we are foreigners.

KR: You feel there is [pause] prejudice?

Zola: Yes it is 100%. Because I saw her dealing with the other people; she is talking with them so nice. She is talking; she is creating conversation with them. Or she is laughing with them or they are laughing... But the doctor is very nice, he is very helpful. He explained to me. He is a very nice man. Even the lady doctor, she is nice, but I don't know, my feeling now is with Dr W, that he is better than the lady doctor.

Earlier in this thesis, in Chapter Five, the questionnaires showed that social context, ethnicity, immigration status, and faith were likely to be significant factors in illness and healthcare experience. These factors are seen again as important from the analysis of the interviews, where illustrations indicated that

perceived discrimination also affected healthcare experiences. Also in this chapter, practices and procedures are seen to be important for understanding perceived indirect discrimination.

Conclusion

Descriptions of direct discrimination by participants' evoked immigration status, ethnicity and faith as reasons for not receiving healthcare. Comments in the first section were collated as indirect discrimination and pointed to the likelihood of practices and procedures giving rise to experiences which were perceived as discriminatory. Some participants tried to explain this in terms of their GP being a kind of 'gatekeeper' to secondary care as discussed by Forrest (2003). For them, these procedures were being overzealously guarded, indicating that possibly structural factors overlapped. Warmala et al.'s quantitative study refers to the significant effects of perceived discrimination, arguing that discrimination can be linked to changes in health-seeking behaviour of patients in terms of greater avoidance of healthcare (Warmala et al.2007).

The locations (in terms of type of health services) where direct and indirect discrimination was experienced varied. Moreover, although these findings present a case study, it is argued they are unlikely to be particular to one administrative locality, city or type of service but more widespread in terms of place. Indirect discrimination related to different services -- secondary,

maternity and emergency – and references were also made to referral practices in primary care. Direct discrimination often related to poor communication from particular interactions. The conclusion from this chapter supports the findings arrived at in previous chapters: that recent migrant status affects illness and healthcare experiences. Specifically, it argues that practices and procedures, communication and factors such as immigration status and ethnicity were linked to perceptions of discrimination.

Chapter Nine: Conclusion

III health and migrants

Constructivism is the interpretative framework underlying this thesis, and in which the ontological stance taken is that 'multiple realities are constructed through our lived experiences and interactions with others'. The epistemological beliefs adopted are that 'reality is co-constructed between the researcher and the researched and shapes individual experiences'. Finally the methodology applied is 'inductive' with 'consensus' approaches and is 'obtained' using methods such as interviewing Creswell (2013:37). This has allowed common, specific and overlapping factors that might affect illness experience and the healthcare use of a group of recent low income international migrants to be explored.

To recap on the context of this study, migrants are a broad category of people.³⁸

One of the reasons for selecting recent international migrants as a group for study is that public discourses about them have become negative (Doctors of the World 2012). As has been discussed in the introduction, the term 'health

³⁸ A person who moves from one place to another in order to find work or better living conditions

<http://www.oxforddictionaries.com/definition/english/migrant?q=migrant> (Last accessed 1st November 2013)

tourism' has become associated with migrants and is a discourse transmitting the idea that large numbers of migrants are moving to the UK to seek treatment for their health problems. Increasingly over the last two years, this view has been challenged by organisations who are advocating for migrants' rights³⁹.

Government discourses on migrants have been reflected in one particular UK health policy called the Overseas Visitors Hospital Charging Regulations (OVHCR) (Department of Health, 2004 revised 2007), which has been concerned with the procedures for charging 'overseas visitors' for their use of secondary NHS healthcare. This policy draws on the discourse that the potential for 'health tourism' justifies a restrictive policy towards overseas visitors (who are predominantly migrants). The OVHCR changed in 2004 in

³⁹ <http://doctorsoftheworld.org.uk/blog/entry/the-truth-about-health-tourism> (Last accessed 11th November 2013)

<http://doctorsoftheworld.org.uk/blog/entry/proposed-uk-healthcare-restrictions-are-dangerous-and-unnecessary> (Last accessed 11th November 2013)

<http://www.migrantsrights.org.uk/migration-pulse/2011/access-primary-health-care-migrants-right-worth-defending> (Last accessed 11th November 2013)

<http://www.migrantsrights.org.uk/migration-pulse/2013/five-points-which-must-not-be-lost-debate-nhs-access> (Last accessed 11th November 2013)

response to the accession of ten countries to the European Union (and specifically because eight of these countries gained access to the UK labour market for the first time). The UK government argued again that they were justified in revising the OVHCR policy to protect the NHS from a predicted rise in usage by migrants. The OVHCR policy was revised in 2010, following a public consultation, and yet more changes were proposed as part of the 2013 Immigration Bill (Department of health, 2013). Medical and non-governmental organisations criticised the OVHCR (Department of health, May 2009, Refugee council, 2010), arguing that the policy would have a negative impact on the diagnosis and treatment of patients, and in particular on migrants. Moreover, the contention was that this health policy was unethical and undermined the principle of universal healthcare laid out in the NHS constitution (Department of Health, 2012b). The criticisms pointed to the policy being a possible factor that could increase health inequalities among, between migrants as a whole and others. The Immigration Bill was introduced to parliament on the 10th October 2013 and the government (at the time of submitting this thesis) hoped this Bill would receive royal assent in the spring of 2014. A significant proposal in it was the introduction of a health levy on temporary non-EU migrants⁴⁰. Widespread

⁴⁰ <https://www.gov.uk/government/collections/immigration-bill>
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/249315/Factsheet_08_-_Health.pdf

(Both accessed on 11th November 2013)

criticism was heard again about how such changes would be costly to implement and concerns that the economic impact on national tourism and education would be significant⁴¹.

The other significant part of the rationale for this research was to study an under-researched group who may face inequality and to understand the possible links between illness and migrant status. Health inequality is a broad subject area in health research which examines difference from many angles relating to an array of health outcomes, issues of access to healthcare, healthcare-seeking practices and perspectives. Health inequality is concerned with processes which may be unfair (Scambler, 2012) and can be investigated using a wide range of variables and methods. Health inequality therefore underscores a wide body of health research concerning income, race, culture, behavioural differences and *migration* (Davey-Smith, 2002). Nonetheless, literature which pertains to migrants was found to be scarce and sometimes

⁴¹ Doctors of the World Policy Briefing August 2013. Page 5 refers to health tourism and their views about the proposed changes following the 2013 consultation. <http://dnwssx4l7gl7s.cloudfront.net/droftheworld/default/page/-/upload/blog/Doctors%20of%20the%20World%20UK%20policy%20paper%20-%20access%20to%20healthcare%20in%20England%2016.08.13%20FF.pdf> (last accessed 11th November 2013)

contentious. Moreover, some health-related studies interchange the concept of ethnicity as though it is a proxy for understanding migrants. It is argued that caution should be exercised following debates that broad ethnicity groupings can mask important variations. Other limitations with regard to ethnicity were noted such as the fact that ethnicity can be objectified and seen as a biological rather than a social construct (Senior 1994, Ahmad and Bradby, 2007a, Bloch 2013). These debates have influenced the methodology for studying migrants in this thesis.

Migration encompasses temporality as well as movement (Cwerner 2000).

Temporality has been considered as an aspect of the health differences among migrants – the ‘healthy migrant effect’ contends that migrants are healthy on arrival but migrant health deteriorates over time. Although this observation has held in some cases (Abraido-Lanza et al.1999), elsewhere the same trend has not been seen. In other cases the process of migration has been argued to have a more immediate negative effect on migrant health (Friis et al.1998).

Furthermore, temporality overlaps with the concept of acculturation, where the passage of time has been argued to affect migrants in non-linear ways which can indirectly relate to health - often negatively. Time, as a natural element of the biological aging process, also introduces another overlap with health among migrants (Hunt et al, 2004, Lara et al, 2005, Abraido-Lanza et al, 2006).

Despite the importance of time as a factor, the period of residency has rarely

been taken up as a dimension of migration in UK health research despite socio-political interests in the issue of time outlined above. For these reasons, and those given above, the category of 'recent migrants' has been used to define this research. The term 'recent' refers to people who migrated from another country to the UK over a *six-year period* leading up to the start of interviewing that began in 2010.

As mentioned above, the impact of migration on health status is complex: early studies in the 1980s used broad categorisations of 'immigrants' and 'ethnic minorities' in the USA and UK to highlight differences in health status (Marmot et al.1984, Markides and Coreil 1986). Other studies have examined the healthcare use of migrants and noted that migrants can be differentiated by immigration status; other studies indicated that migrants with undocumented immigration status avoided using health services as much as possible (Schoevers et al.2010, Romero-Ortuno, 2004, Bloch et al.2011). Studies on the health status of migrants have tended to focus on refugees and asylum seekers and have shown that stress and mental ill health is caused by traumatic migration experiences (Blight et al.2006, Lindert et al.2009, Bhugra 2004, Feldman, 2006). Research on aspects of experiences of refugees has found that the migrant's experience has wide effects including poor interactions with GPs (Bhatia and Wallace 2007).

Studies of variations in health service use by migrants as a broad categorisation are few. One notable exception is a study by Hargreaves and colleagues (Hargreaves, 2006), a quantitative study of international migrants from 'refugee generating countries' and 'non-refugee generating countries. They found that migrants from refugee-generating countries used Accident and Emergency departments in London less frequently than those from non-refugee generating countries. This challenged the discourse that many migrants use emergency health services inappropriately (Hargreaves et al.2006). In addition, women migrants giving birth have been shown to have poor maternal health outcomes, a problem linked to a tendency among female migrants to avoid using antenatal services (Bragg, 2008). The fear of being charged for maternity services has been suggested as one reason for this trend (Bragg 2008, Bloch et al.2011).

The connection between income and health inequality is well researched (Davey-Smith, 2002). Other factors such as ethnicity and 'race' have also been studied. For example, comparisons between ethnic minority groups and majority populations have indicated that health inequality in populations occurs through an interplay between social factors (Modood et al.1997, Nazroo, 2003, Kelly and Sriskandarajah 2005, Kofman et al.2009). There is growing evidence that social factors intersect and my analysis of a group of recent low-income migrants points to this population being vulnerable to health inequality. In light

of the wellknown influence of income on health inequality and the more complex effects of time since migration, this research contributes new perspectives from the experiences of recent low-income migrants to this literature.

The main question that has guided this thesis was how a group of recent low-income migrants are affected by illness and healthcare in a provincial city in the UK. The methodological approach recognised that recent low-income migrants were both an under-researched and a hard-to-reach group. Moreover, this approach suited both a qualitative and collaborative approach which could use local contacts to access and help recruitment. Finally, the rich texture of the interviews contrasts well with impersonal quantitative surveys of patient experience in the NHS and offers new insights into the healthcare experiences of this research population.

Summary of main findings

This thesis illuminated the connections between migrant status, illness and healthcare use on the one hand, and other factors such as income, faith, gender, age, education, language proficiency, and social networks on the other. All of these factors shaped the experiences of low-income recent migrants within the UK healthcare system to some degree.

Overall, the language proficiency of the participants varied greatly. Twenty-one of the 46 participants in the questionnaire used an interpreter. Some of the participants reported in the interviews that they were unclear about their rights to an interpreter when using health services. There were also strong suggestions that participants felt complex emotions about using interpreters, including embarrassment, shame and guilt. Some participants had decided *not* to use interpreting services and gave reasons such as helping to save the NHS money, feeling their health problem was not serious enough, and because they were trying to develop their language skills. Some participants also indicated that they preferred certain interpreters, suggesting that the participants valued the professionalism of the interpreters and the quality of their translations.

Ethnicity and immigration status were found to be important issues which were examined using the questionnaire and semi-structured interviews. The three ethnicity classifications used in the questionnaire raised questions for the participants about their accuracy and utility and were frequently disliked. More participants of colour (as opposed to identifying as white) raised ethnicity as an issue of concern; only two participants identified themselves as white and also fluent in English, identifying ethnicity and nationality as partial explanations for their unsatisfactory healthcare experiences. More of the participants identifying as 'white' raised language proficiency as a factor for unsatisfactory experiences.

Work status was an important contextual subject for the interviewees, who encompassed a range of terms of employment, welfare programmes and caring responsibilities. Nearly all participants in the interviews had a low income except for two. However, income was a difficult variable to ascertain without damaging the rapport needed to interview a generally hard-to-reach group. There were identifiable trends in the relationship between certain immigration statuses and work statuses; for example, most economic migrants were in work and nearly all the refugee participants were unemployed. Many participants had caring responsibilities. Topics related to work and illness also concerned the disruptions that illness had caused and the consequent loss of the ability to work and loss of earnings. In addition, a number of working participants linked injuries or health problems to the strenuous nature of their jobs. This association between illness and working conditions challenged the healthy migrant hypothesis which suggests that new migrants (in particular economic migrants) stay healthy for a considerable period of time after migration. For the unemployed participants the mental distress caused by not working and the stresses of poverty were reported as being very high. Specifically, for most of the male participants (many of whom were refugees) unemployment had become a longstanding and upsetting reality. For both males and females in work, a fear of losing work was a stress that was frequently articulated in the interviews, indicating the precariousness of their positions. Many of the unemployed participants expressed emotions such as frustration, sadness and

shame. The link between psychological illness, worklessness and refugee status was evident in many of the interviews.

Faith and religion were often viewed as supportive elements in participants' lives. However, in some cases the converse was discussed as participants said they had experienced discrimination inside and outside healthcare situations that they felt were related to being Muslim. Such experiences had an effect on the mental wellbeing of the participants.

This study included more female respondents than males. The debate about health inequality between genders challenges the notion that gender is solely a biological matter and points to the fact that the social construction of gender cannot be ignored even within a qualitative analysis like this one. The participants here presented a range of health problems, some of which were gender specific, such as gynaecological, obstetric, childbirth and domestic abuse stories. The women participants appeared more interested in discussing illness than some of the men, despite many women having constraints on their ability to participate in the study, for example as a result of doing both childcare and paid work. Men who were in work were less willing to find a time to participate in the study. A point of interest was gender differences in healthcare-seeking. It was noted that some men who had agreed to participate were less keen to discuss their illness in depth in their interviews. This may

have been related to the researcher's gender but it is also likely to be because some men said they disliked being ill, and did not want to talk about illness as their priority was to get better so that they could go back to work or find work (O'Brien et al.2005).

Educational qualifications closely intersected with language proficiency and social class, with educated participants most often having fluency in English. Many of the participants who had a high level of English proficiency had a university level of education (in languages of their countries of origin). Many of the participants interviewed who were in work tried to make some use of their educational qualifications and wanted to develop their English language skills in order to further their work opportunities. Patient-doctor interactions seemed to be positive for many of those who were educated, and for most of those who were fluent English speakers. Some male refugees who were not fluent in English but who were educated were able to overcome the language barrier by using professional interpreters to convey their ideas, suggesting education and English proficiency could separately impact upon and produce a satisfactory patient-doctor relationship.

Participants had varying degrees of social resources they could draw upon when they were ill. Those who were educated (and/or came from high social classes in their countries of origin) had more social capital to draw upon in the

UK (as seen in the ability of these participants to make new friends or rekindle old contacts) and these were sometimes used when trying to access healthcare. For example, such participants would contact friends and relatives to recommend GPs, help make appointments, accompany participants to appointments, help with childcare in a health emergency, offer loans when work was lost due to illness and help with transportation to hospital appointments.

In Chapter Six, four of the 41 semi-structured interviews were presented in an analysis that showed they possessed some common characteristics of illness narratives. The majority of interviews were about chronic illnesses; however, all of them depicted a loss of normal functioning and severe and prolonged disruption due to their illnesses. Frank's typology of illness narratives was applied and it was found that the majority of interviews reflected a chaos narrative typology, with some making attempts at a restitution narrative, and even fewer a quest narrative (Frank, 1995). Many participants expressed unhappiness about being ill and saw illness as a significant disruption (Bury, 1982). Diagnosis was a prominent characteristic, with participants referring to contested diagnoses and treatments (Jutel, 2011a) as a source of distress. Temporality was evident in the interviews as participants tried to tell their illness story chronologically, ordering events and information beginning in the past and moving towards the present.

The illness narratives were also shaped by migrant status, highlighting three aspects related to the specific experience of migration: first, participants showed a tendency to make comparisons between the health services of their countries of origins and the UK. Second, and mostly noted among the refugees, was the effect of traumatic and forced migration on the mental and physical health of participants. Third, the migrants in this study both accepted and avoided using health services and occasionally resorted to using Accident and Emergency services and this was in a way that could be interpreted as mainly appropriate.

Participants made comparisons between national health care services for a number of reasons: i. to gather more diagnostic information; ii. to get a second opinion; iii. to investigate other treatment options which might be effective; and iv. to get a better understanding of their diagnosis in order to manage their illness. These activities fitted Frank's illness narrative typology of moving from a 'chaos' to a 'restitution' type. They also corresponded with Jutel's notion of diagnosis being central to illness narratives. Many participants responded to their situation, particularly those experiencing prolonged illness, by phoning contacts or otherwise contacting local social networks. Some of the participants who had the means and did not face any danger by travelling back to their countries of origin did so, going in person to make comparisons and use services there. Other participants made comparisons by imagining what would

have happened had they been able to use health services in their country of origin. Some of those participants who had travelled undertook medical tests and presented the results to their GP or specialists in the UK when the referral came through. Several of these participants found providing additional information including second opinions were not received well, suggesting the behaviour was perceived as strategic. I anticipate that some of the doctors who saw participants carrying additional medical information viewed them as visitors according to NHS policy. Conversely, in a few refugee cases, some GPs gave priority referrals based on the pre-existing health information being presented for the first time to doctors. These accounts were from refugees who had been recently granted status, or were newly arrived in Brighton and Hove having relocated from their original dispersal areas to join relatives. The positive responses from GPs were highly appreciated by participants. Several working migrants pointed out that they were UK taxpayers and therefore were no longer entitled to any free treatment in their country of origin and were eligible for NHS care. Treatment in their countries of origins was only feasible for migrants who had some savings and/or needed one-off or infrequent treatment and could afford to pay. None of the participants in this study were able to do more than get selected diagnostic investigations.

The chronic illnesses of many of the participants can be seen as a factor influencing behaviour. Indeed, having chronic illnesses encouraged the seeking

of information within and beyond doctor-patient meetings but the chronic nature of a problem was also discussed in interviews as an obstacle to getting help from GPs who were perceived as showing less interest when illness was prolonged. Chronic health problems were a feature for many participants, and they could not be helped in the ongoing way they desired. Most could not afford to make regular trips abroad for treatment or monitoring. Therefore compared to acute health problems or those in the early stages of illness, this route of health-seeking was not available.

The tendency for participants to make comparisons could be also understood in terms of having different expectations of healthcare services based on *past* experiences and knowledge. Furthermore, such expectations could also be framed as differences in health beliefs and cultures with regard to biomedicine and health seeking practices. Most notable was the idea articulated in several interviews that the cure for the illness in question required tablets or tinctures but that these were not being offered. GPs prescribing practices were not understood by some participants and seen as very different to what they were used to in their countries of origin. Other participants noted there was a tendency for some GPs to mainly prescribe paracetamol, which they did not like. Contestation such as this is conceptualised as part of participants making comparisons. Indeed, the tendency to make comparisons can also be associated with participants' need for reassurance, explanation and good

communication about the healthcare being offered. As shown in Chapters Six and Seven, many of the participants contested the healthcare they received during patient-doctor interactions; communication was perceived to be insufficient, uncaring and lacking compassion. The theme of access was used as a part of patient experience analysis, suggesting difficulty for many of the participants. Diagnoses and referrals were mediated by the GP, who was functioning as a gatekeeper to secondary health services. Waiting times, which were felt to be too long, were a related aspect of perceived lack of access.

Another aspect of the study was to look at the interviews as illness narratives and to see if they were also specific to migrants. The experience of persecution and/or traumatic journeys was one clear area of difference, and this came across strongly in most refugee and asylum seeker narratives. However, some economic migrants' illness narratives also indicated that migration had been traumatic. These cases of voluntary migration suggested an array of hidden problems (such as domestic violence and divorce) that continued to cause stress even after a voluntary migration journey was over. Therefore among many participants of differing migrant statuses, the long-term psychological impact of migration was connected to present health problems and appeared significant to their illnesses. Finally, the illness narratives of the two undocumented destitute migrants appeared distinctive in the way they clearly referred to avoiding health services. Resorting to Accident and Emergency

rather than primary care appeared to be a coping strategy for these participants.

At the same time they emphasised their desire to leave the service as soon as they were able. The avoidance strategy by stigmatised groups is regarded as a feature of this state of being (Warmala et al.2007) and was shared by some others in the group (asylum seekers, refugees and economic migrants).

The concept of patient experience (Department of Health 2012d) structured the analysis in Chapter Seven and supported the interpretation that the majority of participants had unsatisfactory to poor patient experiences. Communication between participants and healthcare staff was frequently identified as inadequate in interviews. Comments related to communication included perceived negative attitudes, feeling deliberately ignored, and not feeling well understood. Some of the participants interpreted interactions with staff as also being disrespectful and uncaring. Patient experience was related to access problems, including long waiting times, not being given referrals when they were asked for, referrals taking a long time to come through and doctors not following up on the care being offered. This chapter also raised the question of links between migrant status and poor patient experience based on participants' own interpretations of the term migrant. This supported a conclusion that many of the participants felt stigma, and arguably these feelings could have a negative effect on health.

The last analysis looked at whether some of the experiences recounted in the interviews could be seen as discriminatory. Link and Phelan's concept of discrimination (2006) was used to analyse the interviews for participants' perceptions of indirect and direct discrimination. Some participants' comments resonated with the critiques of the practices. These related to being asked questions that participants felt were repetitive and lengthened the process of admission to emergency and secondary health services. Other respondents remarked on receiving letters from secondary care which repeatedly asked for identification. These experiences were upsetting and created doubts and fears about participants' entitlement to healthcare services. Finally, some participants in this study stated clearly they perceived discrimination and associated it with their migrant status, ethnicity and/or faith. The study concludes that some of the participants perceived what is conceptualised as direct discrimination that is by definition borne out of an individual's prejudice rather than structural problems.

Recent public discourses and health policy changes have suggested that migrants may be using health services excessively or inappropriately but this was not a trend seen in these interviews. In only a few cases was confusion or differing expectations voiced and enacted. One southern European migrant worker (who was a nurse by training) chose to go to Accident and Emergency for medical help on one occasion. She did so because she felt sure she would

not be given medication by her GP. The medication she wanted was not available at a pharmacy, unlike in her country of origin. However, in most other interviews the use of health services that was recounted appeared appropriate to the health need. To conclude, the interviews of a group of recent low-income international migrants showed complex bio-psychosocial and economic linkages to illness and healthcare use. The four data analysis chapters demonstrates that a group of recently ill participants had common yet distinctive characteristics in terms of their experiences and that this was due in some part to their recent migrant status.

Final thoughts and next steps

Further research could investigate the impact of the latest OVHCR on patients, particularly in light of further changes being made following the 2013 consultation and the Immigration Bill (Department of health, 2013). New research could interview health professionals in order to explore their views of the OVHCR and their awareness of indirect and direct discrimination. Views of the impact of these changes on universal health care and the ethical implications of the policy could be explored. A longitudinal study of the experiences of recent migrants could employ semi-structured interviews over a longer period of time, and through repeated interviews patterns of healthcare use could form the basis of a new study. Specific illnesses and departments in secondary healthcare services could be focused on. Alternative designs could

use quantitative approaches if an NHS hospital database containing residency of patients could be accessed. Comparative methodologies, for example including recent European and non-European migrants could be formulated to explore the experiences of these specific groups' use of secondary NHS healthcare. The tendency to make comparisons and the trend of participants returning to their countries of origin for healthcare could be further explored by researching recent migrants in the UK from an EU country and/or by studying British migrants in EU and non-EU countries.

Over the course of this research the NHS has been changing. In 2010 the importance of the patient was firmly embedded in the NHS constitution. However, this development was shaken up in 2013 by the Francis Inquiry (Francis, 2013) which reported serious failings in the Mid-Staffordshire NHS Foundation Trust. The report raised questions about standards in one hospital in particular, but also more widely and on many levels about the NHS in general. Patients who had formally complained about the service in Mid-Staffordshire NHS Trust were ignored for over two years before the inquiry was set up. The findings of the inquiry were extensive, casting doubt on the monitoring procedures in many areas including on patient satisfaction surveys and other monitoring data. The conclusions triggered debates about the 'culture of the NHS' and whether services remained caring and transparent.

This thesis has collected the interviews of the *lived* experiences of a group of recent low-income international migrants who are marginalised in UK society and as such were seen as likely to be less visible to the NHS. In sum, the illness experiences and healthcare use by the group studied in this doctoral research project illuminates some of the marginalisation felt by migrant individuals and clarifies the multiple factors affecting the healthcare experiences of recent low-income international migrants.

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Appendix 1: Calculation of Low Income

The definitions used for low income were taken from the ONS website in 2009. However, the link to the webpage has been broken and replaced with an up to date report on 'Household Below Average Income' (HBAI) data. The information below uses the 2009/2010 figures and references currently available reports.

ONS data for Low Income

In 2009 the proportion of the population getting 60% of median income in England was calculated at £402.5 and annually £21,673 (taking England only).

| | |
|--------------------------|---------------------------------------|
| Low pay (below 60%): | £241 per week |
| | £13,000 per year |
| | £1,083 per month |
| Low pay as hourly rates: | Over 21 years of age was £5.80 |
| | 18-21 year of age was £4.88 . |

Equivalisation: The McClement's equivalence scale was used to calculate income. The above scale takes the income before housing costs and multiplies it by these values (adding up the score for each household). This enables different household sizes to be equivalised and comparisons are then possible.

| Type of household | Equivalence value |
|----------------------------------|-------------------|
| a. Married head of household | |
| 2 adults | 1.0 |
| 1 st additional adult | 0.42 |

| | |
|----------------------------------|------|
| 2 nd additional adult | 0.36 |
|----------------------------------|------|

b. Single head of household

| | |
|----------------------------------|------|
| 1 st additional adult | 0.61 |
|----------------------------------|------|

| | |
|----------------------------------|------|
| 2 nd additional adult | 0.46 |
|----------------------------------|------|

| | |
|--|------|
| 3 rd or more additional adult | 0.42 |
|--|------|

c. Children aged

| | |
|-------|------|
| 16-18 | 0.36 |
|-------|------|

| | |
|-------|------|
| 13-15 | 0.27 |
|-------|------|

| | |
|------|------|
| 8-10 | 0.25 |
|------|------|

| | |
|-----|------|
| 5-7 | 0.23 |
|-----|------|

| | |
|-----|------|
| 2-4 | 0.18 |
|-----|------|

| | |
|---------|------|
| Under 2 | 0.09 |
|---------|------|

References:

Harmonised concepts and questions for social data sources: Secondary

Standards Income Version 1.0, ONS. June 2004 harmonisation@ons.gov.uk

Tel 01329 812637

www.statistics.dwp.gov.uk/asd/hbai.asp

Other sources of information used to consolidate the methodology were:

Institute of Public Policy Research 2009. *When times get tough: Tracking household spending and debt through diaries: Interim Findings*. London:

IPPR broad definition of low income was used in this report to reflect low income. The selection criterion was based on a measure of equivalised

income (in this case incomes were equivalised to that of a couple with one child and slightly lower in this report this was £226 per week or £11,752 per year). Criteria such as ethnicity and employment status were also studied.

The ANNUAL SURVEY OF HOURS AND EARNING (ASHE) produced by the **ONS** is the source of the ONS data for the country. In 2009 this survey was the source of the website summary which gave the full time median weekly income in England to be £402.5, and annually £21,673. Differences by gender were revealed as males in full time work in the UK having a median per weekly income £538.2 and annually £28,664, therefore low income for males only was £318.6. Females had a full time national median weekly income of £431 and annually the median was £22,437. Breaking down the ASHE data for the Southeast of England the weekly gross median incomes were slightly higher than the national average at £415.8 and annually £22,518 (the numbers of people in the survey begin to decrease, in this case to 3,319, so reliability decreases). Interestingly, for Brighton and Hove the weekly income was lower than the southeast at £377.8 (however, the numbers of people in the survey from Brighton and Hove was low at 93) and similarly for the annual income figure which was £20,435 (the number of people in the survey was 68).

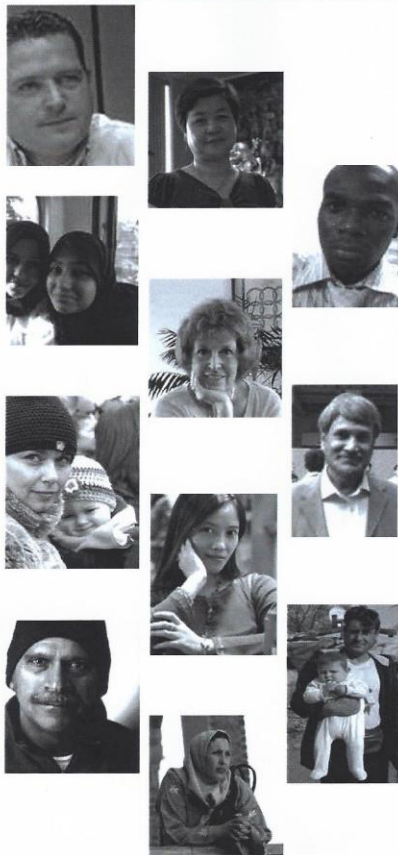
The following organisation's website also verified the above methodology:

<http://www.poverty.org.uk/01/index.shtml#g3>

Appendix 2: Flyer/Poster used in recruitment

WANTED:

YOUR ILLNESS AND HEALTHCARE STORIES



HAVE YOU BEEN ILL RECENTLY (RECENTLY MEANS IN ABOUT THE LAST SIX MONTHS)?

HAVE YOU ARRIVED TO LIVE IN THE UK FROM ANOTHER COUNTRY (BETWEEN ONE AND SIX YEARS AGO)?

WOULD YOU BE WILLING TO TALK TO A RESEARCHER ABOUT YOUR EXPERIENCE OF ILLNESS (WITH THE HELP OF A PROFESSIONAL INTERPRETER IF NEEDED)?




WE WOULD NEED YOU TO SPEAK TO US TWICE; ONCE TO DISCUSS THE PROJECT IN SOME MORE DETAIL AND THEN A SECOND TIME TO TELL US ABOUT YOUR EXPERIENCE OF ILLNESS, INCLUDING ANY EXPERIENCES OF USING HEALTH SERVICES. THIS RESEARCH IS BASED AT THE UNIVERSITY OF SUSSEX WHERE WE WILL ENSURE ALL THE INFORMATION GIVEN IS KEPT STRICTLY CONFIDENTIAL, SECURE AT ALL TIMES AND IS ONLY USED FOR THE PURPOSES OF HEALTH RESEARCH.

THE TIME AND PLACE OF THE INTERVIEW WILL BE ARRANGED SO THAT IT SUITS YOU AND THEREFORE SHOULD CAUSE YOU MINIMAL INCONVENIENCE. WE WILL BE ABLE TO REFUND YOUR TRAVEL COSTS.

YOUR INDIVIDUAL STORY IS AN IMPORTANT CONTRIBUTION TO OUR UNDERSTANDING OF THE EXPERIENCES OF MIGRANTS AND NON MIGRANTS. THIS COULD HELP IMPROVE THE WAY THAT HEALTHCARE IS PROVIDED IN BRIGHTON. SO, PLEASE DO **CONTACT US**, IF ONLY TO ASK FOR SOME MORE INFORMATION.


EITHER BY **PHONING ON 07779 611 535 AND TALKING TO KIRAT** (IN ENGLISH). OR, BY **PHONING, ON 07779 611 535 AND LEAVING A MESSAGE WITH YOUR CONTACT DETAILS** IN THE LANGUAGE THAT YOU FIND EASIEST TO SPEAK.

OR, FINALLY, BY **FILLING IN AND SENDING BACK THE CONTACT SLIP BELOW** WITH YOUR DETAILS (AGAIN YOU CAN DO THIS IN THE LANGUAGE YOU CAN WRITE IN EASIEST). HOWEVER YOU GET IN TOUCH WITH US, WE CAN CALL YOU BACK WITH A PROFESSIONAL INTERPRETER TO HELP:

Brighton and Hove

----- cut along the dotted line -----



YOUR NAME:CONTACT PHONE NUMBERS:.....

GOOD TIMES OF DAY TO CALL YOU BACK.....LANGUAGE TO SPEAK TO YOU IN.....

SEND THIS SLIP BACK TO US (YOU CAN DO THIS WITHOUT A STAMP) TO:

Appendix 3: Project information used in recruitment



Experiences of healthcare and illness among recent low-income migrants in Brighton and Hove

Project Rationale: This project will investigate the kinds of illness experiences some recent low-income migrants have whilst using health services in Brighton and Hove. There are four main reasons why this study is important: **Firstly**, the NHS is interested in patient experiences to improve quality, for increasing fairness in services, and to improve choice for all users of services. **Secondly**, the NHS is interested in understanding if the needs of migrants are different from other groups of people. There is already some evidence this is the case with migrants such as refugees and asylum seekers, but with other migrants this is less clear. **Thirdly**, it is possible that migrants use services in particular ways that are different to other groupings of people and a greater knowledge of this would be helpful. More information about how certain groups get services that they are entitled to would be useful for planning. **Fourthly**, by focusing on recent low-income migrants who face poverty, the study may be able to highlight issues affecting low-income people in general as well as specific issues affecting new migrants.

This research will meet the ethical standards of the University of Sussex and National Health Service with the main research objective to protect participants in all reasonable ways and do no harm. All interviewees will be volunteers. The Data Protection Act will be followed, with no personal information obtained being passed on to any agency, whether the organisations are collaborators or not. Only in extreme cases where information leads to the researcher believing the health of a participant or another associated person is at serious risk would an agency be contacted to assist.

Three main criteria for participation: **Firstly**, participants should think of themselves as international migrants and have been living in the UK between 1 -5 years and Brighton for at least the last year. **Secondly**, participants must be willing to talk about their personal lives, especially their health, ill health and reasons for using the health services. **Thirdly**, participants should be willing to identify an income band in which they belong and using this information the researcher would be able to classify them as being on a low-income household band by most government definitions.

Project Methods: The project will involve two meetings. The first meeting would be brief to ascertain suitability and to collect some basic information, explain the project and ask for consent to be interviewed, and to set up the interview. The second meeting will be the main interview. This will be taped with an interpreter present if previously agreed. The interview will be one to two hours in length, in which the participant will be asked to tell the story of their illness and use of health services in detail. Participants in the second interview will receive a voucher worth £25 as a token of appreciation for participating in the report.

Informed Consent and Confidentiality Agreement

I understand the above purpose of this research and am willing to participate and give my consent for my story to be used for the purposes of this research project. My consent is based on the following conditions being met:

I understand the researcher ensures the following: The original interview and my contact details will be kept in a locked cupboard in a secure building at the University of Sussex, with the keys held by the researcher only. All data will be password protected.

I can expect that my identity will be kept confidential and protected by the researcher and the transcriber (if this is a different person to the interpreter) in the process of arranging the interview and in transcribing from the original interview. In the transcription this will be done by changing names of people and places.

I give permission to the researcher to contact me after the interview, for the purpose of asking me if I want to see the transcription and to check over it if necessary. I will also be asked if I would be interested in further conversations with the researcher at this stage.

I understand that I can request that the original interview data can be destroyed. I also have the right to change my story or remove parts of my story at any time. I would do this by contacting the researcher before publication of the research.

I can contact the researcher on the researcher's phone number or email concerning the project and she will call back as soon as possible during the six month interview period and after this six month period she would respond as soon as she can (in case she is away).

Participant Name:

Date:

Participant Signature:

Researcher Name: Kirat Randhawa

Telephone no:

Email k.randhawa@sussex.ac.uk

Date:

Researcher Signature:

Interpreter Name:

Date:

Interpreter Signature

Appendix 4: Questionnaire

Thank the person for coming. Go through the information about the project in the project information sheet and on the consent form and discuss confidentiality. Ask if the participant has any questions. Ask if this first interview can be taped otherwise take full notes. Let interviewee know the tape can be stopped at any time. The key points to get across at this point are: That the purpose at this stage is to collect some basic information to help the researcher group people and decide who should be interviewed a second time. The seriousness of illness *is not* the deciding factor for inclusion, it will have to also be based on other factors – such as gender, age, visa status, length of stay, and income, so that there can be a mix of the sample.

Migrant identity:

1. How long have you lived in the UK?
2. Do you consider yourself to be a 'migrant'?

Do you consider yourself to be a recent or new migrant?

3. How long have you lived in Brighton & Hove?
4. What are the reasons you came to Brighton?
5. What is your age?
6. Note gender of participant.
7. How would you describe your ethnicity?

SHEET 1 Then show or read laminated card of 2011 census categories.

SHEET 2 The shows the additional local categories being used by the B&H health centre drop-in.

8. Ethnicity (2011 census)

9. Ethnicity walk in clinic

10. What is your nationality according to your passport?

(Stress confidentiality for the next lot of question. The honesty from the participant will be important for this research. Therefore honesty about visa expiry or overstaying would be helpful for looking at links with how this group of people use healthcare.

11. What is your current visa type and its validity?

See SHEET 3

Note Student visa Tier 4, Student visa (less than six months), Entry clearance visa for non visa nationals (all student here on a programme of more than six months qualify as ordinarily resident) less than six months they have less entitlement to healthcare.

12. Has your visa type changed since arrival?

13. How does visa affect you?

14. How do you manage any restrictions that are placed on you by your visa status?

Income:

15. What is your current job or your job?

16. If you are not working do you any government benefits? If so, which ones do you get?
(Housing benefit, free school meals for children)

17. If you have been in the same job for the last 12 months? If no what other jobs have you had?

18. What other jobs have you had whilst living in Brighton & Hove?

19. What is your current income level? (You can say it as a weekly or monthly amount after tax and before housing costs.

20. How many people including children are there in your household? Please give their ages if they are dependents, if other adults just say adults.

SHEET 4 Work out McClement's equivalisation value. Calculate the income level.

Multiply the two to get a rough total disposal income figure.

21. Do you *send* any money to dependents in your country of origin.
22. How regularly do you do this and roughly how much?
23. Who do you send money to?
24. Are you *receiving* money from abroad?
25. How regularly and roughly how much?

(Consider doing a rough readjustment of income level based on this information. Adjust it only if remittances are monthly and or a large amount. Bear in mind this information could significantly reduce/inflate the disposable income as though they have another member in their household.

26. If decide to adjust income; the new level is:

Other information:

27. What was the education level you reached in your country or origin before leaving?
28. If not mentioned above ask if participant is currently a student? (If yes find out if full/part-time, HE or FE). Secondly, ask if studies are funded/self-funded)
29. What additional qualifications have you gained (if any) since being in the UK?

SHEET 5 Show the list of education qualifications to be used in national census and ask participant to identify which ones they currently have.

30. What is your main spoken language?
31. In your opinion, how well do you speak English? Very well, well, not well, not at all.
32. In your opinion, how well do you write English? Very well, well, not well, not at all.
33. Would you say you belong to a religion?

- 34. Which one?
- 35. Do you go to a place of worship?
- 36. What is the name of the place?
- 37. Roughly how regularly do you go?

Illness identity

- 38. This question will be asked in the census quite soon. How would you describe your health in general? 'Very Good, Good, Fair, Bad, Very bad'
- 39. In addition (as maybe you may answer differently) how would you describe your health at present? Very good, Good, Fair, Bad, Very bad'
- 40. You have agreed to be interviewed because you have an illness story you could tell me, would you **briefly** describe the illness(I say briefly because we will be discussing this in more detail in the second interview).
- 41. Ask again only if it is not clear from Q43. Was/is the illness given a name?
- 42. In your opinion, would you say you were/are: Seriously ill, Ill, Quite ill and not very ill
- 43. How long would you say your illness(s) went on for/or has been going on?
- 44. Are you currently registered with a GP in Brighton?
- 45. Were you registered with a UK GP before coming to Brighton?
- 46. If the participant is/was not registered here ask why?
- 47. When was the last time you used health services?
- 48. Which health facilities have you used in the last three months/six months?
- 49. Which health professionals have you seen in the last three months/ six months? E.g. GP/or other community staff type or hospital health professionals type/in or outpatient.

Appendix 5: Interview Guide for Semi-structured Interviews

A. Possible general open questions:

Please tell me the story of the illness(es) you previously mentioned, you can begin from where you prefer. **Some open questions might be necessary, particularly for those with chronic illnesses:**

1. So to summarise, when did you first see yourself as ill/get ill?
When/where did you first seek help for the problem?
2. Now if you can focus on what happened to you with regard to this illness(es) since living in Brighton & Hove and then in the last year?
3. Please explain what **help** you got for your illness from the **health services in Brighton & Hove for each illness?**
4. Do you feel the illness (or illnesses) are still going on/is with you?
5. **Why** do you think these things **happened** to you the way they did? (This might lead to a narrative about wider ideas or causes of illness, or the narrative may stay focussed on the health services or professionals. It might also raise some questions as about why the person did not use health services earlier or when they could/should have used them which will hopefully emerge in the next lot of questions)

B. Possible structured questions: Exploring the causes and effects of the ill health

1. Do you think being a migrant/or your migration story has affected your illness? (If the answer is it hasn't then maybe prompt for positive links?)
2. Do you think there are other aspects of your life (your family background, life situation, cultural differences, your age, being a woman/man, your ethnic origin, nationality) that affected your actual illness? (Note if this focuses on treatment in services and how these conditions are seen in the medical context or outside of this setting and these conditions have interacted with the illness. If no effects, then prompt for any positive effects?)
3. Has your legal or visa status affected your health or illness? Do you think it has affected your illness and how you managed it? Do you think your legal status has affected the way you have been treated? (If no effects, prompt for positive effects?)

4. What identification, if any, were you asked to show to get health care (Initially when registering with a GP and later for secondary referral such as the pre-attendance form or when trying to access emergency care). What identification did you show? Were they satisfied with this? How did you feel about this process?)
 5. Do you think your financial situation has affected your illness? Your healthcare experiences? Can you say a bit more about this? E.g. Problems in meeting transport costs, affecting work or not working.
 6. Did this illness affect your relationships with others you are close to (for e.g. your partner, family and friends)? (If they were not affected negatively, then ask if affected positively?)
 7. How has this illness changed you? (Prompt: E.g. Mentally and emotionally. In practical day to day ways of managing? And in terms of how you now might choose to use the health services. If the answer is not really, then ask about any positive changes?)
- C. Possible questions about level of satisfaction with health professional/diagnosis/treatments/services
1. I would like to be sure you have told me about all the health services you have used. Please list them. (Check: practice nurse, specialist services, family planning, including those health services run by the council or voluntary organisations). **Then for each of them or select some of the health services answer the following:**
 2. Can you tell me about the satisfaction you feel with the x health services you used?
 3. How did you feel about the **time** it took for you to find out what illness you had and then the time it took to get the treatment you needed (prompt: any specialist referral and treatment)?
 4. How do you feel about **the way you were treated** by the x health care professionals and staff? Do you think your age, being a woman/man/ethnicity affected the way you were treated?

5. Did you feel that you developed **trust with** the x health care staff? (What does/did trust mean for you in this situation?)
6. Were you able to understand what you were being told by x health professionals in x service?
7. What things would you say got in the way of understanding or communicating for you in x service? What helped?
8. Did your English language ability affect your experiences in x service?
9. Were you offered an interpreter? If not, why do you think not?
10. If yes, how was/were your experiences of having an interpreter present?
11. Did you feel any negative feelings from staff during your treatment in x service? (Prompt: Such as impatience, getting a feeling of lack of respect, making assumptions about you, other prejudice, or any feeling of racism). Did you get any positive feelings from staff in x service (friendly and respectful treatment, asking questions and answering sympathetically, being patient with you when you don't understand) in x service?
12. How do you think being a migrant/foreign national affected your **treatment** in x service? (if this been answered with a focus on treatment question B1)
13. Do you have any other comments about the health facilities in x service (about cleanliness/the waiting times/ your privacy /anything else)
14. Finally, the last question: Are there any other things you haven't mentioned about your experience of illness or the situations you faced that might have delayed, stopped or affected your going to the doctor at the beginning of your illness? Then later on affected going to other health professionals/services?

Appendix 6: NHS Patient Experience Framework

Respect for patient-centred values, preferences, and expressed needs, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;

- ☐ **Coordination and integration of care** across the health and social care system;
- ☐ **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;
- ☐ **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings;
- ☐ **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances;
- ☐ **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers;
- ☐ **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions;

□ **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

This framework is based on a modified version of the Picker Institute Principles of Patient-Centred Care, an evidence-based definition of a good patient experience. When using this framework the NHS is required under the Equality Act 2010 to take account of its Public Sector Equality Duty including eliminating discrimination, harassment and victimisation, promoting equality and fostering good relations between people.

NHS National Quality Board (NQB), October 2011

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf

(Last accessed 6.11.2013)

Appendix 7: Names and demographics of participants

| Name | Questionnaire completed | Narrative Interview used | Gender | Visa status | Region (ignoring nationality changes) | Faith affiliation |
|-----------|-------------------------|--------------------------|--------|------------------|---------------------------------------|----------------------|
| Saidah | Yes | Yes | M | Refugee | East African | Muslim |
| Alicja | Yes | Yes | F | No visa required | EU/East European | Catholic |
| Jana | Yes | Yes | F | No visa required | EU/East European | Catholic |
| Carlota | Yes | Yes | F | No visa required | EU/European | Christian (not spec) |
| Adele | Yes | Yes | F | Student | EU/European | Christian (not spec) |
| Peta | Yes | Yes | M | Undoc | EU/East European | None |
| Riki | Yes | Yes | M | Undoc | EU/Europe | Catholic |
| Adwoa | Yes | Yes | F | Refugee | East African | Muslim |
| Daina | Yes | Yes | F | No visa required | EU/East European | Christian (not spec) |
| Mohamed | Yes | Yes | F | Refugee | Central African | Muslim |
| Zatkik | Yes | Yes | M | Refugee | East African | Judeo Christian |
| Christina | Yes | Yes | F | No visa required | EU/East European | Catholic |
| Jahander | Yes | Yes | M | Asylum seeker | West Asian | Muslim |
| Kismet | Yes | Yes | F | Spouse | Non-EU/East European | Muslim other |
| Klaudia | Yes | Yes | F | No visa required | EU/East European | Lutheran Christian |
| Isak | Yes | Yes | M | Asylum seeker | Central African | Muslim |
| Aneta | Yes | Yes | F | No visa required | EU/East European | Orthodox Christian |
| Bella | Yes average income | Yes | F | Spouse | South American | Christian evangel |
| Lara | Yes | Yes | F | No visa required | South American | Catholic |
| Esta | Yes | Yes | F | Refugee | West Asian | Christian Baptist |
| Layla | Yes | Yes | F | Refugee | North African | Coptic Christian |
| Pedro | Yes | Yes | M | No visa required | EU/South European | Orthodox Christian |
| Zola | Yes | Yes | F | Refugee | Central African | Coptic Christian |
| Garai | Yes | Yes | M | Refugee | East African | Muslim |

| | | | | | | |
|-----------------------------|-------------------------|--------------------------------|--------------|------------------|-----------------------|----------------------|
| Leticia | Yes | Yes | F | No visa required | EU/Mediterranean | Coptic Christian |
| Morayu | Yes | Yes | F | Refugee | East African | Christian (not spec) |
| Parveen | Yes average income | Yes | F | Spouse | South Asian | Hindu |
| Maryla | Yes | Yes | F | No visa required | EU/East European | Christian (not spec) |
| Seth | Yes | Yes | M | No visa required | North African | Christian (not spec) |
| Idra | Yes | Yes | M | Refugee | Middle Eastern | Muslim |
| Chun | Yes average income | Not used | F | Spouse | East Asian | None |
| Samiya | Yes | Yes | F | Spouse | Middle Eastern | Muslim |
| Rehan | Yes | No, tape damaged | M | Refugee | Central African | Coptic Christ |
| Beata | Yes | Yes | F | No visa required | EU/European | Agnostic |
| Catalena | Yes | Yes | F | No visa required | EU/East European | Catholic |
| Bahar Jaak | Yes | Yes | F | Spouse | North African | Muslim |
| | Yes average income | No | M | No visa required | EU/East European | Catholic |
| Nikoletta | Yes average income | No | F | No visa required | EU/East European | Muslim |
| Melchior | Yes | Yes | M | Refugee | West Asian | Christian Baptist |
| Rosaan | Yes | Yes | F | Refugee | West Asian | Christian Baptist |
| Jasmine Josef | Yes | Yes | F | Spouse | North African | Muslim |
| | Yes | Yes | M | Refugee | Central African | Coptic Christian |
| Sachin | Yes | Yes | M | No visa required | South Asian | Hindu |
| Kirsty | Yes | Yes | F | No visa required | EU/East European | Catholic |
| Brona | Yes a | Yes | F | Student | Non EU/ East European | None |
| Gizela | Yes average income | No | F | No visa required | EU/East European | Catholic |
| Total Participant 46 | Total questionnaires 46 | Total narratives interviews 41 | M 15 F 31 | See Figure 6 | See Table 2 | See Figure 10 |