A Sense of Injustice: Experiences of the Central and Eastern European Roma in Accessing UK Health and Public Services

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A SENSE OF INJUSTICE

Experiences of the Central and Eastern European Roma in accessing UK health and public services

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Abstract

This study explores how Central and Eastern European Roma communities perceive and experience UK health and public services. The Roma arguably experience poorer health than any other minority ethnic group in the UK, according to a range of indicators, measures and outcomes. Health issues in UK Roma communities are reported to stem from language barriers, difficulties in registering with a GP and mistrust of health professionals. To date, there has been little comprehensive exploration of the influence of social, cultural and political factors on health in Central and Eastern European Roma communities in the UK. Much of the literature provides an overview of barriers to access, yet gives limited attention to the complex social dynamics underlying interactions between the Roma and health service providers. This study investigates the interplay of Roma migration experiences, personal histories of discrimination, barriers to accessing health and benefits systems and the influence of public policy decisions in shaping UK Roma people's experiences of health services.

This study incorporates data collection through participant observation and interviews, as well as an analysis of national and local policy attention to the health situations of Gypsy, Roma and Traveller (GRT) communities. The policy analysis occurred concurrently with fieldwork, and findings helped to contextualise Roma interviewees' impressions of health system functioning. Field data was collected over the course of volunteer work carried out at Roma community organisations in London and Luton. Field notes were recorded throughout the course the this fieldwork, and interviews with 27 Roma community members and 10 health professionals began after approximately 5 months of active participant observation. Analysis of field data proceeded according to a strategy that hybridised grounded theory and narrative methodologies. This entailed an initial round of grounded theory analysis, which involved the constant comparison methods of analysing concepts arising from the data, and provided an overarching framework for understanding the social phenomena under observation. Fieldnotes and selected interviews were then subjected to a second round of scrutiny, with particular emphasis on their narrative character. Analysing these individual stories added nuance and depth to the results of grounded theory analysis, and provided insight into the ways in which Roma migrants experience discrimination, unconscious bias and unequal treatment within UK public service environments.

The time period in which this study occurred – 2014 to 2018 – was a time of substantial political change in the UK, and the results are best understood in the context of growing public hostility to migrant groups. Within a policy landscape of limited official attention to the needs of the Roma, intra-community development of health-related knowledge, direct contact with health services and engagement in a broader environment of public service provision contribute to the development of power differentials between Roma individuals and service providers. Many participants in this study suffered from long-term ill health, yet intra-community networks of health information-sharing aided participants in better understanding their health conditions and empowering themselves to seek out support. Their contact with health and benefits systems, however, revealed barriers related to limited language support, lack of transparency in administrative procedures, difficulties in navigating complex and unfamiliar systems and cultural disparities between patients and providers. Analysis of these factors in light of participants' distinct narrative revealed further dimensions of service providers' unconscious bias, participants' efforts to assert their right to equitable access to services and the long-term emotional impacts of unequal treatment.

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Explanatory symbols for interviews

❖ Interview conducted in English

■ Interview conducted in Polish with the assistance of an interpreter

✜ Interview conducted in Romanes with the assistance of an interpreter

Abbreviations

A&E – Accident and Emergency

APPG – All-Party Parliamentary Group

BHA – Black Health Agency

CBT – Cognitive Behavioural Therapy

CCG – Clinical Commissioning Group

CEE – Central and Eastern Europe

DCLG – Department for Communities and Local Government

DfE – Department for Education

DLA – Disability Living Allowance

DoH – Department of Health

DWP – Department for Work and Pensions

EC – European Commission

EESC – European Economic and Social Committee

EHRC – Equality and Human Rights Commission

ESA – Employment and Support Allowance

EU – European Union

FFT – Friends, Families and Travellers

FRA – European Union Agency for Fundamental Rights

GCSE – General Certificate of Secondary Education

GP – General Practitioner

GRT – Gypsy, Roma and Traveller

HSCA – Health and Social Care Act of 2012

HWB – Health and Wellbeing Board

IAPT – Improving Access to Psychological Therapies

JSNA – Joint Strategic Needs Assessment

JHWS – Joint Health and Wellbeing Strategy

LRT – Luton Roma Trust

MHCLG – Ministry of Housing, Communities and Local Government

NFGLG – National Federation of Gypsy Liaison Groups

NHS – National Health Service

NRIS – National Roma Integration Strategy

OHCHR – Office of the High Commissioner for Human Rights

RSG – Roma Support Group

PCT – Primary Care Trust

PIP – Personal Independence Payment

WHO – World Health Organization

Statement of Copyright

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Chapter 1: A brief overview

1.1 Setting the scene

Canning Town, east London, is a study in contrasts. Across from the station is a construction site that will one day be a complex of shops and a hotel and luxury flats – where the developer promises to build a whole new neighbourhood – yet pass under the Canning Town flyover and the gentrification abruptly stops. The sterile high-rises give way to African and Turkish and Romanian shops; greasy spoon cafes; East End working class pubs; Portuguese and Ukrainian restaurants; McDonalds and Greggs. Walk east along Barking Road and this is what you'll see; yet if you turn around, the financial monoliths of Canary Wharf rise up in the distance.

It was a rainy day in April 2015 when I first took that walk down Barking Road, on my way to interview for a volunteer position with the Roma Support Group, feeling completely uninitiated into the daily realities of those who would one day be participants in my PhD research. I was looking at health in Roma communities – primarily, as I conceived of it at that early stage, access to services and communication barriers between patients and practitioners – and never was I more acutely aware of my status as a detached, external observer than during that 15-minute walk from Canning Town Station.

By this point, my literature review had initiated me into questions of Roma integration – whether the Roma needed to adjust their lifestyles in order to achieve some nebulous state of 'inclusion' into UK social structures – yet at the forefront of my thoughts were questions of personal integration. Would I be able to attain a sufficient degree of involvement in the research field to establish the all-important relationships of trust with participants? To what extent does the researcher need to be a part of the social world under observation? How would a year in this place change my impressions? How would I remain sensitive to novelty when all of the foreignness surrounding me became commonplace?

There are times when I wish I could harness that wide-eyed naivete of those first few days, to return to the moment when I walked that narrow, dimly lit entry corridor of the Roma Support Group office and noted how everyone seemed to be speaking in languages I did not understand. One day, though, I would come to understand the basics of Polish and Slovak and Romanes, would be able to grasp the thread of a conversation even if the nuance was lost on me. I would explore the neighbourhoods where Roma migrants established their networks of social contact in the UK and see first-hand how they grappled with establishing post-migration identities. Where my early impressions of Roma social worlds had been informed by writings on the purported 'isolation' of these communities, my involvement in the field revealed that none of their experiences in fact occur in isolation, and instead are continually shaped and re-shaped by the ever-shifting socio-political position of ethnic minority and migrant communities in the UK. As I sought to grasp how Roma community members came to terms with their membership in a stigmatised ethnic minority group within the growing stigmatisation of Eastern European migrants, my own outsider status provided a basis for understanding some of the complexities of the Roma social position in the UK: I was never far from that precarious state of questioning my own belonging.

1.2 Why the Roma?

It was at once a foundational question of my research and one that proved extremely difficult to answer: how do I define the subject population of my study? I grew up in Michigan, where questions of the Roma were decidedly outside the public radar; my first awareness of the ethnic group came when I wrote an essay on the Roma for a final-year German class at university. Before beginning this research, my academic work had centred on languages, public policy and social theory, and my MA thesis presented a comparative analysis of migrants' access to health services in the UK and Germany. It was from this basis that I began to consider further research at the intersection of migration and health inequalities. I wrote up a general project proposal within this topic area and sent it to academics working in the field. One suggested that I narrow my focus to the situation of Roma migrants in the UK, and it was from there that this study took shape.

It was only after my arrival in the UK that I began to see how polarising my choice of research topic could be, how everyone seemed to have an opinion on the Roma – whether it was sympathy for a perceived abject deprivation or an all-too-common repetition of a Roma-are-beggars-and-thieves mantra. In a sense it was to my advantage to enter into this study as something of a blank slate – there was no need to shed any casual prejudices acquired through years of exposure to hostile media coverage of the Roma – yet my lack of background to the topic also created challenges in filtering through the numerous and often contradictory accounts of Roma identity and identifying characteristics.

As I familiarised myself with the history of anti-Roma discrimination, the persistent conditions of deprivation in Roma communities and the disproportionate challenges of obtaining adequate access to health services, it was never far from my mind that I was conducting research on a community to which I do not belong and writing about discrimination that I had never experienced. As I grappled with understanding the environment in which my research would take place, it was vital to first understand what was meant by the term ‘Roma’ and its numerous implicit connotations and contradictions. The designation had seemed initially clear-cut, yet it grew continually in complexity as I delved deeper into my research questions. I used the term ‘Roma’ as a means of distinguishing participants in my study from other social groups, and I referred to ‘community’ as a means of describing the intra-group interactions in the research field. As these interacting concepts of Roma identity and community recurred through data collection and analysis, it became increasingly imperative to develop a guiding conception of the way in which Roma individuals understand the designation of ‘Roma’ and how this in turn feeds into an understanding of community.

1.3 The tensions implicit in Roma identity

The purpose of my research was not to develop a theory of Roma identity, yet it was vital to arrive at a consistent and coherent understanding of the numerous (and sometimes conflicting) definitions of what it means to be Roma, both from the perspectives of community members and from perspectives external to the community. Before explicating the term ‘Roma’, however, it was first necessary to develop a working definition of the concepts of culture and ethnicity, both of which can be seen as key descriptive factors in a concept of Roma identity. Culture refers to a shared set of symbolic markers, encompassing objects, ideas and activities, which gain significance through a group of individuals’ mutual agreement on their meaning (Blumenthal, 1940). Ethnicity can be closely associated with culture in the sense that it reflects a common conception of group origin and a unifying belief system, yet membership in any given ethnic group also incorporates a common biological origin (Office for National Statistics, 2011; British Medical Journal, 2017). In the case of the Roma, reports of a common origin in India unite the global Roma population in an ethnic group (Matras, 2015; Leeds GATE, 2014). While it is outside the scope of this research to offer an all-encompassing discussion of Roma cultural beliefs and practices, it is relevant to consider certain cultural markers – such as a shared language and conceptions of purity – that take on key significance both in defining a Roma identity and shaping their engagement with health care institutions (Matras, 2015).

There is no consensus as to the most accurate means for constructing a concept of Roma identity, and substantial debate exists in the field of Romani studies as to the definition of group boundaries. Tremlett (2009a) highlights an academic shift away from 'Roma' as an ethnic classification, instead suggesting that Roma are distinguished from other groups through either cultural practices or material deprivation. Whether defining Roma as an ethnic group or a cultural/socio-economic division, each of these viewpoints postulates continual shifting of group boundaries, through which Roma identity is constructed and reconstructed in terms of relationships with other social groups (Tremlett, 2009a). Acton, Cemlyn and Ryder (2014) elaborate on the ways in which Roma identity can be defined through external circumstances, emphasising how Gypsy, Roma and Traveller '"identity" communities are often geographically dispersed and their relationship with localities is frequently overwhelmingly conflictual' (p. 6). In this sense, any efforts to establish a view of Roma identity are beset by the forces of geographic diaspora and frequent opposition to the presence of the Roma from non-Roma populations.

While all ethnic and cultural groups engage in – and are subject to – external and internal conceptions of collective identity, a long history of discrimination against the Roma can lead to construction of Roma identity along the lines of tension with non-Roma groups (Acton, Cemlyn & Ryder, 2014). Social boundaries – which can be defined as 'objectified forms of social differences manifested in unequal access to and unequal distribution of resources (material and nonmaterial) and social opportunities' – therefore take on particular significance in describing Roma identity (Lamont & Molnar, 2002, p. 168). Within these social boundaries, Roma fall into unequal relationships with other groups and institutions, and inequalities in access to opportunities develop according not only to ethnic and cultural divisions, but also to gender, class and socio-economic differentials (Crenshaw, 1995). Facing disadvantage from such a range of sources, Roma individuals may elect to turn inward as they seek to understand their individual and group identity (Powell, 2012). It is perhaps for this reason that the concept of a Roma 'community' has come to occupy such a prominent position in descriptions of Roma social experiences.

The concept of community is fluid, and there is not one single way to be Roma, but rather numerous intersecting groups bound together by a common conception of a Roma culture. In specific terms, this thesis will look at Polish, Slovak and Romanian Roma groups living in London and Luton. While distinct in their external expressions of Roma identity and experiences in their countries of origin, all self-identified as Roma. They shared the historical experience of migration and the challenges to identity that arose as they encountered external hostility from non-Roma groups, though individual responses vary significantly. Some attributed the hardships they had experienced in life directly to the fact of being Roma, where others presented them more as inescapable aspects of the human experience.

1.4 Internal belonging; external racialisation

Running through this study are questions of ‘integration’ as a means of challenging the subaltern status of Roma and bringing Roma populations to a position of social equality. This concept operates on the basic idea that the ‘ultimate definition of racial justice’ is to offer all people equal opportunities regardless of racial identity (Peller, 1995, p. 128). Criticisms of this concept of integration as a means for advancing equality, however, contend that it discounts the cumulative impacts of histories of oppression and intersecting forces of unequal treatment within social institutions (Peller, 1995; Crenshaw, 1995). Often advanced by progressive, liberal – yet also socially dominant – political classes, minority groups have interpreted initiatives aimed at promoting integration as facilitators of assimilation into an assumed ideal of ‘whiteness’ (Peller, 1995). Also at issue are the fundamentally individualistic principles behind integration, which are predicated on a notion that incidences of racism represent isolated aberrations, all the while disregarding the collective experiences of minority groups (Peller, 1995).

For Roma in the UK, questions of integration relate not only to their status as an ethnic minority, but also as a migrant group. All participants in this study shared the experience of migration to England from Eastern Europe, and with this came the question of how they reconstruct community boundaries and identities post-migration. Grill (2018) observes how Roma migrants may be subject to ‘migrating racialisations’, through which media representations of Roma populations serve to translocate stigmatisation of Roma identity across national boundaries (p. 1137). Assumptions about Roma culture and identity may furthermore lead public service workers to make unfounded assumptions about the lifestyles and behaviours of Roma communities, e.g. that Roma families would ‘disappear’ due to a presumed cultural preference for travelling (Humphris, 2017, p. 511). Highly attuned to public hostility, Roma migrants engage in careful negotiation of external representation of their identity upon migration to the UK (Grill, 2018). Sometimes this occurs through individual lifestyle decisions – such as the choice to abandon traditional Roma styles of dress – which at once allows an individual to minimise external stigmatisation, yet can also produce tensions and divisions within a Roma community group (Tremlett, 2009a). In other cases, Roma may choose to limit their contact in non-Roma cultural and community spaces as a means of avoiding hostility, thereby allowing them to sustain a sense of cultural integrity (Powell, 2012). Underlying both of these responses is a concept of ‘community’, and varying degrees of adherence to the rules and practices that internally and externally demarcate community identity.

The idea of community bears mentioning again at this stage, as does the related concept of belonging. For the Roma, belonging indicates shared characteristics – such as language and cultural values – and a common network of social connections (Acton, Cemlyn & Ryder, 2014, p. 6). Community boundaries and priorities are ever shifting on the basis of spatial orientation, political developments and contact with adjacent (non-Roma) communities. In the case of the Roma, the idea of community formation can be particularly fraught, as the wider society’s perceptions of Roma – and Roma people’s perceptions of their own social position – can be shaped by their ‘ghettoisation’ in poorer neighbourhoods or on the outskirts of cities (Lamont & Molnar, 2002; Price 2010; Powell, 2012). Creating a strong sense of belonging within an exclusively Roma group can promote a sense of pride in identity and aid in the development of support mechanisms against experiences of discrimination. In this sense, what external observers may view as a preference for isolation may in fact be a protective mechanism against external hostility (Powell, 2012).

It is not only relations to other groups that define sense of belonging in Roma communities, but also sense of geographical orientation and personal histories of migration. As migrants from Eastern Europe, experiences of discrimination and open hostility on the basis of their Roma identity produced fraught relationships with their countries of origin. hooks (2009) explores this tension in an investigation of the concept of belonging, explaining how origin in a particular location, especially for groups that have historically faced discrimination, does not guarantee the sense of belonging that may otherwise accompany the idea of home. Roma who are geographically mobile may feel a greater sense of belonging in their adopted home countries, where the physical act of migration has effaced the effects of past discrimination. Findings from a series of focus groups conducted with Roma across England, for example, support this concept of belonging through migration, with participants describing how they could blend in to multicultural UK neighbourhoods and thus escape the instant identification of their ethnic identity that they experienced in their more ethnically homogeneous countries of origin (Brown et al., 2017). In this sense they were able to at once express their Roma identity while also avoiding much of the external hostility that they experienced in their countries of origin.

The ways in which Roma communities fit into social structures, as well as the ways in which they then negotiate their relationships within social institutions defined by dominant groups, constitute foundational considerations of this study. As I spent time in Roma community spaces – and community members relayed stories of the institutional environments of health and benefits systems – what arose was a picture of individual efforts to fight back against perceived challenges to their rights to equitable access. This reflects the phenomenon of 'dual consciousness' within minority groups, through which they recognise their theoretical right to participate on equal terms in society, yet also understand that those in power determine the extent to which they can exercise their rights (Matsuda, 1995, p.67). For Roma migrant communities in the UK, this must be understood not only in terms of their ethnic minority status, but also in terms of their identity as a stigmatised migrant group at a time when EU migrants' rights in the UK became subject to continually greater challenges.

1.5 Context and trajectory of this research

The timeframe in which this research took place – 2014 to 2018 – saw dramatic changes in the political situation in the UK, which called into question the future status of immigrant communities (Morris, 2016; Brown, 2018). Anti-immigrant sentiments fuelled much of the public discourse preceding the referendum vote on the UK leaving the EU, and in the context of pre-existing media hostility towards Roma migrants (Okely, 2014; James & Smith, 2017), this created uncertainties about their future residency rights and diminished their sense of safety and security in the UK (Morris, 2016). It would be impossible to fully grasp the significance of the accounts from Roma migrants included herein without looking to their places of origin, their histories of migration and their length and location of residence in the UK, just as it is impossible to understand their post-migration experiences without accounting for the political climate of the receiving country.

It is furthermore vital to acknowledge that fieldwork took place in some of the most deprived areas in the UK, and participants' experiences of public services were indelibly affected by high demand and limited resources. In this sense this thesis addresses not only Roma participants' distinct health experiences, but also looks to immigration and access to benefits systems. These social factors shaping Roma migrants' health experiences shed light on their wider experiences of life in the UK and their position within UK social institutions.

This thesis opens with an overview of the current state of research on Roma health and an outline of the theoretical and methodological perspectives that guided the study, and then reports the results from field observations and interviews. Analysis then addresses the social, cultural and political factors that impact on Roma migrants' health experiences, looking specifically to the ways in which Roma individuals interact within a range of UK public service institutions. Running through the analysis are key themes related to experiences of discrimination, operations of UK public services and Roma individuals' variable empowerment in their interactions with these services.

This study takes an interdisciplinary approach in the interest of answering a broad range of questions about Roma migrants' interactions within UK public institutions. Undertaking a degree in Health Studies within Durham University's interdisciplinary Centre for Public Policy and Health, I was provided substantial latitude for incorporating multiple disciplines and was indeed encouraged to do so within the academic environment in which I formulated this study. I situated it at the intersection of sociology, anthropology and public health policy, operating on the premise that social power differentials, cultural values and policy frameworks intersect to provide key insights into the situation of Roma in the UK. To delineate these into clearly ordered disciplinary divisions would be to discount broad swathes of my observations in the field, and would present a one-dimensional view of the complex social world I endeavour to represent.

Identifying a methodology that captured this range of experience and observation was fraught with obstacles. Two rounds of policy analysis – undertaken first in 2016 and updated in 2018 – provided a foundation for this study's exploration of Roma community members' experiences within UK health and benefits institutions. Policy analysis only formed part of the picture; it revealed how UK public services intend to treat Roma people, yet it did not reveal the human impacts of those intentions. To understand how Roma individuals understand and experience the UK public service environment, my initial intention was to take an inductive approach to the data – a choice predicated on my lack of prior exposure to Roma communities and my desire to avoid unsubstantiated assumptions about their lives. Utilising grounded theory techniques, I analysed interviews and fieldnotes first through line-by-line reading of participants' stories, assigning descriptive codes to these narrative segments and fitting these codes together into frameworks intended to represent Roma individuals' experiences at the levels of health services and wider society. It was a start, but something was missing. Language barriers, for instance, arose time and time again, yet what did those language barriers signify? When participants discussed difficulties in communicating with health professionals, were they really expressing some deeper grievance? Ultimately, granular codes and grounded theory analysis frameworks and snippets of participants' stories were not going to answer these questions. To gain a deeper understanding of what participants were trying to tell me, I employed narrative analysis techniques to look at their stories as whole entities, to understand their contexts and to consider why participants had chosen to tell these stories to me. Grounded theory alerted me to the sense of injustice that participants felt as they ran up against seemingly discriminatory operating procedures of health services and wider societal prejudices, yet it was only as I looked to their complete stories that I could understand why this sense of injustice has become such a driving force in their lives.

Chapter 2: Literature review

2.1 The situation of the Roma in Europe

2.1.1 The term 'Roma' and its significance

'Roma' refers broadly to a diverse variety of groups comprising a total population of 10 million people, which is believed to have origins in the Indian subcontinent and now has populations concentrated in Central and Eastern Europe (European Commission, 2014; Council of Europe, 2012). Roma communities across Europe have numerous distinct tribal affiliations, speak a wide variety of languages and adhere to a number of different religious belief systems, yet they also maintain a set of core cultural traditions that encompass, for example, purity laws, conceptions of shame and family ceremonies (Matras, 2014; Cook et al., 2013; Council of Europe, 2012; Ringold et al., 2005). The Roma are the largest ethnic group in Europe without their own state – nor do they have a conception of a Roma 'homeland' – yet due to their stateless status, they do not necessarily gain official recognition as an ethnic minority (Bartlett, Benini & Gordon, 2011; Silverman, 1995).

Many studies focusing specifically on the UK apply the label of Gypsies, Roma and Travellers (GRT) to any groups that have a common history of travelling, disregarding the differences between these populations. Notably, the Roma in the UK are a migrant community, while Gypsy and Traveller communities have lived in the UK for centuries (Scullion & Brown, 2016). Others further maintain that the broad 'GRT' terminology is inaccurate, as Irish Travellers are not considered to share the same ethnic origins as European Roma and English Gypsies (Cemlyn et al., 2009; Greenfields, 2014; Van Hout & Staniewicz, 2012; Kosa & Adany, 2007; Hancock, 2002; Hajioff & McKee, 2000).

For policy purposes, use of the umbrella term 'Roma' carries the practical utility of characterising these diverse communities as a single, homogeneous entity, yet group members themselves contest such designations (McFadden et al., 2018; Council of Europe, 2012). While a common language – Romanes – unites sizeable segments of the global Roma population (though not all Roma individuals speak Romanes), different tribal affiliations and national origins give rise to variations in lifestyle, self-perception and self-identification (Ringold et al., 2005). The term 'Roma' itself thus becomes emblematic of the difficulties of accurately representing Roma diversity, as its primarily academic and policy applications do not necessarily have significance to the communities it describes (McGarry, 2017). For some members of the broad ‘Roma’ population, ‘Gypsy’ (or one of its variants) offers a more accurate characterisation of identity, perhaps because it suggests a historical and geographical orientation, whereas the term ‘Roma’ does not (McGarry, 2017; McFadden et al., 2018). Many European Roma, however, regard the term ‘Gypsy’ as derogatory, recognising it as a designation applied by outsiders in their efforts at degradation and subjugation (McFadden et al., 2018).

This table further clarifies the distinctions between Gypsies, Roma and Travellers, emphasising ethnic origins, language profiles and history in the UK as key distinguishing factors.

Table 1: Overview of Roma, Gypsy and Traveller groups in the UK

Group name	Ethnic origins	Main languages	History in the UK	Estimated population in the UK
Roma	Origins in India, with migration from the Indian sub-continent beginning approximately 1,400 year ago (Greenfields, 2017)	Romanes, languages of countries of origin (and receiving countries in cases of migration) (Roma Support Group, 2012)	First arrived as asylum seekers after fall of Communist states in Eastern Europe; more recently arrived as economic migrants after 2004 and 2007 EU accessions (Greenfields, 2017)	200,000 – conservative estimate (Brown, Scullion & Martin, 2013)
Gypsies	Origins in India – same ethnic origins as the European Roma, but with a different migration history (Greenfields, 2017)	English, Rromani-chib (Marsh, 2017)	First arrived in the UK in approximately 1500 (Greenfields, 2017)	300,000 – inclusive of both Gypsies and Travellers (Greenfields, 2014)
Travellers	Distinct ethnic group within Irish society (Greenfields, 2017)	English, Gammon, Shelta, Cant (Marsh, 2017; Van Hout & Staniewicz, 2012)	Present in the UK since the 12th century (Greenfields, 2017)	

2.1.2 The problematic merging of Gypsy, Roma and Traveller designations

The presumption of commonality between Gypsy, Roma and Traveller experiences arises largely out of pragmatic policy decisions to simplify frameworks for responding to inequalities faced by these groups (Greenfields, 2014; Greenfields & Home, 2006; McFadden et al., 2018). Marsh (2017), writing on narratives of health and wellness of Roma and Traveller communities in Wales, notes that the acronym 'GRT' is 'creating an elision of cultural and linguistic diversity amongst Romani and Traveller communities, which is ultimately discriminatory in its impact, reducing as it does, complex ethnicities to a formula' (p. 5). By presuming homogeneity instead of diversity, simultaneous discussion of Gypsies, Roma and Travellers can reduce Roma concerns to a secondary status, as Roma have a much shorter history in the UK and thus gain less official recognition as a distinct group with specific needs. This is apparent, for example, 2011 UK Census's inclusion of 'Gypsy/Traveller' as a top-level category in the 2011 Census, while 'Roma' as an ethnic category was not included (Warwick-Booth et al., 2017).

In the interest of capturing the complexity of interactions between public services and communities with a travelling history (and also exploring the multiple dimensions of discrimination against these groups) this literature review is not limited to studies addressing European Roma groups, though it divides the literature into three distinct categories: those addressing the Roma in Europe, those addressing Roma migrants in the UK and those addressing Gypsies and Travellers in the UK. Building on the migration history data outlined above, the term 'Roma' herein refers to groups self-identifying as ethnically Roma that are either currently resident in Europe or are recent migrants to the UK; 'Gypsy' refers to a group that is ethnically and culturally similar to Roma, though with a much longer history of residence in the UK, while 'Traveller' refers to a group that is ethnically distinct from both Gypsies and Roma yet is commonly described in conjunction with Gypsies and Roma due to a common cultural tradition of travelling (Cemlyn et al., 2009; Greenfields, 2017; Leeds GATE, 2014). This naming strategy emphasises the migrant profile of Roma communities in the UK, which is vital in understanding the health experiences of this study's focal group.

2.1.3 A history of subjugation: The social position of Roma communities in Europe

Roma often conceive of their position in society as separate from all other social groups, dividing the world into Roma and non-Roma (Cook et al., 2013). This, as McGarry (2017) notes, can be interpreted as a response to external stigmatisation of the Roma identity. From the point of their first appearance in the historical record, the Roma people have experienced tense, and sometimes violent, encounters with non-Roma. Commonly viewed with suspicion by the non-Roma, Roma people were enslaved and forcibly expelled during their centuries of movement throughout Europe. Expulsion from Spain occurred in the 1600s, and from Slovak to Czech territories following World War II (Matras, 2015). It was also during this time that an estimated 600,000 Roma were exterminated in the Holocaust (Silverman, 1995). In 1999, 74 Slovak Roma asylum seekers were expelled from Belgium (Cahn & Vermeersch, 2000), and more recently, the 2013 removal of a Kosovar Roma family from France was reported to have occurred on the basis of ethnic identity (McGarry, 2017). In further instances of discriminatory treatment, coercive and involuntary sterilisation practices in communist Eastern Europe (and post-communist Slovakia) targeted Roma women, through which they were either offered monetary payment if they agreed to sterilisation, or sterilisation was performed without consent in conjunction with other medical procedures (Holt, 2005; Silverman, 1995).

In addition to these instances of direct deprivation of rights, Roma are disadvantaged through discriminatory governmental policies or institutional operating frameworks (Cahn, 2007). When nomadism was made illegal in Czechoslovakia in 1958 and in Poland in 1964, Roma people were forced to move into permanent accommodation and were thus deprived of their traditional way of life and right to express their culture (Silverman, 1995). Following this forcible settlement, there is often clear physical separation between Roma populations and other social groups, with Roma living in poor quality accommodation and lacking of access to basic sanitation facilities (Eurofound, 2012). Schools in Eastern Europe engage in systematic misdiagnosis of learning disabilities to justify disproportionate placement of Roma children in special needs classes, even when they have no special needs (FRA, 2018c). Teachers are furthermore reported to favour non-Roma over Roma children (Lee et al., 2014; Marsh 2017). Roma face discrimination in the area of health and, encounter significant barriers arising from culture, language, health system operating practices and economic disadvantage (McFadden et al., 2018). This is exemplified by study of access to health services amongst Roma in Macedonia, who are denied medical treatment, required to pay for free treatment, and at times subjected to physical violence by health professionals (Salioska et al., 2017). I will further explore these issues later in this chapter.

This long history of discrimination against Roma and external stigmatisation of the Roma identity strengthened the sense of division between Roma and non-Roma, contributing to the proliferation of public narratives about the Roma that focus on criminality and anti-social behaviour (Clark, 2014; FRA, 2018b). The disadvantages faced by Roma communities are framed as the consequences of social deviance, with Eastern European governments historically classifying Roma as a social group rather than as a nationality, thereby removing any official governmental accountability for protecting the Roma population (Silverman, 1995). In response to the persistence of anti-Roma prejudice, the European Parliament adopted a 2017 resolution calling for the European Commission and all Member States to take action against anti-Gypsyism, presenting racism against the Roma as a key challenge to Roma inclusion (FRA, 2018b). The second half of the twentieth century has furthermore seen the establishment of Roma political organisations that work to promote greater public attention to Roma rights and counter the stigmatisation of the Roma identity, yet these movements struggle to sustain widespread public and political attention (Matras, 2014; McGarry, 2017).

2.1.4 The concept of ‘exclusion’ and its applicability to Roma communities

Public health, sociological and policy literature alike emphasises the purported isolation of Roma communities, their limited mixing with other groups and consequent difficulties in ensuring sustained access to public services, encapsulating this within a concept of ‘social exclusion’ (Scullion & Brown, 2016). Carrying connotations of both externally mandated and self-imposed isolation in exclusively Roma communities, social exclusion is reflected in barriers to health care access, high unemployment rates, low levels of educational attainment and segregation in poor-quality housing (European Commission, 2014; Brown, Scullion & Martin, 2013; Cook et al., 2013; Bartlett, Benini & Gordon, 2011). Health policy furthermore highlights the ‘vulnerability’ of Roma migrant communities, highlighting how their migrant status and membership in a commonly disadvantaged group may make them more susceptible to physical, emotional and psychological exploitation (Aspinall, 2014). Yet identifying social exclusion as a universal factor influencing limited access to public services oversimplifies the situation of Roma populations. To assume that the Roma are ‘excluded’ assumes, first, that their culture and group identity creates fundamental barriers between them and other social groups and, second, that they are seeking to be included in an undefined ‘mainstream’.

In the UK context, the term ‘social exclusion’ came into widespread usage through the Blair government’s efforts to reframe the term ‘poverty’ to express the range of interconnected disadvantages – such as unemployment, low income and poor housing (Office of the Deputy Prime

Minister, 2004). After adoption by the European Union, it has come to describe any limitation of participation in public institutions (European Parliament, 2018), which is commonly thought to arise from lack of skills, poor housing or poor health (Cretan & Turnock, 2009). While this concept of participation appears frequently in the literature addressing the social position of Roma communities, it fails to describe exactly what constitutes 'social participation'. Conceivably any social act – whether it occurs in the so-called 'mainstream' of society or not – should be classified as social participation, yet many publications on Roma health espouse the idea that they are not participating in society (European Commission, 2014). This terminology furthermore disregards how powerful groups may develop policies that 'claim all sides were considered, but makes it possible for only some of those sides to benefit', thus precluding meaningful involvement of disadvantaged groups in political and economic processes (Arnstein, 1969, p. 216). It must therefore be assumed that the concept of limited social participation in fact refers to limited involvement in selected public institutions, such as schools and health systems. What is also unclear is whether Roma do, in fact, participate in social institutions, yet reluctance to self-identify as Roma prevents their 'participation' from being captured in official statistics.

Van Baar (2012b) argues that the proliferation of these terms with regard to the Roma reflects a neo-liberal policy development, in which 'issues of democratically organized redistribution tend to be reduced to a "social inclusion" agenda that narrowly focuses on problem groups, while calls for democratic minority participation in decision making tend to be reduced to cooption' (p. 292). European strategies for 'Roma inclusion' assume, firstly, that participation in mainstream economic systems is the key to eliminating social and economic disadvantage and that 'social inclusion, cohesion and self-empowerment' will ensure the maintenance of peaceful and productive relationships between the Roma and other groups (Van Baar, 2012a, p. 1298). What this formulation neglects to address, however, are the impacts of a long history of discrimination and marginalisation, which are unlikely to be erased simply through encouraging greater participation in employment and education systems. Rather than advocating cross-agency collaboration and structural changes to the manner in which social institutions address the needs of Roma communities, the onus is on the victims of centuries of institutional discrimination to behave in accordance with the dictates of the same institutions that have denied them access (van Baar, 2012a).

2.1.5 Measures to promote Roma inclusion

Official efforts to improve the situation of Roma have been largely based on principles adopted at the first meeting of the EU Platform for Roma Inclusion, which set common standards for EU Member States to address inequalities faced by Roma populations (WHO, 2014). Critiques of such initiatives emphasise how policies aimed at Roma inclusion simultaneously promote improvement in their situation and singles them out as different and (in some cases) may create a perception that they are in receipt of preferential treatment from authorities (Richardson & Codona, 2018; Salioska et al., 2017). With these targeted approaches comes the danger of propagating a 'perception that there is something inherently at fault in the Roma population, rather than in the structurally racist behaviour of many non-Roma people' (Ryder & Taba, 2018; p. 61). On the other hand, policy measures aimed more broadly at promoting the rights of minority groups have the potential to further subjugate the Roma, as measures promoting equality across social groups often fail to capture the distinct profile and needs of Roma communities (Salioska et al., 2017). Without attention to Roma cultural values and the long-term impacts of official measures to suppress this culture, efforts to promote the integration and inclusion of Roma populations can take on an assimilationist tone, in which the victims of structural inequalities to carry the dual burden of cultural preservation and pressures to conform to an unaccustomed social order (Bourgois, 2003; Peller, 1995).

Initiatives to improve the situation of Roma communities often take the form of governmental efforts to combat anti-Roma discrimination and to improve access to public services. It was amid calls to bring greater consistency to Roma integration efforts that the Decade of Roma Inclusion, from 2005 to 2015, was adopted as a World Bank initiative to coordinate measures to improve the situation of Roma in countries with substantial Roma populations[1]. This began when the involved countries signed an agreement pledging to institute policies and programmes to combat discrimination against Roma and to improve Roma 'participation' in society. According to Bruggemann & Friedman (2017), bringing about meaningful involvement of Roma communities in the Decade proved to be a challenge, with NGO representatives and academics taking on key roles yet failing to offer Roma individuals tangible means of improving their situations. Also at issue in the delivery of the Decade was the lack of commitment from the participating state governments, which in many ways led it to be an exercise in developing

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[1] Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Hungary, Macedonia, Romania, Serbia and Montenegro, Slovakia and Spain; with Slovenia, the US and Norway participating as observers

integration plans without any political will for implementation (Bruggemann & Friedman, 2017; WHO, 2014).

Despite the challenges associated with the Decade of Roma Inclusion, the European Commission adopted a similar strategy when it published the *EU Framework for National Roma Integration Strategies up to 2020*, which set out requirements for Member States to develop initiatives aimed not simply at fighting discrimination, but also at improving the situation of Roma across the areas of education, employment, healthcare and housing (European Commission, 2010; European Commission, 2011; Scullion & Brown, 2016). Each country has a National Roma Contact Point, which is responsible for the implementation of National Roma Integration Strategies (NRIS) (European Commission, 2011). The European Commission is then responsible for assessing each Member State's progress on NRISs and evaluating their effectiveness in meeting the needs of Roma populations, working with data gathered from the European Union Agency for Fundamental Rights (FRA), as well as data submitted by Member States (European Commission, 2011). The European Economic and Social Committee (EESC) is furthermore involved in monitoring Member States' Roma integration activities, housing a permanent study group on Roma that monitors the implementation of the EU Framework on NRIS from the point of view of civil society organisations (EESC, 2018). Despite these monitoring measures, questions remain as to the consequences for non-compliance with the EU framework, perhaps limiting its effectiveness is achieving sustainable change (WHO, 2014).

According to European Commission guidance, implementation of NRISs should be based on the Open Method of Coordination – in which Member States share good practice methods – to address the disparities in inclusion programmes and ensure that the most effective possible policies are adopted across Europe (European Commission, 2011; Ringold et al., 2005). Actual development and delivery of NRISs, however, is grounded in each Member State's individual policy-making environment, with substantial variations in approach from one country to another. Some Member States have adopted 'targeted schemes' that focus exclusively on Roma, while others instituted 'mainstream approaches' that fall within broader measures to minimise social inequalities (Scullion & Brown, 2016). The UK, for example, lacks a concerted NRIS and instead asserts that Roma inclusion can be achieved through local and regional initiatives to improve service accessibility and equal opportunities across social groups (European Commission, 2018). Much like the Decade of Roma Inclusion, EU objectives to promote Roma integration are beset by lack of political will, lack of capacity for implementation of NRISs, lack of national funds to supplement EU funds, lack of integration of targeted services into mainstream services, lack of meaningful involvement of Roma in strategy design and delivery, and persistent statutory prejudices towards the Roma (Andor, 2018; FRA, 2018b; Scullion & Brown, 2016; Ryder, 2015). Such initiatives have also been criticised as applications of post-colonial development practices to Roma in the aim of making them 'less dependent, less vulnerable, less poor, less isolated and more "capable" to become full members of the societies in which they live', and all the while representing the Roma as 'inferior' (van Baar, 2018, p. 448).

Where governmental initiatives have fallen short in bringing about tangible improvements in Roma individuals' life situations, Roma people often turn to other sources of social support. Religion can be a key factor for some Roma in gaining a sense of social acceptance, yet this does not necessarily occur through adherence to the majority religion, which can in fact reinforce Roma individuals' sense of distance from majority communities. It is perhaps due to perceived hostility within majority religions that there has been an increasing trend within Roma communities towards the adoption of forms of 'charismatic Christianity', with many Roma turning towards the Pentecostal, Jehovah's Witness and Adventist segments of Protestantism as a means of seeking out social acceptance. Within these belief systems, Roma are not demonised as the 'other', but are instead empowered to participate in religious traditions on equal terms (Todorovic, 2012).

Efforts to counteract discrimination and stigmatisation of the Roma identity can also be seen in the inward-looking nature of social life in Roma communities. This reluctance to engage with non-Roma social groups and institutions suggests an impulse toward self-protection, avoidance of hostile attitudes and preservation of cultural identity, yet it can also place limitations on access to necessary support services (Sime et al., 2017; Jarcuska et al., 2013; Kolarcik et al., 2009). For migrant Roma communities, this impact of inward-looking social networks can be further compounded by limited knowledge of the language of the receiving country (Sime et al., 2017). The focus on life within the community thus represents a simultaneously self-protective and pragmatic preference from the perspective of community members, yet non-Roma may view this inward turn with suspicion. Powell (2012) identifies how the increasing 'ghettoisation' of European Roma in spaces defined by shared ethnic and cultural identity distinguishes them from an overall trend towards ethnic desegregation. Policy makers and service providers may perceive a tendency towards 'isolation', which, when interpreted as social nonparticipation, can be harnessed as a mechanism of coercion, control and further exclusion from services (Powell, 2012).

2.1.6 Roma health inequalities in a European context

Poor living conditions make Roma in Europe more susceptible to illness than other groups, with documented outbreaks of tuberculosis, hepatitis, measles and parasitic disease among Eastern European Roma communities (European Commission, 2014; Lee et al., 2014; Orlikova et. al, 2010; Veseliny et al., 2014). European studies comparing Roma health with that of the majority population furthermore identify lower life expectancy, higher infant mortality rates, higher rates of non-communicable and chronic disease, lower vaccination rates and higher rates of disability among the Roma, as well as lower levels of psychological wellbeing and health-related quality of life (Cook et al., 2013; Kolarcik et al., 2009; Ringold et al., 2005; Zeman et al., 2003; Koupilova et al., 2001). Evidence from a study of the mental health of Roma children in Romania and Bulgaria furthermore indicates higher rates of phobias, anxiety disorders, hyperactivity and major depressive disorder[2] (Lee et al., 2014).

Where early research on Roma health focused on communicable disease (reflecting actual or perceived low levels of hygiene), more recent studies have expanded their focus to encompass non-communicable disease and the social determinants of health (Foldes & Covaci, 2012; Hajioff & McKee, 2000; Koupilova et al., 2001; Ringold et al., 2005). Discussion of communicable and non-communicable disease prevalence highlights limited use of health services in Roma communities, supposedly resulting from a combination of personal attitudes and external barriers to access, as well as the persistence of poor living conditions in Roma communities and few opportunities for social mobility (Cook et al., 2013; Warwick-Booth et al., 2017).

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[2] Data collection was based on parents' and teachers' assessments of child mental health through the Strengths and Difficulties Questionnaire, as well as children's self-reporting on their mental health through the Dominique Interactive. Basing results on self-reporting avoids official overdiagnosis of mental health issues in Roma children on the basis of their marginalised ethnic identity.

2.1.7 Social determinants of health in a European context

The EU Framework for National Roma Integration Strategies sets out education, employment, housing and health as the target areas for tackling ethnicity-based discrimination against Roma (FRA, 2018a). To understand the social underpinnings of Roma community members' experiences of health, these intersecting indicators provide a useful starting point for assessing the social and environmental factors that shape Roma expectations of health and access to services.

Poorer Roma health status arguably has origins in the conditions of poverty, segregation and marginalisation in which many Roma live (FRA, 2018b). In 2016 the EU Agency for Fundamental Rights (FRA) conducted a survey of self-identified Roma in all 28 EU Member States and then analysed data for nine of these countries[3]. Analysis showed that 80% of Roma live below the threshold placing them at risk of poverty, which is defined as 60% of the median income after social transfers (FRA 2016). Rechel et al. (2009) call attention to the impact of poverty in determining the extent to which the Roma are able to access health services, drawing connections between conditions of poverty (defined as $2.15 purchasing power parity per capita per day), quality of accommodation and proximity to health and public services. Limited financial resources can furthermore create perceived financial barriers to seeking out care, even in cases where no real barriers exist, as individuals may avoid medical care under the assumption that they will be unable to afford insurance, treatments or transportation to health care facilities (Rechel et al., 2009; Ringold et al., 2005; Gill, 2009).

This occurs in the context of discrimination in labour markets, which prevents Roma from obtaining employment and diminishes the quality of work available (Craig, 2011; FRA 2016). Restriction on available employment leads in turn to persistent conditions of poverty, reliance on state support and segregation in isolated, low-income communities (Bartlett et al., 2011; Fesus et al., 2012; Martin et al., 2017; Council of Europe, 2012). Although FRA surveys revealed a reduction in the proportion of Roma reporting discrimination in seeking employment between 2011 and 2016, this number remains higher than non-Roma reporting discrimination at work (FRA, 2018b; FRA, 2018c). Furthermore, many Roma in employment in the UK tend to work in low-wage, irregular, cash-in-hand jobs, with little security and opportunity for progression (EHRC, 2016). Responding to these disadvantages, countries involved in the Decade of Roma Inclusion instituted programmes aimed at promoting Roma employment opportunities.

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[3] Bulgaria, Czech Republic, Greece, Spain, Croatia, Hungary, Portugal, Romania, Slovakia

These included, for example, vocational training for Roma young people (in Albania, Bulgaria, Hungary and Spain), awareness-raising about employment opportunities (Albania and Spain) and improved access to ongoing training for workers (Spain) (WHO, 2014).

Poverty and unemployment can have profound impacts on the mental and emotional states of Roma individuals, creating feelings of defencelessness and shame (Ringold et al., 2005; Toth et al., 2017). For Roma interviewed in a Hungarian study of multiple suicide attempts, for example, long-term unemployment was found to have a disproportionate impact on Roma individuals' perceptions of marginalisation and discrimination in comparison to other ethnic groups, and was also found to be a significant motivator in their decisions to attempt suicide (Toth et al., 2017). Fear of experiencing greater discrimination can additionally preclude Roma individuals' decision to seek out mental health support (Lee et al., 2014). There is a wider literature on the impacts of intergenerational trauma on populations that have historically experienced violence and persecution, with studies highlighting higher rates of depression, anxiety and post-traumatic stress disorder across generations (Sangalang & Vang, 2017; Lehrner & Yehuda, 2018). While these studies have not made specific reference to Roma, there is potential that Roma populations' long history of hostility and subjugation could have an impact on reported high rates of mental health issues in Roma communities.

The impact of the poverty cycle experienced by many Roma communities presents itself perhaps most tangibly in the area of housing, with many Roma living in overcrowded, substandard accommodation, in some cases outside the reach of public utility services (FRA, 2009b; Eurofound, 2012; FRA, 2018c). Roma in Europe often lack access to basic sanitation facilities and clean drinking water; and overcrowding in their homes furthermore increases the risk of fire and domestic accidents (Eurofound, 2012; FRA 2016). This can be seen in the striking example of the Lunik IX housing estate in Kosice, Slovakia, which houses approximately 7000 city's Roma inhabitants in an estate cut off from public services. Roma living in Lunik IX experience almost total unemployment and restricted access to health services (Eurofound, 2012).

The physical separation of Roma from other social groups is not uncommon. As defined in a United Nations Development Programme survey of Roma in Slovakia, Roma live in three types of accommodation: diffused, in which Roma are integrated with the majority population; separated, in which the Roma population is concentrated in a certain part of a town or village (often on the outskirts); and segregated, in which a physical barrier separates Roma population from other communities

(Kolarcik et al., 2009). An estimated 50% of the Roma population in Slovakia lives in separated or segregated accommodation (Kolarcik et al., 2009). Separation and segregation – even if they represent Roma individuals' response to adversarial attitudes based on past experience – can reinforce public stereotypes, minimise knowledge of the Roma community outside the community itself and perpetuate the idea of fundamental difference between Roma and majority populations. Public officials can then harness these representations as justification for deprivation of Roma rights and restriction of access to services, operating on the assumption that Roma simply cannot integrate (Powell, 2012).

In addition to residential segregation, school segregation constitutes another key factor perpetuating the social separation of Roma and non-Roma communities (FRA, 2018c). The proportion of Roma children attending Roma-only schools in the EU ranges from 27% in Bulgaria to 3% in Spain, and often manifests itself in placement of Roma children in special needs schools and classes, even when they have no special educational needs (FRA, 2018c; Amnesty International, 2017). This can create situations in which instruction is not tailored to ability level and teachers have low expectations of Roma students, thus decreasing the likelihood that Roma children will actively engage in school and advance to secondary and post-secondary education (Amnesty International, 2017; Council of Europe, 2012; Ringold et al., 2005). Even when school segregation is not officially mandated, schools with high proportions of Roma pupils may be afforded substandard facilities and limited opportunities for academic development, leading non-Roma parents to withdraw their children from these schools (FRA, 2018b). The practice of school segregation has been challenged in the European Court of Human Rights, yet the problem persists in Bulgaria, Greece, Hungary and Slovakia, despite official legal prohibitions on the practice (FRA, 2018c). Not only does incorrect placement in special schools cause educational, psychological and emotional harm, but it also has contributed to the persistent marginalisation of Roma communities (Ivanov, 2017).

These structural barriers to education contribute to low levels of educational attainment in Roma communities, low performance across all educational indicators and perceptions of discrimination in schools (Sime et al., 2017; FRA, 2018b; FRA, 2018c). According to FRA survey data, 18% of Roma in nine EU member states attend school at a lower level of education than would be expected for their age, and Roma are more likely to leave school early than their non-Roma peers (FRA, 2016). Not only does educational discrimination against Roma have a pronounced negative impact on individual life opportunities, but it can also lead to intergenerational cycles of low educational expectations. After being subject to discrimination and limited opportunities in their own schooling, many Roma parents approach educational opportunities for their children with low self-esteem (Sime et al., 2017). In the particular case of Roma girls, parents may choose to withdraw their daughters from school in order to prepare for marriage or to take on responsibility for looking after the household (FRA, 2003). To combat these barriers, some European countries have implemented targeted measures to improve Roma experiences of education. A programme in Greece, for example, provided education support and cultural mediation for Roma children; another in Romania reserved places for Roma in high school and universities and included Romani language teaching into curricula (WHO, 2014).

By outlining a key set of social determinants of health, the preceding discussion provides essential context for understanding the health situation of the Roma in Europe. While by no means offering an exhaustive explanation of poverty, employment, housing and education, these examples nonetheless indicate the extent to which discrimination and segregation draw clear lines between Roma and non-Roma communities in Europe and the ways in which Roma integration initiatives have as yet had little tangible impact of improving the situation of the Roma. Against this background of disadvantage, segregation and marginalisation, Roma face disproportionate barriers in accessing health services and obtaining desired levels of medical input.

2.1.8 Issues with health service accessibility for Roma in Europe

In a study of maternal health care amongst Roma women in Serbia and Macedonia, Janevic et al. (2011) identify three categories of racism affecting Roma women's experiences of health services: 1) personally mediated racism, which refers to individual perceptions of discrimination; 2) internalised racism, which refers to patients' low self-esteem and fear in accessing services; and 3) institutional racism, which refers to the environments in which Roma live and the ways in which their relative disadvantage can impact on access to health services. Studies addressing systemic barriers to health services further reveal how administrative procedures and providers' attitudes towards Roma can limit Roma individuals' health service use. Access to health services can be restricted at the point of contact, with barriers to registration arising from lack of identification documents, physical distance from services, lack of transport and lack of funds to purchase insurance (Council of Europe, 2012; Idzerda et al., 2011; Kuehlbrandt et al., 2014; McFadden et al., 2018; Rechel et al., 2009; FRA, 2018c). While restrictions on access sometimes have a legal basis (the requirement to purchase insurance, for example), they can also result from miscommunications between Roma individuals and health professionals about entitlement to services and requirements for registration. Fear of intrapersonal discrimination and poor past experiences of health services can also lead Roma to choose not to access services, as was reported by Roma surveyed in Slovakia (Jarcuska et al., 2013).

There is also a body of evidence indicating that Roma women across Europe face particular barriers and challenges in accessing health services, leading to poorer health outcomes and poorer self-reported health (FRA, 2003; Carrasco-Garrido et al., 2010; Sedlecky & Rašević, 2014; Logar et al., 2015). According to FRA survey data, Roma women are often the primary caregivers for their families, which may lead them to de-prioritise their own health needs. Community expectations and cultural stigmas related to sexual and reproductive health may also lead Roma women to view family planning services as inapplicable to their particular life situations (FRA, 2003). When Roma women in Slovenia were asked about their views on reproductive health, respondents revealed how transmission of health information amongst female family members forms the basis of their reproductive health knowledge, though they reported increasing levels of professional input (Logar et al., 2015). Survey data from Spain further reports that Roma women experience higher rates of anxiety and depression and poorer self-reported health than population averages, as well as lower rates of accessing preventive services such as mammograms and smear tests (Carrasco-Garrido et al., 2010). Focusing specifically on sexual and reproductive health amongst Roma women, questionnaires collected from Roma settlements in Serbia reported higher fertility rates, adolescent birth rates and poorer overall levels of sexual and reproductive health, which were likely linked to socioeconomic disaparities between Roma and the general population (Sedlecky & Rašević, 2014).

After Roma patients establish initial contact with health services, they may encounter segregated facilities, as well as ‘hostile, patronising, judgemental, unsympathetic and even abusive attitudes of healthcare staff’, leading them to feel that health professionals do not take their needs seriously (McFadden et al., 2018, pg. 78). Despite reports of discrimination and restricted access, however, there are also key examples of programmes that have effectively enabled Roma to access health services. Health mediator programmes in Romania, Bulgaria and Slovakia – in which members of the Roma community actively assist their fellow Roma in establishing meaningful contact with health services – have led to increases in use of health services, vaccination uptake and patient satisfaction (European Commission, 2014; Roman et al., 2013; FRA, 2018b). Additionally, peer education programmes based on active outreach by community members have brought about increased knowledge of tobacco risks and safe sex (Carr et al., 2014). While such enablers can be effective in building community health literacy and actively involving community members in taking charge of their health situations, they also run the risk of over-emphasising behavioural factors and individual choice as key health determinants, thus minimising health services' and policy makers' accountability in promoting minority community health (Aboud & Singla, 2012; Schrecker, 2013).

Barriers to health care access have been linked to poorer self-rated health, and the greater the perceived barriers, the lower an individual's overall self-reported health (Janevic et al. 2012; Jarcuska et al., 2013; Masseria et al., 2010). The Roma tend to report poorer self-rated health than population averages, which is associated with discrimination, lower levels of education, higher levels of poverty and higher unemployment rates (though levels of self-rated health improved between 2011 and 2016 FRA surveys) (Janevic et al. 2012; Ringold et al., 2005; FRA, 2018b). Masseria et al. (2010) note, however, that self-reported health is not always a reliable indicator of an individual's precise health situation:

> 'the self-reported worsening in health status indicator does not tell anything about the actual health condition of an individual. It is, therefore, possible that Roma are still less healthy than the national majority population even if their self-reported health status did not deteriorate more than for the latter, simply because their initial health was worse. Moreover, the Roma may have a different perception of what worsening health is than the non-Roma' (p. 553).

What self-reported health can indicate, however, are levels of access, perceptions of discrimination and the psychological impact of barriers to care (Janevic et al., 2012).

Particularly in the area of mental health, external stigmatisation of mental illness can also have a pronounced impact on Roma individuals' decisions to disclose issues and to seek out support. While the tight-knit nature of Roma communities can from one side be seen as an asset to community members' wellbeing, close community bonds can also contribute to increased feelings of shame in disclosing mental distress (Lee et al., 2014). In this sense, Roma may be reluctant to disclose mental health issues out of fear that other community members will perceive mental ill health to be a sign of weakness. This can bring shame not only on the person experiencing mental illness, but also on that person's family (Roma Support Group, 2012; Warwick-Booth et al., 2017; Tobi et al., 2010). Yet mental health stigma also transcends community boundaries, and can be seen in Roma community members' fears to seek out formal support for mental health issues out of fear that this will further damage the wider society's perception of Roma and bring about greater discrimination (Lee et al., 2014).

2.2 The situation of Roma in the UK

2.2.1 Migration to the UK

Roma in the UK are a migrant group with origins in Central and Eastern Europe (Brown, Scullion & Martin, 2013). Migration to the UK began in the 1990s, after the opening of the borders of former Communist states (European Dialogue, 2009), as Roma sought asylum in response to racism, discrimination and persecution experienced in their countries of origin, yet in many cases the Home Office actively denied the severity of their circumstances (Refugee Council, 1999; Craig, 2011; European Dialogue, 2009). The Refugee Council (1999) reported that mass refusal of asylum application from Central and Eastern European Roma on the grounds of being "manifestly unfounded," which effectively ignored the context of human rights abuses against CEE Roma and reflects the atmosphere of public hostility that encountered upon their arrival in the UK.

Since the accession of the A8[4] and A2[5] EU Member States and the extension of free movement rights to their citizens, the UK Roma population has increased substantially. Although there are limited data on the number of Roma currently resident in the UK – due in part to reluctance to self-identify as Roma and in part to difficulties in reaching Roma populations – a 2013 estimate places the population size (conservatively) at approximately 200,000 (Brown, Scullion & Martin, 2013). Roma in the UK are reported to reside in the North of England, the East Midlands, Kent, and North and East London, with the largest populations located in urban areas in the North West of England and London (Brown, Scullion & Martin, 2013; European Dialogue, 2009). Roma migrants to the UK tend to undertake this move in pursuit of employment opportunities, equal access to education and a perception that they will be able escape from racialisation in a diverse UK society (Brown, Scullion & Martin, 2013; Sime et al., 2017; Grill, 2018).

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[4] Czech Republic, Estonia, Hungary, Latvia, Lithuania, Slovakia and Slovenia joined the EU in 2004.

[5] Romania and Bulgaria joined in 2007.

Roma settlement patterns in the UK are based largely on prior experience with an area, family networks and access to accommodation (Brown, Scullion & Martin, 2013; European Roma and Travellers Forum, 2014). In choosing a location for settlement, a survey of Roma migrants found that their decision was driven by perceived lack of discrimination, good access to services and affordable housing (Brown, Scullion & Martin, 2013). Matras (2015) suggests that the desire to maintain social 'invisibility' may contribute to the selection of a place of residence, leading the Roma to choose to live in urban settings where they are less likely to attract the attention of outsiders or become involved in conflicts (Richardson & Codona, 2018). Yet a preference for segregation in Roma-only communities does not necessarily reflect the attitudes of all Roma in the UK, and in a nationwide survey of A2 and A8 Roma migrants, 66% of respondents reported a desire to mix with other ethnic groups (European Dialogue, 2009). Roma do not appear to possess an inherent preference to segregate themselves in exclusively Roma communities, and any self-imposed limitations on contact with other social groups can be interpreted as a defence mechanism against external hostility (McGarry, 2017).

Although Roma in Europe were predominantly nomadic prior to the Second World War, those living in the former Soviet bloc were forcibly settled as a component of governmental attempts to transform them into a 'homogenised "proletariat"' (European Commission, 2004, p. 8). Only an estimated 20% of European Roma now adhere to their traditional travelling lifestyle, though they nonetheless maintain high levels of mobility, moving frequently from one area to another in pursuit of employment and family connections (FRA, 2009a; Brown, Scullion & Martin, 2013; European Commission, 2014). Even with the decline of nomadism in Roma communities, evidence presented by Grill (2012) suggests that Roma continue to draw connections between physical mobility, the maintenance of social relationships and the concept of forward movement in life.

2.2.2 Experiences of discrimination and stigmatisation of the Roma (migrant) identity

As an ethnic minority community with origins in Central and Eastern Europe, Roma in the UK face negative stereotypes and public hostility related to both their ethnic identity and their status as migrants (Richardson & Codona, 2018). Hostile public perceptions were captured in a 2014 Global Attitudes Survey conducted by the Pew Research Center, in which 50% of people in Britain reported an unfavourable view of the Roma (EHRC, 2016). In a further example of the apparent social acceptability of anti-Roma sentiments, a 2013 opinion piece in the *Spectator* magazine, the author described Gypsy, Roma and Traveller people as lazy, criminal and unintelligent, claiming that the terms ‘gyppo’ and ‘pikey’ were a ‘useful means of lumping them all together’ (EHRC, 2016; p. 113). Even relative to other stigmatised migrant and minority groups, there is a tendency to actively distinguish themselves from Roma communities, representing the Roma as ‘morally flawed’ (Morosanu & Fox, 2013, p. 446; European Dialogue, 2009). Historically, this reputation has been reflected in national policies towards the Roma in the UK, with the needs of Roma migrant populations disregarded or deemed invalid by government officials (Craig, 2011; Refugee Council, 1999).

The UK’s 2016 decision to leave the EU added a further dimension to the marginalisation of Roma migrants in UK society, raising questions of the security of their immigration status and creating a culture of fear in many Roma migrant communities (Richardson & Codona, 2018). With the frequent representation of Roma migrants as undeserving social deviants (Richardson, 2014), EU social directives (such as the call for all Member States to develop National Roma Integration Strategies) may have contributed to debates over UK sovereignty, sparking resistance to EU recommendations that the UK government address the needs of disadvantaged marginalised EU migrant groups (Richardson & Codona, 2018). The very presence of Roma migrants in the UK and their eligibility to receive public services and welfare benefits taps into UK nationals’ perception that the state prioritises assistance to vulnerable migrants while neglecting its own citizens (Richardson & Codona, 2018). In this culture of resentment and distrust, the Brexit vote coincided with an increase in hate crime against migrant Roma (Morris, 2016).

The context of Brexit contributes to a sense of insecurity and uncertainty regarding the future of Roma individuals’ right to residency in the UK. Although drawing from data gathered in a pre-Brexit context, Humphris (2017) explores how Romanian Roma migrants’ uncertain residency rights can shape their decisions in accessing UK public services, noting that the ‘creation of a context of pervasive uncertainty is representative of the processes of racialisation’ (p. 507). In this formulation, uncertainties about future right to reside in the UK can reproduce fears of denied access to services and racial subjugation carried over from Roma individuals’ countries of origin (Humphris, 2017).

On a more practical level, impending changes to UK immigration policy for EU migrants could fundamentally alter the status of Roma in the UK. Family connections, for instance, have provided a key impetus for Roma migration, yet potential changes to UK immigration policy could close this route to entry and jeopardise the continued residency rights of Roma who entered via this path (Morris, 2016). James and Smith (2017) counter this point, arguing that existing EU frameworks have had little practical success in combatting anti-Roma discrimination and that the UK's exit from the EU should have little impact on the daily lived experiences of Roma in the UK. It is important to note, however, that this article was published before the UK government outlined its plans for granting post-Brexit residency rights to EU migrants, and thus does not account for the practical difficulties that Roma may face in regularising their immigration status. Under these plans, all EU migrants resident in the UK before 31 December 2020 will need to apply for 'settled status' in order to ensure their future legal right to reside (Home Office, 2018). It is unclear how vulnerable and marginalised migrants with restricted social support networks and limited knowledge of English will navigate this additional bureaucratic procedure, nor is it clear how EU migrants with low incomes will be able to pay the £65 fee for a right to residency to which they were once entitled without cost (Migration Observatory, 2018).

2.2.3 Roma health inequalities in a UK context

There is limited epidemiological evidence specific to the situation of Roma migrants in the UK, and cautious inferences must therefore be drawn from studies of indigenous Gypsy and Traveller communities or Europe-wide studies of Roma health. Reporting from the UK's Equality and Human Rights Commission (EHRC) does, for example, briefly address Roma health status, yet its material is drawn from the European Commission's 2014 *Roma Health Report*. The EHRC cites evidence that health inequalities between Roma people and the overall population are similar to those identified in Gypsy and Traveller communities, including a high prevalence of diabetes, cardiovascular disease, premature myocardial infraction, obesity, asthma and mental health issues such as stress, anxiety and depression (EHRC, 2016; European Commission, 2014). The EHRC suggests that poor familiarity with healthcare provision and language barriers may make it difficult for them to access health services, and limited contact with health services may in turn exacerbate treatable conditions and contribute to poorer long-term outcomes (EHRC, 2016).

2.2.4 Social determinants of health as they affect Roma migrants

Beyond the limited epidemiological evidence pertaining specifically to the health of Roma migrants, a growing body of research describes Roma migrants' experiences of education, access to stable accommodation, position in labour markets and access to benefits. While these studies do not necessarily link directly to health, they do offer insight into the broader conditions of disadvantage and discrimination experienced by Roma migrants in the UK.

Work undertaken by Roma in the UK post-migration is commonly obtained through family connections, and often involves precarious employment agreements, temporary jobs offered through non-statutory agencies, long hours, harsh working conditions and dangerous work (Dagilyte & Greenfields, 2015; Poole & Adamson, 2008; Morris, 2016). Many Roma will engage in self-employment directly after their arrival in the UK, which can help to ease difficulties created by language barriers and discrimination in employment (Dagilyte & Greenfields, 2014). The decision to enter into self-employment can be compounded by difficulties, as Roma migrants struggle to apply for National Insurance Numbers and to prove the validity of their self-employment to HMRC (Her Majesty's Revenue and Customs) (Humphris, 2017). When they do enter into work for an employer, Roma migrants are more vulnerable to exploitation due to low levels of education and limited knowledge of UK norms (Craig, 2011). While there is relatively little evidence of forced labour amongst the Roma, employers may exploit them by lowering already low wages, putting them in a position of increased marginalisation and thus increasing their vulnerability to gangs and human trafficking (Craig 2011).

Low income and barriers to employment may put Roma individuals in a position of reliance on state support systems in order to maintain basic conditions of subsistence. Although studies focusing on Roma community members' experiences of claiming benefits identify this action as a response to extreme financial hardship (Dagilyte & Greenfields, 2015; Martin et al., 2017), a hostile UK media has harnessed these personal experiences of deprivation to demonise migrant communities, citing benefits systems as a pull factor for migration (Dagilyte & Greenfields, 2015). In an analysis of representations of GRT communities in the populist news media, Okely (2014) emphasises how the stereotypical position of Roma people on the margins of society allows for easy portrayal as a threat to the established social and economic order. In the particular case of Roma migrants from the EU, media discourse focuses on the concept of 'benefit tourism', which has propagated an inaccurate perception that Roma are unwilling to work and come to the UK with the express intention of living on benefits (Martin et al., 2017; Richardson, 2014; Dagilyte & Greenfields, 2015). Such accounts succeed only in 'hampering the fight against poverty and offering protection for vulnerable groups in society, including Roma' (Clark, 2014, p. 42).

Contrary to media portrayals, Roma migrants in fact express very limited pre-migration awareness of UK benefits systems, and even when they do make claims for benefits, they find their efforts beset by literacy issues and limited knowledge of English (Dagilyte & Greenfields, 2015; Martin et al., 2017; Humphris, 2017). Roma migrants instead tend to rely on networks of family support and advice from non-governmental organisations (NGOs), only resorting to benefits claims when these networks are insufficient to meet their needs (Dagilyte & Greenfields, 2015; Martin et al., 2017). Upon making the decision to claim benefits, however, limited awareness of UK benefits systems and flawed assessment of eligibility can make Roma migrants particularly vulnerable to exploitation and unlawful treatment within benefits systems (Poole & Adamson, 2008). Roma benefits claimants commonly receive rejections of their benefits applications based on decision makers' errors, lack of response to complaints regarding incorrect decisions and long delays in benefit payments, which heighten the burden of poverty on Roma benefits claimants (Paterson et al., 2011). Additionally, EEA migrants must prove that they earn a minimum of £150 per week and that their work is 'genuine and effective' in order to quality for work-related benefits, which can restrict access for those in precarious employment (Dagilyte & Greenfields, 2014; DWP, 2014; Humphris, 2017). Immigration status can also have a significant impact on Roma benefits claimants, with applications commonly rejected on the basis of flawed interpretations of an applicant's right to reside in the UK, such as failure to account for residency rights derived through family connections (Dagilyte & Greenfields, 2015). Moreover, the UK's exit from the EU could reduce EU migrants' access to UK benefits systems, making Roma communities increasingly vulnerable to poverty and marginalisation (Morris, 2016).

Roma migrants are at a marked disadvantage not only in their efforts to claim benefits, but also in securing adequate accommodation. Reduction in the UK supply of social housing has led to segregation of marginalised and minority groups from the wider society (Greenfields & Smith, 2010). With their lack of prior experience of seeking out housing in the UK compounded by language barriers and limited literacy, Roma migrants are particularly vulnerable to exploitative landlords in the private housing sector (Van Hout & Staniewicz, 2012; European Commission, 2018). Unscrupulous landlords put them in danger of forced evictions and frequent moves from one tenancy to another (Craig, 2011; Van Hout & Staniewicz, 2012). Many live in substandard housing with high rents, lack of tenancy agreements, poor maintenance, unhygienic conditions and overcrowding (Craig, 2011; Morris, 2016; European Dialogue, 2009; Van Hout & Staniewicz, 2012). This lack of housing security can disrupt efforts to maintain a healthy lifestyle and contribute to increased psychological pressures (Van Hout & Staniewicz, 2012; Carr et al., 2014).

Roma in the UK live almost exclusively in permanent, settled accommodation – representing a contrast to many Gypsy and Traveller communities – yet this can nonetheless create challenges to the maintenance of their distinct cultural traditions (Van Hout & Staniewicz, 2012). There is a body of work on the transition of traditionally mobile Gypsies and Travellers into housing, and the need to 'reformulate an approximation of traditional communities within housing' (Greenfields & Smith, 2010, p. 153). While this refers to different communities, it has relevance to the experiences of Roma migrants and their creation of 'cultures of survival' through replication of close-knit community structures in the face of external hostility and opposition (Greenfields & Smith, 2010). This can be seen, for example, in concentrations of Roma communities in certain areas of cities in an effort to retain their sense of intra-group cohesion (Powell & Lever, 2017). Powell and Lever (2017) have argued, however, that this inward-turning self-protection can in fact function to solidify other groups' perception of Roma as outsiders, which gives them licence to scapegoat Roma for a wide range of social ills. With the spatial segregation of Roma communities and a 'taboo on social contact' between Roma and non-Roma, stereotypes associating Roma with 'criminality and deviance' have become entrenched in public discourse (Powell & Lever, 2017, p. 684).

Roma furthermore experience marked disadvantage in the area of education, and display significantly higher absence rates, higher exclusion rates and interruptions of education compared to other ethnic minority and socially deprived populations (Wilkin et al., 2010; Ofsted, 2014). These indicators of poorer educational experience are reported to stem at least in part from racist bullying, discriminatory attitudes of school staff and lack of meaningful recourse towards the perpetrators (Shallice & Greason, 2017). Roma parents may furthermore have a limited knowledge of local school systems and difficulties in communicating with education providers, and schools may be reluctant to admit Roma children (European Dialogue, 2009; Wilkin et al., 2010; Sime et al., 2017). Barriers arise as well from practical financial limitations, with many Roma parents unable to purchase uniforms and school supplies, leading to higher drop-out rates (Sime et al., 2017).

Schools are currently the only UK public institution that gathers data on Roma ethnicity (using the category 'Gypsy/Roma'), although some Roma may be reluctant to self-identify their ethnicity out of fear of discrimination (Wilkin et al., 2010; Ofsted, 2014; Morris, 2016; Warwick-Booth et al., 2017). The existing school data reveals striking ethnic disparities, with 70% of Gypsy/Roma children reported not to exhibit a good level of development at the end of Reception (The Health Foundation & Institute of Health Equity, 2018). To provide insight into these disparities, the Department for Education (DfE) and Ofsted have produced reports investigating the situations of Roma pupils. In a report from the DfE, for example, a secondary school teacher characterises Roma pupils as 'very self-sufficient, and not trustful of routes society provides for progression', while other school staff view Roma parents as 'overprotective' (Wilkin et al., 2010, p. 14; Sime et al., 2017). Roma are reported to believe that secondary school is inappropriate and unsafe for girls, and that boys (who often follow their fathers into self-employment) would be better served by entering directly into work (Wilkin et al., 2010; Sime et al., 2017). Other Roma parents feel unable to support their children in education due to their own illiteracy (Sime et al., 2017). Inadequate measures to address cultural differences create a situation in which the Roma do not feel comfortable sending their children to school, yet educators are rarely afforded the cultural awareness training that would enable them to more effectively support to Roma pupils (Ofsted, 2014).

2.2.5 Perceptions of health amongst UK Roma migrant communities

While acknowledging the importance of a wider social context in understanding Roma migrants' health behaviours, it is furthermore relevant to note that intra-community transmission of health information can have a deep impact on the ways in which Roma individuals make decisions about health and engage with services. Cultural norms and stigmas may prevent some Roma individuals from accessing services for support with mental health issues, sexual health, and drug and alcohol misuse (EHRC, 2016). Multi-generational transmission of familial health knowledge also plays a vital role in Roma individuals' health decisions, which was explored in a study of infant feeding behaviours of Romanian Roma mothers (as well as Gypsies and Travellers). To capture the nature of intra-family transmission of health information, both mothers and grandmothers were recruited for interview. Participants highlighted how close community bonds and observations of their mothers' behaviours shaped their decisions about breastfeeding their children, which could in some cases create discord between family traditions and health professionals' advice (Condon & Salmon, 2015). Even in cases where Roma cultural knowledge of health and medical models appear to conflict, Warwick-Booth et al. (2017) argued that Roma do not actively avoid contact with health services. They do, however, approach health services with clear conceptions of appropriate interpersonal contact between patient and provider and value the UK's person-centred approach to health care as compared with their countries of origin.

Emphasis on culture as a key determinant of Roma health behaviours has received criticism for presuming homogeneity of Roma communities, reducing ethnicity to a causal factor behind differences in health behaviour rather than one of many components in more complex social frameworks (Smith & Newton, 2017). In this vein, a study of immunisation uptake in UK GRT communities notes that 'a common experience of marginalisation, prejudice and exclusion spans these groups and frames their engagement with society, its health systems and immunisation programmes' (Smith & Newton, 2017; p. 240), thus emphasising the primacy of social context in understanding the development of health perceptions within a given social group.

2.2.6 Mental health and wellbeing in UK Roma communities

The area of mental health provides a particularly salient example of the ways in which cultural perceptions and external pressures interact to influence the ways in which Roma individuals address a particularly sensitive health issue. Open disclosure of mental health issues tends to produce feelings of shame, and although this perception is expressed across many social groups, it takes on particular relevance in light of the tight-knit nature of Roma communities (Roma Support Group, 2012). Accounts from Roma individuals experiencing mental health issues emphasise the social consequences of public disclosure, revealing the threat of isolation from the rest of the community as a key concern in deciding to seek out support (Roma Support Group, 2012; Warwick-Booth et al., 2017; Tobi et al., 2010). Furthermore, Roma participants in Roma Support Group's mental health advocacy project reported a belief that mental health issues can be passed down genetically within families. If an individual is thought to suffer from mental illness, this can damage not only that person's marriage prospects, but also that of the entire family (Roma Support Group, 2012). Similar trends have been observed across BME groups, with individuals from Black and Asian communities in England reporting reluctance to discuss mental health issues, fearing that disclosure of mental illness would bring stigma on the entire family and thus leading to delays in treatment (Memon et al., 2016).

There are no nationally collected data on the mental health and wellbeing of Roma communities in the UK. At present, the most reliable UK data on the prevalence of mental health issues amongst Roma come from the evaluation report of a mental health advocacy project conducted by Roma Support Group between 2008 and 2012. Of the project's approximately 100 service users, 61% were reported to suffer from depression, 11% from anxiety, 7% from schizophrenia and 3% from psychosis. An additional 9% were reported to have learning difficulties (Roma Support Group, 2012). The evaluation report notes that many service users approached the project with a degree of trepidation, which was largely attributed to the fear, stigma and shame associated with mental health issues in the Roma community (Roma Support Group, 2012).

In light of the social consequences of disclosing mental health issues, as well as limited vocabulary for expressing mental health concerns, many Roma individuals report difficulties in discussing their problems with both family members and non-Roma professionals (Darnall Wellbeing, 2018). This problem is related in part to practical language barriers and limited vocabulary for describing mental health, as well as reluctance to exacerbate pre-existing stigmas related to Roma identity (Roma Support Group, 2012; Warwick-Booth et al., 2017). For Roma migrants in the UK, barriers to discussing mental health issues also have roots in public hostility to migrants. Roma experiencing mental illness fear not only that open acknowledgement will bring shame on both themselves and their families, but also that British nationals could use their disclosures of mental ill health as an argument in favour of returning them to their countries of origin (Warwick-Booth et al., 2017). In other BME communities, family and social networks could be seen as both barriers and enablers to accessing services. Families could provide emotional support and fill gaps in service provision, yet family input could also be seen as an alternative to professional attention (Memon et al., 2016).

2.2.7 Structural barriers to health service accessibility for migrant Roma

When Roma make contact with UK health services, they face a number of practical impediments to communication with health professionals, many of which bear a direct connection to their migrant status. Barriers to adequate care may arise from limited understanding of UK health systems, difficulties in registering with GPs and inability to communicate with health professionals due to language barriers (Craig, 2011; Tobi et al., 2010). This has also been observed in wider BME communities, in which long waiting times for appointments, perceived lack of cultural sensitivity within services and a tendency to take a generalised approach to individual needs were cited as key factors in diminishing patients' confidence in services (Memon et al., 2016). Furthermore, health services do not monitor for Roma ethnicity, which places restrictions on providers' knowledge of the ethnic and cultural backgrounds of the patient groups they serve (Greenfields, 2017; Traveller Movement, 2014). The Traveller Movement (2014) has flagged this issue, highlighting the lack of inclusion of Gypsy, Roma and Traveller ethnicities in the NHS data dictionary.

For Roma migrant communities, communication and language barriers have a significant impact on accessibility of health services, awareness of screening and immunisation programmes and overall satisfaction with services (Warwick-Booth et al., 2017). Not only are Roma frequently reliant on interpreters to communicate with health care practitioners – which can create barriers to the disclosure of sensitive information – but they must also communicate with interpreters in a second language due to a lack of interpreters in the Romanes language (McFadden et al., 2018). Even amongst Roma who speak some English, low levels of education may contribute to difficulties in understanding medical terminology and communicating their needs to health professionals (Roma Support Group, 2015).

Limited health-related vocabulary and understanding of medical terminology can also restrict Roma patients' ability to explain their needs and to understand communications from health practitioners, particularly in the context of accessing specialist services (McFadden et al., 2018; Darnall Wellbeing, 2018). It is worth noting, for example, that the Romanes language does not include terms for terms such as 'depression' and 'anxiety attacks', which may create barriers to accurate self-expression in mental health settings (Roma Support Group, 2012, p. 68; Darnall Wellbeing, 2018). Furthermore, migrant Roma may be either completely illiterate or unable to read English, which can create barriers to understanding written health promotion materials and communications from health services (Condon & Salmon, 2015). A Roma participant in a study of Roma health needs in the London Borough of Barking and Dagenham captures the practical problems created by functional illiteracy and UK health services' reliance on written methods for making contact with patients: 'We do not understand the system and find it difficult to communicate. When we receive letters we do not understand what they mean' (Tobi et al., 2010; p. 19).

2.2.8 Provision of interpreting and cultural competence of health care providers

Underlying these issues of language and communication are more fundamental concerns related to health care providers' knowledge of the distinct linguistic, ethnic and cultural profiles of the patient groups they serve. While this could be remedied in part by increased ethnic monitoring, there is also a need to consider the cultural competence of health service providers (Traveller Movement, 2014; McFadden et al., 2018). This reflects the concept of ‘cultural competence’, which refers to professional attention to the ways in which cultural beliefs may influence patients’ health-related communication and behaviour (Garran & Rozas, 2013; Pinderhughes, 1989). Applied effectively, cultural competence frameworks should reflect diversity in cultural groups and aid practitioners in taking into account all aspects of a patient’s identity in assessing a patient’s health situation, equipping them to shape their practice around the practical circumstances of patients’ lives (Garran & Rozas, 2013). Services can also enhance their overall cultural competence by employing staff from immigrant or ethnic minority backgrounds (Kluge et al., 2012).

McFadden et al. (2018) highlight how Roma may find it particularly difficult to communicate with health professionals of a different gender, especially when discussing issues such as sexual and reproductive health, while also suggesting that the ‘stigma and shame’ associated with disclosure of health issues may have connections to a sense of ‘devalued identity’ arising from discrimination (p. 78). A study of Roma in Spain also elaborated on the gendered dynamics of communication between Roma patients and health professionals, with some professionals appearing to assume that Roma women would be unwilling to discuss gynaecological topics due to ‘the cultural value of virginity’ (Aiello, Flecha & Serradell, 2018, p. 386). This study also emphasised, more generally, how health professionals neglected to explain medical information to Roma patients under the assumption that Roma either would not be interested or would not understand (Aiello, Flecha & Serradell, 2018). Professionals’ assumptions about Roma patients reflect Janevic et al.’s (2011) categorisation of personally mediated racism, in which Roma feel that they were treated differently on the basis of their ethnic identity. While Aiello et al. (2018) recognised that this differential treatment could have it roots in socioeconomic different between Roma patients and health professionals (controlling for this possibility by recruiting Roma participants of mid-socioeconomic status), their participants still highlighted a sense of disrespect from professionals stemming from outward expressions of Roma identity. These issues point to a need for additional diversity and cultural competence training amongst health service staff, which, even if not directly related to Roma culture, can raise awareness of effective methods of meeting the needs of patient from ethnic and cultural background different from those of service providers (McFadden et al., 2018; Kluge et al., 2012).

Closely linked to the concept of cultural competence – and of great relevance to Roma migrant communities in the UK – are issues of language barriers, which have been shown to increase the potential for miscommunication between patient and provider, reduce patients' satisfaction with services and increase the likelihood of emergency room visits (Kluge et al., 2012; Memon et al., 2016). In a study focusing on access to interpreting services for BME communities (specifically Indian, Pakistani, Bangladeshi and Chinese), Gill et al., (2009) analysed data from the Health Survey for England to find that approximately 300,000 individuals across the focal ethnic groups spoke no functional English, yet health services did not routinely document English language ability in ethnic monitoring (Aspinall, 2007). For Roma, the near-total lack of ethnic monitoring (Traveller Movement, 2014) could complicate this issue further. When an interpreter is not present in a consultation, language discord has been shown to undermines patients' confidence in quality of care and reduces the quality of health promotion information conveyed to the patient (Ngo-Metzger et al., 2007). Aspinall (2007) notes that monitoring patients' language support needs has not traditionally been a priority, though the lack of data on immigrant populations' health service use represents a trend across Europe (Kluge et al., 2012).

While NHS England's principles for interpreting and translation services recommend provision of interpreting services at the point of delivery, this does not constitute a guarantee that professional interpreters will be provided across NHS services (NHS England, 2015a). Notably, the NHS's Accessible Information Standard does not make provision for interpreting services, claiming that requiring health service providers to account for patients' differing language needs would place disproportionate burden on services operating in areas with large immigrant populations (NHS England, 2015a). Provision of high quality language support is patchy across the UK, and even when interpreters are available, this does not guarantee culturally sensitive delivery of health information (El Ansari et al., 2009). In this vein, bilingual health advocacy programmes – which provide not only literal translation, but also give patients a 'voice' – have been cited as models of good practice, yet there are no established methods for commissioning, monitoring or recruiting for these services (El Ansari, 2009).

Despite statutory recognition of the potential for heightened risk of interpreting errors when family members without formal training serve as interpreters (NHS England, 2015b), patients may see no option but to bring English-speaking family members to appointments when services do not provide formal interpreting support. In these cases, the close personal relationship between the patient and the interpreter decrease the likelihood that patients will disclose sensitive health information, thus inhibiting providers' ability to make diagnoses and recommendations (Hadziabdic et al., 2014). Lack of prior personal contact with an interpreter can help to mitigate feelings of shame in disclosing health conditions, and can moreover eliminate the fear that the interpreter will spread personal details about a patient to other members of the patient's community (Hadziabdic et al., 2009). Even in the absence of language barriers, limited constructive dialogue between provider and patient can increase the likelihood that the patient will view the provider's communication methods as 'patronising' and lead to low expectations of care (Van Cleemput et al., 2007; Gill, 2009; Parry et al., 2004; Greenfields, 2017).

2.2.9 UK policy responses to inequalities faced by Gypsy, Roma and Traveller communities

The deprivations faced by Roma communities have received little formal recognition by the UK government. The dearth of meaningful policy development for addressing Roma needs arguably has its roots – at least in part – in the lack of monitoring on the basis of Roma ethnicity within UK public services (McFadden et al., 2016). Although the UK government took a step towards greater recognition of inter-ethnic inequalities with the publication of its Race Disparity Audit – which reported on ethnic disparities in health, housing, education, employment, criminal justice and community integration – a lack of specific data on Roma effectively precludes any targeted policy development, as the needs of Roma remain difficult to quantify (HM Government, 2017; Roma Support Group, 2017a). Roma migrants often bear the burden of austerity policies in the areas of health, education, welfare and housing, and there has been little effort by the UK government to mitigate the cumulative impacts of public hostility towards Roma migrants, discrimination (whether direct or indirect) within public services and overall conditions of social marginalisation (Ryder et al. 2012; European Commission, 2015). Despite recommendations from the European Commission against Racism and Intolerance and the United Nations International Convention on the Elimination of All Forms of Racial Discrimination (as well as requests from the Roma NGO sector) that the UK develop a National Roma Integration Strategy, the UK Government has made no concerted effort to craft policy responses to the marked inequalities faced by Roma migrant groups, claiming instead that general policy streams for promoting social integration will capture the needs of the Roma (European Commission, 2015; European Commission, 2018).

Although the government has not adopted a National Roma Integration Strategy, it has (in a minimal step towards complying with EC recommendations) situated a National Roma Contact Point at the Ministry of Housing, Communities and Local Government (MHCLG), which hosts a quarterly Gypsy, Roma and Traveller Liaison Group and reports to the European Commission on measures to advance Roma integration (European Commission, 2017; European Commission, 2018). The National Roma Contact Point purportedly coordinates incorporation of Roma issues into the socio-economic policies and action plans of other ministries and governmental institutions, yet it is notable that, at present, only the Department for Education conducts specific activities focusing on Roma inclusion (European Commission, 2018). There is also an All-Party Parliamentary Group for Gypsies, Travellers and Roma – members of which have laid questions before Parliament and government ministers to represent GRT concerns – yet securing sustained funding for the group has presented significant challenges (European Commission, 2018).

The government's last substantive engagement on the topic of GRT equalities occurred in 2012, when the Department for Communities and Local Government (now MHCLG) published a set of 28 'commitments' arising from the work of a ministerial working group on inequalities faced by Gypsy and Traveller communities (DCLG, 2012). Focusing on the areas of education, health, housing, hate crime, criminal justice and employment, the working group brought together ministers from relevant departments and was chaired by the Secretary of State for Communities and Local Government (DCLG, 2012; European Commission, 2018; FFT & NFGLG, 2018). Commitments included measures such as: incorporating GRT into Ofsted monitoring frameworks; closing evidence gaps in the field of Gypsy and Traveller health; and showcasing 'well presented and maintained' Gypsy and Traveller sites (DCLG, 2012, p. 18). Focusing predominantly on Gypsy and Traveller communities, there is a complete omission of European migrant Roma from all commitments but those related to education (European Commission, 2018). Furthermore, in the absence of any clear oversight and monitoring of progress towards the ministerial commitments, the working group only met once, and governmental actions to implement changes across the target areas have been inconsistent at best (FFT & NFGLG, 2018).

The 28 commitments have received criticism from academics and community groups alike, with Ryder et al. (2012) describing the policy as 'hierarchical' and emphasising how it 'does not engage with or adequately promote community groups and opposes forms of positive action' (p. 1). Looking at the area of health as an example, the 28 commitments emphasise joint working across the Department of Health, the National Inclusion Health Board (discussed in Chapter 5) and local government to identify key areas of need for Gypsy and Traveller communities and to develop interventions to improve health outcomes (DCLG, 2012). The specific situation of Roma migrant communities is not included in any of the health-related commitments, and migrant Roma are only addressed through a passing reference to the challenges posed by language barriers and (DCLG, 2012). Furthermore, as Ryder et al. (2012) note, there is no substantive exploration of the ways in which the commitments will operate in the context of health service reforms instituted through the Health and Social Care Act of 2012 to ensure attention to the needs of vulnerable groups (discussed in greater detail in Chapter 5).

In light of the limited progress towards meeting the inter-ministerial working group's 28 commitments, the parliamentary Women and Equalities Committee undertook a 2017 inquiry into the inequalities faced by GRT communities (European Commission, 2018; House of Commons Library, 2018), issuing a call for evidence from groups with expertise in GRT issues. The table below summarises the content of evidence submitted to this inquiry and assesses its relevance to the situation of Roma communities.

Table 2: Written Evidence Submitted to the Women and Equalities Committee Inquiry in to 'Tackling inequalities faced by Gypsy, Roma and Traveller communities'

Submitted by	Commitments reflected	Issues identified	Actions taken	Relevance to Roma communities
Ofsted	1: GRT children added in 2012 to the list of groups requiring special attention during inspections 2: Kent was the only local authority to retain its virtual headteacher as of November 2014 (when central funding for the pilot ended), despite reports of the pilot's success 3: Inspectors pay particular attention	Poor rates of educational achievement and high absence rates amongst GRT pupils Poor outcomes at GCSE for Roma migrant pupils Difficulties for Roma pupils in transitioning between primary and secondary education Difficulties in engaging Roma pupils with little	2013 meeting between GRT communities and Ofsted's previous National Director for Schools – requested further inspection activity and highlighted examples of good practice Chief Inspector visited Sheffield to see how schools address GRT educational issues Commissioning of a survey to identify	Identifies newly arrived Roma from Eastern Europe in Sheffield Report on Roma engagement and achievement in education Recommends specialist support staff and partnership working across agencies to improve Roma engagement Ofsted inspectors found that arrival of Roma pupils had no

	to attendance make comparisons for each pupil group 4: Inspectors pay particular attention to exclusion rates and make comparisons for each pupil group 5: 2012 survey on bullying included a reference to Traveller pupils	prior experience of formal education Difficulties in accessing the pupil premium and other resources when large numbers of new pupils join during a school year Shortage of staff to support pupils who do not speak English as a first language Difficulties in keeping track of highly mobile families High dropout rates Fears of discrimination	examples of good practice and to investigate Sheffield and Derby local authorities Publication of a report focusing on Roma pupils Publications of case studies focusing on Gypsy and Traveller pupils	adverse effect on the attainment of other pupil groups
NHS England	7: Inclusion Health subgroup reports to Equality and Diversity Council, though there is no specific discussion of how this group influences commissioning decisions 9: Design of a leaflet addressing service accessibility issues at the point of registration	Lack of sustainable accommodation and GP registration are the main health-related difficulties for GRT communities GRT patients may have difficulties in registering with GPs because they are turned down as problematic users Discriminatory	Equality and Diversity Council receives reports from Inclusion Health and Lived Experience subgroups NHS England and subgroup members consulted on a draft leaflet for GRT communities Leaflet was launched on 1st	Unclear whether Lived Experience subgroup includes Roma communities Does not make specific reference to migrant Roma Focus is on general measures to improve outcomes for disadvantaged groups

	(leaflet no longer available on NHS England's website)	attitudes may underlie some GP practices' refusal to register Gypsy and Traveller patients	March 2017 and sets out reasons why a practice may be unable to register a patient Practices complete a form to explain why they are unable to register a patient Leeds CCG engaged in a workshop with GRT community members and support organisations to look at barriers to registration and discrimination	
Crown Prosecution Service	14: Addresses methods for increasing reporting and understanding of hate crime	Low levels of reporting hate crime due to reluctance to come forward and lack of awareness of what hate crime is GRT community members feel that authorities do not understand the context in which crimes are committed and thus do not respond appropriately	Hosted a National Security Panel to gather information on GRT community members' specific concerns with regard to hate crime Published two guides defining hate crime and explaining how to respond (general – not targeted at any specific community)	Identifies that Roma may be a target of hate crime due to both ethnic identity and national origin
Irish Chaplaincy	19-21: identifies shortcomings in ethnic monitoring and staff training	Prisoners unwilling to identify as GRT out of fear of discrimination	Produced a report on Irish Travelers in prison	Does not specifically mention Roma

		Lack of ethnic monitoring in prisons and poor staff awareness Requirement to submit written requests for mental health support in prison excludes many members of GRT communities Prison education does not effectively engage GRT individuals		
National Bargee Travellers Association	12: Identifies shortcomings in planning policy	Frequent violations of the rights of Bargee Travellers Lack of access to basic facilities, welfare, health care, electoral registration and postal mail	Submission of evidence to raise Parliamentary awareness of the rights of Bargee Travellers	Focus is on Bargee Travellers, who do not have any direct connection to Roma
Dr Maria Faraone	12, 13: Identifies shortcoming in planning policy and the detrimental health outcomes that this can have on Gypsies and Travellers	Limited Government attention to private sites Planning law does not recognise caravans as a legitimate home, and those who have ‘permanently’ stopped travelling are no longer entitled to site	Submission of evidence to raise Parliamentary awareness of Gypsies’ and Travellers’ right to site provision	Focus is on site provision and planning policy, thus making this largely inapplicable to migrant Roma communities, who tend to live in brick-and-mortar accommodation

		provision Many local authorities do not comply with 2012 requirement to allocate sites Insecurity of accommodation creates a psychologically unhealthy living environment		

As the above table demonstrates, UK policy responding to the distinctive needs of migrant Roma is extremely limited, and Roma generally gain recognition only when their interests are incorporated into policy responses aimed more broadly at Gypsy and Traveller communities. Presuming commonality of experience across these groups carries the danger of neglecting their specific needs. However, given the frequent merging of Gypsy, Roma and Traveller concerns, a discussion of Roma in the UK would be incomplete without recognition of the deprivations faced by Gypsies and Travellers. This allows for contextualisation of policy responses to purported GRT disadvantages, and further provides a basis for understanding where policy development aimed at Gypsies and Travellers fails to reflect the needs of Roma migrant groups. The next section offers an overview of the situation of Gypsy and Traveller communities in the UK.

2.3 Health inequalities faced by Gypsy and Traveller communities

As Gypsy and Traveller communities have a longer history in the UK than the European Roma, there is a more robust UK-specific public health literature regarding the epidemiology and health perceptions of these groups.

2.3.1 Epidemiology of Gypsy and Traveller communities

Multivariate analysis of the health and illness profiles of Gypsy and Traveller groups relative to comparator samples composed of other ethnic minorities, urban deprived 'white' groups and socioeconomically mixed rural and urban groups revealed stark health inequalities, which were manifested in higher rates of infant mortality, bronchitis, asthma, angina, anxiety, depression, diabetes and obesity, as well as low rates of immunisation uptake (Parry et al., 2004; Parry et al., 2007). Van Cleemput and Parry (2001) compared the UK Gypsy and Traveller population with non-GRT urban deprived groups, finding that the overall health status of Gypsies and Travellers was significantly worse than the comparison group (Parry et al., 2004; Van Cleemput & Parry, 2001). This data cannot be viewed in isolation, and likely has its origins in a range of adverse environmental factors stemming from insecurities in accommodation, difficulties in adapting to formal education and restrictions on employment opportunities that facilitate a traditional culture of travelling (Cemlyn et al., 2009).

Gypsies and Travellers were furthermore found to be significantly more likely to have a long-term illness, health problem or disability that limits daily activity in a study that assessed self-rated assessments of mobility, self-care, pain, anxiety and depression (Parry et al., 2004; Parry et al., 2007). A further study found Gypsies and Travellers to have significantly poorer health outcomes, higher rates of smoking and lower levels of education in a comparative analysis of these factors against comparator samples of African Caribbean, Pakistani Muslim and socioeconomically mixed white populations living in England (Peters et al., 2009).

2.3.2 Social determinants of health as they affect Gypsies and Travellers

Gypsies and Travellers have traditionally engaged in flexible and informal employment, with a preference towards self-employment, family-based and mobile jobs (Smith & Greenfields, 2011). Work that enables the maintenance of a travelling lifestyle is central to Gypsy and Traveller employment, yet it has recently led to increasing marginalisation in low paid sectors of the economy, such as scrap metal dealing, car dealing and construction (Smith & Greenfields, 2011). Unemployment has also been increasing, partially as a consequence of increased pressure from public officials to move into permanent housing, and partially due to an overarching trend towards 'formalisation of casual work' through requirements to complete written applications and provide National Insurance numbers (Smith & Greenfields, 2012; p. 58).

Given the cultural preference for a travelling lifestyle, housing and accommodation is a key concern for Gypsy and Traveller communities. Although the Housing Act of 2004 required local accommodation assessments for Gypsy and Traveller communities, access to land and planning permission for caravan halting sites remains a contentious subject, as the physical environment can have detrimental health impacts and the locations of sites can be seen as a means of 'separating and controlling' communities (Greenfields & Home, 2006; p. 116). Increasingly, the lack of halting sites has led public officials to adopt policies that effectively force Gypsies and Travellers into permanent accommodation (Smith & Greenfields, 2015; Carr et al., 2014). An estimated two thirds of UK Gypsies and Travellers currently live in permanent accommodation, and the transition away from a nomadic lifestyle is associated with the break-up of social networks and psychological distress in the form of anxiety, depression, isolation, stress and panic disorders (Carr et al., 2014; Parry et al., 2004; Greenfields & Home, 2006; Greenfields & Smith, 2010; Smith & Greenfields, 2015). In addition to separation from family and community support networks, housed Gypsies and Travellers also encounter difficulties in adjusting to behaviours associated with life in housing, such as requirements to pay household bills (Greenfields & Home, 2006; Greenfields & Smith, 2010).

With the transition into housing, Gypsies and Travellers become less readily distinguishable from the 'White British' population, thus diminishing awareness of their protected ethnic minority status within housing authorities (Smith & Greenfields, 2015). Whether living on sites or in housing, however, Gypsies and Travellers report disengagement from group outside their cultural communities, perhaps as a form of 'explicit ethnic boundary maintenance' in response to past experiences of racism (Greenfields, 2010, p. 62). From the perspective of Gypsy and Traveller communities, resisting assimilation to dominant cultural practices through maintenance of collective lifestyles even in permanent housing can be seen as an enactment of 'adaptive resilience' (Smith & Greenfields, 2015, p. 14). This occurs, for example, though systems of exchange, in which Gypsies and Travellers 'swap' accommodation with other members of the community in order to put them in closer contact with family networks (Smith & Greenfields, 2015).

Gypsies and Travellers furthermore experience marked disadvantage in the area of education, and have borne a disproportionate burden of governmental austerity policies and cuts to public services (Daroczi et al., 2018; Ryder et al., 2012). This is especially apparent in the discontinuation of Traveller Education

Support Services (TESSs), which provided culturally specific in-class support to pupils from Gypsy and Traveller communities (Shallice & Greason, 2017). As local authorities increasingly discontinued TESSs, many Gypsy and Traveller children encounter greater difficulties in adjusting to formal education, ultimately exhibiting low levels of educational attainment an achievement and high rates of exclusion (EHRC, 2016). According to school data, GRT pupils fell far behind white children in their achievement of 'a good level of development' in early years education, and a substantially lower percentage of GRT children reached GCSE level (13.8% of Gypsy and Roma children and 17.5% Traveller compared with 60.3% of other White children in 2012-13) (EHRC, 2016, p. 106).

2.3.3 Perceptions of health amongst Gypsy and Traveller communities

Gypsies and Travellers tend to have low overall expectations of individual health and adopt a fatalistic acceptance of ill health, which may be in part attributable to negative past experiences of health service use (Smith & Ruston, 2013). Some are reluctant to acknowledge chronic health problems – such as chronic bronchitis, asthma and angina – which may lead to avoidance of care until health issues severely interfere with daily activities (Van Cleemput et al., 2007; Parry et al., 2004). Further, Gypsies and Travellers perceive health benefits arising from frequent movement, through which they are able to live in extended family groups and maintain autonomy in choosing their places of residence (Cemlyn et al., 2009; Parry et al., 2007; Van Hout & Staniewicz, 2012).

Prejudice and discrimination may also impact on Gypsies' and Travellers' access to services (Van Cleemput & Parry, 2001; Parry et al., 2004). When Gypsy and Traveller individuals perceive that they have been provided inadequate service, word travels quickly within their communities:

> 'Close community and large family networks ensure stories of unpleasant experiences, medical mishaps or adverse outcomes are frequently recounted and so make the incidence of negative events appear higher. The reverse is also true with good reputations being well circulated' (Parry et al., 2004, p. 49).

Mistrust of health professionals has roots in discrimination within health services, which may manifest itself in GP surgeries' refusal to register GRT patients and perceptions of dismissiveness or impatience on the part of providers (Greenfields, 2014; McFadden et al., 2016). Perceiving health professionals to be inattentive to their needs, Gypsy and Traveller patients may avoid medical care and preventative practices such as immunisation, immersing themselves in family and community networks as a means of compensating for the lack of formal medical input (Greenfields, 2014; Parry et al. 2004; Smith & Ruston, 2013).

2.3.4 Mental health and wellbeing in Gypsy and Traveller communities

Much as in Roma communities, the experience of life in a stigmatised minority can have substantial impacts on Gypsy and Traveller perceptions of mental health. Studies highlight high rates of anxiety and depression related to poor environmental conditions, financial insecurity, loss and grief, as well as limited access to mental health services (Cemlyn et al., 2009; Parry et al., 2004; Smith & Ruston, 2013; Goward et al., 2006). In a study of mental health perceptions amongst Gypsy and Traveller communities in Sheffield, stigmatisation of mental health issues, limited awareness of available services and conditions of socioeconomic deprivation were shown to limit service accessibility (Goward et al., 2006). The authors note that 'most participants in this study do *not* describe serious and enduring mental health problems, but they *do* describe difficulties that are distressing, difficult to address and disabling' (p. 324). As this study was localised and based on self-reporting, however, it is difficult to draw conclusions as to national prevalence of mental health issues. Gypsies and Travellers report no clear preference for specialist mental health services, though they could benefit from support that targets not only their mental health needs but also the wider challenges stemming from socioeconomic disadvantage (Cemlyn et al., 2009; Goward et al., 2006). While social stressors can contribute to mental ill health, strong family bonds and feelings of community solidarity in the face of external pressures have also been reported to enhance the psychological wellbeing of Gypsies and Travellers (Smith & Ruston, 2013).

A further social precursor to mental ill health arises from the coercive transition from a travelling lifestyle into settled accommodation, with governmental settlement policies negatively impacting on the mental wellbeing of Gypsies and Travellers (Greenfields & Home, 2006; Smith & Greenfields, 2014; Smith & Ruston, 2013). This arises not only due to the sense of 'cultural aversion' that many Gypsies and Travellers feel toward housing, but also due to overt expressions of racist sentiments from members of the public, contributing to a sense of social isolation (Greenfields, 2010; Smith & Ruston, 2013, p. 66; Smith & Greenfields, 2014).

2.3.5 Issues in health service accessibility for Gypsy and Traveller communities

Gypsies and Travellers encounter numerous institutional barriers to preventive screening and primary care services, in some cases finding GP practices reluctant to register Gypsy and Traveller patients or refusing to register them outright (frequently citing lack of a fixed address as the reason for refusal) (Cemlyn et al., 2009). When compared to other minority ethnic groups, Gypsies and Travellers have been found to have lower levels of health service use, which is especially pronounced amongst Gypsy and Traveller individual with greater health needs (Peters et al., 2009). Parry et al. (2004) frame the issue of health service accessibility in terms of confidence, explaining how feelings of insecurity their interactions with health services may decrease Gypsy and Traveller individuals' motivation to out care, and may also make them less likely to ask for clarification about the treatment they receive. This sense of discomfort in health care setting has been observed across numerous studies of Gypsy and Traveller health and has been uniformly linked to disinclination to seek out formal medical support (Parry et al., 2004; Cemlyn et al., 2009; Greenfields, 2014; Marsh, 2017; Smith & Ruston, 2013). As a response to difficulties with registering with GPs, Gypsies and Travellers may resort to A&E services to gain access to routine treatment (Marsh, 2017; Cemlyn et al., 2009).

In addition to institutional barriers to care, social and cultural disparities between health care providers and Gypsy and Traveller patients can affect the nature and quality of patient-provider communication. Intense fear of cancer within Gypsy and Traveller culture may lead community members to avoid screenings (Parry et al., 2004), and cultural stigmas associated with discussion of sexual and reproductive health may preclude contact with relevant services (Cemlyn et al., 2009). Gypsy and Traveller communities also tend to have clear expectations of professional conduct, and when an appointment feels hurried or patients' literacy issues produce embarrassment or discomfort, patients are much less likely to disclose key symptoms or to adhere to treatment plans (Greenfields, 2014). More generally, volatile relationships of trust and distrust with service providers means that extent of prior contact with a service and strong interpersonal relationships with individual professionals are fundamental in shaping Gypsy and Traveller patients' ease of access (Marsh, 2017; Cemlyn et al., 2009).

2.4 Summary

This literature review cuts across issues of public representation, disadvantage across a range of social indicators and lack of concerted policy responses to reveal a picture in which Roma face multiple challenges in meeting their basic health care needs. The early sections of this chapter provide background to Roma migrant communities' efforts to gain equitable access to public services. Both the UK media and the state have associated Gypsy, Roma and Traveller identity with nomadism, vagrancy, itinerancy, deviancy and anti-social behaviour (Greenfields & Home, 2006; Okely, 2014; EHRC, 2016). Due to external hostility, these communities have developed coping mechanisms based in the maintenance of strong intra-community social bonds, along with reluctance to engage with external social networks (Smith & Greenfields, 2011; Marsh, 2017). For Gypsies and Travellers, this can be achieved by maintaining collective lifestyles within permanent housing, while Roma may do this through settlement in multicultural neighbourhoods, where their ethnic identity is less visible than in their countries of origin (Brown, Scullion & Martin, 2013; Smith & Greenfields, 2015). In further efforts to resist discrimination, Gypsies, Roma and Travellers are increasingly entering into religious communities such as Pentecostalism, in which they feel a greater sense of social acceptance than is afforded by majority belief systems (Todorovic, 2012; Marsh, 2017).

Despite these commonalities in experiences of racism and exclusion, Gypsy, Roma and Traveller individuals rarely express a sense of common cultural values across the different communities (Greenfields, 2010). Indeed, across the areas of health, housing, education and employment in the UK, GRT communities differ substantially in their key concerns. Taking health service accessibility as a case study in cross-group disparities, Roma often find their experiences of health services defined by language barriers, difficulties of communicating through interpreters and difficulties of navigating a foreign health system (McFadden et al., 2018; Tobi et al., 2010). Central concerns in Gypsies' and Travellers' efforts to health services often arise as a consequence of their travelling lifestyle and greater visibility as a minority group in the UK, with Gypsy and Traveller community members identifying direct discrimination from health service providers and physical distance from health services as key barriers to access (Parry et al., 2004; Cemlyn et al., 2009).

Despite these differences in interactions with health services, notable similarities arise in the distinct case of Gypsy, Roma and Traveller community members' perceptions and experiences of mental health issues. Studies addressing GRT groups note the prevalence of anxiety and depression across all communities, often drawing connections between mental health issues and social stressors, such as insecurity in employment and housing situations (Toth et al., 2017; Parry et al., 2004; Goward et al., 2006). Stigmatisation of mental health issues and reluctance to show ‘weakness’, however, contribute to disinclination to access mental health services amongst GRT individuals (Marsh, 2017; Warwick-Booth et al., 2017; Roma Support Group, 2012; Lee et al., 2014; Goward et al., 2006; Parry et al., 2004). Instead, GRT individuals frequently rely on strength of family ties to enhance feelings of psychological wellbeing (Smith & Ruston, 2013; Lee et al., 2014).

Amid these multiple indicators of disadvantage and deprivation, Roma individuals bear one final, overarching distinction from Gypsies and Travellers in the sense that they are an immigrant group in the UK. Particularly in the context of the UK’s decision to leave the EU, this has become an overwhelming concern in Roma communities and a vital determinant of their inclusion in UK policy agendas (Morris, 2016; Brown, 2018). For many Roma, basic access to services may come to be precluded by insecurity in their future immigration status and their increased vulnerability in ensuring that they will be able to continue living in the UK post-Brexit. The possibility of losing their right to reside in the UK is likely to represent an increasingly pressing concern, and it will be vital to consider the human implications of potential involuntary returns to repressive conditions in Roma communities’ countries of origin.

Chapter 3: Theoretical and methodological review

3.1 Aims and objectives

Building on the literature, this study aimed to understand the ways in which Roma migrants in the UK interact with UK health and public services, and how their experiences in turn offer insight into their position in a wider socio-political landscape.

These were the research questions:

- To what extent do language and communication barriers influence Roma community members' health service use and interactions with health professionals?
- To what extent does the experience of claiming disability benefits impact on Roma community members' sense of stability, security and emotional wellbeing?
- To what extent do the Health and Social Care Act of 2012 (and associated health system restructuring) reflect the needs of Roma communities?
- To what extent do institutional and bureaucratic structures of UK health and welfare systems create power differentials between Roma community members and service representatives?
- To what extent do wider socio-political factors – including immigration, discrimination and racism – influence Roma community members' conceptualisations of their position within UK social institutions?

The questions focused on the nature of interaction between Roma community members and social institutions, building on the accounts of deprivation, discrimination and restricted access to essential support that were so prevalent in my literature review. With this emphasis on power differentials across social groups, I chose to base this study in the traditions of critical theory, which offers perspectives on the structural origins of inequalities faced by disadvantaged and minority communities. I then went on to select an analytical framework for approaching my data. My foremost aim was to avoid a representation of Roma experiences that would favour my perspective as a non-Roma researcher over those of Roma participants in my study, and the inductive approach offered by a grounded theory methodology seemed closely to align with this research goal.

Data were collected over the course of approximately two years, during which I spent four days per week in the research field, conducting interviews and engaging in participant observation. Grounded theory did indeed provide a means for outlining participants' key concerns as they considered their interactions with health services, yet this approach ultimately fell short in capturing the pronounced storytelling aspect of many participants' accounts. Revisiting my data after the first round of analysis, I retained the descriptive categories identified through grounded theory frameworks, yet ultimately chose to re-analyse selected data using a narrative methodological approach. The frameworks I developed through grounded theory analysis served as guidelines for understanding key themes in participants' stories, and narrative analysis in turn added depth and nuance to the grounded theory categories, ultimately giving rise to a 'hybrid' grounded theory and narrative methodology. This chapter sets out in greater detail my pathway to this approach.

3.2 Developing a theoretical perspective

Paradigms are the basic sets of assumptions that guide interpretation of literature, development of a data collection strategy and selection of analysis methods (Denzin & Lincoln, 2008). I reviewed a range of paradigms – including positivism, postpositivism, constructivism, interactionism and critical theory – all of which describe means of conceptualising social realities, yet diverge in the weight they place on individual thought processes and social power structures in understanding of the nature of reality. Positivism establishes links between social circumstances and a single knowable reality that exists independent of the observer. Constructivism, interactionism and critical theory each offer perspectives on the manner in which individual realities can be shaped by orientation in time and place, interactions with other people and contact with social institutions, emphasising that each individual observer will develop a distinct view of a social reality on the basis of past experiences and the conditions of a particular time and place (Burrell & Morgan, 1979; Denzin & Lincoln, 2008).

In addition to providing abstract guidance on the nature of reality, paradigms also aid in the selection of concrete steps for interpreting phenomena (Denzin & Lincoln, 2008; Guba & Lincoln, 1994). These next steps (methodologies) involve operational choices about data collection and analysis, as well as understandings related to the social context of the data. Much in the way that I considered a range of paradigms, I also assessed a variety of methodologies, including case study analysis, phenomenology, ethnography, ethnomethodology and grounded theory. In designing my study, I sought to avoid frameworks that could lead to unsubstantiated assumptions about Roma identity and their position in society. I wanted to understand the social world of Roma communities from the perspective of those who make up these communities, and also to discern their relationships with other segments of society and social institutions. This required theoretical and methodological perspectives with the potential to elucidate multiple dimensions of Roma identity, health perceptions and social interactions, while also allowing for contextualisation of these interactions.

3.3 Addressing social structure and power dynamics: The selection of an interpretive paradigm

Denzin and Lincoln (2008) elucidate the concept of researcher as bricoleur, in which a strategy of inquiry is formed through borrowing from different disciplines and interpretive processes. The term 'bricoleur' refers in French to a handyman or tinkerer, which, applied to a research context, suggests a process of piecing together a number of distinct component parts to form a whole and – perhaps most significantly – making continual adjustments to ensure proper functioning. As I considered my theoretical stance in this study, it became increasingly clear that restricting myself to one paradigm or methodology could limit my understanding of the numerous social, cultural and political forces shaping life in Roma communities and contact with external groups and institutions.

Developing an interpretive paradigm incorporated a number of theoretical traditions, with my understanding of Roma health experiences undergoing constant revision. My theoretical perspective initially focused, for instance, on individual conceptualisations of health as the primary force shaping interactions with services, yet as I spent more time in Roma communities, I became increasing cognizant of social power imbalances as a fundamental force behind participants' discussions of health care. While I did not abandon my early interest in individual constructions of reality, that interest ultimately came to represent only one of many components in a wider view of social power differentials. In this application of the researcher-as-bricoleur concept, I formulated a theoretical perspective that 'steer[ed] clear of pre-existing guidelines and checklists developed outside the specific demands of the inquiry at hand' and allowed for adjustment of my thinking about Roma health experiences as my involvement in the field progressed (Kincheloe & McLaren, 2008, p. 21).

3.3.1 Analysing social structures

Key to my approach to understanding Roma health experiences are the interrelated concepts of ‘structure’ and ‘power’. In simplistic terms, structures can be defined as the systems, rules and institutions that shape each person’s behaviour in society (Lukes, 1974). A concept of structure must encompass both the conscious and the unconscious rules of behaviour: the institutions we participate in knowingly and those that operate outside of our recognition (Lukes, 1974). Structures shape social interaction at various levels – ranging from close interpersonal relationships to the individual’s interactions with government institutions – and regulate people’s relationships with each other and within social groups. Cultural conceptions of morality, for example, constitute social structures that produce a deeply engrained sense of which actions can reasonably be undertaken in a given social setting, thus limiting the range of socially ‘acceptable’ behaviours (Giddens, 1976).

Structures have the potential to play a key role in shaping individual social consciousness, yet they also can place limitations on those who do not hold a privileged position within them. Different positions within social structures give rise to ‘unequal opportunities for self-development and access to resources, to make decisions about both the conditions of their own action and that of others, or to be treated with respect or deference’ (Craig, Burchardt & Gordon, 2008, p. 80). Structures have their basis in repeated actions that allow certain groups to take on roles of greater influence in political, social and economic activities and decisions, while other groups are comparatively marginalised and unable to influence social systems to function according to their needs (Giddens, 1976; Young, 1990). Marginalisation then perpetuates patterns of dominance, in which institutions display bias in favour of particular social groups, and those with less social power are deprived of the freedom to act and the ability to influence the external conditions of their lives (Lukes, 1974; Young, 1990). In this vein, Lukes (1974) argues that ‘restrictions on the scope of decision-making may “stunt the political consciousness of the local public”’ by confining minority opinions to the social spaces that these groups occupy and preventing minority groups’ views from gaining recognition beyond local spheres of influence (p. 48).

This concept of structure – in which individuals and groups come to be subjugated within institutional measures to perpetuate hierarchies of dominance – emerged as particularly relevant in the context of my hybrid analysis strategy (described in more detail in Chapter 4). Acknowledging Guba & Lincoln’s (2008) notion that ‘active construction and co-creation of knowledge by human agents that is produced by human consciousness' (p. 269), analysis sought to capture how both Roma individuals and the broader Roma community constructed their views of UK health systems within the confines of pre-existing structures. Grounded theory analysis offered a granular view of Roma participants' understanding of their position within the institutional structures of UK health and public service systems, while narrative analysis revealed how the power differentials identified through grounded theory analysis shaped individual perceptions. Paying attention to the role of social structures and power relationships at the interface of group and individual experiences – particularly with reference to social marginalisation – can offer insight into the Roma community's collective understanding of disadvantage within UK public institutions, as well as individual efforts to combat (or cope with) discrimination.

3.3.2 Power differential and the critical theory paradigm

The critical theory paradigm has its basis in power relationships and systems of oppression as the primary factors underlying the development of individual and group conceptions of reality (Guba & Lincoln, 2008). This perspective stipulates that 'certain groups in any society and particular societies are privileged over others and, although the reasons for this privileging may vary widely, the oppression that characterises contemporary societies is most forcefully reproduced when subordinates accept their social status as natural' (Kinchloe & McLaren, 2008, p. 405). Every person belongs to a complex, heterogeneous, interacting and flexible set of social groups – and although it is an oversimplification to attribute social power entirely to group membership – it nonetheless provides a useful model for representing how social divisions lead some people to 'have' and others to 'have not' (Arnstein, 1969). As Arnstein (1969) observed in the context of citizen power as a force for upsetting the social status quo, collective citizen action is only effective when it allows for 'redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future' (p. 216).

Each society produces its own self-perpetuating order in which a dominant group's 'sense of reality' gains widespread social acceptance, and every interaction 'owes its form to the objective structures which have produced the dispositions of the interacting agents and which allot them their relative positions in the interaction and elsewhere' (Bourdieu, 1977, p. 81). As Arnstein (1969) posits, people hold power when they have the ability to actively participate in and influence the political and economic conditions in which they live. To preserve their influence, powerful groups throughout history have created social institutions that reflected a desired social order, which function in the maintenance of a political status quo and the preservation of a powerful group's influence (Arnstein, 1969; Bourdieu, 1977; Swartz, 1997). An official language, for example, can create power structures by ensuring that the 'authorised language' commands the most attention and enabling its speakers to gain power from the ability to publicly discuss their thoughts and experiences (Bourdieu, 1977). Members of society who fall outside the group of official language speakers are less able to exert influence in public life.

3.3.3 Critical race theory

Power, privilege, oppression and marginalisation take on particular relevance in looking at the situation of the Roma and – with an emphasis on inter-ethnic relations – lead on to a discussion of critical race theory. This theoretical tradition arose out of legal studies and operates on the assumption that the law cannot be seen as a 'neutral and objective' set of rules, but rather favours groups falling into the 'white' racial category (Price, 2010, p. 150). Focusing on the relationships between majority and minority ethnic groups, critical race theory rejects the possibility of a neutral perspective on cultural differences, stipulating that every viewpoint on an issue represents the perception of either the oppressed or oppressor group (Peller, 1995). Critical race theorists further posit that ethnic minority groups – and particularly ethnic minority women – face 'compound marginalisation' based on the intersecting disadvantages arising from race, gender and poverty (Crenshaw, 1995, p. 374).

Within this framework, the racialised marginalisation of the Roma provides a means for investigating how interactions between Roma individuals and public institutions fit into historical patterns of dominance and subjugation. Critical race theory offers frameworks for understanding how marginalised minority groups' communications and expressions of experience to the wider society requires them to conform to the expectations and communicative practices of the majority, while also stipulating that this is often the only way for minority voices to be heard within a hegemonic social order (Torres & Milun, 1995). In this way, though, the views of oppressed racial minorities also hold the potential to 'adapt and transform standard texts and mainstream consciousness' to reveal key areas for social reform (Matsuda, 1995, p. 65). These concepts take on particular salience when considering the tensions that arise when non-Roma study the Roma, as Roma research subjects find that research reports draw false parallels between Roma culture and social disadvantage (Munte, Serradell & Sorde, 2011). With this study’s focus on the conditions of Roma marginalisation, critical race theory offers a powerful means for representing the ways in which Roma individuals harness their individual stories and experiences to counteract dominant social orders, allowing for the reversal of narratives of intrinsic disadvantage.

3.3.4 Rationale for applying a critical theory perspective

I identified critical theory (incorporating critical race theory) as most appropriate for my study, as it directed my enquiry towards the questions of social inequalities and power structures that my literature review had revealed as fundamental factors shaping Roma health. The overarching aim of this research was to identify the social and systematic interactions that shape Roma individuals’ contact with health services, looking specifically at the intersection points between immigrant status, membership in a marginalised ethnic minority group and efforts to access public systems of support. Applying a critical (race) theory perspective provided a means for recognising the power structures implicit in these interactions, thus offering insight into the manner in which Roma communities’ marginalised social position influences the quality of their interactions with health services, while also shedding light on the ways in which discriminatory attitudes toward the Roma ethnic identity can perpetuate unequal treatment by health care providers.

Individual and group consciousness is not merely abstract, but reflects social and political realities (Burrell & Morgan, 1979). The decision to seek out health care and subsequent interactions with health systems are inherently social, in that they require an understanding of which services provide the care required for a given condition, as well as a calculation of the potential risks associated with seeking out care in an unfamiliar health systems. People do not react to ‘objective conditions’ but to the practical interpretations they produce of those conditions, creating a social world in which ‘technical or ritual practices are determined by the material conditions of existence’ (Bourdieu, 1977, p. 116). This emphasis on power structures can serve as a foundation for understanding how the Roma community’s long history of discrimination and social marginalisation continues to exert its influence in conscious and unconscious behaviours and biases, situating Roma health experiences in their wider context.

3.4 Developing a methodology

In outlining the theoretical and practical basis of scientific enquiry, Kuhn (1996) states that ‘the determination of shared paradigms is not, however, the determination of shared rules’ (p. 43). As such, where paradigms provide overarching philosophical frameworks for understanding the nature of life, the concrete steps utilised in collecting and interpreting data – known as methodologies – are not necessarily connected to any one given paradigm. Selecting a paradigm helped to elucidate the focal points of my research – namely the need to acknowledge a range of social, cultural, political and economic structures in order to develop an understanding of the health situation of the Roma. I was then primed to set my priorities in selecting a means for analysing participant observation, interview and policy analysis data. I aimed to create a research strategy that would integrate analyses of varying aspects of the Roma social position into a coherent description of their health situation. I was furthermore cognizant of the fact that – given my attention to power structures – it was important to consider how certain interpretations of the data could reinforce the marginal position of Roma communities, essentially placing my views as a researcher above the views expressed by the participants in my study (Ryder, 2015). It was therefore vital to situate Roma community members’ perspectives at the core of my analysis. Each of the methodologies I reviewed provides different options for giving voice to community members, with some offering a granular approach to extracting meaning from raw data and others taking a more holistic view of individual lives and stories.

3.4.1 Incorporation of ethnographic methods

As I contemplated my entry into the research field and considered how I would interpret data gathered through day-to-day interaction in Roma community spaces, ethnography came to my attention as a valuable approach to data collection and analysis. Ethnography involves attention not only to concrete behaviours and practices, but also to the abstract features of a situation: the wider social context and the perceptions underlying visible acts. Frequently this involves a substantial period of time in the field, though recent developments in ethnography have adopted a more fragmented approach (Lewis & Russell, 2011). The ethnographer records notes on observations and conversations, which forms the basis for describing the beliefs and behaviours of a given segment of society (Lewis & Russell, 2011; Hammersley & Atkinson, 1983; Hammersley & Atkinson, 1994). The core method associated with ethnography is participant observation, through which the researcher engages actively with the subjects of research, recording fieldnotes and memoranda to develop sensitivity to key social practices, and to ensure that the research subject does not become so familiar that the critical insight is lost (Hammersley & Atkinson, 1983).

An ethnographic account should make no value judgements about the groups under observation, yet public readings of ethnographic texts – particularly those that address traditionally marginalised communities – may be prone to undue assumptions reflecting deeply engrained stereotypes. As Bourgois (1995) observes:

> ‘Most ethnographers offer sympathetic readings of the culture or people they study. Indeed, this is enshrined in the fundamental anthropological tenet of cultural relativism: Cultures are never good or bad; they simply have an internal logic . . . This imperative to sanitise the vulnerable is particularly strong in the United States, where survival-of-the-fittest, blame-the-victim theories of individual action constitute a popular “common sense.” The result, as I have noted, is that ethnographic presentations of social marginalisation are almost guaranteed to be misread by the general public through a conservative, unforgiving lens’ (p. 15).

This hostility to anthropological representations of marginalised groups occurs not only on the level of the public, however, but also within political, professional and academic settings, where activist tendencies in anthropological research may be interpreted as subversion (Beck, 2011). Beck (2011) takes the view that activism through participant observation is the moral imperative of the researcher, and that the participant observer working with subjugated groups must work to facilitate an environment of mutual learning and data generation (as opposed to the more one-sided practice of data collection).

Approaching ethnography from a critical perspective can minimise unconscious bias in ethnographic data collection and analysis, and also help to ensure that ethnographic methods do not perpetuate power imbalances between the researcher and the subject group (Harvey, 1949; Beck, 2011). Critical ethnography is concerned with provoking social change, and it involves ‘choosing between conceptual alternatives and making value-laden judgements of meaning and method to challenge research, policy and other forms of human activity’ (Thomas, 1993, p. 4). Potential imbalances in the researcher-subject relationship come into focus with a critical perspective on ethnography (Lewis & Russell, 2011), in which differences between the researcher’s social position and that of the subject group mirror wider social hierarchies and carry the danger of erasing the subject group’s concerns (Peller, 1995). Ethnographers conducting research with Roma communities have further flagged ethnography’s tendency to draw artificial distinctions between Roma and non-Roma, reinforcing the misconception that there is some fundamental difference between Roma and other groups in society (Tremlett, 2012). At the same time, it is important to consider that non-Roma researchers may encounter difficulties in gaining access to Roma community spaces and that entry into the field will need to be carefully negotiated (Risteska, 2015). Participants may serve as gatekeepers to their social spaces, initially viewing researchers with a degree of mistrust (Hammersley & Atkinson, 1983). The researcher's methods of self-presentation may influence participants' responses and openness, with active demonstration of the 'fieldworker's willingness to stay and learn' serving as a key strategy in overcoming some of the barriers created by social difference (Hammersley & Atkinson, 1983, p. 72).

While acknowledging the value of critical ethnography in subverting some of the power imbalances implicit in traditional ethnographic frameworks, I nonetheless remained concerned that a wholly ethnographic methodology could obscure participants' voices behind my own impressions as a non-Roma researcher (Beck, 2011). I was furthermore conscious of the potential for ethnographic data to focus overwhelmingly on difference between Roma and non-Roma comparators (Tremlett, 2012). This latter contention was of particular relevance in light of the policy analysis element of my study, which was predicated on specific reference to Roma as an ethnic group within policy frameworks. It was important to present Roma as a distinct group, yet also to avoid representations that perpetuate stereotypes. To negotiate this methodological tension, my ethnographic observations focused not on establishing an outsider's concept of 'Roma culture', but rather on the nature of interactions between participants and health/public services. Where cultural values appeared to influence the manner in which Roma participants interacted with public institutions, I recorded these impressions; yet I did not view 'Roma culture' as a monolithic entity, separating them from and impeding their interactions with the 'wider society.' I was instead concerned with forces of racism, discrimination and subjugation (of which assumptions about Roma culture likely form a part).

3.4.2 Grounded theory

Grounded theory adopts an inductive perspective on data collection and analysis, in which the researcher enters the field of study without a theory or hypothesis to be tested, and instead utilises the observations made over the course of research to develop a new theory of a given social phenomenon (Glaser & Strauss, 1967). By employing a grounded theory methodology, I allowed the raw data to guide my interpretation of Roma health experiences. Glaser and Strauss (1967) articulate the importance of aligning data and theory to achieve an accurate representation of a social phenomenon, stating that 'the generation of theory from such insights must then be brought into relation to the data, or there is great danger that theory and empirical worlds will mismatch' (p. 6).

Analysis of data according to the grounded theory methodology is based fundamentally in identifying concepts that typify a social situation and specifying the relationships between these concepts. Grounded theory analysis is based on a method known as constant comparison, which entails grouping data according to similarity and difference to identify common themes in the data and to orient participants' accounts in a wider social context (Strauss & Corbin, 1998). Over the course of comparison, the researcher develops a scheme for assigning codes to the data that indicates their wider social significance (Strauss & Corbin, 1998; Bryant & Charmaz, 2007). Grounded theory coding procedures begin with the assignment of general 'open' codes, which serve to heighten the researcher's sensitivity to major themes in the data. The coding process then proceeds with the assignment of 'axial' codes, which establish the relationships between the categories and subcategories defined through the open coding process. Codes facilitate the grouping of concepts identified from the data into categories that represent the social, cultural, political and historical context of the situation under observation. To develop an understanding of these multiple dimensions of the social reality, the coding process includes writing memos offering analysis, commentary and suggestions for further research. By concurrently assigning codes and recording broader theoretical memos, coding moves analysis from identification of specific concepts toward more general statements on the nature of a phenomenon, leading ultimately to a theory encapsulating the social circumstances under observation (Strauss & Corbin, 1998; Bryant & Charmaz, 2007).

While conventional grounded theory seeks to present the subject of enquiry in a manner that aligns as closely as possible with the 'empirical world', some grounded theory researchers take a 'constructivist' perspective on the data (Glaser & Strauss, 1967; Charmaz, 2008). Charmaz (2008) characterises this mode of enquiry as one in which researchers 'giv[e] close attention to empirical realities and our collected renderings of the – *and* locating oneself in these realities' (p. 206). The 'empirical reality' refers to an 'external but discernable world', the characteristics and processes of which can be verified through repeated unbiased observation (Charmaz, 2008, p. 205). Constructivist grounded theory departs from traditional grounded theory's positivist leaning, requiring that the researcher continuously account for multiple dimensions of individual perception – social, individual, historical, political, etc. – while also adhering to the conventional grounded theory technique of basing all theory development in specific segments of data. In first gaining familiarity with major emergent themes and subsequently drawing inductions from the data, the constructivist grounded theorist must consistently place conclusions within a wider social context, thus 'avoid[ing] the hegemonic reach of over-generalisation with its erasure of positionality, difference, time and location' (Bryant & Charmaz, 2007, p. 50).

With its emphasis on social position and experience as vital contributing factors in the development of power imbalances, constructivist grounded theory adhered to my broader paradigmatic perspective. Moreover, grounded theory provided a clear framework for asking questions about experiences of life in social groups other than my own, elucidating interconnections between different aspects of this unfamiliar social world. I took an inductive approach to data analysis, basing all conclusions in specific segments of data in an effort to align my findings with participants' distinct impressions.

3.4.3 Narrative methodologies: Analysing stories to understand reality

As I took a first pass through the development of a methodological approach to my study, I was primarily concerned with the possibility that hegemonic assumptions would arise from my analysis, simply because I occupy a position of advantage in comparison with the majority of my study participants. I aimed to select a methodology that would bring forth participants' distinct voices and experiences, and grounded theory's emphasis on analysing data based on codes drawn directly from participants' accounts presented a path forward. After grounded theory analysis, however, the ensuing results seemed to lack much of the nuance of the raw data. There were powerful details of participants' accounts that lost their meaning when broken down into discrete codes and that could only be understood in the wider context of an individual's life situation. I had identified storytelling as a defining feature of Roma health communication, yet my grounded theory analysis gave little attention to participants' distinct stories. With this in mind, I revisited methodological approaches and identified narrative analysis as a means for capturing the key details of participants' health communication, and also for giving voice to participants in a deep and meaningful way.

Organising life events into stories can be seen as a means of making sense of a chaotic reality, and narrative analysis looks to understand the connections that people draw across events in their lives and their reasons for relating particular stories at particular times (Josselson, 2011; Riessman, 1993; Clandinin & Connelly, 2000; Greenhalgh, 2016; Robert & Shenhav, 2014). Narrative analysis is not concerned with representing events exactly as they happened, but rather focuses on the holistic development of an individual's story in light of the social and cultural settings in which both the events of the story and its telling occurred (Josselson, 2011; Muller, 1999; Gubrium & Holstein, 2008; Greenhalgh, 2016). This mode of analysis traditionally avoids division of the story into thematic categories, seeking instead to represent an individual's lived experience as a coherent whole (Josselson, 2011; Muller 1999; Gubrium & Holstein, 1998).

The first step towards narrative re-analysis of data was to consider the narrative character of my ethnographic observations. When taken together, ethnography provided a broad view of the patterns arising from social interaction – such as differentials in social status and collective behaviours of a social group – and narrative analysis supplemented these broader accounts through individual stories (Gubrium & Holstein, 1999). Interspersing individual narratives with a wider ethnographic account can thus 'constitute meaningful social experience, as well as produce distinction and nuance', while simultaneously upholding the overarching attention to social structures and patterns of interaction (Gubrium & Holstein, 1999, p. 568).

Narrative ethnography operates on the central premise that the external social and cultural environment in which storytelling occurs is the main factor determining the details and structure of the resulting narrative (Gubrium & Holstein, 2008). Key to this analysis model is the idea that there are multiple perspectives on every story and multiple contextual factors that shape the way in which the storyteller chooses to represent events (Gubrium & Holstein, 2008). Where multiple interpretations of a narrative are possible, it is the role of the researcher to determine where these perspectives diverge, and then to identify the sources of this divergence. Culture influences both the individual's choice of which stories to tell and also the method of telling, and narrative research seeks to understand how these individual narratives are broader cultural narratives, and the ways in which members of a culture collectively understand events (Muller, 1999). Narrative ethnography thus is key in providing context to individual life stories and in elucidating the impacts of external social and cultural factors on participants' representations of reality. This can help to establish the link between the individual and the wider social environment, which, when viewed through a critical theory lens, can also shed light on the power differentials implicit in participants' narratives.

The idea of control over the means by which stories are told highlights connections between narrative research and critical theory, in which storytelling can be harnessed as a tool for marginalised groups to 'frame and probe the status quo' (Price, 2010, p. 158). Narrative analysis looks at the unique social position and profile of the storyteller, giving attention to which voices are silenced and which voices are heard and revealing how the stories people tell are indelibly bound with the collective impact of life experiences within systems of social dominance (Price, 2010; Robert & Shenhav, 2014). Furthermore, particularly when employing narrative ethnographic frameworks, the researcher must be careful to present the research subject not as an 'exemplar of culture', but rather as a complex individual with a varied array of life experiences (Clandinin & Connelly, 2000, p. 45). Narrative inquiry seeks to provide as nuanced a view of the research subject as possible, achieving this through analysis models that take a holistic view of life experiences, behavioural factors and environmental influences in explaining how individuals understand their lives.

Narrative analysis must account for the multiple perspectives and interpretations of events that emerge through a research text, as well as the many ways in which they can be interwoven to produce a nuanced view of the social world under observation (Muller, 1999; Clandinin & Connelly, 2000). In considering these multiple perspectives, it is important that a researcher's understanding of a social phenomenon may differ fundamentally from a participant's perception (Clandinin & Connelly, 2000). Neither interpretation should be privileged over the other, and the researcher should seek to understand potential social and cultural sources for the discrepancy. The narrative researcher is thus continually filtering through alternate readings of research texts, looking at what is said, what is not said and the reasons for inclusions and omissions of information (Riessman, 1993). Despite an overall focus on the voice of research participants in creating meaning through narrative, it is important as well to consider how the researcher is integrated into the development of participants' narratives and the ways in which the researcher's personal impressions shape the representation of the field (Muller, 1999; Riessman, 1993). On one level, the presence of the researcher influences the stories that respondents choose to tell and the details that they choose to disclose (Muller, 1999). Yet the researcher's personal experience in the field also constitutes an individual story in itself, which can shed light on elements of the research environment that participants in the research environment may take for granted (Clandinin & Connelly, 2000).

3.4.4 Arriving at a hybrid analysis strategy

I sought to identify an approach to my data that would yield a nuanced understanding of participants' individual experiences and their interactions within a wider social environment. The initial use of grounded theory was intended to establish interconnections across participants' experiences and health service practices and policies, with the ultimate view of formulating a theory that would encompass Roma participants' distinct views of their disadvantage within health systems. Had all interviews adhered to the semi-structured topic guide, a grounded theory approach might have been effective. However, a number of participants' responses to interview questions departed substantially from the topic guide, expounding at length on a key health related concern. Analysis according to grounded theory provided a basic framework for understanding the key themes emerging from the data, but it left out much of the richness of detail of personal stories that did not fit neatly into grounded theory categories. Josselson (2011) reflects on the potential for grounded theory to disregard much of the nuance of personal narratives, explaining how 'Categories that are too separate are artificial. Human life is of a piece, multilayered, contradictory and multivalent, to be sure, but the strands are always interconnected' (p. 232).

The view of the data generated through line-by-line coding and constant comparison of categories nevertheless offered a useful framework for understanding the social and institutional world in which individuals' stories were situated. Furthermore, some interviews had followed a largely semi-structured framework, and a full reanalysis according to narrative methodology could have resulted in the loss of this data from the study. Taking into account that narrative methodologies usually reflect individual cases, while grounded theory tends to generalise across cases (Floersch et al., 2010), I developed a hybrid approach to data analysis, which would at once capture the grounded theory framework for understanding the social environment and the nuance of individual stories. In this model, grounded theory categories provide signposts for understanding narrative development and show interconnections between patterns in the data, while narrative analysis adds depth to the findings, enriching grounded theory categories with concrete examples of their personal significance (Floersch et al., 2010).

Hybridising narrative analysis and grounded theory to interpret interview and participant observation data can also provide additional perspectives on the policy analysis dimension of this study. Greenhalgh

(2016) notes how personal stories have an ethical dimension that can alert policy makers to alternative means for addressing social issues, and policy analysis discussions can then reveal the extent to which policy decisions reflect the concerns emerging from participants' accounts. Furthermore, a growing stream of narrative research analyses policy discourse, looking at the representation of traditionally marginalised voices in policy decisions (Greenhalgh, 2016). Taken together with grounded theory, this hybrid analysis framework allows for interpretation of policy decisions in light of both broader group experiences of interacting with health services and immediate personal narratives of health.

3.4.5 Precedent for hybrid methodologies and re-analysis of data

My development of a hybrid methodology draws on a body of research that applies narrative analytical techniques to provide additional perspectives on results obtained through other analysis methods. In a study of the interactions between physicians and medical students, Muller (1999) conducted initial grounded theory analysis to determine thematic categories, and later reanalysed data to look for content, plot and placement within the larger cultural framework. While the study was not initially conceived as a work of narrative analysis, Muller sought to describe the ways in which medical students constructed their patients' therapeutic narratives over the course of contact with a licensed physician. This example is loosely reflected in a framework outlined by Floersch et al. (2010), which posits that thematic and grounded theory analysis serve as an effective foundation for subsequent analysis of data according to a narrative methodology. Applying this methodological model to a study of adolescents' conceptualisations of psychiatric medications, thematic analysis allowed for initial identification of key themes arising from the data, grounded theory analysis described the interrelations across these themes and narrative analysis then describes how the data is situated in time and place.

In a larger scale study of disruptive events in life and individuals' subsequent attempts to re-establish a sense of continuity, Becker (1997) applied narrative analytical techniques to ethnographic and interview data originally analysed according to different methodologies. With an intention of investigating the (seemingly) conflicting notions of order and chaos in individual lives, the selection of narrative as a secondary analytical strategy was predicated on the idea that narrative allows people to reformulate their understandings of identity and the world around them. The narrative reanalysis particularly emphasised the structure of the participant's account, and the way that this revealed the participant's understanding of the progression of life events and attempts to create coherence out of trauma (Becker, 1997).

3.5 Summary

In reviewing methodological and theoretical literature, I gave consistent attention to the social position of Roma communities and the manner in which each perspective could shed light on the character of Roma community members' engagement with UK public institutions. With its focus on power differentials, adopting a critical theory perspective provides a means for achieving a holistic view of UK Roma health and for understanding the numerous intersecting factors that shape their access to services. After defining my theoretical perspective, I discussed the applicability of ethnographic participant observation methods to my study, while also expressing my reservations at adopting a fully ethnographic approach when a primary goal was to represent participants' voices. This led on to a discussion of the central tenets of a grounded theory methodology, and the utility of grounded theory's inductive approach in gaining insight into participants' concrete concerns. Recognising the limitations of grounded theory in representing participants' individual stories, however, I moved on to make the case for apply a methodological framework that hybridises grounded theory and narrative approaches (and also incorporates ethnographic participant observation methods). This section discussed the shortcomings of analysing data exclusively according to a grounded theory methodology and justified the inclusion of a narrative approach to supplement grounded theory findings. I explored how overlaying grounded theory themes with individual participants' health narratives can add nuance to the data and then outlined previous studies that have employed similar approaches.

Chapter 4: Data collection: Policy analysis, participant observation and interviews

4.1 Introduction

This chapter outlines the data collection methods employed in this study, describing my approach to policy analysis, participant observation and interviews. Given that I did not have contact with Roma communities prior to this research, I implemented this three-pronged approach to data collection with the intention of gaining as wide a view of participants' health experiences and their context as possible. The first stage of data collection was a review and analysis of UK policy responses to Roma health inequalities, which revealed the extent to which Roma are (and are not) recognised within official service provision frameworks, and also provided insight into power imbalances that was vital to my critical theory perspective. Participant observation and interviews then captured details of day-to-day life in Roma communities and Roma participants' distinct impressions of their experiences within health and benefits institutions. Gaining access to Roma communities was not without its challenges, and my entry into the field necessitated careful consideration of potential participants' views of the presence of a researcher within their community spaces.

4.2 An overview of data collection strategies

4.2.1 Approaching the field

Entering my study sites as a complete outsider, I was highly conscious that building necessary trust with participants would require me to develop research relationships that did not simply involve collection of data for my own benefit, but that also addressed some of the needs of research participants (Beck, 2011). While a lengthy fieldwork period and daily involvement in Roma community centres offered a starting point for building trust, my presence alone was not enough to ensure that prospective participants understood my research goals and felt confident in sharing details of their health experiences with me. Carr et al. (2014) formulate this contention in terms of the 'inverse role of trust and negotiation' (p. xxv), which stipulates that trust is not automatic, and that researchers will need to expend significant effort in building trust at the start of a study.

To address these concerns, I developed close collaboration with two charity organisations working to challenge the persistent discrimination against Roma. Each of these organisations conducts activities aimed at improving access to health services, education and housing, as well as to increase public awareness of Roma rights. I volunteered with these organisations as a health advocate, which enabled me to gain deep insight into the challenges that Roma people face in accessing health services, and also to provide direct support to individuals who were experiencing difficulties in engaging with health services. Although this approach was effective in allowing me to demonstrate an active commitment to improving community health experiences, it also brought certain challenges to maintaining my objectivity and ensuring the representativeness of my sample. I acknowledged that my depth of involvement in health advocacy activities could put me in disproportionate contact with individuals who face serious challenges in accessing health services. I further understood that my association with community organisations could impact on the nature of the information that respondents disclosed. Despite these potential limitations, health advocacy provided regular opportunities for gathering observational data and offered a direct means of making contact with potential participants for interview.

4.2.2 An overview of data collection methods

I adopted three strategies of data collection to achieve a multifaceted look at the health situation of Roma communities in England. They were: 1) a review of health policy documents; 2) participant observation in Roma community organisations; and 3) interviews with community members, community support workers and health professionals. Data collection methods were selected with the aim of developing a holistic view of the environment in which Roma community members interact with health professionals, as well as to capture broader interactions with UK public institutions (focusing specifically on health-related benefits and immigration insecurity).

This table provides an overview of my three modes of data collection, outlining the specific activities involved in each method and defining their connections to my research questions.

Table 3: Data collection methods

Method	Research questions	Data collection activities
1) Policy analysis	To what extent do the Health and Social Care Act of 2012 (and associated health system restructuring) reflect the needs of Roma communities?	a) Review national policies related to health services and equalities b) Review critical analysis of national legislation c) Review Joint Strategic Needs Assessments (JSNAs) addressing Gypsy, Roma or Traveller health
2) Participant observation	To what extent do language and communication barriers influence Roma community members' health service use and interactions with health professionals? To what extent does the experience of claiming disability benefits impact on Roma community members' sense of stability, security and emotional wellbeing? To what extent do institutional and bureaucratic structures of UK health and welfare systems create power differentials between Roma community members and service representatives? To what extent do wider socio-political factors – including immigration, discrimination and racism – influence Roma community members'	a) Engage in volunteer work with Roma community organisations b) Record fieldnotes based on events and interactions observed in the field

	conceptualisations of their position within UK social institutions?	
3) Interviews	To what extent do language and communication barriers influence Roma community members’ health service use and interactions with health professionals? To what extent does the experience of claiming disability benefits impact on Roma community members’ sense of stability, security and emotional wellbeing? To what extent do institutional and bureaucratic structures of UK health and welfare systems create power differentials between Roma community members and service representatives? To what extent do wider socio-political factors – including immigration, discrimination and racism – influence Roma community members’ conceptualisations of their position within UK social institutions?	a) Develop a topic guide based on literature review and field observations b) Engage in semi-structured conversations on the basis of this topic guide c) Adjust interview questions based on topics arising from prior interviews and continuing participant observation

An analysis of policies related to GRT health (Chapter 5) offered a view of current levels of health service provision to Roma populations, revealing striking local variations in the extent of local decision makers’ recognition of Roma needs. The policy analysis provided a foundation for collection and analysis of field data. Comparative analysis of policy documents furthermore indicated the current state of thinking about Roma needs within UK health care institutions, suggesting the power relations implicit in decision makers’ efforts to define Roma health needs (often without community consultation).

Where the policy analysis responded to my research questions by elucidating aspects of the relationship between Roma communities and health system institutions, it did not provide insight into Roma experiences of health services, nor does it facilitate description of day-to-day life in Roma communities. My field research investigated Roma experiences of accessing services, with a view *inter alia* of discovering whether there are discrepancies between governmental accounts of service provision to Roma communities and their experiences 'on the ground'. Achieving this aim required a robust strategy for developing an understanding of Roma participants' beliefs, opinions and experiences, and I adopted a combination of participant observation and interview strategies to capture multiple dimensions of Roma health experiences.

Participant observation occurred throughout my fieldwork and was key to facilitating a smooth entry into an unfamiliar research field, as well as for honing my impressions as I moved into data analysis. This method enabled me to develop initial familiarity with the Roma community and to formulate impressions of the ways in which Roma interact with health systems. Furthermore, by beginning data collection as an observer and conducting interviews only after I had spent a number of months in the field, I was able to build relationships with participants before beginning formal recruitment for interviews. This proved to be essential to gaining the trust of prospective participants and ensuring that they engaged in my project with an understanding of my research goals and activities. Participant observation was not only vital in offering an introduction to a novel social setting, but it also aided in contextualisation of data gathered via other channels. I actively collected data between April 2015 to June 2017, during which I spent approximately seven hours per day, four days per week primarily in Roma community centres, though there were also opportunities to accompany participants to meetings with health care providers and local councils. Once I had concluded my formal period of data collection, my ongoing employment with Roma Support Group allowed me to remain partially entrenched in the field as I analysed and wrote up my results. Spending this substantial amount of time in community spaces – and also observing how participants interacted in more official institutional settings – increased my sensitivity to beliefs and lifestyle preferences that may impact health-related perceptions and behaviours, and thus allowed me to refine the questions for interviews.

As participant observation largely yields data informed by the views and impressions of the researcher, interviews constituted a key component of my data collection in giving voice to Roma community members, community advocates and health professionals. Interviews validated and further explored concepts derived from participant observation, and the interview topic guide was regularly updated based on concepts emerging from interviews and participant observation (in accordance with guidelines for developing sensitivity to concepts outlined in Strauss and Corbin's (1998) text on grounded theory methodology). While I loosely followed the topic guide, I found it vital to remain flexible in the interview process and allow participants to discuss areas of personal significance in-depth. This strategy was intended to minimise the unequal power relationships that can arise in the researcher-respondent relationship, thus subverting the typically dominant role of the researcher in determining the direction of the conversation (Beck, 2011; Harvey, 1949; Peller, 1995).

In some cases, interviews diverged substantially from the topic guide, taking on the form of a non-directive narrative interview (Brinkman, 2018). These interviews centred on pressing and at-times overwhelming concerns in participants' lives; while these concerns did not necessarily address topic guide questions, I ultimately deemed it most appropriate to afford participants the space to discuss issues that were of greatest relevance to their lives. This resulted in a set of nine interviews that were largely narrative in character – incorporating stories of traumatic health events or distressing experiences of claiming health-related benefits – which formed the basis of my narrative re-analysis of this subset of interview data.

Adopting this three-pronged approach to data collection allowed for consistent interrogation of multiple dimensions of Roma health experiences. I sought to holistically explore the concepts arising through observation and analysis by drawing connections across the results from different modes of data collection, thus revealing the relationships between Roma cultural beliefs, current and historical social positions of Roma communities, health system policies, attitudes of health professionals and the role of non-Roma community advocates.

4.3 Policy review and analysis

4.3.1 Review of policies related to Roma health

The first component of data collection was a policy review and analysis assessing local and national measures for addressing the health situation of the Roma. Guided by existing literature on government responses to (GRT) health inequalities in England (Acheson, 1998; Cemlyn et al., 2009; Craig, 2011; FFT, 2015; Marmot et al., 2008), I reviewed national policies aimed at reforming and restructuring systems of health service provision and (purportedly) promoting equality within public institutions. The Health and Social Care Act (HSCA) of 2012 was fundamental to this reviews, as it provides the statutory framework for health service development in England and allocates primary responsibility for defining local health improvement priorities to bodies known as Health and Wellbeing Boards (HWBs).

To assess levels of attention to GRT communities in local health policy, I obtained a list of all 172 local authority areas in England (each of which are associated with a HWB) and reviewed their most recent Joint Strategic Needs Assessments (JSNAs), first in the summer of 2016 and again in the autumn of 2018. The 2016 review of JSNAs involved a close reading of each JSNA's inclusion of GRT health needs, looking at key identified health issues, barriers to accessing services, recommendations for service improvement and commentary on the social determinants of health as they affect GRT communities. I conducted a keyword search of the terms 'Gypsy', 'Roma', and 'Traveller', focusing specifically on inclusion of CEE Roma. The goals of the 2018 update to the JSNA review were: to assess any disparities in GRT (and especially CEE Roma) coverage; to determine whether local awareness of GRT communities had undergone any marked change; and to understand whether there was any correlation between local GRT population size and extent of inclusion in JSNAs. The addition of population size comparison represents a minor divergence from the methods of my 2016 reviews, and was intended to provide insight into one of the key outstanding questions following completion of my 2016 JSNA analysis. In light of the fact that schools are the only UK institution to gather data on Gypsy/Roma ethnicity and local population size, I compared the JSNA database against school census data for each local authority area to ascertain whether there was correlation between inclusion of GRT in JSNAs and local GRT population size.

4.3.2 Documentary analysis of health policy documents

Upon identifying JSNAs addressing GRT populations, documentary analysis proceeded by interpreting the structure and content of the policy documents, with attention to the details included and the ways in which these may reflect a wider social order (Prior, 2004). Often this involved comparative analysis of the key health concerns identified in the JSNAs, the accompanying recommendations for service improvement and the manner in which this reflects JSNA authors' perceptions of Roma communities. If, for example, a JSNA gave substantially more attention to lifestyle risk factors than to poor access to services, this could imply certain value judgements about Roma culture (Munte, Serradell & Sorde, 2011) and individual responsibility more generally. It was furthermore essential to consider the extent to which health policy development incorporated consultation with Roma communities, in light of Munte et al.'s (2011) finding that the most meaningful policy responses to inequalities faced by Roma communities were formulated with specific involvement of Roma community members.

4.3.3 Frameworks for policy analysis

After compiling the database of local policies, I reviewed a set of analytical frameworks, which would allow me to assess whether policy responses are commensurate with GRT health issues and project the efficacy of service development recommendations. Focusing on frameworks for evaluating policy decisions, I identified a set of methodological texts outlining steps for analysing policy responses to social problems. While these frameworks varied in specificity, they shared a number of core features, including projection of consequences of a policy decision, consideration of alternative policy options and assessment of the effectiveness of a particular policy decision in addressing a specific problem (Bardach, 2000; Collins et al., 2008; Dunn, 1981). With this emphasis on evaluation in the context of wider social issues, these strategies aligned with the critical perspective of my research and allowed me to select an analysis procedure that went beyond an exclusive focus on policy efficacy and to address the complex social factors underlying policy decisions.

The following table displays the issues considered in applying an evaluation-oriented policy analysis framework and outlines how each stage in the policy analysis process relates to questions of policy development around issues of GRT health.

Table 4: Stages of policy analysis

Steps in analysis process	**Application to questions of GRT health**
Define the context	• Poorer health outcomes • Barriers to accessing health services • Recent migration of Roma from Central and Eastern Europe
State the problem	• Lack of consistent response to GRT health inequalities
Search for evidence	• National policy review • Local policy review • Policy analysis literature review
Consider different policy options	• Responses in other EU countries • Local variations in attention to GRT health
Project the outcomes	• Compare service improvement recommendations against barriers to access outlined in GRT health literature – do recommendations reflect need?
Apply evaluative criteria	• Review critical literature on service improvement recommendation strategies (e.g. behavior change initiatives) • Investigate lack of parity between size of GRT population and attention in JSNAs • Compare JSNA content against epidemiological literature
Weigh the outcomes	• Analyse content of JSNA update documents • Examine evaluation reports on service changes
Make the decision	• Do recommendations outlined in JSNAs and Health and Wellbeing Strategies address GRT community needs? • How might local differences in coverage impact GRT health?

Based on Collins et al., 2008

This framework achieved a balance between structure and flexibility that facilitated critical expression of policy decisions and social context (Collins et al., 2008). Each aspect of the criteria bore a clear connection to evaluation of policy decisions, yet they could also be applied to developing an understanding of Roma community responses to health care provision strategies and trends in Roma health status, thus offering insight into the manner in which policies are likely to impact on Roma communities.

4.4 Data collection in the field

4.4.1 Site selection

After determining that data collection would proceed through a community-based approach, I conducted an internet search of organisations that are involved in promotion of GRT rights in the UK and contacted them to enquire as to the ways in which they could support my research. I began by sending a series of emails introducing my research, explaining my aims and expressing an interest in collaborating on projects for providing support and advocacy to Roma communities. These introductions went to a range of charities and community organisations working with Roma communities, including the Roma Support Group (RSG) based in Newham, London; Black Health Agency (BHA) in Manchester; Cheetham Hill Advice Centre in Manchester; the Manchester Refugee Support Network; Gypsy, Roma and Traveller Achievement Service in Leeds; Leeds Gypsy and Traveller Exchange (GATE); Migration Yorkshire; researchers at the University of East London; the Advice on Individual Rights in Europe (AIRE) Centre in London; and the Luton Roma Trust (LRT).

Contacting the Roma Support Group served as a logical first step in the process of selecting partner organisation, as it is the most prominent organisation in the UK focused on the situation of Roma communities. After sending an introductory email, I was contacted by one of the leads of the Roma Support and Engagement Programme, who invited me to submit a volunteer application form, and subsequently to meet with her to discuss possibilities for my involvement with the organisation.

Responses from other organisations were varied, with some maintaining that they did not have adequate experience in Roma health issues to be of assistance. Others were either unable to take on volunteers at the time or did not work in health-related areas, but made suggestions for further contacts. Although a representative from the BHA initially expressed an interest in supporting my research, he ultimately took an extended period of leave due to health problems, after which I was unable to make further contact with the organisation. As I intended my research to take a comparative look at Roma health experiences in different locations, I sought to make contact with other organisations that could provide introductions into the community.

It was ultimately through contact with the AIRE Centre – a charity organisation that provides free legal advice on EU citizens' rights – that I was able to identify my second research site. I met with a member of staff who had previously been involved in a project focusing on Roma rights, and she passed on the contact details for the head of the Luton Roma Trust. After a meeting to discuss my project, we agreed that my involvement with LRT would follow a similar model to my volunteer work with Roma Support Group. As LRT was in an early stage of its work with Roma communities, however, there were relatively few opportunities for me to engage in specialised health advocacy or research work, and I thus to volunteered with the organisation's general advice provision service. I began attending weekly drop-in sessions, where I updated the organisation's database with service users' contact details, read and explained letters from health and other statutory services, and made phone calls to services on community members' behalf.

As I did not enter into this research with a pre-existing network of contacts with Roma community organisations, my site selection was limited to organisations that were able to offer me long-term volunteer positions. In hindsight, I was fortunate that the two organisations that did so worked specifically with Roma migrant groups, as expanding my focus to organisations working more widely with Gypsies and Travellers would likely have diluted my results and provided me with fewer opportunities to engage with Eastern European migrants. Adopting a research model involving two distinct research sites was intended to provide insight into differences in experience arising from country of origin and length of stay in the UK (though, as I will discuss in Chapter 9, the differing capacities of my partner organisations limited my ability to engage in robust comparative analysis). In London I made contact with primarily Polish and Slovak Roma communities, whereas the Roma community in Luton was almost entirely Romanian. Furthermore, many members of the London Roma communities had been in the UK for ten or more years, while those in Luton had arrived relatively recently. Despite their relative proximity, my research sites in London and Luton provided ample opportunities not only to compare differing experiences of health service provision, but also to gain insight into the impacts of past experiences on the development of health-related beliefs and behaviours.

4.4.2 Participant observation

As outlined in my methodological review, a critical ethnographic approach served as a component of my data analysis framework. I thus employed participant observation strategies in which my participation in the daily activities of community organisations led me to become ‘embedded’ in the field, while also engaging in reflexive practice to maintain the sensitivity to my impact on the social environment (Hammersley & Atkinson, 1983; Lewis & Russell, 2001). Through my close involvement with Roma community organisations, I was in a position in which I had near-daily contact with participants – ‘independent from but familiar with’ organisational practices (Lewis & Russell, 2011, p. 400). A critical approach to ethnography aided in identifying target areas for data collection, calling for my consistent reflection on the social structures underlying events and behaviours observed in the field and considering how these observations could be channelled into activities to effect social change (Harvey, 1949; Thomas, 1993; Lewis & Russell, 2011).

Participant observation occurred over the course of volunteer advocacy work carried out at RSG and LRT. Each of these organisations provides support and advice to members of the Roma community through improving access to education, aiding in engagement with health services and assisting in the navigation of UK systems of social support. Differences in operating procedures and target areas for work led to minor variations in the nature of my volunteer activities at each research site, yet the aims and structure of volunteer work remained similar.

Volunteer work began at the Roma Support Group in London in the spring of 2015, during which I assisted with the organisation’s Roma Support and Engagement Programme. This programme serves as a link between Roma community members and professionals supporting them, often in a health and social care context. This first involved research support and programme development activities, such as writing a training guide for health professionals, updating a health awareness training presentation and compiling a database of organisations and government agencies with an interest in Roma rights and engagement with Roma communities.

As these activities did not put me directly in contact with Roma community members, I was initially concerned that they would limit the reach of my connections within the community. As my involvement progressed, however, I came to conceive of this phase of my research as a vital stage in the process of building trust not only with community members, but also with my partner organisations. Community organisations do not have the implicit trust of community members. Much like researchers, they must build this trust through consistent demonstration of their commitment to the wellbeing of the communities they serve. My organisational partners understood that there is a tendency within Roma communities to view researchers' interest as tokenistic – as they often see no concrete results of their participation in research projects – and knew that providing a researcher with a point of entry into the community had the potential to damage to the community's regard for the organisation (Tobi, Sheridan & Lais, 2010; Arnstein, 1969). As such, community organisation staff members facilitated my introductions to community members only after I had demonstrated commitment to the organisational ethos and a sufficient understanding of community members' expectations in receiving organisational support.

Although I was relatively rapidly able to enter into direct contact with LRT service users, building organisational trust with RSG required more time than was initially anticipated. After five months of desk-based volunteer work, my duties expanded to encompass direct involvement with RSG's service users. At this point I began to provide assistance to the organisation's advice and advocacy project, concentrating on health advocacy work. I provided assistance in making appointments with health services, following up on referrals, requesting interpreters and making complaints in cases of inadequate service provision and inappropriate actions of health professionals. By focusing on health-related matters, I not only formulated impressions of health experiences in the Roma community to explore in later analysis, but also provided community members with a practical reason for opening a dialogue with me. This helped me to introduce my research goals to community members and to lay a foundation for eventual invitations to participate in interviews.

My involvement with the LRT began in October 2015 (after a number of setbacks in carrying out my initial site selection plans, discussed above) and followed a somewhat different trajectory than my volunteer activities with the RSG. In contrast to the RSG, which has been in operation since 1998, the LRT was in its first year as a registered charity at the time that I began my volunteer work. The relative newness and smaller size of the LRT meant that there was a much shorter period of building organisational trust, as well as greater opportunities to become involved in all dimensions of the organisation's work. Where my volunteer work with RSG service users focused exclusively on health advocacy activities, volunteer work with LRT encompassed GP registrations, filling in school registration forms, benefits applications and assistance with housing concerns. These activities provided insight into the broader context of health concerns in Roma communities, allowing me to develop a fuller understanding of the multiple and interconnected factors that can have an influence on health and wellbeing.

I recorded fieldnotes throughout volunteer work, detailing events and interactions observed in the field and outlining my initial impressions of these occurrences. I generally avoided active note-taking during the process of participant observation and instead recorded impressions directly afterward, as I recognised that taking notes could create social barriers between participants and myself, and could also place strain on the trusting relationships I was working to develop (Emerson, Fretz & Shaw, 1995). Participants whose experiences I recorded in my fieldnotes were in all cases made aware of my status as a researcher and gave their verbal consent for me to describe their situations, while excluding any potentially identifying details.

Each instalment of my fieldnotes began with the description of a situation, noting order of events, verbal statements, behaviours and reactions. Then in the latter portion of an entry, I framed events in terms of their wider significance, taking a preliminary look at the social structures and power relationships implicit in the interactions between research subjects, social institutions and myself as a researcher (Emerson, Fretz & Shaw, 1995). My field observations progressed according to the concept that no field researcher can be entirely neutral and detached from the surrounding environment, and I thus understood that my interpretations of events would change and develop based on my increasing depth of involvement in the field (Emerson, Fretz & Shaw, 1995). In this sense, I was always conscious that my presence impacted on the social circumstances under observation, and that my individual impressions were altered through my experiences in the field (Burgess, 1984; Hammersley & Atkinson, 1983). Fieldnotes were not only a record of my observations, but also a tool for developing a critical view of surroundings, to avoid simple acceptance of the status quo and to understand the processes underlying concrete behaviours (Jackson, 1990).

Despite the usefulness of fieldnotes in developing a critical perspective, there were a number of challenges in ensuring that participant observation yielded consistently high quality data. Deep and long-term involvement in the field carried the danger that I would come to view events and experiences as commonplace and prevent recognition of social novelties (Burgess, 1984). Furthermore, my involvement in advocacy work could in some cases place me in a non-neutral position in analysing community members' perceptions of health service inadequacy. While recording fieldnotes aided in developing sensitivity to novel experiences in the field, it was also important to acknowledge that my 'own standpoints, historical locations and relative privileges shape[d] what [I *could*] see' (Bryant & Charmaz, 2007, p. 44). Although I was involved in the day-to-day functioning of Roma community organisations, my non-Roma social position and my lack of prior involvement in these communities led me to have very limited opportunity to see the conditions of participants' lives once they had left the controlled environments of the community centres. Acknowledging the limitations of my knowledge became particularly important during the data analysis process, but was also worth considering during data collection, as it aided in avoiding generalisation and inadvertently taking a single example as a wider-reaching representation of Roma health experiences.

4.4.3 Interviews

While participant observation afforded a broad understanding of conditions in the field and facilitated initial contact with participants, interviews were essential in understanding Roma participants' distinct experiences of using UK public services and their impressions of life in the UK. Furthermore, interviews with health professionals and community advocacy workers offered alternative perspectives on the operations of health and public service institutions, thus providing insight into dimensions of the broader social context of health in Roma communities.

I considered a range of frameworks for structuring interviews, considering the relative advantages of structured, semi-structured and unstructured interviews. Structured interviews adhere strictly to a pre-determined set of questions and do not deviate from these topics, even in cases where novel impressions arise from the conversation (Green & Thorogood, 2009). While this strategy may have ben productive in studies that seek to validate or invalidate a pre-determined set of concepts, I intended my research to explore dimensions of Roma health beliefs and experiences that I might not have considered in the development stages of my project and thus deemed structured interviews to be unsuitable for meeting my research objectives. Unstructured interviews, by contrast, lack the rigid framework and predetermined questions of structured interviews, and instead allow the interview to progress as an open conversation between interviewer and interviewee (Brinkman, 2018). The interviewer refrains from actively guiding the discussion and encourages the exploration of topics identified by the interviewee. Semi-structured interviews strike a balance between structured and unstructured interviews, adhering to a set of pre-determined questions while also allowing for exploration of unanticipated topics that arise over the course of the interview (Green & Thorogood, 2009).

My initial intention was to use semi-structured interviews, which would allow me to select a set of topics that were relevant to my research questions. While asking each participant the same general set of questions, however, I remained open to the development of conversation along previously unanticipated lines, which, as discussed earlier in this chapter, could lead to substantial divergences from the topic guide. Early in the process of conducting interviews, I observed that health-related communication often took the form of storytelling and that, in many cases, I could gather the richest data if I could stimulate participants to narrate a specific interaction with health or social services. Adhering too strictly to a discrete set of interview questions could put strain on interactions with interviewees, as highly structured questioning could recall experiences of interactions with officialdom in participants' countries of origin (Brown et al., 2017). As such, I found it effective in many cases to ask broad questions at the beginning of each interview to build the respondent's familiarity with the topic and then to allow each individual's particular experiences and impressions to guide the direction of the interview.

Once my health advocacy volunteer work put me in direct contact with participants, I engaged in participant observation as my sole method of data collection for approximately one month before inviting community members to participate in interviews. This enabled me to formulate a set of initial impressions to further explore and verify. Considering these impressions in conjunction with information gathered through my literature review, I developed an interview topic guide (Appendix 4) that addressed health-related beliefs and behaviours in the Roma community, perceptions of health services and interactions with health professionals. In order to ensure that non-directive questions 'stimulate[d] the interviewee into talking about a particular broad area' (Hammersley & Atkinson, 1983, p. 117), I employed a topic guide from a previous study conducted with Eastern European Roma communities as a template for developing my own interview questions, adjusting this as my knowledge of the field increased (Tobi, Sheridan & Lais, 2010).

My questioning strategy evolved over time, as participants' prior responses suggested new topics to explore. This practice of making continuous adjustments to the topic guide aligns with the grounded theory methodology, which calls for adjustment of questions to reflect new concepts arising from previous interviews or observations in the field (Strauss & Corbin, 1998). When, for example, I noticed that benefits for people with disabilities and chronic illnesses appeared to be significant to many community members, I incorporated a set of related questions into my topic guide.

Language barriers between participants and myself constituted a major practical consideration in conducting interviews. While a number of interviewees were confident in participating in an interview in English, many required the assistance of an interpreter. Bilingual RSG and LRT staff members provided invaluable support to my research in serving as interpreters and moreover as cultural mediators. They were able to inform me when my interview questions might need clarification, and helped to explain the goals of my study in a manner that participants found meaningful (Hennink, 2008). In the event that participants preferred that the interview proceed without the presence of an RSG/LRT advocacy worker, I included the option of allowing family members to serve as interpreters.

Although use of family interpreters carried certain risks associated with interpreters' objectivity and the accuracy of the information provided, there is precedent for use of family members as interpreters in health research settings (Hadziabdic et al., 2009; Hadziabdic et al., 2014; Karliner et al., 2007). While acknowledging that interpreters' English language skills, their understanding of the purpose of my study and participants' possible reluctance to answer questions in the presence of family members could impact the quality of my data, excluding non-English speakers would have imposed greater limitations on my study. Furthermore, as my interview questions did not ask participants to disclose sensitive details of health conditions, there was limited risk that they would find the interview too invasive in the presence of a family member. If, however, the presence of a family member appeared to make a participant uncomfortable, I would check to make sure that the participant was still happy to continue with the interview and would discontinue the interview if necessary.

To ensure that interviews were conducted in settings that were convenient for all involved parties, they took place either in community centres or nearby cafes. All participants were provided with an information sheet prior to interview, which was read to them in the event that they were illiterate or unable to read English. After ensuring that participants understood the purpose of the study and the nature of their involvement, all interviewees signed written consent forms. Interviews were audio recorded with participants' consent and were transcribed verbatim. Two participants declined to be audio recorded, and in these cases I took detailed notes during the interviews, noting direct quotes as much as possible.

In total, I conducted 28 interviews with Roma community members and an additional ten Interviews with health professionals and advocacy workers. I began to interview professionals at approximately the midpoint of my interviews with Roma community members, after I was sufficiently confident in my understanding of Roma health experiences to explore them from a different perspective. My topic guide for health and advocacy professionals focused on access to services and challenges in cross-cultural communication, seeking to reveal other dimensions of Roma community members' responses.

Interviews lasted between 30 minutes and one hour. Although topic guides aimed to present questions as straightforwardly as possible and were reviewed with Roma community members for clarity, some Roma interviewees encountered difficulties in formulating the abstract responses required by certain interview questions. Narrating a sequence of events presented no challenge, yet when asked questions such as 'how would you describe communication with your GP?' participants would often respond with either 'good' or 'bad', and appear confused when asked to elaborate. When I discussed this observation with one of my community organisation partners (who is from the Roma community himself), he explained that many respondents had never been educated beyond the primary school level and therefore might have been unsure of how to answer questions that sought to capture more abstract feelings and impressions. To address this, I constructed questions that stimulated respondents to tell stories about their interactions with health services. Where direct questions about health experiences could be intimidating to some participants, encouraging them to construct narratives effectively removed many of the communication barriers imposed by more formal interview frameworks.

4.4.4 Supplemental focus group

Despite largely concluding data collection in June 2017, I remained present in the field through my work with Roma Support Group. As the UK's exit from the EU drew closer, the precariousness of Roma migrants' future in the UK seemed to increase steadily. When I re-analysed my fieldnotes for their narrative content, I identified immigration as a major factor driving my personal narrative of the field. Although vague expressions of uncertainty related to immigration had emerged through grounded theory analysis, I had not at the time singled this out as a major theme, nor had it arisen as a common topic in interviews. With the impending shift in EU migrants' status, however, it seemed an oversight not to gather participants' views of the changing socio-political environment and its impact on their lives. With this in mind, I conducted a supplemental focus group in July 2018, which was attended by nine Roma community members (from Poland, Slovakia and Romania) and two community advocacy workers (who provided interpreting support). Focus group questions centred on participants' impressions of recently published Home Office guidance outlining settlement procedures for EU migrants, as well as changes to their perception of life in the UK following the Brexit vote. The resulting data was then incorporated into narrative analysis of my fieldnotes, substantiating my observations of immigration uncertainty with participants' impressions.

4.5 Sampling and recruitment

4.5.1 Precedent for community-based recruitment methods

Past research addressing the health situation of Roma in the UK has established a precedent for employing community-based methods in carrying out data collection (Tobi, Sheridan & Lais, 2010; Van Cleemput, Bissell & Harris, 2010; Ryder, 2015). As researchers often come from outside the community, they may lack the depth of local expertise required to establish contact with participants who may be initially sceptical of formal research projects. Close partnerships with community organisations aid in minimising this gap in knowledge, facilitating the sharing of information about effective methods for engaging community members, and also helping to ensure that contact between researchers and respondents will be acceptable within community standards of appropriate conduct (Tobi, Sheridan & Lais, 2010). Entering into the fieldwork phase of my research without any prior contacts within Roma communities, I depended heavily on my organisational partners to introduce me to potential participants, though as my understanding deepened over the course of my volunteer work, I gradually gained more independence in recruiting participants for my study.

4.5.2 Stages of sampling

Throughout the sampling and recruitment process, I was conscious that my involvement in health advocacy could put me disproportionately in contact with individuals who had experienced difficulties in accessing health services or communicating with health professionals, which could limit the representativeness of my sample (Burgess, 1984). My early sampling was opportunistic by necessity, as my only contacts within Roma communities were those with whom I had engaged in health advocacy sessions. Provided that a degree of rapport had been established during an advocacy meeting, I would explain the details of my study to potential participants and invite them to take part in an interview. As an early strategy for making contact with participants, this method of sampling was effective in helping to ensure that participants had experiences of health service access and would be able to offer commentary on their interactions with UK health systems. Furthermore, engaging participants in interviews following advocacy sessions helped me to identify of topics that were of relevance to participants, thus facilitating the development of further interview questions. Recruitment for interviews through volunteer health advocacy came to take the form of an exchange between participants and myself, in which I offered assistance in addressing issues in engaging with health services, and they in turn were able to help me in progressing with my research. Not only did this assuage some of my concerns about my inability to offer a payment in exchange for participation in my research, but it also helped to counteract some community members' perception that researchers extract information without any tangible commitment to improving community members' situations.

Once I had begun my engagement in health advocacy work, I developed a network of contacts fairly rapidly, and sampling then proceeded according to a snowballing strategy, which involved establishment of contact with future research participants through pre-existing networks (Creswell, 1998). This occurred as community members became increasingly aware of my involvement in health projects and began to approach me for support in accessing health services. It was at this point where I was able to introduce my research activities and explain the possibilities for engagement in my study.

After approximately three months of recruiting for interviews through a combination of opportunistic sampling and snowballing, I began to focus recruitment on participants who could offer insight into particular topic areas. In keeping with the grounded theory methodology, I had begun to formulate key concepts in an overarching theory of Roma health experiences, and I sought in my interviews to address new dimensions of these concepts (Strauss & Corbin, 1998). Selection of participants according to their ability to elaborate on concepts in an emergent theory is known as theoretical sampling, and it was based largely on my involvement in health advocacy and consequent understanding of which individuals may be able to comment on a specific topic area (Glaser & Strauss, 1967). Theoretical sampling involved regular reviews of the data I had already gathered, evaluating whether I had reached the point of 'having enough evidence, having enough data in a particular area, and deciding when to move on to other related problems' (Burgess, 1984, p. 45; Glaser & Strauss, 1967).

4.5.3 Questions of representativeness

Employing a range of sampling techniques enabled me to capture the views of people of different ages, with different countries of origin, places of residence in the UK and experiences of UK public institutions (Appendix 9). It is nonetheless important to note that even assuming this sample's representativeness of RSG and LRT service users, my findings cannot necessarily be extrapolated to other Roma populations. Here it is vital to once again emphasise that there is no single 'Roma community', and that there are likely to be wide variations in experiences of health and perceptions of interactions with public institutions. To generalise the findings of this study to all Roma communities, or even all Roma communities in the UK, would be reductive. What this study provides is not an all-encompassing description of Roma health (if such a project is even feasible) but rather an overview of the varied ways in which a particular group of immigrant, minority ethic and marginalised individuals interact with health service providers.

4.6 Data analysis

4.6.1 Overview

Data collection and analysis occurred concurrently and iteratively, as the tenets of theoretical sampling require consistent re-interpretation of incoming data to identify concepts for further exploration. Through this non-linear approach to the data, I aimed to ensure that I was consistently attuned to new categories that arise within the data and require additional inquiry to uncover their multiple properties and dimensions. Analysis began during transcription of interviews and recording of fieldnotes, and the process continued until I was satisfied that concepts had been assessed from all discernible angles and the linkages between different phenomena had been fully elucidated. This culminated in the development of a theory, which refers to a conceptual framework defining the relationships between key observations from the data (Strauss & Corbin, 1998).

Before moving forward with a description of data analysis techniques, I should first identify a set of key terms. 'Phenomena' refer to the main ideas that emerge from the data, which are described through 'concepts'. Concepts are then grouped into 'categories', which are assessed according to their defining 'characteristics' (or 'properties') and the variations they contain ('dimensions'). Comparison of categories allowed me to gain a detailed understanding of the ways in which categories describe phenomena, and furthermore revealed the connectivity across different categories. Once no new categories could be identified from the data, and analysis did not reveal any new properties or dimensions within the categories, the categories were considered saturated. At this point I was able to undertake a process known as 'integration', in which I interpreted the relationships between categories to develop a theory that offered an explanation of the overarching phenomena implicit in field observations and interviews (Strauss & Corbin, 1998).

The figure below displays the linkages between these key elements of grounded theory analysis, showing how data reflecting social phenomena are first described as concepts, which then are assessed for similarities and differences to form broader categories. Categories are then described according to their dimensions, properties and subcategories, and ultimately the relationships across all of these groupings and descriptions are refined to arrive at a single overarching theory.

Figure 1: Grounded theory data analysis

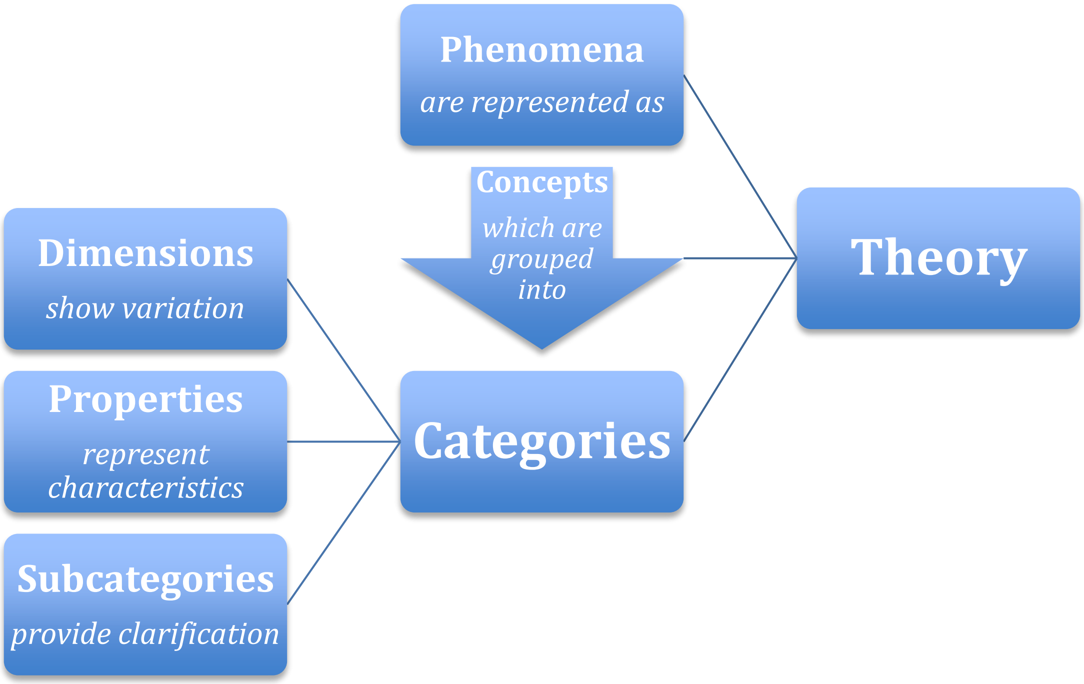

Figure based on frameworks outlined in *Basics of Qualitative Research: Techniques and procedures for developing grounded theory* (Strauss & Corbin, 1998).

4.6.2 Constant comparison and coding procedures

The emphasis of grounded theory analysis is ultimately on the ways in which discrete concepts identified in the raw data relate to and interact with each other. Thus, as new data were gathered, they were consistently compared against existing data to determine whether they reinforced previously identified concepts, revealed new dimensions of emerging categories or suggested areas for further data collection. This is in keeping with the data analysis methods outlined in Strauss and Corbin's (1998) *Basics of Qualitative Research*, which calls for the use of theoretical comparisons as the foundation of grounded theory analysis. This entailed close reading of the data with attention to key themes and consistent assessment of emergent concepts for their similarities and differences (Glaser & Strauss, 1967; Straus & Corbin, 1998). One of the goals of theoretical comparison was to develop sensitivity to the underlying meanings in the data, leading ultimately to an understanding of the interconnections between the dimensions, variations, causes and consequences implicit in the data (Strauss & Corbin, 1998).

Comparisons occurred at the dimensional level, meaning that they sought to address the variations that displayed across a given category (Strauss & Corbin, 1998). In the context of my research, for example, this occurred when I observed that language and communication were emerging as a major category, yet issues arising from language discord between health professionals and Roma community members were by no means uniform across my sample. As such, I proceeded to analyse the areas in which participants' accounts diverged from each other, and identified a number of key variables that contributed to the experience of communicating with health professionals. Over this course of my analysis, these properties and dimensions of language and communication were linked to other emergent categories, such as misunderstandings between claimant and assessor over the course of applications for disability benefits.

Analysis began during the transcription process, in which I listened to each interview recording twice, first noting initial impressions and then refined my impressions and assigned codes. Coding was the key activity in generating concepts from raw data, and the nature of codes becomes increasingly abstract as data analysis progressed and the overarching theory drawn from the data took shape. Coding aimed to describe relationships between concrete data, my own perceptions and the wider social environment in which the data were gathered (Strauss & Corbin, 1998). The process of coding involved continuous questioning of my assumptions and attempted to look at emerging concepts from the perspective of the participants (Star, 2007). Codes were drawn from my individual perceptions and experiences, yet they also reflected my growing sensitivity to social novelty developed through theoretical comparisons. While recognising that the conclusions drawn from a qualitative study would never be entirely distinct from my individual impressions, achieving objectivity through grounded theory analysis aimed to reflect participants' unique voice in describing their experiences (Strauss & Corbin, 1998).

Grounded theory studies incorporate three main types of coding: open coding, axial coding and selective coding. (See Appendix 5 for an example of coding.) Open coding involved the identification of concepts and elucidation of their properties, and was aimed at the preliminary generation of categories. This occurred through line-by-line analysis of transcripts and fieldnotes, and also through analysis of the overall meaning of an interview or fieldnotes entry (Strauss & Corbin, 1998). Once a set of concepts were identified and named, they were analysed for similarity and difference and grouped into categories. I then applied a process known as 'axial coding' to seek further understanding of the relationships between categories identified in open coding and to define the subcategories contained within them, specifying the conditions under which a given social phenomenon will likely occur. Selective coding focused on refining categories – often through diagramming processes or writing theoretical memos – to identify a central category that explains the relationships between all other categories (Strauss & Corbin, 1998).

4.6.3 Integration and data saturation

Before 'integrating' all concepts into a coherent theory, I needed to determine that all categories were 'saturated'. Saturation can be seen as the point at which no new data emerge in a particular category and the full range of its properties and dimensions have been defined (Strauss & Corbin, 1998). This required me to reflect on my theoretical sampling methods to determine the point at which I reached data saturation. I began to find that my interview questions were yielding responses that largely reflected those from previous interviews. While there were greater challenges associated in determining a saturation point in the data arising from participant observation – as there was seemingly no end of novelties to be observed in the field – I ultimately found it useful to reflect on my aims and objectives and to consider whether the data I had gathered would enable me to answer my research questions. My fieldnotes reflected and added depth to the key concepts that had emerged from interview data analysis, yet also did not reveal any major new concepts, I deemed that my data had reached a saturation point and concluded active data collection.

4.6.4 Re-analysis of data through a hybrid of grounded theory and narrative methodologies

The initial grounded theory analysis provided a set of guidelines for revisiting the data and re-analysing selected interviews according to a narrative methodology. Interviews were chosen for narrative re-analysis according to the strength of plot progression throughout the interview and elements of causality in the events described (Robert & Shenhav, 2014). I recognised that the narrative research text represents 'an ongoing process of composition rather than a coherent reporting of experience' and thus gave substantial consideration to *how* the story was told (Gubrium & Holstein, 1998, p. 165; Riessman, 1993; Josselson, 2011). One means for capturing a participant's unique representation of events was to focus on 'narrative editing', in which participants adjust their personal narrative to manage the listener's perceptions (Gubrium & Holstein, 1998).

I was also attuned to connections between each participant's story and other stories gathered over the course of research to identify 'narrative linkages' (Greenhalgh, 2016; Gubrium & Holstein, 1998). In all selected interviews, participants had diverged from the topic guide to tell a story of personal significance, and the narrative analysis interpreted each story's contextual markers, selection of detail and narrative editing in light of the key categories identified in the grounded theory analysis. The full narratives were then entered into a spreadsheet (Appendix 7), which included segments for analysing the narrative's context, temporality, plot and characters, as well as the details that the participant elected to include (or omit).

Analysis focused largely on context and selection of detail, as these provided the clearest means for analysing the social significance of the story and the participant's reason for telling it. This also involved consistent reflexive attention to my own presence as a listener, and the ways in which each narrator's sensitivity to my presence influenced the details they chose to explain (Robert & Shenhav, 2014). On a more granular level, the analysis of each segment of narrative text made particular note of instances in which the participants' account reflected categories arising from the grounded theory analysis (i.e. mental health, language barriers, inadequacies of service provision and social distance between Roma and health care providers). This was achieved through 'analytic bracketing', in which I assessed one aspect of the narrative independently of the others (Gubrium & Holstein, 1998). Although not relevant to holistic readings of narrative texts, selectively analysing segments of narrative data shed light on key distinctions within and across narrative texts.

When I looked to achieve a holistic representation of individual narratives, analysis frameworks looked at 'experiences, storying practices, descriptive resources, purposes at hand, audiences and environment' (Gubrium & Holstein, 2008, p. 250). While these elements of narrative analysis provide a general guide for understanding personal stories and the factors that shape them, it was vital to note that narrative analysis is a very broad field, encompassing numerous strategies for capturing individuals' characterisations of their experiences and lifeworlds (Robert & Shenhav, 2014). Taking a critical view – which is particularly relevant when looking at interactions between marginalised groups and the wider society – narrative analysis I gave particular attention to 'tensions between system and lifeworld' and the ways in which these tensions influence individuals' communicative actions (Greenhalgh, Robb & Scambler, 2006, p. 1172).

As I approached narrative texts, I considered whether each story represented an objective reality, or whether the construction of the story instead represented a departure from 'lived reality', with participants selecting detail to convey the emotional impact behind events described (Robert & Shenhav, 2014, p. 6). I conducted multiple readings of each narrative account, focusing first on basic content and structure, then looking at plot and narrative progression, and finally comparing the various narratives collected over the course of a study to identify their similarities and differences (Brinkman, 2018; Robert & Shenhav, 2014). This, in turn, aided in addressing two of the central contentions in narrative analysis – namely who determines the narrative means and whether alternative readings are possible (Riessman, 1993, p. 25). With this emphasis on the contextual factors underlying narrative construction, my narrative analysis methods sought to explore the social significance of participants' stories and to capture the power differentials shaping their decisions to narrate their chosen series of events.

4.7 Reflexivity

The concept of reflexivity addresses the possibility that the presence of the researcher introduces novel social dynamics that might not be observed in the researcher's absence, and furthermore that the researcher's perception is altered through involvement in the social world of the field. As Guba and Lincoln (2008) state the point, reflexivity has numerous dimensions, requiring engagement not only 'with our choice of research problem and with those with whom we engage in the research process, but with ourselves with multiple identities that represent the fluid self in the research setting' (p. 278).

Negotiating my multiple roles and identities in the field presented one of the greatest challenges in carrying out fieldwork, as I was at once part of community organisations yet also separate from them; in part an active participant in the social world of Roma communities yet also a detached observer. Reflection on my shifting identities was essential to ensure that my behaviour in the field was respectful of cultural norms, and also to maintain sensitivity to the impact that my presence in the field may have had on participants' behaviour. While my initial motivation to conduct research in Roma communities was an interest in the intersection between migration and health inequalities, I rapidly discovered that this choice of topic carried a distinct set of social and political connotations. As my study involves interrogation of inequality, discrimination and disadvantage, there were numerous cases in which I questioned whether my status as white middle class woman served to propagate the unequal representation of Roma community views within social institutions dominated by non-Roma. Furthermore, volatile public and political representations not only of Roma communities – but also of EU migrants more generally – made many of my research findings inseparable from political contentions. It was vital at all times to ensure that my analysis reflected an explicit understanding of the political dimensions of my research and, where possible, proposed pathways for improved recognition of Roma within public service provision frameworks (Foley & Valenzuela, 2008).

With this awareness of the broader political connotations of my work came further reflection on the power structures implicit in my relationships with participants, in which I analysed their experiences of discrimination and deprivation yet lacked the personal lived experience of social disadvantage. Critical social research literature suggests that one method for redressing power imbalances between researchers and research subjects is to harness findings to promote genuine social change, explaining that 'stimulus for change may come from the critical researchers' ability to expose the contradictions of the world of appearances accepted by the dominant culture as natural and inviolable' (Kinchloe & McLaren, 2008, p. 406). This occurred in part through my data collection activities, as involvement in health advocacy enabled me to take on a direct role in improving participants' communication with health services. As I went on to analyse my results, I formulated recommendations for policy development and health care practice that would promote attention to Roma migrants' often overlooked needs.

Yet it was not only political and social considerations that shaped my understanding of my position in the field, but also interrogation of my personal behaviours, impressions and assumptions in approaching my research topic. In establishing relationships with participants in the field, I found in fact that my status as an outsider in the UK served to establish rapport. There was always an initial moment of puzzlement when I told them that I came from the US – many aspired to live in America someday and were confused as to why I would ever have decided to leave – yet we could commiserate about the experience of immigration and the challenges of building a life in London. There were also, however, points on which I needed to adjust my behaviour. It is customary in Roma culture, for example, for women to wear floor-length skirts, and while I did not necessarily adopt this practice, I did make a point of wearing either knee-length skirts or trousers during my time in community centres. This may appear to be a superficial, insignificant change, yet it reflects a broader process of coming to recognise my own cultural assumptions and changing my behaviours.

This may be viewed as an effort to subvert some of the hierarchical relationships that can develop through interactions between researchers and respondents with varying levels of social privilege. Harvey (1949) outlines how a researcher's 'invest[ment of] his or her own personal identity in the relationship' can help to equalise the research/respondent relationship, and may also require the researcher to abandon some of the formality of traditional data collection structures (p. 116). In a sense this investment of my personal identity can be viewed as a partial erasure: by adjusting the way in which I physically present myself, I indicated to those I encountered in the field that I respect their cultural practices and thus took steps toward establishing trusting relationships. Incorporating aspects of my personal identity into my research activities created a strong sense of responsibility to do justice to the stories that respondents had allowed me to hear. Conducting data analysis thus became not only an exercise in interpreting information, but also in expressing the changes that my perception had undergone through deep involvement in the research field.

4.8 Ethical considerations

During my time in the field, it was vital that participants understood the nature of my research and gave their informed consent before I included them in my study. This posed particular challenges in the context of participant observation, as it would have been infeasible to gain written consent from every person I encountered in the field. I thus adopted measures – including information sheets and informational posters – to help participants to understand the nature of my research. To ensure informed consent for participant observation, I formed an advisory panel at each research site composed of community centre staff and community members. These groups advised me on the best methods for explaining my project aims to potential participants and assisted me in informing community centre users of the nature of my research. Participants were informed that they were able to opt out of this component of my project. Although no participants withdrew consent during observation, I would have stopped recording details on that person's actions for the remainder of the day, but also would have clarified whether the participant intended to withdraw from the study entirely.

In addition to verbally communicating information about my study, participant information sheets – detailing the nature of interviews and participant observation – were available at both community centres (Appendix 2). If participants were unable to read the information sheet, either I or a member of community centre staff provided a verbal description of my research. At the outset of my fieldwork, I provided all community centre staff with information sheets and briefed them on the nature of my study in case participants come to them asking for details. To further ensure that Roma community members were aware of the nature of my study, I hung posters in the community centres where I will be volunteering to explain who I am, what sort of work I am doing and inviting questions from community members (Appendix 3).

I closely considered the challenges of obtaining written consent in light of the discrimination historically faced by Roma community members. Not only are there low levels of literacy in this community – which calls participants' understanding of consent forms into question – but many Roma also associate written forms with officialdom and may feel sceptical about researchers' reasons for asking for written consent. Roma from Eastern Europe have faced severe institutional discrimination in their countries of origin and could have been fearful that written records of their participation in my study could be used against them (Emmel et al., 2007). In deciding whether to seek an amendment to my ethics approval that would allow me to implement a system of verbal consent, I observed participants' responses to my requests for written consent in my initial interviews and furthermore asked my partners in community organisations for their thoughts on the matter. As my partner organisations used consent forms to allow them to communicate with external organisations on service users' behalf, community members who access their services were already familiar with the process of giving written consent. I thus deemed a verbal consent procedure and the accompanying ethics amendment unnecessary.

4.9 Summary

This chapter details my fieldwork, data collection and data analysis strategies. After describing the policy analysis foundations of this study, I outlined the ways in which I entered Roma community spaces, made contact with participants and engaged in data collection through participant observation and interviews. I then discussed my methods for conducting grounded theory analysis of observational and interview data, followed by re-analysis of selected interviews according to narrative analysis strategies. Consistently reflecting on the contentions of representation and reflexivity in my data collection strategy, I aimed to elucidate the steps I took to ensure that my actions in the field and my characterisations of Roma health experiences did not perpetuate hegemonic practices in conducting research with traditionally marginalised communities. This concluded with a discussion of my reflexivity as a researcher, in which I considered the development of my role as a mediator between Roma community members and health care institutions, and how that informed my perspectives on the inequalities that Roma face when they come into contact with health services. As I move forward to describe the results of my policy analysis, my community advocacy perspective shapes my interpretation of policy data and emphasises the relative invisibility of Roma migrant concerns within national and local policy.

Chapter 5: An analysis of UK policies addressing the health of Gypsy, Roma and Traveller communities

5.1 Introduction

This chapter looks at the extent to attention to the needs of Gypsy, Roma and Traveller in UK health policies, with particular emphasis on the incorporation of the specific challenges faced by Roma migrants. After a discussion of the national landscape of health and equalities policy, it analyses local service development strategies and compares recommendations for improvement, offering a view of current trends in commissioning for GRT communities. Broadening the scope of this chapter from a specific focus on migrant Roma reflects the terminology employed in UK policy documents, many of which only make references to Gypsies and Travellers. Although there are clear differences between GRT groups in terms of their culture, background and health needs, UK health policy generally does not address these distinctions. If anything, UK policy gives less attention to the European Roma than to Gypsies and Travellers, with many local health strategies and research reports focusing exclusively on the latter two groups. Even in cases where 'Gypsies and Travellers' is used as an umbrella term that includes European Roma populations – purportedly to reflect the discrimination that all GRT communities face – it does not capture the complexity and variation within Roma culture (Craig, 2011). Policy makers' decision to address the Roma in conjunction with Gypsies and Travellers likely reflects a pragmatic response to perceived cross-group commonalities in health service barriers, yet it fails to address issues related to language barriers, lack of familiarity with UK systems and structures, and the stresses associated with immigration.

To understand the nature of policy attention to Roma communities, it is essential to first provide a basic overview of how Roma concerns make their way onto policy agendas and how policy initiatives purportedly intended to promote Roma rights can in fact perpetuate inequalities. Roma concerns generally come to the attention of policy makers through academic research reports and lobbying from local community groups, as most government datasets do not disaggregate by Roma ethnicity (Craig, 2011). This creates a situation in which there is limited attention to the specific needs of Roma within UK policy spheres, and what attention Roma do receive tends to be based on quantitative academic reports, all the while failing to capture the nuance of lived experience in Roma communities (Ryder, 2015). Ryder (2015) notes how an 'academic elite' purporting to represent the needs of Roma communities can ‘act as substitutes for an absence of genuine community involvement, while failing to question the state of affairs’ (p. 16). In this sense, Roma themselves have traditionally had little voice in UK policy development, and this chapter explores some of the consequences of that lack of meaningful involvement in the areas of health policy.

5.1.1 The equalities policy landscape

Before investigating recent developments in health policy as they apply to GRT communities, it is important to consider overarching legislative and policy frameworks that secure the equal treatment of anyone with a ‘protected characteristic’[6] within UK public services (though the associated ‘public sector equality duty’ does not apply to private actors). Under this central tenet of the Equality Act of 2010, it is unlawful to engage in any act that either directly or indirectly places a person with a protected characteristic at a disadvantage (EHRC, 2015). UK law in turn classifies Romany Gypsies, Irish Travellers, Scottish Gypsies and Scottish Travellers as protected ethnic groups that must be treated equally by public institutions (EHRC, 2015). Despite this protection under the ‘race’ category of the Equality Act (EHRC, 2016), there is a tendency to underreport instances of discrimination and a lack of official monitoring of GRT ethnicity within most UK public services likely means that instances of discrimination against GRT go largely undetected (European Commission, 2017).

In considering equalities policy as it applies to the UK Roma migrant population, it is worth noting that the UK government had decided to forego adoption of a National Roma Integration Strategy, asserting instead that broader policy strategies will address Roma concerns alongside those of other social groups (European Commission, 2018). To advance the policy objective of widespread social integration, the UK published its Integrated Communities Strategy Green Paper in early 2018, in a supposed move towards the creation of a more tolerant society for all. This strategy operates on the vague premise that social integration should function as a ‘two-way street’ – in which migrant and ethnic minority communities adjust their behaviour to reflect UK norms, while resident communities create an environment that is more accepting of cultural differences (HM Government, 2018). In this vein, the Green Paper outlines an array of policy proposals – including measures to reduce residential and school segregation, and to strengthen provision of English language teaching – that appear to be broadly aimed at encouraging

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[6] Age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation

tolerant social mixing. Underlying this vision of social openness, however, is a view of migration as a source of 'strain on local services and amenities, particularly in deprived areas' (HM Government, 2018, p. 20). With a strategy that presents disadvantaged migrant communities as a source of social pressure, it is difficult to envision how future policy decisions arising from this strategy will operate in favour of the interests of one of the most disadvantaged migrant groups in the UK.

5.2: Analysis of national health policies in the context of GRT needs

5.2.1 National measures to promote equality in health services

In terms of health policy, reports commissioned by the Government between the late 1990s and late 2000s brought socioeconomic inequalities and their impacts on health to the forefront of the policy discussion. The *Independent Inquiry into Inequalities in Health* (commonly known as the Acheson Report) was commissioned by the Department of Health in 1997 to investigate socioeconomic inequalities in health, and it highlights disparities in education, employment, income and lifestyle as key health determinants (Acheson, 1998). This report does not specifically address GRT communities, though it does identify connections between ethnicity, socioeconomic status and rates of long-term illness. Although the report recommends a range of policy measures aimed at reducing income and employment inequalities, social gradients in health increased between 1998 and 2008 (Marmot et al., 2008; Thomas, Dorling & Smith, 2010). In response, the Secretary of State for Health commissioned the report *Fair Society Healthy Lives* (commonly known as the Marmot Review) in 2008 to inform the development of a system to tackle the underlying causes of health inequalities (Marmot et al., 2008).

Although the Marmot Review was not in itself a policy development, it can be seen as a step towards greater governmental recognition of the relationship between socioeconomic status and the incidence of health problems. This report set out key policy objectives – including improved services for children and young people, work creation programmes and development of preventive services – as target areas for reducing inequalities. To implement these strategies, the Marmot Review recommended a policy of proportionate universalism, in which the most disadvantaged social groups would be the beneficiaries of the most extensive support (Marmot et al., 2008). In defining the direction of future health policy, the Marmot Review increased attention to the complex impacts of socioeconomic status in determining health outcomes and contributed to an emphasis on targeted local responses as the best method for improving population health (HM Government, 2010a).

With reference to GRT health, the Marmot Review offers only a simplistic view of the multiple and interrelated issues that impact health in these communities. It makes a passing reference to low levels of educational attainment, inferring that GRT children's lower likelihood of finishing school is correlated with the lower socioeconomic status of their parents (Marmot et al., 2008). What the Review fails to do in the case of GRT communities, however, is explore the disadvantage and history of discrimination underlying these lower levels of educational attainment. While implying that GRT communities experience disproportionately poor health outcomes, the Marmot Review does not specifically recommend policy measures to improve health in these communities, nor does it make any statement as to whether targeted health improvement measures could be implemented to counteract the unusually high levels of deprivation.

Responsibility for addressing GRT health needs falls broadly to the National Inclusion Health Board, which seeks to gather evidence and provide commissioning recommendations aimed at reducing health inequalities faced by Gypsies, Travellers and Roma, homeless people, sex workers and vulnerable migrants, although this group has been largely inactive since 2013 (HM Government, 2017b). The Board is composed of representatives from the Care Quality Commission, University College London, St Mungo's homelessness charity, the Faculty of Public Health, the Association of Directors of Adult Social Services and Public Health England, with Board membership intended to reflect leadership in 'clinical and academic communities' (HM Government, 2010b, p. 10; HM Government, 2017b).

The Board's main activities have been in the production of guidance for data collection and health service commissioning, roughly in line with the government's 28 commitments for addressing health inequalities faced by GRT communities (discussed in Chapter 2) (House of Commons Library, 2018; DCLG, 2012). In this vein, the Data and Research Working Group of the Board produced a report on capturing data on vulnerable groups (Aspinall, 2014). The Board has also produced a guide on practical steps in commissioning services for vulnerable groups (Inclusion Health, 2013), and worked in conjunction with the Royal College of General Practitioners to produce recommendations for combatting health inequalities within GP services (Royal College of General Practitioners, 2013). Inclusion health publications do largely display sensitivity to the distinctive situation of Roma migrant communities – placing their needs at the intersection of vulnerable migrants', Gypsies' and Travellers' concerns (Aspinall, 2014; Inclusion Health, 2013) – yet group meetings appear to follow an irregular schedule, potentially limiting progress towards target areas. Furthermore, placement of Roma largely in the category of 'vulnerable migrants' carries the unfortunate connotation that all Roma are vulnerable. This presumption could obscure the wider issues of stereotyping, discrimination and unconscious bias on the part of health care providers, which have been reported to affect Roma regardless of their socioeconomic status (Aiello et al., 2018).

Despite the National Inclusion Health Board's efforts, other areas display superficial – and ultimately inadequate – attention to key health concerns for migrant groups, NHS England's 2014 adoption of an Accessible Information Standard purportedly reflects a commitment to meet the communication needs of all patients (NHS England, 2015a). Notably, however, the Accessible Information Standard does not make provision for supporting patients who do not speak English as a first language, which has particular relevance to Roma migrant communities. Guidelines for implementation state that 'due to huge national, regional and local variations in the numbers of people needing foreign language interpretation / translation, the level of burden placed by any national framework would vary substantially between different organisations depending on their geographical location' (NHS England, 2015a, p. 20). Operating on the argument that variations in patients' demographic makeup across services makes a single standard 'inappropriate', the Accessible Information Standard leaves the provision of foreign language support at the discretion of local providers (NHS England, 2015a). Not only does this reflect inadequate attention to the negative impact that lack of adequate language support can have on a consultation, but it also falls short in addressing the vagaries of local providers' decision to provide interpreters for patients with language support needs.

The Accessible Information Standard suggests how health services balance equalities duties with the increased emphasis on cost effectiveness. Looking at the intersection between health and equalities policies reveals a largely superficial commitment to promotion of equal access to health services, with minimisation of financial 'burden' taking precedent over the experience of non-English-speaking patients. This reflects an emphasis on local discretion in determining service provision, which, as will be discussed in the next section, represents a growing trend towards shifting responsibility away from central government in the interest of saving costs.

5.2.2 An emphasis on localism and individual responsibility

In response to a perceived discrepancy between NHS operating costs and quality of services, the Government published two strategic white papers in 2010 – *Equity and Excellence: Liberating the NHS* (Department of Health, 2010b) and *Healthy Lives, Healthy People* (HM Government, 2010a) – which set plans for developing local health service capacity, identifying areas of need and commissioning services to meet these needs. Operating under the principle that health services should be granted 'assumed liberty rather than earned autonomy', these strategy documents made the case for granting local government and health professionals more authority over systemic operating procedures, as well as greater responsibility for monitoring and improving local health outcomes (Department of Health, 2010b, p. 5). With this plan for downgrading measures for national oversight of health service provision, the national policy framework that developed since 2010 has placed responsibility for strategic development of health services largely in the domain of local bodies (Murphy, 2013; Speed & Gabe, 2013).

Strategy documents make the case that population health can be best improved by granting local government and service providers greater authority in determining which programmes should be implemented. In this vein, *Liberating the NHS* focuses more on the structure of the reformed health service than on the impacted communities – envisaging a system in which local service providers set priorities for purchasing services – and *Healthy Lives, Healthy People* makes the case that this restructured health system will effectively meet population health needs (Department of Health, 2010b; HM Government 2010a). Largely following the health equity promotion framework outlined in the Marmot Review, *Healthy Lives, Healthy People* espouses the goal of improving health outcomes across life stages and socioeconomic divisions (HM Government, 2010a). Yet it diverges fundamentally from the Marmot Review in arguing that local actors should take primary responsibility for improving health outcomes, with central government stepping in only when 'absolutely necessary' (i.e. in areas such as emergency preparedness) (HM Government, 2010a, p. 8). Cost-effectiveness of services lies at the heart of the reforms proposed in these documents, and in this climate of maximising value for money, there is the danger that cost-saving measures could take precedence over sensitive responses to health inequalities (Davies, 2013).

According to *Healthy Lives, Healthy People*, the aims underlying the increased involvement of local government in health commissioning are intended to better target specific areas of local need. Purportedly, 'embedding public health within local government will make it easier to create tailored local solutions in order to meet varying local needs', thus suggesting that health inequalities faced by marginalised groups could be most effectively addressed through targeted local attention (HM Government, 2010a, p. 53). In this vein, *Healthy Lives, Healthy People* praised local strategies such as the Altogether Better Community Health Champions programme, through which community health advocates received training in health promotion techniques and were then sent into their communities to lead projects encouraging the adoption of healthier behaviours (HM Government, 2010a). While programmes of this type can be effective in reaching marginalised communities, they do not necessarily make provision for the retention of health advocates, who must often balance their advocacy work around other employment- and family-related commitments. Without adequate funding, these local initiatives represent only short-term solutions, with support withdrawn at the conclusion of a funding period (Roma SOURCE, 2013).

5.2.3 The Health and Social Care Act of 2012 and the new NHS structure

The reform proposals outlined in *Healthy Lives, Healthy People* and *Liberating the NHS* culminated in the Health and Social Care Act (HSCA) of 2012, which phased out Primary Care Trusts (PCTs) and replaced them with Clinical Commissioning Groups (CCGs). In CCGs, GPs take the lead on identifying areas of need, planning service delivery and commissioning secondary care services (NHS England, 2015c). The HSCA also created Healthwatch as a body responsible for monitoring NHS activities and providing advice and information to patients (Healthwatch England, 2017). Under the new legislation, local authorities, CCGs and Healthwatch chapters were granted joint responsibility for determining local objectives for health service provision and identifying the best methods for meeting these targets. This represented a departure from the previous system of local commissioning in the sense that GPs were granted significantly more responsibility for determining health care priorities for the communities they serve.

The HSCA instituted a new organisational structure in the English health system. As before, the Department of Health provides general oversight of the health services and, under the most recent legislation, allocates funding to NHS England. The HSCA created NHS England and granted it a range of functions, including commissioning primary care and highly specialist services and, most significantly for this policy analysis, monitoring the commissioning priorities and strategic decisions of local health care providers (NHS England, 2015c). On the local level, each local authority has a Health and Wellbeing Board, which brings together the local authority directors of public health, adult social services, and children's services, as well as representatives from CCGs, Healthwatch, and an elected representative from the community (The King's Fund, 2016).

Among the main responsibilities of Health and Wellbeing Boards is the development of joint strategic needs assessments (JSNAs) and joint health and wellbeing strategies (JHWSs), which outline local areas of need and priorities for health service provision. Each local authority area is required to produce a JSNA outlining the key local health needs, which then informs the development of health and wellbeing strategies (The King's Fund, 2016). JSNAs and their accompanying JHWSs are intended to 'plan and commission integrated services that meet the needs of their whole local community, in particular for the most vulnerable individuals and the groups with the worst health outcomes' (Department of Health, 2011a, p. 7). CCGs are then responsible for making and implementing commissioning decisions that reflect the health improvement methods identified in the JSNAs and joint health and wellbeing strategies (Department of Health, 2011a; NHS England, 2014). Taking this framework in conjunction with the legislative framework outlined in *Healthy Lives, Healthy People* and *Liberating the NHS* – which called for central government oversight of the needs of groups facing the greatest barriers to care – it is unclear precisely which government authorities are responsible for ensuring that all population groups have equal access to quality care (HM Government, 2010a; Department of Health, 2010a; Department of Health, 2010b). Although the government's 28 commitments for reducing inequalities faced by GRT communities stated that the Department of Health would 'explore how health and wellbeing boards can be supported to ensure that the needs of Gypsies and Travellers with the worst health outcomes are better reflected in Joint Strategic Needs Assessments' (DCLG, 2012, p. 15), the only concrete step towards this commitment has been publication of a guide for commissioning inclusive services (OHCHR, 2014). This guide does make specific reference to migrant Roma (Inclusion Health, 2013), yet the extent of its reach across health and wellbeing boards is unclear.

While CCGs control approximately 60% of the total NHS commissioning budget, NHS England assumes commissioning responsibilities related to highly specialist services and primary care (NHS England, 2014). Its main role is regulatory, however, and in this capacity it measures the effectiveness of CCGs, focusing on improvements in quality of services, health outcomes and cost effectiveness (NHS England, 2014). Under the NHS England monitoring framework there is some provision for ensuring that CCGs are allocated sufficient resources for supporting groups in need, yet there is no direct mechanism for ensuring that CCGs address service delivery to disadvantaged and marginalised groups (NHS England, 2014; Nuffield Trust, 2015). Moreover, ministers are unable to exert direct influence over frontline decision makers, with their recourse limited to criticism of CCG activities through the NHS Commissioning Board. This places the responsibility for commissioning decisions almost wholly in the domain of health service providers and purchasers, thus creating a system in which local commissioning decisions have the potential disproportionately to reflect commissioners' personal areas of interest, while simultaneously overlooking areas of population need (Davies, 2013).

The HSCA makes only limited provision for national oversight of CCG activities. It grants some regulatory powers to the NHS Commissioning Board, allowing it to intervene in CCG decisions if the Board believes that CCGs are not acting in the best interest of the NHS (Department of Health, 2011b). Underlying this deregulation of local health service development is one of the key goals of the HSCA – namely to introduce a system of competitive priority-setting in health care spending. Each CCG is allocated specific funds to purchase services, all the while competing with other CCGs to provide the highest quality of care. By making the NHS function as a market, competitiveness among CCGs and prioritisation of more affordable services– as opposed to equal access for all – increasingly becomes the main principle guiding health service commissioning decisions (Davies, 2013).

Underlying this legislative change is the assumption that greater involvement of clinicians with 'concrete' knowledge of patients' needs will lead to more tailored service provision (Perkins et al., 2014). In terms of commissioning services for disadvantaged, vulnerable and marginalised groups, however, the service development strategy outlined in the HSCA does not address problems associated with identification of need within communities that have difficulties in accessing GP services and may moreover be largely unknown to local authorities. Although there are no figures on GRT engagement with health services, levels of access may represent only a fraction of total populations due to limited understanding of health systems, preferences for self-treatment and difficulties in communicating with health professionals (Parry et al., 2004; Van Cleemput et al., 2007). Furthermore, the lack of monitoring of GRT ethnicity by health services may limit local awareness of the numbers of GRT patients accessing health services (Traveller Movement, 2014).

There is no mechanism built into the HSCA to ensure that GPs and local government officials have any particular expertise in identifying areas of need. Moreover, there is no protection against commissioning decisions that prioritise cost-saving over addressing health inequalities (Davies, 2013). In this sense, the HSCA introduced only a superficial attentiveness to community needs in commissioning, while in fact creating a system in which commissioning priorities are subject to variations in local commissioners' preferences, attitudes and areas of knowledge. Without a strong mechanism of national oversight, this has thus far created a health system in which the particular needs of GRT communities are, at best, given patchy and irregular attention.

5.2.4 Applications of GRT health data in policy development

To date, the most in-depth governmental effort to understand the health needs of GRT communities occurred under the Pacesetters Programme, which ran from 2006 to 2009. This Department of Health-sponsored study focused on the development of community-centred methods for addressing health inequalities in a number of disadvantaged groups, focusing on GRT communities in one of its core strands (Department of Health, 2009). The Pacesetters Programme sought to involve members of target communities in health promotion activities, often by training community members to provide health information to their peers. Although this programme was successful in increasing uptake of health services, evaluation reports noted that sustained funding and engagement would have been essential to its continuation (Van Cleemput et al., 2010). However, since the 2010 conclusion of the Pacesetters Programme, there have been no national government-sponsored initiatives to promote improved access to services and health outcomes for GRT communities.

Health and Wellbeing Boards hold the primary responsibility for determining whether GRT gain inclusion in the development of health strategies. To offer insight into the extent of local attention to GRT health needs, the charity organisation Friends Families and Travellers (FFT) conducted a 2015 review of JSNAs across the South East and South West of England (FFT, 2015). This report employed close reading of JSNAs to gain insight into the inconsistency in local attention to the needs of these communities, revealing significant underrepresentation of GRT communities in service development strategies (FFT, 2015). The present inconsistency of service provision in line with need may be seen as a reflection of the marginalised position of GRT groups in UK society, and Roma migrant communities are perhaps the most marginalised of the three. Craig (2011) notes how the circumstances of Roma migration to the UK occupy a grey area between economic migrants and asylum seekers, and this somewhat irregular status often contributes to a lack of basic awareness of Roma groups amongst health professionals and policy makers. Even where local services are aware of the presence of Roma communities, limitations on service capacity may lead policy makers to disregard Roma needs, or to take steps to improve the situation of Roma only at a point of crisis (Morris, 2016).

5.2.5 The position of Roma migrants in UK health policy

Roma communities across England face a complex set of challenges in using health services, yet there is no consistent strategy within national health policy for addressing the situation of Roma migrants. Despite government statements asserting that the new commissioning frameworks instituted under the HSCA would allow the development of more targeted, tailored local services (Department of Health, 2011a), Roma frequently fall outside commissioners' attention. As many Roma community members lack a strong voice for self-advocacy within public institutions (McGarry, 2017), local health commissioners may not be aware of their situation. This could lead, inadvertently or otherwise, to neglect of Roma needs in health service development. Moreover, in areas in which distinctive Roma needs are recognised by local health policy decision makers, the complexity of ensuring effective communication with Roma patients and the potentially high cost of relevant service improvement measures preclude the development of support mechanisms. It can thus be argued that the most vulnerable groups in society in fact suffer under the HSCA and the consequent lack of a national framework for ensuring attention to their health needs (European Commission, 2018; FFT & NFGLG, 2018; Scullion & Brown, 2016).

In the absence of a national framework requiring policy development to meet the health needs of Roma communities, provision of services for this frequently marginalised group can be subject to variations in local dynamics. Although the National Inclusion Health Board has produced a commissioning guide that outlines strategies (i.e. engagement with local community groups) to promote attention to GRT in JSNAs, this represents a mere advisory message and furthermore tends to eclipse Roma migrants' concerns within the broader category of Gypsy and Traveller needs (National Inclusion Health Board, 2013). An array of factors – including, but not limited to, size of local Roma populations, influence of Roma community groups and personal opinions of local decision makers – interact to determine whether Roma needs receive attention in the funding and development of health services. Without official recognition of Roma as a distinct ethnic community, however, it is likely that commissioning decisions will propagate their marginal status within UK health services.

5.3 Local strategy development under the Health and Social Care Act of 2012

5.3.1 JSNA development and the perpetuation of inequalities

Increased local responsibility for commissioning of services is believed to increase health care providers' accountability to the populations they serve. In theory, conducting detailed local needs assessments and designing services accordingly should lead to the development of services that reflect community health priorities (Department of Health, 2010a; Department of Health 2010b; HM Government, 2010a). In practice, however, Health and Wellbeing Boards incorporate only limited public voice (in the form of one elected representative) and there is no clear and consistent framework for conducting consultations with members of local communities to discern their preferences for health service design. Critiques of service design under the HSCA have noted that 'rather than universal provision, there will be different levels of provision within different CCGs depending upon what the CCG decides to prioritise in that locality. One CCG may not offer the same services as a neighbouring CCG' (Speed & Gabe, 2013, p. 571).

Prior to passage of the HSCA, patient and public involvement forums and local involvement networks (LINks) afforded local communities the opportunity to evaluate health systems (Department of Health, 2007). Healthwatch (the closest equivalent to LINks under the HSCA), however, functions primarily in providing advice and information, while lacking the capacity to influence service improvement that was afforded to past public engagement bodies. While the HSCA required that a representative of Healthwatch sit on each Health and Wellbeing Board, there is no requirement that community involvement activities of CCGs must incorporate Healthwatch, nor is there any consistent mechanism for feeding back on commissioning decisions to the public (Tritter & Koivusalo, 2013). Local health system decision-makers are accountable only to NHS England and not to the communities impacted by their decisions, creating a situation in which actual public satisfaction with services is secondary to statutory requirements to meet community engagement targets (Tritter & Koivusalo, 2013).

Under the current commissioning system, JSNAs are the only consistent vehicles for promoting commissioners' accountability to community needs (Tritter & Koivusalo, 2013). JSNAs are, in theory, intended to highlight key inequalities, yet lack of guidance on assessment of need can give rise to significant local discrepancies in commissioning for marginalised groups. In the case of GRT communities, these variations are particularly striking.

5.3.2 Inclusion of GRT in JSNAs

Building on FFT's review of JSNA coverage in the South East and South West of England, I conducted an expanded review, which addressed the whole of England and looked specifically at inclusion of Roma migrants in JSNAs. This review occurred in two waves – first during the summer of 2016 and again in the autumn of 2018 – to capture the impacts of annual cycles of JSNA updates. The method for each review was the same: after obtaining a list of all local authority areas in England, I then identified the most recent JSNA documents for each area and conducted keyword searches using the words 'Gypsy', 'Roma' and 'Traveller.' I then entered this information into a database breaking down JSNA content by area, inclusion of GRT, extent of attention to GRT needs, inclusion of CEE Roma and key health issues and barriers to care identified. At the conclusion of the 2018 review, I compared JSNA data against school census data denoting the number of 'Gypsy/Roma' pupils for each local area, which aided in ascertaining whether the extent of JSNA coverage was commensurate with population size.

Each phase of the policy review utilised the most recent published JSNA data, though it is relevant to note that all local authorities had not made their most recent JSNAs publicly available (and others did not list the year of publication). In 2016, 49 out of 152 included references to GRT in their JSNAs, 14 of which specifically addressed Roma migrants. In 2018, 52 local authorities produced JSNAs that made reference to GRT health, with 10 mentioning Roma migrants. GRT coverage in JSNAs could range from a chapter dedicated to GRT health to a sentence mentioning that these groups are likely to experience poorer health outcomes. While omission of GRT populations from JSNAs may simply indicate a small local GRT population or Health and Wellbeing Board members' lack of awareness of these groups, comparing JSNA data against school census data showing Gypsy/Roma populations reveals no apparent correlation between population size and JSNA inclusion. School census data for Bath and North East Somerset, for example, report two Gypsy/Roma pupils in school, yet the JSNA includes a full chapter on Gypsy and Traveller health needs (likely as a consequence of the 2012-2013 Gypsy, Traveller, Boater, Showman and Roma Health Survey conducted by Greenfields & Lowe). Bradford, by contrast, lists 651 Gypsy/Roma school pupils, yet does not include GRT in its JSNA.

Each phase of my JSNA review revealed very low levels of attention to Roma migrant communities. This may be attributable to limited local awareness of Roma communities, though it is worth noting that neither JSNA for my research sites (London Borough of Newham and Luton) made reference to European Roma as of 2018. This omission occurs despite engagement with both of my partner organisations with local authority and CCG officials. On a national level, the lack of data on Roma migrant populations makes it difficult to ascertain the extent to which JSNAs reflect actual population size, as school census data disaggregates only by Gypsy/Roma, yet does not allow for distinction between Gypsy and Roma identity. It can only be posited that the current state of Roma inclusion in JSNAs underrepresents population size and that the extent of attention to Roma migrant health needs far underestimates the reality of community demand for improved attention within services.

5.3.3 Comparisons of 2016 review and 2018 update

Comparing the results of the 2016 and 2018 JSNA reviews reveals minor variations in GRT inclusion in JSNAs, with Gypsy and Traveller groups receiving marginally greater coverage and European Roma receiving marginally less. A set of 41 local authorities represented areas of change (either omitting references to GRT where they had previously been included or including GRT where they had previously been omitted) with regard to inclusion of GRT in their JSNAs. Of these, 22 local areas did not mention GRT in 2016 but included them in 2018. A total of 13 local authorities represented areas of change with regard to CEE Roma, with only four including Roma where they previously had been omitted.

It is difficult to ascertain the precise reasons for these variations. Omissions of GRT from JSNAs in which they were previously included could be attributable to changes in the makeup of Health and Wellbeing Boards, through which new members may not be adequately briefed on previous target areas. This could be a particular issue for ensuring inclusion of Roma migrant communities, as the lack of reliable data on Roma populations could lead them to be routinely overlooked. In the 2018 review, JSNAs additionally appeared to increasingly follow a standard format in which they track population health across life stages, rather than focusing on particular disadvantaged groups. When the focus is shifted to broader population health, it becomes less likely that any given ethnic minority group will be identified as a target for health promotion activities or adjustment of service provision.

5.3.4 Characterisations of GRT health and recommendations for services improvement

Nearly every JSNA addressing GRT groups highlights their poorer levels of self-reported health compared with other disadvantaged and marginalised groups. Other commonly reported problems include low life expectancy, high infant mortality rates, low immunisation uptake and higher rates of anxiety and depression. These issues are frequently attributed to the generally disadvantaged socioeconomic profile of GRT populations, which is reported to impact other key areas such as access to adequate housing and levels of educational attainment. Problematically, many JSNAs present GRT health issues in the context of travelling behaviour, focusing on high levels of mobility and limited experience of living in settled accommodation as key health determinants. Misconceptions about travelling behaviours, communication methods and cultural taboos could lead to the development of services that disregard segments of GRT populations whose behaviours do not reflect official conceptions of GRT lifestyles. In this sense, an emphasis on the needs of highly mobile Gypsies and Travellers could cause the needs of European Roma living in permanent accommodation (as well as housed Gypsies and Travellers) to go unnoticed in the development of commissioning priorities.

Many JSNAs make no concrete recommendations for improvement of service in light of GRT-specific needs. Of those that do, there is often a focus on methods for enhancing communication between health service staff and GRT patients. Cultural awareness training for frontline staff and development of resources through consultation with GRT communities are common recommendations for promoting better mutual understanding between GRT community members and service providers. Some JSNAs additionally seek to increase engagement of GRT communities with health services by outlining health champion programmes, in which trained GRT health advocates provide heath advice to their communities. Finally, there have also been vague calls for ‘awareness raising’ as an area for action, yet these do not specify whether awareness raising activities will be directed at service providers, service users or both.

5.4 Evaluation

5.4.1 Disparities in GRT inclusion in JSNAs

The reasons underlying the wide disparities in inclusion of GRT in JSNAs are largely unclear and likely represent regional variations. In some cases, the depth of attention to GRT communities may be directly related to population size. Kent, for example, has the largest reported representation of Gypsy/Roma pupils in schools and also has a nuanced JSNA chapter capturing variations in GRT community profiles, prevalence of health issues and social determinants of health. In other cases, research reports may provide a foundation for including GRT in JSNAs, even where school census data indicates small local populations (as is evidenced by the case of Bath and North East Somerset). Finally, analysis of JSNA data reveals a tendency for Health and Wellbeing Boards to recycle data from Gypsy and Traveller accommodation needs assessments in developing JSNA content. While this practice may be useful in assessing population size and gaining insight into certain social determinants of health, it fundamentally disregards the experience of Roma migrant communities, perhaps offering a partial explanation as to the reason for such minimal inclusion of European Roma in health strategy development.

Representation of GRT communities in JSNAs also raises questions related to stakeholder engagement and the extent to which Health and Wellbeing Board representatives directly consulted with GRT communities in the process of strategy development. In this area there are notable examples of good practice, as well as notable shortcomings. Salford, for example, undertook action research with GRT communities in the development of its JSNA, which involved European Roma, Irish Traveller and English Gypsy families in investigating the social and cultural underpinnings of GRT health concerns (Stables, 2014). Also in this vein, Haringey engaged a panel of GRT community members to provide insight on the specific issue of men’s health (Haringey Council, 2013). Many JSNAs also appear to reproduce the findings of the Parry et al. (2004) study of health in Gypsy and Traveller communities, thus substituting generalised national findings for local intelligence. Not only does this study exclude Roma migrant communities, but JSNAs’ reliance on this national data also defeats the HSCA’s purported aim of building local commissioning strategies on local knowledge. It would appear that, when assessing GRT health needs, Health and Wellbeing Boards are opting for desk-based research rather than community consultation, leading to a lack of robust and locally specific data on community members’ distinct concerns. Moreover, an apparent failure to undertake meaningful engagement with JSNAs’ target groups may lead local policy developers to overlook more recent Roma migrant communities.

5.4.2 An example of good practice

Despite the irregular attention to Roma within JSNAs, a small subset of local authorities demonstrate effective models for capturing both community members' perspectives on their needs and providers' experiences of working with Roma patients. Sheffield, for instance, is reported to have a sizeable Slovak Roma population – estimated at 6000 as of November 2015 – and the city council has a long history of engagement on the specific topic of Roma migrant health. Needs assessments were conducted in 2009, 2010, 2011 and 2016, offering perspectives from both Roma community members and health professionals (Gill, 2009; Moore, 2010; Ratcliffe, 2011; Willis, 2016). The 2016 *Slovak Roma Health Needs Assessment* offers a detailed look at Roma history and origins, motivations for migrating to the UK, disease prevalence and usage of health services (Willis, 2016). By employing Roma community members as researchers, this needs assessment provided a nuanced look at the complex and intersection factors informing Roma community members' impressions of health systems. It looked not just at Roma migrants' experiences of accessing health services in the UK, but also at the multi-layered impacts of discrimination and deprivation on Roma patients use and expectations of health services (Willis, 2016).

As was noted in many JSNAs, the lack of codes for recording Roma patients' ethnicity can create barriers to monitoring the needs of the Roma community, leading JSNA authors to effectively discount Roma inclusion in health strategy development. In the absence of service-wide ethnic coding, however, GP practices participating in the Sheffield needs assessment manually extracted data on the number of registered Roma patients, representing practice staff's high level of awareness of their patient base. Yet this awareness was apparent not only amongst frontline practitioners but also service commissioners, as was evidenced by CCG-funded 'Slovak clinics', which allowed patients to register with the assistance of an interpreter, undergo routine health checks and receive initial vaccinations (Willis, 2016). Not only did this help to ease migrant Roma patients' transition into health services, but it also displayed sensitivity to the poor access and abusive treatment that patients had experienced in Slovakia. The case of Sheffield, however, appears to represent the exception rather than the rule.

5.4.3 The shortcomings of commissioning in addressing GRT health needs

Results of this policy analysis indicate an overall lack of attention to GRT health within both national and local policy frameworks, and a pronounced lack of attention to European Roma in the development of commissioning decisions. Given the likelihood that GRT communities across England will encounter barriers to adequate health care and have poorer experiences in service use, this legislative inattention represents a serious oversight in developing strategies for promoting the delivery of quality services across different population groups (Craig, 2011; Parry et al., 2004; Tobi, Sheridan & Lais, 2010). Coupling these findings with a review of secondary analyses of the impacts of recent health service reforms, this policy analysis suggests that higher quality data informing the commissioning of services for GRT communities must be accompanied by more consistent monitoring to ensure that GRT communities are not overlooked. Although some local areas have made a strong effort to address the needs of GRT communities, this is by no means consistent across local health strategies in England.

As noted in the literature review, the health needs of Gypsy, Roma and Traveller communities diverge fundamentally along the lines of the migrant identity of UK Roma. Thus, where Gypsy or Traveller community members may encounter communication difficulties related to limited knowledge of health conditions and mistrust of professionals (Parry et al., 2004), the situation of Roma may be further compounded by limited understanding of English and histories of migration (McFadden et al., 2018). There are members of the Roma community who are only comfortable in speaking Romanes, and measures to provide language support in the Romanes language would constitute a health service development that is highly sensitive to the particular needs of European Roma communities (McFadden et al., 2018). Additionally, many Eastern European Roma experienced extreme degrees of discrimination in their countries of origin, particularly in their encounters with public services (Poole & Adamson, 2008). Health systems were no exception, and in some cases the Roma were entirely excluded from services (Rechel et al., 2009). Experiences in their countries of origin can exert a substantial impact on the health-related behaviours of the European Roma (Warwick-Booth et al., 2017), yet health policies taking a broad view of GRT communities do not capture such nuances underlying difficulties in accessing services and communicating with providers.

Underlying this discussion of commissioning is an implication that it is (in its present form) ill-suited to addressing the health needs of GRT communities. Contrary to the commissioning model’s emphasis on competitiveness and cost-effectiveness of services, providing effective and culturally sensitive health care to communities with greater support needs is rarely a straightforward or inexpensive process. Services targeted at the specific needs of marginalised groups are necessary to ensure that the NHS provides services that are tailored to patients' needs (Department of Health, 2015). Even when service developers engage in consultations with marginalised groups – and specifically GRT communities – the question remains as to whether there is a will to change service delivery mechanisms to reflect consultation results.

When considered in the context of prejudice and discrimination against GRT, local attitudes could take on additional significance. Prejudiced attitudes may be unlikely to manifest themselves in the form of overtly discriminatory policies, yet they could lead to a form of discrimination by omission, in which the need of groups with particular support requirements are excluded from policy decisions. For European Roma communities – particularly in the context of growing anti-immigrant sentiment in England – this could carry the added danger that local decision makers will disregard their duty to commission equitable services in favour of acting on their personal views of Roma communities and misconceptions of their right to access services.

5.5 Summary

This policy analysis opened by providing an overview of UK national policies for promoting equality and integration of ethnic minority communities, then moving on to a general discussion of the extent to which GRT concerns have influenced the development of health policies. This chapter charted the development of the HSCA, focusing on its promotion of a localism agenda and cost-saving mechanisms in developing health services. Then, in light of the HSCA's emphasis on local determination of health system agendas, this chapter presented data from a review of JSNAs produced in England as of 2016 and 2018. Focusing on these documents' reflections of GRT community needs, this review outlined the key health issues identified in each JSNA and looked to modes of data collection to assess the extent of engagement with communities. Perhaps the most striking finding of the review of JSNAs was the extent of variation in local characterisations of GRT health needs, which does not exhibit any clear correlation to local GRT population size. Instead, GRT communities seem to gain inclusion in JSNAs according to varied – and sometimes opaque – mechanisms, with some Health and Wellbeing Boards building their sensitivity to GRT needs through community engagement and accommodation needs assessments, while others appear to rely on existing data on GRT heath. Across local authority areas that do not include GRT communities in their JSNAs, comparisons with schools census data indicate substantial underrepresentation of GRT health within commissioning frameworks, potentially leaving large portions of GRT communities with unmet health needs.

Chapter 6: Patterns of perception and interaction revealed through grounded theory analysis

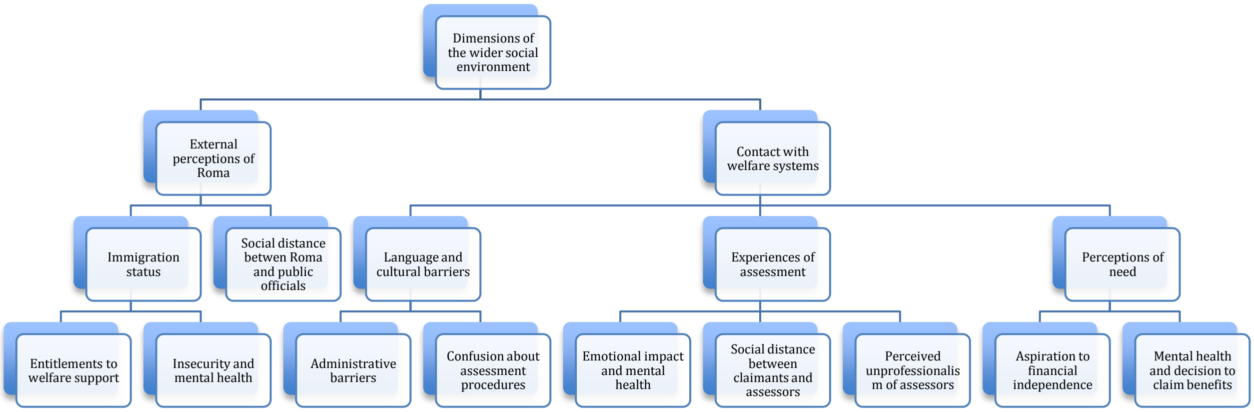
6.1 Overview of grounded theory methods

In conducting grounded theory analysis, my first step was to undertake a line-by-line reading of interview transcripts and fieldnotes, assigning descriptive codes to segments of text. These codes captured topics such as ‘need for interpreters’ and ‘cultural clashes with health professionals’. Then, to understand the broader meaning behind the codes, I wrote theoretical memos elaborating on key underlying contextual factors. This provided a fuller view of the social world under observation and prepared me for grouping the codes into categories (e.g. ‘language barriers’). Groups of categories then fit into higher-level concepts (e.g. ‘language and understanding of health conditions’). The final theory arising from grounded theory analysis posited that Roma community members’ experiences of health operated on three key levels: personal conceptualisation of health, interactions within health services and interactions with immigration and benefits systems. This chapter outlines the results of my analysis, defining the categories and concepts within these three key thematic areas.

With its emphasis on building a theory from discrete segments of data, I intended my analysis to give specific voice to participants in the write-up of my results and to avoid any undue assumptions stemming from my status as a relative outsider in the field. I did not want to make statements about Roma experiences that were not directly substantiated by participants’ accounts, and to this end, grounded theory analysis was effective in providing an overview of the trends I observed in the field. It allowed me to define the conceptual interconnections across different segments of data and to see the common threads running through seeming distinct elements of Roma participation within social and institutional frameworks. It moreover alerted me to the commonalities in Roma participants’ means of representing their health conditions and their contact with services, providing insight into Roma health communication strategies that informed later re-analysis of the distinct personal narratives contained in my interview data. In presenting this data, I reflected on Janevic et al.’s (2011) categorisation of racism, considering whether the dimensions of unequal treatment outlined in participants’ accounts and field observations could best be understood as personally mediated, internalised or institutional.

6.2 Theme 1: The wider social and institutional context of this research

Figure 2: Categories informing the development of Theme 1



Although the primary focus of this research is on participants' perceptions of health and interactions with health services, field observations revealed a much more complex set of interconnected factors underlying the accounts provided in interviews. It was outside the scope of this study to undertake a complete investigation of the social determinants of health as they impact Roma communities, yet concepts related to participants' experiences within UK welfare institutions arose strongly from the grounded theory analysis. As a corollary of these observations, participants' immigration status also called attention to their precarious entitlement to benefits, creating a sense of fear and uncertainty as they considered their ability to sustain their lives in the UK. Through a joint look at immigration and benefits, this section elaborates on the broader concept of security, looking at the forces that destabilise participants' lives and their efforts to shore up their sense of a more certain future.

6.2.1 Immigration status, insecurity and entitlement to services

The UK's vote to leave the European Union occurred at approximately the midpoint of my fieldwork. As the majority of Roma in the UK are EU nationals, the referendum result called into question their future ability to maintain basic rights of residency, and this heightened anxieties across the community. Participants expressed that they had no home in their countries of origin and that the family and social connections that they have established in the UK are stronger than those that remain in their native countries. Even prior to the referendum vote, participants expressed fears of potential disruptions to their lives:

> *Yes, the referendum. I not have a home to Poland, my child born here.*
>
> - Female, Polish Roma [005] ❖

While there were no immediate threats of deportation, participants' sense of detachment from their countries of origin made the prospect of returning untenable. At the time of grounded theory analysis, however, the above quotation represented the only direct reference to immigration in my interview data, which was likely due to the fact that I was initially advised to avoid questions related to immigration in interviews (so that participants would not draw associations between my research and immigration enforcement). Yet as I re-considered my observational data post-grounded theory analysis, I began to see patterns pointing to the impact of immigration insecurity on participants' lives. This dimension of Roma participants' experiences will be explored in greater detail when I discuss my re-analysis of data in Chapter 7, yet in the immediate term, grounded theory analysis did reveal connections between immigration and benefits entitlement.

Following the referendum, increasing numbers of Roma community members approached my partner organisations with letters citing their ineligibility for benefits on the basis of immigration status:

> *We had three people come in with Child Benefit refusal letters, all of which cited reasons (no right to reside, insufficient period of residence in the UK) that were directly contrary to the reality of the situation.*
>
> - Fieldnotes, Luton, 27/06/2016

It was unclear whether such examples represented a form of *de facto* immigration policy made outside the law, yet they highlighted how the interactions of benefits systems and immigration rules mediates vulnerable migrants' security and stability in the UK. Immigration status presented a barrier to benefits, particularly amongst the most disadvantaged segments of the Roma community. This must also be understood in the context of high rates of disability and long-term illness in my participant group, which often precluded their ability to work and necessitated benefits claims to maintain a basic level of subsistence.

6.2.2 Roma participants' experiences of applying for disability benefits

Participants with long-term health problems were frequently in receipt of benefits aimed at people with chronic illnesses and disabilities. These include Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and Disability Living Allowance (DLA).[7] Making claims to these benefits involves a lengthy application process, consisting of a detailed form describing health conditions and a face-to-face medical assessment with a 'healthcare professional'[8] subcontracted by the Department for Work and Pensions (DWP). In the event of an unsuccessful application, many participants elected to go through a process of appeal, which could take many months. The claimant must initially make a written request to DWP asking for reconsideration of the decision. If the claim is still unsuccessful at the reconsideration stage, the claimant can make a further appeal to an independent tribunal.

The decision to make a new claim for benefits (or to challenge the rejection of a claim) involved careful consideration of the advantages and drawbacks of an application. This was captured in a fieldnotes entry, in which two participants weighted their options in making a claim for PIP:

> *In Luton a couple came in looking to claim Carer's Allowance. I explained to them that Carer's Allowance is only available to carers of people in receipt of PIP or DLA, which neither of them was. So I called DWP and requested a PIP form. This couple came back the next week explaining that they didn't want to fill in the PIP form out of fear that they would lose their Employment and Support Allowance.*
>
> - Fieldnotes, Luton, 17/03/2016

While it is possible to receive PIP and ESA concurrently, these individuals feared that it would upset the delicate balance of their income from employment and benefits, leading to an overall reduction in their income. This offers insight into the manner in which participants navigated benefits systems, the precariousness of their economic situations and their reluctance to upset the delicate balance of income stability.

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[7] PIP looks at an individual's need for assistance with a range of daily living activities and is awarded without consideration of income or employment status. ESA focuses on an individual's ability to work. DLA bears a close resemblance to PIP, but is exclusively for people under the age of 16.

[8] It is unclear how the firms contracted by DWP (Atos, Capita and Maximus) recruit and train assessors (BBC, 2018). Capita's eligibility requirements state, for example, that assessors must simply be 'fully qualified healthcare professional[s]' with at least two years' experience (Capita, 2018). It is unclear whether assessment firms make any effort to match claimants' needs to assessors' qualifications.

While the above example demonstrates a relatively advanced knowledge of benefits systems, other segments of Roma communities had more limited understanding of state support systems and the requirements of making claims for health-related benefits. In these cases, participants' decision to apply for benefits brought substantial confusion, as became apparent when assisting a participant to apply for DLA for her son:

> *It was the first child's DLA form I had seen filled out in Luton, and the mother appeared relatively disengaged and confused throughout the process. She seemed reluctant – or unable – to offer any in-depth description of the issues created by her son's diabetes.*
>
> - Fieldnotes, Luton, 10/10/2016

The mother lacked the vocabulary necessary to describe her son's health conditions (an effect of limited education, as well as limited prior access to health services), and she felt intimidated by the level of medical detail that the claim form required her to provide. Even with the support of an advocacy worker, she found it difficult to answer questions regarding specific details of her son's support needs.

Often it was only with external support from voluntary organisations that Roma community members were able to understand the stages of a benefits claim process, ensure that claim forms were completed correctly and engage in follow-up communication with DWP. A fieldnotes entry describing the process of assisting with an ESA application captured the difficulties of assembling the documentation necessary to complete the application form:

> *To get a sick note, we needed to request a replacement from the psychologist who had written the original. When I called him, though, I found out that he had changed jobs. So I then called his new workplace, and he told me that the system had been somehow restructured, making it impossible for him to gain access to the sick notes he had written previously. Our only recourse was to go back to the client's GP and request a sick note, but this particular GP doesn't issue sick notes.*
>
> - Fieldnotes, London, 29/04/2016

The burden of evidence is placed on the claimant, and this could create substantial delays in completing benefits applications. Many participants engaged over the course of fieldwork had misplaced the documentation necessary to evidence their benefits claims; others had kept reams of medical documentation, yet due to language and literacy issues, many did not understand the information contained in these documents, nor did they know which should be submitted to DWP.

After making an initial application for health-related benefits, claimants are required to attend an assessment with a 'healthcare professional' subcontracted by DWP. For those in need of language support, DWP provides interpreters over the telephone as a standard practice, which a participant describing her husband's claim for PIP highlighted as a barrier to adequately explaining his condition:

> *It was hard to understand, and also from this side, it was difficult to express ourselves and to describe everything. You know, like when you have to talk to the phone and not to the real person.*
>
> - Female, Polish Roma [007] ■

Her husband's health problems had an impact on his ability to move his legs, yet he found it difficult to verbalise these difficulties without accompanying physical demonstrations. Not only did this demonstrate participants' impression that benefits systems provide inadequate support in making their claims, but it also reflected how low levels of medical vocabulary could affect benefits applications. Limited formal education meant that many participants lacked the vocabulary to describe their health issues, and they thus relied heavily on mimetic motions to communicate. Interpreters can suggest terminology correlating with participants' movements, at which point participants are often able to confirm the names of their conditions. When an interpreter is absent from the assessment room, however, participants are unable to execute this key form of communication.

In light of the difficulties associated with communicating through a telephone interpreter – especially when the assessment requires demonstration of physical movement – many participants opted to bring an English-speaking family member instead. While this could help to alleviate participants' fears that they would be unable to communicate with assessors, it also had the potential to introduce cultural communication barriers into the assessment.

Cultural barriers to communication were reported to arise when participants felt that the assessment question topics – for example, managing toilet needs or washing and bathing – required them to describe parts of their bodies that Roma culture traditionally considers inappropriate for discussion. While some adopted a pragmatic approach to answering assessment questions and temporarily set aside their conceptions of health-related taboos to provide detailed answers, others were reluctant to detach themselves from their traditional views of health communication. One Polish Roma woman discussed how she found herself unable to disclose the full details of her assistance needs due to their cultural implications:

> *The questions are hard – not the questions but the answers. I need the help, but because of my culture I cannot say.*
>
> - Female, Polish Roma [008] ❖

Field observations also reflected a gendered dimension to this reluctance to divulge sensitive medical details:

> *Men tend to be particularly reluctant to divulge any information that might make them appear weak. One man admitted in the process of filling in his PIP form that he does have problems with washing and bathing, but he didn't want to explain the details because he felt ashamed.*
>
> - Fieldnotes, London, 17/02/2016

Similar observations were repeated across fieldnotes entries, with participants lowering their voices when discussing their needs in using the toilet and bathing themselves.

Even when language and cultural barriers were not an issue, many participants noted tense interactions with DWP assessors. Their accounts highlighted assessors' dismissiveness of the severity of their conditions, and some suspected that assessors inaccurately recorded vital medical information:

> *No, it was really bad. I just want to left and that's it. I'm thinking about to left the room. The lady was, um, she didn't hear me really. I didn't have interpreter with me because I was thinking I don't need it. But she give the answer, she give the, um, questions and she answers. That's what she does. She just sent the reports and write down… I … I'm healthy. She didn't see nothing with my health. What she saying as well? I'm very like, uh… I can manage with other people and everything and stuff, and she can say I'm healthy.*
>
> - Female, Polish Roma [011] ❖

This participant notes how the assessor failed to adequately represent her health problems, making a reference to the absence of an interpreter as a potential reason behind the assessor's dismissiveness. In other cases it was reported that assessors did not make sufficient efforts to gather supporting medical information:

> *When this assessment took place, they haven't asked for any documents from GP, they made decision only what was on the form and based on the assessment. Because I call DWP later, I wanted a report from how they made the decision, so the chap from DWP told me that they haven't asked for any medical evidence from GP doctor or any specialist.*
>
> - Community advocacy worker, London-based [CW001]

Participants repeatedly noted how the DWP assessors would write answers to assessment questions without offering adequate time to give a response. Although participants were aware of the incompleteness and inaccuracies of assessors' accounts, their position of relative vulnerability in comparison to the assessor afforded them little influencing power in affecting the outcome of the assessment.

Many participants lacked the English language proficiency to articulate their dissatisfaction with assessors' behaviour. Assessors, by contrast, asked a set of rigid, pre-determined questions – which many participants found difficult to understand – with a computer forming a physical barrier between assessor and claimant. Participants found the assessment process intimidating, with one likening it to a police interrogation:

> *And when he left I felt like I was shaking, like I was very nervous. I wanted to do it very good. I wanted to be too good – that's why maybe. Basically he asked me one question, he asked me a few times, like 3-4 times, to check if I would give the same answer, so that's why I felt like I was in a police station and like I have to confess something, like I did something and I have to say the truth.*
>
> - Female, Polish Roma [012] ❖

Expressing her feeling she was forced to confess to a crime that she did not commit, this participant conveyed her interacting feelings of stress and powerlessness as she underwent her disability benefits assessment. Yet this account not only reflected her personal distress, but also suggested the fraught relationships between Roma community members and people in positions of authority. For many participants, they described their contact with representatives of benefits systems as decidedly non-neutral, orienting themselves in a position of inescapable disadvantage as they navigated systems of welfare support.

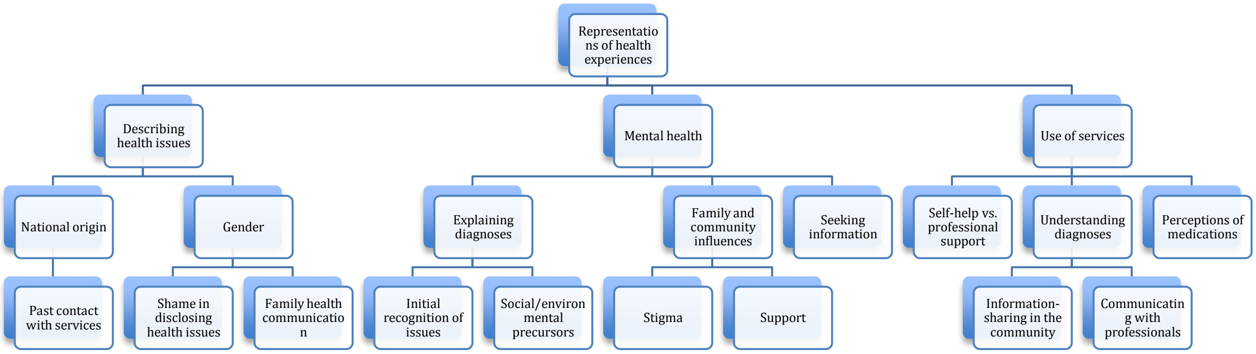
6.2.3 Summary of Theme 1

This section presented dimensions of participants' experiences within a broader UK social and institutional environment. Beginning with brief overview of the political changes that occurred in the UK over the course of fieldwork, I opened with a discussion of participants' fears related to their immigration status and the ways in which immigration insecurity impacted on their efforts to attain financial security. Although the topic of immigration did not arise particularly strongly through grounded theory analysis, it rose to the position of a major thematic element as I undertook narrative re-analysis of data and considered my personal narrative of involvement in the field. Immigration is explored in greater detail in Chapter 7.

The bulk of this thematic section then focused on participants' pathways through the health-related benefits system, elaborating on the complexity of the claim process and their sense of grievance towards the behaviour of DWP assessors and thus revealing an element of personally mediated racism. Participants perceived that assessors were neglecting to treat their cases with requisite seriousness, and in some cases that assessors were actively antagonising them. Although they were aggrieved by assessors' behaviour, many lacked the confidence to challenge assessors or to insist on a more thorough investigation of their health situation, thus revealing internalised racism operating alongside personally mediated racism. To capture the issue of internalised racism, analysis addressed the barriers to successfully making a claim: participants' feelings of powerlessness in gathering evidence and communicating with assessors, as well as their lack of recourse when assessors seem to misrepresent their medical conditions. Looking holistically at the data, this presents a picture in which participants find themselves unable to represent their needs within the machinations of the disability benefits system.

6.3 Theme 2: Social and cultural precursors of health-related decisions

Figure 3: Categories informing the development of Theme 2



Against a backdrop of insecurity, material deprivation and disadvantage within social institutions, the next thematic area that emerged from grounded theory analysis outlines the ways in which participants gathered, shared and understood health information. It addresses the cultural precursors of disclosing the details of medical conditions, the decision-making process involved in seeking out medical support and the socio-cultural challenges involved in communicating about health issues. The analysis then hones in on the specific example of mental health, demonstrating how participants describe and make decisions about a health-related subject that is particularly sensitive in Roma culture (Roma Support Group, 2012).

6.3.1 The social context of health communication

When participants entered into discussions of their health conditions, they tended to present these in terms of relationships of cause and effect, emphasising symptomatic linkages between different health conditions and elucidating the resulting difficulties:

> *Because I have caesarean, it's emergency born. After that I got operation because hernia.*

- Female, Polish Roma [005] ❖

This participant then went on to describe the practical challenges she experiences in caring for her disabled daughter in the context of her physical health problems. She drew connections to the unsuitability of her housing situation in light of her daughter's disability, the local council's inaction in response to her requests for adaptations to her home and her concerns over the insecurity of her immigration status in light of her inability to work. This account took shape with very little prompting or questioning, and highlighted how Roma participants understood health issues as deeply intertwined with their social environments.

When asked broadly to discuss their health concerns, it was common for participants to cite diagnostic information to explain their health conditions:

I have diabetes and I've been sleeping on my bed for two weeks because I'm feeling very sick.

- Female, Romanian Roma [021] ✜

Yeah, my son, my son is two years and then is not heart attack is just go down. All face is black, and then when I go to emergency is just touch and then say, 'your son, it's okay.'

- Female, Romanian Roma [017] ❖

Even when this involved a misattribution of medical terms (as is the case in the latter quotation), participants appeared to value precision in describing health conditions and their impacts, which perhaps had its roots in restricted access to services in participants' countries of origin and past inability to obtain health information. Participants explained how they valued the relative openness of health services in the UK, drawing comparisons to past experiences of restrictions of access:

In Romania I couldn't access medical help because I had no money, because I had no work.

- Male, Romanian Roma [022] ✜

[In Romania] We would be left in the streets to die.

- Male, Romanian Roma [018] ✜

Taking the precise and descriptive characterisations of health issues in conjunction with references to health service accessibility, it seemed that participants' health knowledge expanded following migration to the UK, and they sought to apply this knowledge in health-related discussions.

Despite participants' overall openness in discussing their health conditions, instances did arise in which participants selectively edited their health communication on the basis of the listener's gender. This seemed to be based in Roma cultural expectations, which restricted cross-gender discussions of reproductive health, sexual health or any aspects of reproductive anatomy (McFadden et al., 2018). Participants explicitly stated these communicative limitations, noting as well that it is more acceptable to discuss these issues with a health professional of a different gender:

> *There are some things that are taboo within our culture, but you can disclose that to a doctor, because he is non-Roma.*
>
> - Female, Polish Roma [025] ✜

Professionals working with Roma also noted these gender-based restrictions on health communication. A Polish interpreter who regularly worked with Roma patients described, for instance, self-imposed barriers to health information that arose when a diagnosis dealt with the reproductive organs:

> *I had one situation with a lady who was very, very reluctant, who just did not want to let us out of the room without her consenting to go any further in the situation because we were suspecting cancer, but it was with the female parts and she just did not want to go for this check-up – she just refused.*
>
> - Polish interpreter, Female, London-based [P004]

Avoidance of a potential cancer diagnosis on the basis of a health condition's connection to the female anatomy reveals the depth to which cultural expectations can impact on Roma community members' health-related decision-making.

Another participant who experienced difficulties in communicating with her GP articulated further dimensions of gender-based restrictions on health communication:

> *When I go to see GP doctor, for example, and the doctor has to like, interview me about whether I've got menopause yet, so, he speaks English, but I know, I know what it means: period or menopause. Understand? But because my son is saying to the doctor, you can't ask this kind of question because I can't translate for me, I also can't answer this question even though I understand, because I could answer in Polish. So then my son should translate into English, but it doesn't work. So, like, family matters if there's men.*
>
> - Female, Polish Roma [012] ❖

In another example, a participant reflected on her support needs in using the toilet and washing herself, emphasising how cultural stigmas prevented her from requesting help:

> *I need the help, but because of my culture I cannot say.*
>
> - Female, Polish Roma [008] ❖

The first statement set out an instance of reluctance to provide potentially significant diagnostic information due to gender-based communication restrictions, highlighting how the presence of a male family member precluded even superficial discussion of female reproductive health. The second carried connotations of family as well, as the participant explored concepts of shame in seeking out assistance from even her closest family members.

Yet where family and culture could place limitations on health communication, participants also suggested that family influence, expectations and advice were vital to their decisions about health. When an individual experiences health problems, informal discussion within a family or community setting often constitutes the initial attempt at resolution, with family members validating an individual's decision to pursue a particular plan for accessing services:

> *Sometimes, if something is not very serious, we [my family and I] talk between each other, women, but if something is serious I go to see GP or maybe emergency. If we can't make appointments we go there.*
>
> - Female, Polish Roma [012] ❖

By illustrating the perceived gradations of health issues and recognition of different services for addressing different issues, this revealed nuances in the ways in which Roma community members understand their health and their decisions to access services. Where some of the literature suggests that Roma communities rely disproportionately on emergency services due to limited knowledge of primary and urgent care services, participants' accounts instead pointed to a more complex process of service selection.

Professionals working with Roma patients also suggested that the propagation of health information within Roma communities has a firm grounding in family experience of health and service use. Focusing on the specific context of mental health, an interpreter outlined how intra-family communication amongst her Roma clients resulted in deep understanding of the effects of schizophrenia:

> *You have, like someone with schizophrenia, and when they are describing, talking about their family, you know, their father had schizophrenia, their grandfather had schizophrenia, the brother, and it just seems… well it is a genetic illness, but it just seems to be more profoundly spread in the families; I don't know why, I have no idea. But because of that they often have I think a lot of understanding, maybe not necessarily of the vocabulary around it, but the symptoms, the way how you feel with that, what can happen, how you can develop it.*

- Polish interpreter, London-based [P004]

By this account, community health information develops through generations of familial and experiential knowledge, and this knowledge then informs participants' expectations of formal engagement with services.

6.3.2 Mental health

To expand on the previous discussion of patterns of health communication and the means by which participants made health-related decisions, the next section focuses on the topic of mental health. Roma culture traditionally treats mental health as a topic that is inappropriate for open discussion, which can bring shame not only on the individual experiencing mental health issues, but also on the entire family (Roma Support Group, 2012). Given these fraught cultural precursors, participants showed surprising willingness to engage in discussions about mental health.

Amongst older members of Roma communities, field observations suggested that shame related to mental health remained strong, with some individuals showing active avoidance of even peripheral discussions of mental health. In a telling example, an older woman who visited the RSG office for non-health-related advice was invited to attend a mental health peer support group meeting that was occurring at the same time. She appeared uncomfortable and quickly left the office. Another participant's account suggested a possible explanation for this tense reaction to the topic of mental health:

> *It is much easier to talk [about mental health] with non-Roma people than with Roma people because they [Roma people] would make fun of it.*

- Female, Polish Roma [025] ✜

Stigmatisation of mental health issues is not unique to the Roma, yet the frequency with which it arose in the field nonetheless suggested the strength of community dynamics in shaping participants' mental health decisions.

Evasion of mental health discussions did not occur universally amongst participants. Especially for those who had previously accessed mental health services or who had engaged in my partner organisations' health advocacy programmes, the topic of mental health appeared to have taken on a degree of social acceptability. Not only did engagement with formal mental health advocacy diminish the sense of shame in discussing mental health issues, but it also afforded participants the vocabulary to confidently discuss their mental health. In one case, a participant described the impacts of her path through primary and then secondary mental health services:

> *I'm just, I'm very closed before, but after CBT [cognitive behavioural therapy]… She [the therapist] know how to explain to me, but I don't know how to explain, but she do very good job for me because I open.*
>
> - Female, Polish Roma [009] ❖

This example highlighted the importance of good relationships with mental health professionals in helping participants overcome the stigmas associated with seeking formal mental health support. What was furthermore notable was the participant's knowledge of the distinct form of therapy that she had undergone, revealing how she not only saw the psychological benefits of services, but also learned the details of therapeutic techniques.

In other cases, participants conceptualised their need for mental health support in the context of other problems that they faced in their lives, presenting the development of mental distress as a consequence of the combined impacts of physical health issues, family tensions, housing insecurity and a range of other stressors. Some participants explicitly drew connections between physical and mental health issues and presenting them as equally worthy of professional input:

> *I go to the GP for osteoporosis, high blood pressure, cholesterol and depression.*
>
> - Female, Polish Roma [025] ✜

By framing mental health issues in terms of life circumstances and physical health problems, participants at once rationalised their responses to themselves and provided justifications that make the experience of mental distress more acceptable in the view of the wider Roma community.

With reference to wider community perceptions of mental health, field observations suggested a growing willingness to consider the advantages could arise from access to formal mental health support. Community peer support meetings hosted by RSG offered insight into community members' understanding mental health issues and treatment options, as is expressed in a fieldnotes entry documenting one of these sessions:

> *One woman explained how she had been cooking when, without any warning, her face turned cold and her stomach tightened. She wondered whether this could be an effect of anxiety.*

> *Another expressed how there are times when she will start crying in the morning and will be unable to stop for the remainder of the day. Each voiced a concern that they would never fully overcome their mental health problems, yet they also acknowledged that talking about their concerns amongst themselves did seem to have positive effects.*
>
> - Fieldnotes, London, 21/07/2017

Not only did this entry reveal how physical symptoms of mental distress could be a precipitating factor for seeking out support, but it also pointed to a deeper concern over whether mental health problems can be 'cured.' This question provided a corollary to the previous reference to mental health in conjunction with physical health conditions, with participants displaying preferences towards formal medical input into their mental health conditions.

In some cases, this medical input came in the form of psychiatric medications:

> *When I was in a really bad state, I was paranoid that someone was following me. It was a man with long hair and a knife, and I was hearing voices. I went to a hospital and to a GP, and they prescribed me a lot of medicine, but they had really, really bad side effects, and I felt high. I told them that I'm going back to Poland, and I stopped taking them, and I never went back. I was very weak after the medicine, and I felt like they could do something else. It was like being drunk all the time.*
>
> - Female, Polish Roma [025] ✜

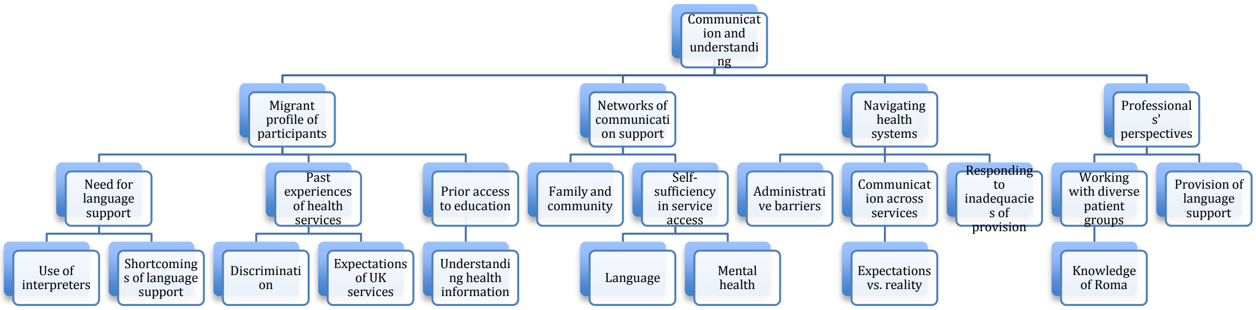
This participant identified lower dosages as a potential solution to this problem, and furthermore expressed her perception that a form of talking therapy could have been beneficial to her in coping with her mental distress. Despite the perceived benefits of psychological intervention, however, she was careful to stipulate that no health care providers had offered her the option of engaging in talking therapy. This perhaps indicates how instrumental health care providers can be in shaping patients' perceptions of which treatments are appropriate for certain health issues, with some providers' apparent reluctance to make referrals to mental health services manifesting itself in patients' belief that medications are the most effective means of overcoming mental distress.

6.3.3 Summary of Theme 2

Institutional racism rises to the forefront of participants' discussions of their perceptions and understanding of health and how these factors influence their decisions to access services. Participants draw attention to the wider social environment in which their health problems occurred – with some making references to their disadvantaged social status and others emphasising intra-community dynamics – reflecting on instances in which external factors prevent them from accessing the care they need. Upon beginning conversations about health, many female participants cited gender as an important factor in determining which health-related discussions they were willing to undertake, stipulating that they could disclose sensitive issues to male health professionals but not to male family members. The family sometimes inhibited open discussion of certain issues – particularly those associated with reproductive health. Other accounts, however, presented family as a key enabler in the process of seeking out health information, with family members serving as the first point of call when health issues arose, and thus providing a means of fighting back against institutional racism. This was especially apparent is discussions of mental health, in which family was presented as a source of information and support. Then concept of mental health then explored how Roma approach discussions of a traditionally sensitive subject, as well as the ways in which formal treatment options – whether in the form of medication or therapy – provided participants with a foundation for understanding their mental health issues.

6.4 Theme 3: Interacting and communicating within health services

Figure 4: Categories informing the development of Theme 3



Building on the previous section's discussion of Roma participants' conceptualisation and communication about health issues, this section presents these factors in the context of interactions between Roma participants and health care providers. Participants' accounts of their contact with health systems revealed convoluted service structures and often culminated in denial of access at the desired level of support. Though these barriers rarely arose at the point of first contact, they developed gradually, as a consequence of discrepancies between patients' communication support needs and inflexible service provision policies. Participants – particularly those who had extensive experience in using UK health services – expressed frustration in considering the systemic restrictions on their access to adequate care:

> *You know, people are sick. I'm sick, this woman is sick, the system is very sick.*
>
> - Male, Polish Roma [001] ■

While participants in this study were generally able to access services at the primary care level, their progression onto secondary care was limited. In the absence of institutional provision for addressing their barriers to access, participants described informal networks of assistance, in which family and community connections take the place of formal, professional support.

6.4.1 The Roma language profile and difficulties of health communication

Coming from a background of limited access to education in their countries of origin, many participants had a vocabulary that did not include words for describing symptoms or treatment plans. Roma community members drew this connection between educational background and health experiences, explaining that education levels can have a substantial impact on the nature of their contacts with health professionals:

> *They are very, very low educated, so understanding of English doesn't ensure that they will understand. If somebody is speaking to them in high level or using some words like medical terminology, this is not understandable to Roma.*
>
> - Male, Bulgarian Roma [013] ❖

Although most Roma speak the languages of their countries of origin, many learn Romanes (the Roma language) as a first language and generally speak Romanes in family and community settings. This may result in only basic understanding of the languages of their countries of origin and greater confidence in communicating in Romanes, as is explained by a Polish interpreter who worked intensively with Roma in health settings:

> *Very often because of Romanes there is a lack of words related to health, and obviously those words exist in Polish, because I say it in Polish and they always say that they understand, and I assume that they do understand. Well now I have doubts that maybe that is not always the case.*
>
> - Freelance interpreter, London-based [P004]

Limited exposure to health-related terminology can creates challenges to effective health communication in any language, and this issue was only compounded when interpreting services were provided in participants' second languages. In some extreme cases, participants did not have a functional knowledge of the language of their countries of origin, making Romanes the only appropriate language in which to conduct a medical consultation.

This was apparent in my experience of accompanying a member of the Polish Roma community to an initial psychological assessment:

> *Then Andrzej [all names included herein are pseudonyms], Samuel [RSG health advocate], the therapist and the Polish interpreter went into the consultation room while I waited outside. They*

> *were there for about five minutes, after which the therapist and interpreter came out, went to the reception desk and began discussing how Andrzej does not speak Polish. The therapist said that Andrzej spoke the Roma language, which, according to her, is a 'dialect of Polish' and 'not a real language.'*
>
> - Fieldnotes, London, 08/03/2016

In this example, the participant had grown up in Poland and attended school there, yet due to learning difficulties had never attained any degree of fluency in the Polish language. He was only fully confident in speaking Romanes, yet the local interpreting service provider did not employ any Romanes-speaking interpreters, making it impossible to request an interpreter in the patient's preferred language. The patient was dismissed. Reception staff agreed to reschedule the appointment after an appropriate interpreter was identified, but ultimately made no further contact with the patient.

Participants reported that, despite requesting interpreters within the timeframe designated by the service in question, interpreters sometimes failed to attend appointments. It was unclear whether this represented errors in processing requests or lack of coordination between health and interpreting services, yet it nonetheless pointed to a breakdown in communication across different levels of service provision. Furthermore, procedures for requesting an interpreter could be complex – requiring multiple phone calls and communication with different offices – which in itself could constitute a barrier to obtaining language support. One participant explained how lack of interpreting support led her to undergo surgery without fully understanding the nature of the procedure:

> *Sometimes before an operation you're supposed to have an interpreter, and then you come there because there was an interpreter before and then the interpreter doesn't show up and you go for the surgery. But they make the surgery anyway. So I sign something that I do not understand at the end and I go for the surgery because I am so desperate to obtain any medical service.*
>
> - Female, Polish Roma [002] ■

Another expressed her confusion at the mechanisms by which services hire interpreters:

> *She is in the GP like six or seven years, and they never booked an appointment with the GP – no interpreter. Never. Last week, the interpreter is there, after so many years.*
>
> - Female, Polish Roma [011] ❖

Other shortcomings in interpreting service provision included non-attendance of interpreters at appointments and long waiting times for appointments with interpreters:

> *Sometimes the interpreter doesn't come to the appointment.*

> - Male, Polish Roma [001] ■
>
> *So basically they give interpreters but you have to wait up to two weeks.*
>
> - Female, Polish Roma [012] ❖

For advocacy workers, the process of requesting language support could be equally opaque, with inconsistencies in language support provision meaning that each service had a different system for registering the need for an interpreter:

> *The process of requesting an interpreter for her Royal Free appointment felt a little bit like going down a rabbit hole of hospital bureaucracy, where the exact details of interpreter provision are vague and you have to navigate this maze of departments and health system levels just in order to get an answer as to who deals with interpreting services. First I called the Royal Free Hospital and asked them which department dealt with interpreting services and was informed that responsibility for making interpreter requests falls to the GP. I then called Ewa's GP and was informed by the receptionist that they don't make interpreter requests. Finally, I emailed language services at the Royal Free, and received a reply saying that they had forwarded my email to interpreting services.*
>
> - Fieldnotes, London, 13/10/2015

Situations such as this, in which a successful interpreter request requires a lengthy process of trial and error, revealed how systems of language support provision could be impenetrable to those in need. It seems one of the fundamental ironies of health care bureaucracy that requesting support for communication requires phone calls and emails across various departments within a health care institution – all tasks that require an understanding of English.

6.4.2 Navigating health service bureaucracy

In addition to issues with language and communication, participants reflected on barriers to adequate care stemming from the challenges of navigating the multiple levels of UK health service provision. According to participants' accounts, these difficulties often occurred as a result of some form of breakdown of communication with the service, thus depriving participants of the information necessary to engage further and creating a sense that their needs had effectively been dismissed.

Participants frequently described challenges to access at the point of first contact, which could be related to behaviour of reception staff, difficulties in understanding written and telephone communications from services and the impression that booking and cancellation procedures occur without patients' direct input. One participant described her sense of grievance at her GP practice's lack of support in helping her to re-book a missed appointment:

> *I went to the GP and I misunderstood the dates, and I wanted to make another appointment, and that was a struggle. I was told that I have to do it via phone and that it was my own mistake.*
>
> - Female, Polish Roma [025] ✜

Even when participants were able to establish a sufficient level of communication with reception staff to carry out the process of booking an appointment (which was by no means a guarantee) they encountered barriers to further communication, which stemmed from the inflexibility of appointment booking mechanisms and interpreter request procedures.

Participants reported attempts to book GP appointments, only to find at the point of booking that it was impossible to request an appointment with an interpreter:

> *So we have very bad experience with previous surgery, when we booked GP appointment and asked also for interpreter, but they didn't call interpreters, so, you know, we went for the appointment but there was no interpreter, so we couldn't communicate. And it happened a few times, so we were crossed from the list without [the surgery] letting us know.*
>
> - Female, Polish Roma [012] ❖

The direct precipitating factor in this restriction of access was the lack of language support provision, which diminished the quality of communication to the point where productive contact became impossible. The precise reasons for this patient's removal from the surgery's patient list are unclear (as attending appointments without an interpreter should not have resulted in discharge from a service), yet the patient's impression that inability to communicate with the GP was the direct reason behind her discharge highlights her perception of inadequate language support.

In a similar vein, another participant recounted the experience of being on the waiting list for a physiotherapy appointment, only to find after seven months that the appointment had been cancelled:

> *I'm going for the reception, yeah, who cancelled my appointment? I'm waiting seven months, who cancelled my appointment?*

> - Female, Polish Roma [002] ■

Members of reception staff were unable to provide an explanation of the reason for cancellation, and the patient was offered no alternative but to be placed again at the end of the waiting list.

Participants also noted disparities between doctors' verbal commitments to provide a specific level of support and subsequent treatment by reception staff in attempting to book follow-up appointments:

> *Sometimes even if the doctor stressed that he wants to make a double appointment for the patient they are not able to or they don't do it, so they just make one appointment, so it's easy to get rid of the patient.*
>
> - Male, Polish Roma [001] ■

Double appointments (that is, twice the length of the standard 10-minute GP consultation) can be essential for ensuring that patients communicating through interpreters receive the same amount and quality of information as patients who do not require language support, yet receptionists may not automatically recognise the benefits of a longer appointment length. From the above participant's perspective, the unfulfilled commitment to an increased appointment length reflected disrespect and lack of regard for the implications of language support needs.

Frustrations also arose over long waiting times for appointments, which were echoed in numerous interviews and could represent a loss of confidence in the UK health system:

> *I have to wait a long time for appointments as well. One of the biggest problems is that you have to wait a long time to see some specialist. In Romania you are not waiting such a long time so I expect this to be sorted out as soon as possible.*
>
> - Male, Romanian Roma [016] ✜

The comparison to the participant's country of origin underlines a general sense amongst participants that health systems in their countries of origin offered a higher standard of care (provided that they were able to purchase the requisite insurance to access these services). It is worth noting the contrast between this participants' characterisation of Romanian health service efficiency and accounts of restricted access in Romania cited earlier in this chapter. This disparity likely stems from the differences in age between these participants – with those noting restricted access representing an older segment of the community – yet it is also useful in exhibiting the range of perceptions of UK health services across my participant group. Impressions were neither uniformly positive nor uniformly negative, but were volatile and shaped by experiences in participants' countries of origin, confusion over health care bureaucracy and individual interactions with professionals. Some expressed a preference to return to their countries of origin to receive care, citing a lack of language barriers and better understanding of systems; others preferred to access services in the UK out of a perception that treatment was less discriminatory.

6.4.3 Frustrated attempts to gather health information

Participants tended to be proactive in their engagement with health services, but actively seeking out health information did not necessarily ensure that they were able to obtain satisfactory explanations of their health issues. In some cases, participants were aware of official diagnoses, but they did not feel that they had full information about their practical implications:

> *I have rectal carcinoma, and I would like to get more information about it, but I don't get it.*
>
> - Male, Polish Roma [003] ■

This suggests an absence of information presented in formats that are accessible to participants. Although written or online information may have been available, participants' frequently limited literacy makes information presented in this format to be fundamentally unsuitable.

Reports of the complex network of referrals shed further light on Roma participants' conceptions of health services' ability to adequately respond to their needs. One participant presented her GP as the only health professional who expressed genuine concern for her wellbeing:

> *Yes, he was listening; he was sending me for that what he thinks I have to go for this. He made me think I have some problems with the health. He sent me to the hospitals and that stuff. And the other ones they didn't done nothing. Only him.*
>
> - Female, Polish Roma [011] ❖

This participant emphasises the physician's key role in motivating her to take stock of her physical wellbeing, reflecting how patient loyalty to a given practitioner can impact on future behaviour in accessing health services. Participants' overall perceptions of health professionals tended to focus on ineffectiveness in achieving results, yet once trust was established, the opinion of the trusted professional would come to serve as a major guiding force in health decision making.

As participants gathered information from medical professionals, they attempted to exert a sense of control over volatile health situations. Documentation of medical input constituted a key concern for many participants, which can be at least partially interpreted as a response language barriers and limited knowledge of medical terminology. When participants felt that professionals were withholding vital information, they construed an oppositional relationship between themselves and professionals:

> *When I ask them about the results they say everything is fine. That question always is usual and normal. You know, is everything fine. But when I take from them because I need the paper, the summary, I need from them, and they would give it to me the summary: what they done and what I had done, what was the problem, why they send me, and I find out that I have a cyst on my back.*
>
> - Female, Polish Roma [011] ❖

Participants commonly attended health advocacy sessions with folders filled with appointment letters, medical records and prescription lists, and when asked to explain their health concerns, they would produce these documents instead of offering verbal descriptions. In this sense, medical documentation not only provided confirmation of diagnostic information, but also served as a communication aid for individuals who may have had limited health-related vocabulary. In light of this perceived importance of official documentation, participants' trust in services could be substantially harmed when they felt that service providers were refusing to provide vital documentary information.

Dissatisfaction with services further arose in relation to UK medical practitioners perceived over-prescription of paracetamol in the absence of genuine investigation into a given health complaint. Participants viewed this as an effort by health professionals to placate patients, passing off their concerns as irrelevant and unworthy of any investment of time and attention. To underline this point, one participant expressed her frustration at the lack of parity between the severity of the health issue at hand and the extent of support provided:

> *When I go to the hospital, to the GP, and then is check, he say, 'no, it's okay, go home and take paracetamol'. And I say paracetamol is not for infection, is just for temperature.*
>
> - Female, Romanian Roma [017] ❖

Taken in context, this woman attended A&E after her son experienced a blackout, and her account reflects a rather sophisticated knowledge of appropriate treatment, which in turn puts her desired outcome at odds with the GP's advice. She was dissatisfied that the doctor made no effort to 'touch' her son, implying a perception that diagnosis could only be effectively achieved through hands-on investigation of symptoms. When the doctor sent her home with nothing more than the recommendation that her son should take paracetamol, she felt that her concerns had been disregarded. Other participants echoed this sentiment, suggesting that a prescription of paracetamol is simply a means of dismissing their concerns:

> *Yeah, this is too much pain everyday, every night, you know, and is not giving medicine, only paracetamol.*
>
> - Female, Polish Roma [002] ■

6.4.4 Professionals' perspectives on Roma health-related behaviours and communication

When contacting health services to identify professionals to take part in interview, I encountered substantial difficulties in recruiting frontline staff to participate. Professionals in management positions generally agreed to be interviewed, but they could not comment on direct engagement with Roma patients. To gain insight into frontline professionals' experiences, data collection proceeded through participant observation during professional training sessions organised by Roma Support Group. I gathered these data between September 2016 and June 2017, during which I assisted RSG to deliver a series of Roma cultural awareness sessions to GP practice and mental health service staff in the London Borough of Newham. These sessions targeted services that RSG survey data had identified as having a large proportion of Roma patients, and the training focused on raising professionals' awareness of the challenges faced by Roma patients in accessing services. The majority of participants in these sessions entered into the training with no prior knowledge of Roma.

Many health professionals encountered during fieldwork did not consider Roma a distinct ethnic group with specific health needs, and a Polish interpreter echoed this common misunderstanding:

> *Many Roma people… maybe not a lot, but, well, some of them, do not want to say that they are Roma, so for the average… if the professional, doctor or whatever, is from Eastern Europe, they would know, but if they are not, and especially if they are not European; if they are African, Asian just with them it is like generic Eastern European people.*
>
> - Freelance interpreter, London-based [P004]

This participant identifies prior contact with Roma communities as key factors underlying professionals' recognition of the situation of Roma communities in Eastern Europe, noting that knowledge of the social history of the Roma and the accompanying issues in accessing services are unlikely to receive attention from non-European health professionals.

Health professionals' limited awareness of Roma communities further emerged as I assisted with training GP practices and mental health services in Roma cultural awareness. Many health professionals were entirely unfamiliar with the term 'Roma' and questioned why the health needs of this community merited a training session:

> *One of the providers asked who the Roma actually are after we had finished our talk on background, history and origins. I tried to reiterate: the Roma are an ethnic group that has recently migrated to the UK from Eastern Europe. She didn't accept this definition, maintaining that she didn't understand how they can be distinguished from other groups.*
>
> - Fieldnotes, London, 30/09/2016

Other health service staff, however, expressed a greater interest in the training once it became clear to them that they had, in fact, worked with members of this community:

> *I found the practice staff to be overall quite receptive to our training and – in the best cases – actively interested in what we said. It seems that once we describe the traditional Roma style of dress, once they realise that they have worked with members of this group, once they have a tangible connection to the community, that then they begin to take a much greater interest in the awareness session.*
>
> - Fieldnotes, London, 18/10/2016

Recognising a need to establish tangible connections between Roma culture and professionals' experiences of service delivery, the training programme was modified to address key outward expressions of Roma culture, such as customary Roma dress. By adding a visual element to otherwise abstract descriptions of culture, discrimination and health inequalities, health professionals began to recognise distinctions between their Roma and non-Roma Eastern European patients.

6.4.5 Professional perspectives on language support provision

Building upon the issues with language support provision explored in interviews with Roma participants, I sought to gain health professionals' impressions of the state of interpreting support for Roma communities. This led to an investigation of Newham's now-discontinued bilingual health advocacy service, which provided not only language support, but also aided patients in navigating health systems. The service was closely involved with Roma communities in East London, and advocates were invited to regular engagement meetings with Roma service users, as described by a former service manager (now a People Participation Lead[9] for a major East London mental health and community services trust):

> *Some of my colleagues who speak Romanian and Polish, they had been invited to go to Roma support community groups, at the same place, in the Barking Road. So they went the meeting and they went to feed back to the rest of the team what's happened in that meeting, so we knew then that there was a community for Roma people. When I became a manager for the advocacy service, myself I attended once the meeting for Roma… and I started liaising with people who used to work there, the leader of the community, and supporting some of their queries and looking for a way of improving their integration in the country.*
>
> - NHS People Participation Lead, London-based [P005]

This represents a level of contact between community groups and NHS services that has not been achieved since.

Through meetings with the service, Roma community members gained awareness of the development of service operating procedures and felt that they were in a position to actively made recommendations for service improvement:

> *The main concern with the Roma community was about the lack of interpreters, and I know once they complained about our service providing interpreter for them, because we have interpreters in-house and we would have to hire that interpreter from outside, and we couldn't hire from outside as well. So myself, I was questioned about that, and how we can bridge the gap and support the community appropriately.*
>
> - NHS People Participation Lead, London-based [P005]

Through complaints about the lack of support provided in Romanes, Roma service users demonstrated an expectation that services should adjust to meet users' needs. It seemed, however, that this strong voice of self-advocacy has been lost from Roma communities' engagement with health services, as there was no mechanism at the time of writing for Roma community members to feed back to language support providers. Since the discontinuation of the bilingual health advocacy service, Roma community members were without culturally sensitive provision of language support and operated within a language support environment that offered only direct translation, but did not seek to facilitate participants' understanding of health-related concepts.

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[9] A role based on gathering patient feedback on service delivery and effectiveness

6.4.6 Examples of good practice

Despite participants' overall focus on the barriers to Roma patients' equal access to health services, fieldwork also revealed examples of good practice in the delivery of targeted support to community members. In an informal discussion, a clinical psychologist working in North East London commented on his experience of establishing cultural common ground with his Roma patients:

> *He had previously worked at a GP practice in Newham, where the surgery hosted a Roma group aimed at providing community members with a place to discuss health issues. The group dissolved after the practice opened it up to other communities, but it nonetheless indicates a surprising awareness of Roma issues. The psychologist at the meeting attributes his ability to form quick bonds with his Roma patients to his own ethnic origins and some of the commonalities between Sikh and Roma culture.*
>
> - Fieldnotes, London, 28/10/2016

With a dedicated space to discuss health issues, Roma community members were able to explore aspects of culture, individual and group history and health with others who understand their experiences. Ultimately, however, the practice deemed that it could no longer hold specific sessions exclusively for one community group. Once the sessions were opened up to the wider patient base, Roma patients no longer felt confident in attending.

Input from community advocacy services also played a vital role in improving health experiences for participants in this study, and accounts from community advocates highlight the extent to which Roma community members rely on their services. Yet for all that advocacy services are able to bring about improvements in the life circumstances of their service users, there is also recognition amongst advocacy workers that the most effective means of achieving long-term improvement in Roma health is to foster their ability to independently access services:

> *Most of the migrant community, and Roma especially, they need to have their English language education, and if somehow the state or the local authorities find out how to provide this, there are many, but this is people's wish to go and to study English. It is not like somebody to require from them to do that, and if this changed and the local authorities or the government started to build up a mechanism which requires from migrants to learn the language . . . which at least would improve their English language knowledge and make the system to work more effectively.*

- Community advocacy worker, Luton-based [CW003]

This account highlights once again the centrality of language skills to Roma migrants' experiences in the UK, emphasising how improvements in patient-provider communication could bring about substantial improvements in service effectiveness. Yet this also comes with the key caveat that community advocacy services cannot achieve these goals in isolation, and that active involvement of health services and local authorities could result in programmes that would fundamentally alter the experiences of Roma in the UK.

6.4.7 Summary of Theme 3

Participants' descriptions of their interactions within health systems revealed patterns of lateral movement, with participants finding their efforts to obtain specialist support stymied by institutional operating procedures. This suggests an element of institutional racism, in which a lack of commissioning attention to Roma migrants' needs precludes the development of specialist language support services and cultural competency training programmes for health professionals. This then impacts on participants' confidence in engaging with services. Despite attempts to access adequate language support, obtain referrals and undergo diagnostic tests, administrative restrictions and difficulties in communicating with providers prevented participants from obtaining their desired levels of support. Barriers rarely arose through the direct antagonism towards Roma patients, but rather as a consequence of broader bureaucratic structures. While cases did arise that suggested negligence and blatant inattention to patients' support needs, these tended to be the exception rather than the rule, and both Roma community members' and health professionals' accounts portrayed a system in which demand on services and bureaucratic procedures created a divide between the patient and provider. The health care practitioner did possess some power to influence which treatments were provided and which referrals requested, but there remained a wider network of funding restrictions that seemed to disproportionately impact on services working predominantly with disadvantaged and ethnic minority patients, perhaps in a reflection of irregular JSNA coverage of Roma at both research sites.

Placing these circumstances in the context of Roma participants' migration history revealed added dimensions of their experiences of UK health services. Some seemed to express an internalised sense of mistrust towards health professionals, leading to questions of whether doctors were committed to their best interests. In other cases, participants cited communication difficulties in booking appointments, seeking diagnostic information and requesting interpreters to frame perceived oppositional relationships with health service providers. Turning to the wider social environment, there was a tendency to identify strengths and weaknesses of health services in their countries of origin, and to use these comparisons to highlight slow pace of service provision in the UK. What emerged was a picture of a health system that almost uniformly failed to prioritise Roma participants' needs, reflecting their virtual absence from health policy and service commissioning frameworks.

6.5 Summary of grounded theory analysis and future directions of inquiry

Grounded theory analysis revealed three overarching thematic areas: 1) dimensions of the UK social environment as it impacts on Roma participants; 2) patterns of health-related communication and understanding in Roma communities; and 3) challenges of direct engagement between Roma patients and health care institutions. Taken together, these themes revealed the impacts of social distance between Roma community members and representatives of public institutions. When attempting to access systems of health and benefits support, Roma participants found their efforts obstructed, sometimes by administrative barriers and unconscious bias on the part of providers, and sometimes by services' lack of sensitivity to the language, communication and cultural profiles of Roma communities.

While offering a framework for understanding Roma community members' health and benefits experiences, grounded theory analysis also came with a certain set of limitations. As I analysed interviews, it became increasingly clear that many of the richest and most detailed interviews did not restrict themselves to the interview questions I had crafted; instead, participants offered in-depth discussions of single distinct and notable incidents in their lives. In many cases, grounded theory analysis did not capture the powerful narrative arcs that many participants put forth. Upon revisiting my grounded theory analysis, the theory I had developed emerged as a road map to understanding the key points of contention in participants' narratives. Grounded theory and narrative analysis thus worked in tandem, with grounded theory adding structure to my results, and narrative analysis revealing nuanced views of participants' feelings of injustice as they navigated UK social institutions.

Chapter 7: Uncertainties and insecurities: Dimensions of Roma experience in a broader social and institutional environment

7.1 A changing social environment

Much of this study's fieldwork took place amid the political upheavals of 2016. With the UK's referendum vote to leave the EU, Roma migrants' thinking about their future position in UK society underwent a fundamental shift as they began to consider the possible revocation of their right to residency. Even in the absence of any concrete legal changes in their immigration status, participants engaged through both fieldwork sites expressed uncertainty, insecurity and fear as they contemplated their future right to reside and access to public services. In the wake to the referendum result, both of my partner organisations organised meetings with immigration lawyers and migrants' rights organisations in an effort to provide Roma community members with a deeper understanding of their rights and their options for securing their status in the UK post-Brexit. These meetings brought about a marked uptick in requests for assistance with permanent residence applications, yet my partner organisations were legally bound to refuse these requests, as neither held the necessary accreditation to provide immigration advice (providers of such advice must be accredited by the Office of the Immigration Services Commissioner). Roma community members were left without a clear path to secure their status in the UK (as even those with proficient English language and literacy skills would struggle to complete the 85-page permanent residence application), and many expressed a sense of being adrift amidst bureaucratic regulations that they did not entirely understand.

As I conducted narrative re-analysis of interview data, I also looked to the narrative arc presented through my fieldnotes. In the post-Brexit environment, my field observations underwent a subtle, yet fundamental, shift. I saw how descriptions of my health advocacy work moved away from the straightforward tasks of making GP appointments and requesting interpreters towards assisting with meetings to assuage the community's immigration concerns and helping to challenge rejections of benefits applications based on a purported lack of right to reside. In this environment of insecurity, access to benefits systems also arose as a key concern, as participants struggled to maintain a basic level of subsistence. Participants' livelihoods did not depend exclusively on benefits, yet as many were on low incomes or suffered from debilitating health conditions, they did receive benefits in helping them to meet their basic needs. Whether a product of the Brexit vote or simply an effect of tightening benefits eligibility regulations, Roma community advocacy workers at both fieldwork sites observed an increase the number of benefits applications refused on the basis of applicants' lack of right to reside. Although many of these rejections were overturned upon appeal – as claimants did, in fact, have the right to reside – they nonetheless heightened participants' fears that their right to reside in the UK would be challenged post-Brexit.

My research continued to focus on health, yet I saw that sphere expanding to encompass the wider health and wellbeing implications of immigration insecurity and restrictions on claims for benefits. Although the social determinants of housing, education and employment have a substantial impact on physical and mental health in Roma communities, immigration and health-related benefits emerged most prominently in my field observations and interviews. To provide a context for the insecurity of participants' wider social environment and its impacts on their personal wellbeing, this chapter first looks at my research journey into the topic of immigration and the manner in which participants conceptualised their sense of (in)security in the UK. I then move on to present participants' narratives of their experiences in claiming sickness and disability benefits. Not only does this chapter shed light on the settings in which the research took place, but it also reveals additional dimensions of key concepts arising from grounded theory analysis, such as mental health, the limited transparency of institutional machinations and the social distance between UK public officials and Roma communities.

7.1.1 A participant observer's view of the changing field

The EU referendum result came as a shock to Roma communities. I remember walking down Barking Road in East London, on my way to the Roma Support Group office, the day after the Brexit vote. The mechanic's shop near the office seemed to be making a statement in support of the result by flying the St George's Cross flag – a reminder of the fact that this once-homogenous white working class neighbourhood had in recent years become one of the most ethnically diverse areas of the country, and that the seemingly peaceful coexistence of longer term residents and newly arrived immigrants may have been less stable than it appeared. When I reached the office, the tension of community members was palpable:

> *Unsurprisingly, the EU referendum results brought a mood of fear to the RSG office. All the immigrants in the country are scared – scared of heightening restrictions on their right to reside,*

> *scared of the sheer mystery surrounding the government's next steps and scared of the mood of anti-immigrant hatred that has engulfed so much more of the country than we ever imagined.*
>
> *T. came to the office in a panic after receiving a phone call in which the only question she had understood was 'where are you from?' Now of course the process of removing EU migrants won't start the morning after the vote (and perhaps will never come to pass), but the fear is nonetheless here. And where there isn't fear there seems to be resignation, because EU migrants been stripped of any power to influence future decisions, and they understand that.*
>
> - Fieldnotes, London, 24/06/2016

RSG service users feared that deportation would be imminent, and rumours were circulating that Roma men had been victims of racist attacks. The RSG organised a meeting intended to dispel the community's fears, but as the government had yet to offer any clarity as to the future status of EU citizens in the UK, RSG could only assure service users that any changes would occur years in the future. The message, fundamentally, was that there was still time to prepare for the worst.

I went to Luton early the next week to look at the situation from the perspective of a different segment of the Roma community. As many of the Roma in Luton had arrived relatively recently in the UK, the sense of uncertainty was perhaps more pronounced than it had been in London, and the impacts on participants' daily lives seemed more immediate:

> *The mood at the LRT was perhaps even more panicked than that at the RSG, though M. said that everyone is relatively calm relative to last week. This was surprising, and seems to indicate either resignation to the situation or desire to get on with things. What's more obvious, however, is the extent to which the benefits system seems to be cracking and how dramatically this impacts their clients' situation.*
>
> *Three people came in with Child Benefit refusal letters, all of which cited reasons (no right to reside, insufficient period of residence in the UK) that were directly contrary to the reality of the situation. When we called HMRC to report these incorrect details, however, we were on hold for half an hour at least and were every time cut off as soon as someone answered the phone.*
>
> - Fieldnotes, Luton, 27/06/2016

Although these benefits refusals may have had no connection to the EU referendum, participants *perceived* that British society was becoming increasingly hostile to their presence and that they were likely to encounter significant challenges to establishing their post-migration lives.

Following the Brexit vote, open expression of anti-Roma sentiments grew steadily more prominent. At times this stereotyping and prejudice came from the most unexpected of sources:

> *RSG policy workers have troubling stories of human rights charity workers who dismiss Roma needs because they 'come here to beg' and 'shouldn't be in this country'. It just goes to show the extent of public misunderstanding of the Roma and how a few negative examples come to be seen as representatives of the whole group.*
>
> - Fieldnotes, London, 13/09/2016

Such instances were startlingly frequent, especially as my health advocacy work took me beyond Roma community spaces. With increasing opportunities to deliver awareness sessions to GP practices, I began representing Roma interests within a wider public sphere. At these sessions, I rapidly found that even seemingly innocuous issues such as language barriers and interpreting support could lead to contentious debate. Although most professionals seemed eager to learn more about Roma culture, I nonetheless encountered surprising instances of stereotyping of the Roma community.

One expression of prejudice from a health professional attending a cultural awareness session stood out particularly:

> *There was a doctor in attendance who clearly had researched the Roma after reading a news story about a Romanian Roma woman who, through her work for Haringey Council, had allegedly committed benefits fraud. With this story as his motivation to learn more about Roma culture, it's perhaps unsurprising that he came away from his research with quite prejudiced views. He had somehow developed the opinion that all Roma people refuse to work, even if they have the necessary skills, giving the example of Roma men with all the knowledge necessary to be mechanics never taking on work in a garage. It goes to show how pervasive media bias can be and how socially acceptable it still is to demonise GRT groups, just because that's what the tabloid newspapers are doing.*
>
> - Fieldnotes, London, 19/10/2016

Such situations make one wonder about the quality of care Roma patients can expect to receive when professionals hold undue and unfounded assumptions about their identity. Although this stereotyping cannot be assumed to represent the views of most health professionals, it was striking to see such assumptions voiced within a formal health care context and also troubling to observe that none of the other professionals in attendance made any effort to challenge their colleague's expression of prejudice.

7.1.2 Revisiting participants' key concerns

My advocacy work put me frequently in contact with health professionals who insisted that the Roma should 'learn English' and rely less on interpreting services, while Roma participants' accounts highlighted the multifaceted challenges of attaining a reasonable standard of health communication. The categories arising from my grounded theory analysis reflected the disadvantaged position of Roma within UK institutional frameworks. On narrative re-analysis of data, I reflected on my personal journey through the field, and my own acute and growing awareness of UK society's unsympathetic attitudes towards migrant communities – and especially towards disadvantaged migrant communities. All participants had arrived in the UK since the dissolution of the Soviet Union, and it was the hopes and insecurities associated with participants' migrant status that distinguished their experiences from other socially disadvantaged and marginalised communities. As I grappled with questions of participants' interactions with UK health care institutions – and also considered how institutional representatives received me, as a health advocate – it became imperative to further investigate the migration dimension of Roma experiences in the UK.

7.2 Uncertainties in the immigration sphere

For many Roma, barriers to engaging in formal immigration procedures are significant. Issues with language and literacy can create extreme difficulties simply in gathering information about immigration requirements, and making applications for residency status becomes nearly impossible without formal assistance. In a supplemental July 2018 focus group held to capture Roma community members' immigration concerns, one Romanian Roma man expressed community fears related to lack of information:

> *We don't know where to go. We have absolutely no information. We have no idea what's happened, so we wait.*
>
> - Male, Romanian Roma [031]

This statement revealed a sense of stasis in Roma community members' effort to secure their immigration status, reflecting how a large proportion of the community as dependent on voluntary sector support to gain even the most rudimentary understanding of the steps necessary to secure their continued residence in the UK.

Amid the numerous uncertainties of the post-Brexit landscape, Roma community members were deeply aware that their right to reside had come into question, and they were firm in their knowledge that they would require formal support in gaining future security. One focus group participant, who worked as a volunteer on RSG's telephone line for making appointments, captured the post-Brexit rush for permanent residence status:

> *I know that because when I was upstairs making appointments, lots of people want to make appointment after Brexit, and they asked, 'do you do the appointment for the residence?' And I said, 'no, we're not able to do that.' That was every single day about three or four times, to help them to fill in the form about residence. Because they need some help. They haven't got any friends [to help] because there is loads of pages, and they need help to fill the form. Because they want to find the help, but where they can go?*
>
> - Female, Polish Roma [028]

Organisations without accreditation to provide immigration advice can put forth general information about immigration policy but cannot offer guidance on individual situations (OISC, 2018). Community members were rapidly stymied in their efforts to secure permanent residence in the immediate post-Brexit period, as they found that the organisations serving as their first point of call were unable to offer them assistance. Beset by language barriers, alternative avenues for advice and support were also closed off, and friends and family members – often facing the same issues themselves – lacked the skills and knowledge necessary to complete the extensive permanent residence application form. Many participants thus found themselves feeling helpless, with no clear idea of where to turn.

Even in light of Roma community organisations' inability to assist with immigration concerns, community members still clung to the idea of voluntary sector support, perhaps as a means of coping with an otherwise overwhelming sense of uncertainty about the future. A Romanian Roma woman captures how desperation and nascent self-sufficiency coalesce in her efforts to combat immigration insecurity:

> *I will come straight [to Roma Support Group] for support. It doesn't matter if you can do it or not; I will come here because I don't know. I will get whatever information I can from you and then I will try to look for support.*
>
> - Female, Romanian Roma [030]

Here she alludes to a piecemeal approach to managing immigration insecurity: a process of gathering information from a variety of sources in the hope that a path to stability will take shape. She planned to first obtain any available clarifying details from the most reliable source she knows and then enter into the unknown, armed only with a basic knowledge of the steps she needs to take.

7.2.1 An overview of EU settlement procedures and barriers for Roma applicants

In June 2018, the Home Office published a Statement of Intent outlining its proposals for granting 'settled status' to all EU nationals in the UK. According to this framework, settlement applications will request that applicants provide evidence of identity, nationality, proof of a minimum of five years' residence in the UK and information regarding any criminal convictions. Applicants who enter the UK before 31 December 2020 but do not have 5 years' continuous residency will be eligible for 'pre-settled status', after which they will be able to compile supplementary evidence to meet the 5 years' residency requirement (Home Office, 2018).

The standard format of the settlement application will be online, with limited provision of paper forms. This constituted a major area of concern for Roma community members, as many have low levels of digital literacy. One Slovak Roma woman outlined this issue:

> *I've got a computer at home, but I don't know how to use it. My children show me something once, but I don't know how to do it independently. They [other Roma community members] will be scared, even if they are doing on their own applications. They will do something wrong and they will be refused the settled status. They will not do it, so that is why they need an office like here.*
>
> - Female, Slovak Roma [023]

Unable to navigate online forms and uncertain of how to access assistance in completing their settlement applications, Roma community members may elect to forego the settlement application altogether. While Home Office guidance remains unclear about the exact consequences for EU citizens who do not apply for settled status, those who neglect to register their presence in the UK by 30 June

2021 will enter into a state of unauthorised immigration (Home Office, 2018), which could in turn serve as grounds for deportation.

7.2.2 Roma participants’ concerns in a changing immigration landscape

For Roma community members facing the requirement to apply to secure their status in the UK, it was not only the practical difficulties of the application process that contributed to their sense of fear and insecurity, but also a sense that they were no longer welcome to settle in the UK. One Romanian Roma woman expressed her view that the support mechanisms that were once in place for migrant communities are no longer available:

> *From this point of view, I have never managed to get any support. It seems so difficult. I heard that before it was easy for people to come here and to settle, but now I feel that it is so difficult.*
>
> - Female, Romanian Roma [030]

She perceived the UK as less welcoming to Eastern European migrants, highlighting how barriers to establishing a stable post-migration life had been steadily growing, and perhaps alluding as well to increasing anti-migrant rhetoric from politicians and the public alike.

Other focus group participants echoed this grievance, reflecting on their perception that EU migrants are no longer afforded equal access to benefits:

> *P1: My daughter is getting income support and housing benefit. When she is moving other house – she go from Newham to Dagenham – is stopping everything. She’s got universal credit and now coming letter from Home Office – she’s not allowed to take any money for benefit because she don’t have… 4 years, something; I don’t know.* [027]
>
> *P2: All these change after Brexit.* [023]
>
> P1: *She live here years and years; my husband have English passport!* [027]

This exchange highlighted one participant’s sense of injustice when the Home Office deemed that her daughter had no right to reside in the UK, despite her many years’ previous residence and her father’s British citizenship. Another participant chimed in to express her perception that the UK’s decision to leave the EU removed governmental accountability for EU citizens’ rights – a view that was also echoed in informal discussions with advocacy workers at both research sites.

In light of Roma communities' long history of disadvantage at the hands of governmental bodies, Roma individuals considered the prospect of applying for settled status with trepidation. A Polish Roma woman highlighted this sense of fear:

> *Probably, because it's the Home Office, people will be scared to do anything.*
>
> - Female, Polish Roma [028]

As an ethnic group commonly facing external stigmatisation, Roma feared rejections of their applications on the grounds of social undesirability. Furthermore, inclusion of criminal record checks (including overseas checks) as a component of the settlement application was named as a contributing factor in Roma community members' fears of applying. As unjust criminalisation of Roma historically occurred as routine practice in some Eastern European countries (Silverman, 1995), Roma focus group participants expressed how experiences in their countries of origin would put them at a disadvantage in securing settled status:

> *Roma have been like slaves, and Roma inherited what their parents and grandparents had, because they have been enslaved, then communists took everything off them. So the social environment forced people to do some things so that they could survive. And this happened in those countries, and now here, they've had the opportunity to do something better, and they've done, and [the Home Office] shouldn't look at what's happening in those countries.*
>
> - Male, Romanian Roma [031]

In completing application for settled status, Roma community members envisaged a situation in which they would relinquish control of their future to Home Office officials, who would be unlikely to understand the context of social disadvantage underlying their applications.

7.2.3 Impact of immigration uncertainty on health and wellbeing

As they contemplated their feelings of lost control over the security of their future immigration status, all focus group participants reported a link between their pending applications for residency status in the UK and heightened levels of anxiety. One Polish Roma man also drew a connection between the settled status application and increased levels of depression:

> *People will have more stress; they will be depressed, because, most of them, they don't know any other organisation [that provides support]; they don't have any other chance.*
>
> - Male, Polish Roma [001]

Again evoking a sense of helplessness, this statement called attention to Roma community members' need for support in completing settlement applications and implied that, without trusted organisations providing dedicated assistance, they would have no other recourse.

Other participants questioned how the Home Office will handle applications from people with severe health conditions, who came to the UK to receive care from family members but never undertook paid employment in the UK. Reflecting on the requirement to provide evidence of 5 years' continuous residence, a Slovak Roma woman expressed her concern that older family members who have lived in the UK exclusively to be looked after will lack the documentary evidence of residence:

> *Like my father is here with me, and he doesn't work because he is very sick. He's here like five years already. What happens with him? Because we have parents here, you know – okay, I was working – but many of these people doesn't have nobody, so I don't know what's [going to] happen with them.*
>
> - Female, Slovak Roma [023]

With no history of employment in the UK, this participant feared that some of the most vulnerable Roma will be unable to demonstrate their right to settled status, and could thus be in danger of forced returns to their countries of origin, where they would have no support networks in place. Another participant raised the issue of Roma women who have never worked because they were caring for their children. Although women in this situation would theoretically be able to secure their status through family relationships (Home Office, 2018), there is no guarantee that their family members will meet the requirements for settled status, thus highlighting yet another pitfall of a settlement system purportedly designed for simplicity.

As participants grappled with the practical and emotional difficulties associated with settlement applications, immigration arose as one of the foremost themes in the wider narrative of my experiences in the field. The quality of life for migrant communities in the UK appeared to be steadily deteriorating as community members grasped for some assurance that their lives could continue as before.

7.3 Seeking greater security: Narratives of the UK benefits environment

For many participants engaged over the course of fieldwork, concerns over their status in the UK operated on two levels: their basic ability to pay for their daily lives, and their longer-term ability to secure their immigration status in the UK and make plans for the future. Participants often had jobs working as cleaners, drivers or factory workers, yet this work tended to be irregular and low paid. Many thus supplemented their income with benefits payments. Yet as legal residency in the UK is a prerequisite for claiming benefits, access to benefits systems and immigration insecurity often went hand-in-hand:

> *The LRT clients are having their benefit applications refused more frequently, and often for the flimsiest of reasons. There have been a number of refusal stating that our clients are not ordinarily resident in the UK, which is blatantly inaccurate, yet perhaps DWP/HMRC's assessment is that these people will have limited education and therefore limited ability to challenge these decisions. LRT staff members suspect that the increase in refusals has something to do with Brexit.*
>
> - Fieldnotes, Luton, 18/07/2016

It was through these intersecting issues of immigration and benefits that participants made efforts to navigate and negotiate their position in UK society.

As I engaged in health advocacy work, I became increasingly involved in assistance with applications for health-related benefits. For many Roma community members, the process of applying for sickness and disability benefits could be confusing and distressing. It involved completion of a lengthy claim form, a face-to-face assessment with a health professional and, in many cases, a two-stage process of appeal. This frequently necessitated intensive advocacy support throughout the claim process, and in my role as a volunteer health advocate, I supported numerous community members from the initial application through to the appeal. When invited to interview, a number of participants spoke in-depth about their experiences of claiming health-related benefits, perhaps because they associated my presence with welfare assistance, and perhaps because the stresses of the claim processes were foremost in their minds at the time of interview. This segment of the chapter presents four distinct narratives from participants who had recently undertaken an application for a health-related benefit, and further explores the grounded theory categories related to Roma community members' perceptions of their need for benefits, their interactions with UK public officials and limited transparency in UK bureaucratic processes.

7.3.1 Benefits Narrative 1: A journey through the health-related benefits system

In this narrative, Elzbieta (all names included herein are pseudonyms), a Polish Roma woman, describes the complications that her husband, Jan, faced in making a claim for Personal Independence Payment (PIP). She was a regular user of RSG advocacy services and one of the first participants I met upon beginning active health advocacy work. I had helped her to obtain multiple referrals and re-referrals to mental health services, and over time we reached a level of communicative openness that is reflected in Elzbieta's discussion of her husband's PIP assessment. In an interview focusing on her impressions of UK benefits systems, Elzbieta opened her account with a description of Jan's health conditions:

> *So, first of all, he's got like, the worst possibility arthritis, so very often he is like housebound, so like, for weeks he stays at home. And, you know, he's got anxiety, which is probably connected to his physical problems, like depression. His legs are like constantly swollen, he got also diabetes. Very often when people have diabetes, the skin is dark, so there is like no circulation or something. Also he has to be on diet because of diabetes.*

As Jan's main carer, Elzbieta had a detailed knowledge of his support needs, and she offered a matter-of-fact representation of the life changes that have resulted from his conditions. She avoided emotive descriptions throughout her narrative, which may have been a product of her own long-term battle with severe depression and a desire to avoid topics that may lead to heightened feelings of distress.

Elzbieta and Jan's personal history revealed numerous stressors preceding and underlying their current health-related insecurity. They entered the UK as asylum seekers, fleeing discrimination in Poland, and their experiences in the UK were fraught with financial difficulties, housing insecurity and the onset of serious illness. The family spent many years in temporary accommodation, and although they were on the priority waiting list for a council house (in light of Jan's health condition), they had received no indication of how long they would have to wait for permanent housing.

After completing the initial PIP claim form, Jan was invited to attend an assessment with a health professional. Although the family was resident in North East London, the assessment centre was located outside of London, necessitating serious consideration of a means of transportation that would not exacerbate Jan's health condition:

> *The appointment was outside of London. Because we don't have car and he can't travel by public transport, we didn't think to arrange something in London. But without family help, he wouldn't*

> *have been able to attend this. He wouldn't be able to travel by public transport. He doesn't even wear shoes; he's got swollen legs. The first thing is it was outside of London, so my son-in-law… we went like three of us. Plus he had oxygen mask with him.*

By detailing the numerous impediments to reaching the assessment centre, Elzbieta created a picture of severe illness that was at odds with the requirement to travel for the assessment. Unable to fit his swollen feet into his shoes, attempting to travel by public transport would have been highly inconvenient and uncomfortable.

Once they reached the assessment centre, Elzbieta and Jan found that interpreting support would be provided over via telephone, which, as they saw it, would impede their ability to communicate freely and openly with the assessor. Their dissatisfaction increased when the assessor neglected to review the translated records from a hospital stay in Poland that they had brought along to the assessment, which to Elzbieta and Jan represented a wilful refusal to undertake a fair and complete examination of Jan's health condition.

Weeks later, when Jan and Elzbieta received the news that his PIP claim had been refused, Elzbieta immediately suspected that the refusal was the product of an incomplete reading of Jan's case. She sought advice from RSG advocacy workers and with their help, contacted the Department for Work and Pensions (DWP) for clarification of the grounds for refusal. It then arose that they had not considered any of Jan's medical records in making the decision:

> *They [DWP assessors] haven't asked for any documents from GP, they made decision only what was on the form and based on the assessment. Because E. [RSG health advocate] called DWP later, they told me that they haven't asked for any medical evidence from GP doctor or any specialist. So then basically he was refused and scored zero points. Yeah, so basically they made decision and haven't gathered any medical evidence.*

In recounting DWP's decision-making procedures, Elzbieta's narrative took on a tone of disbelief and indignation. She drew attention to the senselessness of conducting a medical assessment without reviewing any of the background medical evidence, conveying her feeling that she and Jan had been wronged in the process of assessment.

After the refusal of Jan's claim, Elzbieta and Jan formally requested that DWP reverse its decision, though this request was unsuccessful. From there, they submitted an appeal to an independent court tribunal, where they again found their efforts at achieving a resolution stymied:

> *When he went for tribunal, so when the judge saw him, he said 'I'm sorry I can't make any decision because I see very ill person, and I've got report from DWP and it looks he is totally fit. So I'm sorry, I can't harm you, I can't make any decision. I have to gain more information from medical bodies, like GP or specialist, and they you have to wait for another tribunal.'*

It is significant here that Elzbieta presents the judge's refusal to hear Jan's case as a means of avoiding doing him further 'harm'. Whether or not the judge actually used this word is unclear, yet it nonetheless represented Elzbieta's perception that Jan's pathway through the UK benefits system had had a negative impact on his personal wellbeing, which was only exacerbated by the prolonged process of achieving resolution. Ultimately a second tribunal hearing with a different judge was scheduled and, three years after making the initial claim, the courts overturned DWP's refusal.

While Elzbieta might have concluded her narrative with the court's final decision, she instead revisited the experience of the initial assessment. She stipulated that the assessor did not explain any of his actions and simply entered the information into the computer, all the while leaving Jan in pain and confused as to the exact purpose of the assessment procedures:

> *So even before this assessment, he felt very, very bad, like all his body was in pain, face was swollen and legs, hands as well, fingers. It was, like visible that he is sick, but this person didn't have any reaction, like doesn't care about anything, just probably they are trained like this. No, he was, like, silent, he didn't say anything. But when he was pulling up his legs, he started 'ah, ah, ah'. He went for this assessment without socks because they were so swollen, like legs and everything, only with flip-flops, so he definitely saw his legs and everything.*

Elzbieta presented vivid imagery to highlight the severity of Jan's health condition, conveying the seeming contradiction between Jan's clear physical suffering and the assessor's lack of compassion. She presented the assessor appears cold and unfeeling, thus appealing to my sympathetic perceptions as an advocate and highlighting her sense of the injustice of the assessment process.

7.3.1.1 Connections to grounded theory categories

In conducting grounded theory analysis of the health-related benefits dimension of this study, I sought to capture the principles underlying participants' characterisations of their contact with benefits systems and the barriers they face in gaining access to support. The resulting theoretical frameworks revealed how participants' decision to make a benefits claim tended to crystallise at the interface of severe health conditions and financial pressures, with mental health issues arising in particular as a key motivating factor and also as an impediment to effective navigation of the claim process.

Opening with a discussion of the severity of Jan's illness, Elzbieta's narrative expanded on the grounded theory category addressing community members' conceptualisations of their support needs, revealing vital linkages between perceptions of need and sense of injustice in contemplating application refusals. At the boundary of personally mediated racism and institutional racism, Elzbieta's narrative was rife with instances in which she found that the assessor's behaviour downplayed the gravity of Jan's condition. She highlighted the assessor's dismissiveness in failing to review Jan's medical records from Poland (a possible result of administrative restrictions on eligible documentation) and thereby reinforced her view that the refusal was unwarranted. Even in her portrayal of the tribunal judge – one of the more sympathetic faces of public authority – she emphasised the strain of a prolonged benefits application process. Through these representations of the detachment of public officials from the urgency of claimants' cases, Elzbieta's narrative consistently presented assessors as an oppositional force, and thereby revealed the consequences of social distance between Roma benefits claimants and the executors of institutional procedures. As the fight for resolution drew on over three years, Elzbieta and Jan were thrust not only into a position of increased vulnerability, but also into a position in which they felt that they could no longer trust in the integrity of UK benefits systems.

7.3.2 Benefits Narrative 2: Incompatibility of assessment results and personal circumstances

In a further example of tension between benefits claimants and public service officials, Paulina – a Polish Roma woman in her twenties – discussed her frustrations with a claim for sickness benefits. She was initially claiming Jobseeker's Allowance, but at the advice of her GP, she made an application to receive Employment and Support Allowance (a benefit for people unable to work due to health problems). At the time of interview, her relationship with her husband had recently broken down and she was living again with her parents. In addition to worsening health problems, the tense circumstances of her relationship breakdown and the financial difficulties that came with it created a sense of urgency in accessing support to manage her health condition. She disclosed these details to me in an emotional interview, during which she broke down in tears over her sense of powerlessness and fear for the future.

When Paulina initially made her claim to ESA, she was suffering from severe and debilitating back pain, which could cause her legs to unexpectedly give way. When she attended the assessment, she described how she experienced a sudden attack of pain and fell down. The assessor was outwardly sympathetic:

> *Because of the pain, cause this is what's happening, and when the lady, she goes to me 'Is that what's happening to you all the time?' and I'm like, 'Yeah, this is what I mean about my health', and then the lady was looking at me and she had tears in her eyes and said in two or three weeks we're going to text you or send a letter to you.*

By including the detail of the tears in the assessor's eyes, Paulina conveyed her expectation that the assessor understood the severity of her health problems and that her ESA application would be successful.

As her discussions with the assessor progressed, however, she began to question this expectation. Despite her apparent sympathy for Paulina's condition, the assessor appeared eager to identify alternatives to awarding Paulina regular ESA payments. In this vein, the assessor suggests that Paulina could be provided with a wheelchair:

> *And then the lady said to me that in this case, in my case, that there's a huge chance for them to give me a wheelchair. And then I asked her, 'how am I gonna work in a wheelchair?', and she goes to me, 'you gonna be on the wheelchair, you gonna have the easiest job in the world, and plus we're gonna give you assistance for, like, doing the work with you.' And then I'm like, 'if you're gonna give me a wheelchair, are you gonna give me my own house?' Because there's no chance for me to go in a wheelchair.*

Paulina saw wheelchair use as incompatible with her life circumstances, highlighting the inaccessibility of her house and her belief that she would be unable to perform any work that could be done entirely from a seated position. She narrated this segment to me in an ironic tone, reflecting her perceived absurdity of the situation with the assertion that DWP may as well give her a new house if they expect her to use a wheelchair. Ultimately, however, the assessor disregarded her protestation and deemed her ineligible for ESA.

Frustrated in her efforts to secure an improved standard of living, Paulina turned her attention more generally to perceived inadequacies of UK public service provision frameworks. She described her experiences of attempting to access physiotherapy services, calling attention to administrative inefficiency:

> *Well, they told me that, um, that they're gonna send me to, um, what do you call it? A physiotherapist in hospital, and then I was like, waiting for the letter for like three or four months, and then I received the letter, but I didn't go because when I received the letter it was five days after my appointment. And they put the blame on me that I didn't go, that I missed the appointment. Now again I'm waiting almost three months again.*

With this discussion of inordinate waiting times for appointments and inability to promptly reschedule missed appointments, Paulina presented herself as a victim of service inefficiency. In her interpretation of the situation, it was a service error that led to the late delivery of her appointment letter, yet she ultimately found herself penalised with a longer waiting time for an appointment.

Tying together her experiences with physiotherapy services and her attempts to gain support from benefits systems, Paulina closed her narrative with an overarching criticism of the treatment of individuals within UK public services:

> *Well I'm just gonna say, yeah, I'm not trying to be rude, but honest to god they're working, but they don't know how to do their job properly. And they like to confuse people, but when people get back, like, to them, like getting rude, then they're like "oh, you guys don't have respect, and that's why you end up like that." Well, it's not our fault, it's your fault because you guys are making us to do things.*

Paulina's narrative highlighted the possibility that individual attempts to hold services accountable for their errors will simply lead blame to be turned back on the individual. Presenting herself as helpless in the face of bureaucratic frameworks, she found herself compelled to meet seemingly arbitrary sets of requirements yet saw no potential for recourse when officials misconstrued or underestimated the challenges posed by her health conditions.

7.3.2.1 Connections to grounded theory categories

Where Elzbieta's narrative highlighted the assessor's neglect in failing to take Jan's full medical records into account, Paulina's narrative addressed the lack of transparency on the part of DWP officials with regard to their means for determining claimants' benefits eligibility, revealing additional dimensions of the grounded theory categories focusing on the assessor-claimant relationship. Not only did Paulina feel that she was misled by the assessor's behaviour, but she also expressed frustration that the assessment result failed to account to the practical difficulties of her personal circumstances. In contrast to Elzbieta's representation of the assessor's dismissiveness, Paulina viewed refusal of her claim not as a sign of professional detachment from the challenges in her daily life, but rather as an indicator of ineptitude. In her interpretation, the assessor's suggestion that a wheelchair could be provided in lieu of benefits payments disregarded the practicalities of her daily life – particularly her housing situation – and reflected a failure to undertake a thorough assessment. Perhaps because she entered into the health-related benefits system at the suggestion of her GP, Paulina expected that the assessment process would involve a holistic and sympathetic assessment of her health needs, and she thus saw the refusal of her claim as a failure of the system.

7.3.3 Benefits Narrative 3: Difficulties of communication

Whereas the previous two narratives focused heavily on the nature of the relationship between the claimant and the assessor within institutional processes, the next narrative expands on how mental health issues and communication difficulties can place further strain on the claimant during the assessment process. The narrator was Maria, a Polish Roma woman in her fifties, who suffered from mobility issues and struggles with her mental health. I met with her during an advocacy session to complete renewal forms for her Personal Independence Payment benefits, after which I asked if she could elaborate on the process of initially completing her application and assessment for support. As she discussed this process, her struggles with her mental health issues came to the fore, as she described her sense of being closed off in her interactions with others, as well as the difficulties posed by this feeling of detachment when she completed her disability benefits assessment.

Opening her discussing of the PIP assessment, Maria explained how the assessor entered details of her condition into a form without asking Maria to confirm their correctness. Her selection of narrative detail emphasised disorientation and confusions as she considered the disparities between her expectations and the reality of the assessment:

> *He come to my house, I don't know why, and he give me the form, and I had to sign. I sign the form, and the form is a questionnaire. After I sign he made a question for me, he made a question, maybe two or three questions, but the questions inside the form – I don't know, are there 20 or more? He gave me only two or three questions. Very, very stressing, but – what is it – I think that he joking or something, because this is not normal!*

The sources of confusion were manifold. Maria did not understand why the assessor came to her house, nor could she explain the marked disparity between the number of questions in the form and the number of questions that the assessor asked her. She suspected that the assessor simply wrote answers as he saw fit, without concern for their accuracy, and she attributed this misrepresentation of information to the refusal of her PIP claim after the assessment stage.

Moving on with her discussion of the assessment, Maria expanded on practical difficulties of communication. She had requested interpreting support for the assessment, yet the interpreter's late arrival impeded in her efforts to accurately describe the difficulties arising from her health condition:

> *He start to fill the form but the interpreter isn't there – a little bit late – maybe 10, 15 minutes. But when she come she ask for me the first question: how are you today? I don't remember. How, uh, how can I take the medicine or something. But here I think is no problem: I open the medicine, take the medicine, go to toilet. He explain, I don't know, how he think I can go to shop – more than 100 metres – buy something, bring it to house. But I don't know, I don't understand this, how?*

She included details of the specific physical tasks she was asked to perform, stipulating that these did not represent the daily living activities that constituted challenges for her. Confused and disoriented by the assessor's brusque questioning, she found herself unable to offer clarification of the precise nature of her condition. She came away from the assessment process with the feeling that details of her condition had been unduly manipulated.

In addition to the inapplicability of the assessor's questions to her health conditions, Maria found the interpreter's understanding of medical terminology to be lacking:

> *Sometimes the interpreter doesn't understand the medical information, you know? But she ask me how to explain.*

With this detail, Maria offers an additional indication of her inability to adequately describe her condition during the assessment. Then, continuing with this theme of shortcomings in language support, she specifies how she faces particular difficulties in explaining her mental health conditions through interpreters, especially when the interpreter is an unfamiliar person:

> *Yeah, but you know it is very hard, I don't know, that's my opinion. When I go for example to the psychologist, I got the interpreter. Today, is okay, she explain everything, but next time is a new interpreter, but you know that is very, very bad.*

By expanding on the challenges of mental health communication, Maria voices one of her key health concerns. It is notable, however, that her discussion of mental health communication occurred not in the specific context of the assessment process, but rather as part of a general reflection on communicating through interpreters. This suggests, perhaps, that Maria's struggles with mental health did not arise over the course of assessment, which would represent a severe oversight on the part of the assessor.

7.3.3.1 Connections to grounded theory categories

Maria's narrative expanded on issues regarding the lack of transparency in assessment procedures and the claimants' suspicions that assessors omit or manipulate information undermine the likelihood that claims will be successful. Observing how the assessor asked her only a small fraction of questions on the claim form, she came to the conclusion that the assessor must be formulating his own answers to the questions without her input. While this in itself is damaging to the assessor-claimant relationship, the presence of an interpreter further seemed to impede rather than aid open communication, as Maria was reluctant to disclose her pressing mental health concerns with two unfamiliar people in the room. Maria's narrative thus offered elaboration of the grounded theory concept of mental health, revealing linkages between mental health concerns and benefits claims. Where mental health issues were briefly mentioned in Elzbieta's discussion of Jan's reason for making a claim for PIP, Maria's narrative demonstrated the overwhelming emotional demands of the assessment process.

7.3.4 Benefits Narrative 4: The mental health impacts of health-related benefits claims

Mental health issues are even more prominent in Katarzyna's narrative, a Polish Roma woman who approached RSG health advocacy services with a request for assistance with her mother's Employment and Support Allowance claim. Normally she would fill in these forms herself (she is fluent in English, and in the past had worked as a receptionist for RSG), but her mother's health situation was precarious, and she wanted to ensure that it was presented in the claim form as accurately as possible. As I helped her to answer the application questions, discussion turned to Katarzyna's own paths through applications for PIP and ESA. When I asked her to elaborate on her experiences, her narrative revealed pressures arising from frustrated attempts to claim disability benefits.

Katarzyna's narrative opened in the midst of her PIP assessment, as she struggled to make sense of the assessor's questioning strategy and to perform the set of tasks intended to demonstrate her physical capabilities:

> *It was difficult because when I went for the interview, the self-assessment, the doctor keep asking me some question, then he was coming back to the same question. He ask me to do some exercises, he drop on the floor piece of paper, he was asking me to pick up the paper, which I couldn't do, and on the report, two weeks later, I receive a letter that I can do everything, which was not true.*

When the assessor asked her about her condition, Katarzyna noted how he repeatedly returned to the same question, as though he was seeking to uncover some inconsistency in her answers. She was blunt in her statements of inability, imbuing her narrative with a pragmatic tone that underpinned her sense of disbelief in discovering that her benefits claim was refused.

The PIP assessor's representation of her health condition was blatantly at odds with her perception of reality:

> *He [DWP assessor] didn't tell the truth because when he ask me how often I'm going to the toilet during the night time, I remember that I told him that I'm going between seven to nine times because I have sensitive bladder. And he writed down that I'm waking up only once. He changed everything. And like for example, when they give you a point, like one point for this, two point, he say everything zero. Everything was zero.*

Katarzyna honed in on numbers: the number of times she states that she needed to use the toilet each time, the number that the assessor wrote in his report and the number of points she scored towards an award of disability benefits. Perhaps this selection of detail was intended to reflect DWP's tendency to reduce health conditions to numerical ratings, or perhaps it showed Katarzyna's effort to ground her narrative in a sense of reality in the face of the assessor's wanton distortions of her health conditions. In either case, she appealed to my prior knowledge of the disability benefits system, highlighting the injustice of having scored zero points despite substantial health needs.

After the refusal of her PIP claim, Katarzyna submitted a request for formal reconsideration of her case, and she received a phone call from a DWP representative to discuss the outcome of her assessment:

> *And the lady she asked me, did you have someone with me during the assessment, and I say yes, my daughter was with me, and that she had everything and, yes, she was helping me to answer all this question because my English is not very good, but sometimes I was just getting stuck so she was helping me. And the lady she say, if we ask your daughter where she is at the moment, I say, she is in her own flat, she is living separately, you can call her anytime. I not worry about this: she going to give you all this information. After one hour she did call me back and she said thank you very much, and we are very sorry about that, what the doctor done to you. And we just want to tell you that you are going to get like, how they call it, support group, and since then everything is quiet and nice.*

By drawing a back-to-back comparison between the in-person assessment and the subsequent phone call to assess her request for reconsideration, Katarzyna called attention to the jarring inconsistencies in DWP's handling of her case. After a rigorous and invasive in-person assessment, the decision was overturned with nothing more than a call to Katarzyna's daughter and an apology.

Although satisfied with the final outcome of her PIP claim, Katarzyna was left with a lingering confusion over the contradictory messages she received at different stages of the claim process. Ultimately she could do nothing more than attribute her experience to the unprofessional behavior of a single assessor:

> *If some people understand you clearly and they will try to put themself in your place, then it would be good, but some of the people, they are just rude. Especially I had the time when I couldn't sit, I was standing, and I was holding to his table, and he was like to me, 'why you standing, could you have a seat?' And I say, really, I'm sorry, but I can't do it at the moment. 'Okay, then I cannot talk to you, maybe you should come next time.'*

The assessor's apparent lack of empathy seems almost nonsensical – and perhaps Katazyna engaged in deliberate oversimplification to build on her conception of professional incompetence – yet it also appeared as a means of explanation: her claim was initially denied because, as she saw it, the assessor lacked sympathy and concern for her individual situation.

Moving on from the discussion of her PIP assessment, Katarzyna turned her attention to a separate experience of attending the tribunal hearing in her claim for ESA. She first captured the tension of the waiting room:

> *I had a lot of pain, I was feeling so much dizzy. And I had a panic attack because in the lift there is no window. And when I'm going to some places which is no window, I feel like someone cut off my… I can't breathe. And for this time when I was waiting in the waiting room, there was so many people there, it was so loud, which makes me feel more worry, and I just keep asking 'how long? When are they going to see me? I just want to go home.'*

With repeated references to the lack of windows in the waiting room and the loud voices of the people surrounding her, Katarzyna created an atmosphere of enclosure and entrapment. Her vivid details drew me in to the desperation of the moment, building up the narrative tension and then with a plaintive expression of her desire to go home.

Then, describing her entry into the assessment room, her descriptions of panic gave way to a measured narration of the scene:

> *When I went to this room, it was really big room, and there was three doctors: one lady and two men doctors. One of the men doctors, he was really nice, he was psychiatric doctor. He really understand my situation, he was really nice to me, but when he give me all of his questions, when he was finished, he fell asleep. Yes, he fell asleep, but the other two doctors give me questions and they tell me… they hold me about 20 minutes there.*

Describing how one of the doctors fell asleep after completing his questions, Katarzyna added an element of absurdity to the narrative, thereby underlines her sense of unreality as she progressed through the tribunal hearing. She found herself unable to exert control over her surroundings and situation, which sparked her descent into a second panic attack:

> *I asked them to open the window because I was feeling so much hot over there. They couldn't do. And when they finished, they say okay, you're free to go, and as I was going home, I get the panic attack. I was just stuff in lift and I couldn't breathe, I was feeling like I'm going to die. The good was that my daughter, she was with me, but my daughter she was pregnant, and I was worry about her. And she was worrying about me. We just keep supporting each other. When the windows open I saw security man. I think he realised that something going on and he help us.*

Katarzyna again emphasised the feeling of entrapment as a trigger for her panic attack, interweaving concrete descriptions of her physical surroundings with her heightening emotional distress.

The experience of assessment as inextricably linked to Katarzyna's mental health issues, and as Katarzyna approached the conclusion of her narrative, she reflected on the pervasive impact of mental health concerns on her daily life:

> *And the lady, she give me this question, I remember: would you like to do in the future? I would say, I would like to be without the pain. Because this is the most important, and to feel more comfortable with my mental health so I can cooperate with the other people, so I can help my children out, like to see when my children growing up and be happy. I don't want them to be sad because mummy's… because I'm crying. It's too much, because you have to go back, if something happen previously, you have to remember. Sometimes you're trying to forgot about something that happen in your life, but with this form you have to go back and find out when the beginning was.*

Not only did the assessment process elicit direct experiences of mental distress, but it also sparked a reflection on the triggers and consequences of mental health issues. She had made a claim for benefits in the hope that she could reach a point of stability with her mental health, yet the claim process brought once-suppressed thoughts to the surface, undermining to the sense of balance she had hoped to strengthen.

7.3.4.1 Connections to grounded theory categories

Mental health ran as a key theme throughout Katarzyna's narrative, shaping the way that she engaged with the assessment procedures and perceived her support needs. In narrating her journeys through benefits systems, she initially focused on the nature of interactions with assessors and the inconsistencies between her actual levels of ability and the details provided in final assessment reports. As the narrative progressed, her tone shifted, and she began to disclose more sensitive personal details of mental distress. Her mental health issues seemed to be exacerbated by the assessment process, causing her to feel constrained and deprived over a sense of control over her life. Moreover, she explained how disclosing symptoms of mental ill health during assessment caused her to relive some of her most intense periods of distress, thereby impeding her in her efforts to attain a sense of stability in her life. Through this multidimensional representation of mental health and disability benefits, Katarzyna's narrative reinforced the connections between grounded theory categories related to perceptions of need for benefits and the emotional impacts of assessment. Where in grounded theory analysis these appeared as distinct and separate segments of the data, overlaying the grounded theory frameworks with narrative analysis revealed the ways in which they interconnect, shedding light on their unique significance to individual participants' lives.

7.4 Narrative synthesis: Exploring power imbalances

Connections between health and benefits systems arose unexpectedly over the course of health advocacy work, yet it rapidly became apparent that systems of state support represented a major area of concern for participants in this study. Assisting with benefits applications offered a natural progression into invitations for interview, as the process of guiding participants through the claim form opened up the discussion of sensitive subjects, often leaving them with a desire to further express their frustrations and the complexity of the benefits application process. Participants knew me first in an advocacy capacity, and this likely shaped the tone and content of interviews about their experiences of claiming benefits. Many perceived themselves to be in a relationship of conflict with DWP and, through my active assistance in their efforts to gain access to benefits, they came to view me as an ally in their day-to-day struggles. Their narratives highlighted perceptions of barriers and limitations of life chances. Lack of transparency in assessment procedures, (suspected) omissions of relevant information from assessment reports and assessors' expressions of detachment and dismissiveness arose as common themes across benefits narratives. This brings to light an element of personally mediated racism across all narratives, in which participants saw questionable assessment procedures and poor communication from assessors as direct challenges to their personal wellbeing. Participants expanded on the elusiveness of benefits awards, and assessors emerged as faceless gatekeepers, hidden behind assessment forms and computer screens – impenetrable and disinterested.

As participants developed their views of interactions with DWP as a struggle for recognition of their needs, the concept of mental health emerged as a driving force in narrative development. Whether mental health issues provided grounds for making their benefits claims (as was the case for Jan, Maria and Katarzyna), or whether mental health issues exacerbated the pressures of assessment (as was the case for Maria and Katarzyna), participants' experiences of the UK benefits system revealed new dimensions of their conceptualisations of personal mental health. Especially for Maria and Katarzyna, their mental health issues create an added sense of vulnerability in undergoing assessment, which leads on to expressions of personally mediated racism, in which they perceive assessors to misunderstand and misinterpret their conditions. Even Paulina, whose narrative did not make specific reference to mental health, broke down in tears as she concluded her story, again suggesting overwhelming stressors in participants' engagement with benefits systems.

7.5 Summary

This chapter presented an investigation of two key dimensions of Roma migrants' experiences in the UK – immigration and benefits – that arose over the course of study as key forces shaping their wellbeing. Opening with a discussion of the way in which the volatile state of UK politics ushered in new limitations on EU migrants' rights, I explored how engaging in participant observation in a changing social environment fundamentally altered my perceptions of participants' migrant status. As I witnessed participants' anxiety increasing in light of the uncertainty of their post-Brexit status, my personal narrative of the field led me to undertake additional inquiry into immigration insecurity and its impacts on wellbeing. Connected to the idea of security were participants' frequently obstructed efforts to gain access to benefits systems and thereby gain a degree of independence in managing long-term health conditions. This latter segment of the chapter expanded on grounded theory categories related to experiences and motivations in claiming health-related benefits, and presented four narratives of participants' experiences in claiming benefits. Their narratives explored participants' conceptions of oppositional relationships to DWP assessors and the mental health impacts of interaction with benefits systems.

Chapter 8: Personal narratives of health and interactions with services

8.1 Revisiting grounded theory categories

Initial analysis of data according to a grounded theory methodology identified a range of interrelated categories, which fit broadly into three overarching areas: individual perceptions of health; interactions with services; and other dimensions of social environment. The categories related to individual perceptions of health described methods for explaining health issues, social stigmas that may influence participants' health communication (with a particular focus on mental health) and the manner in which health perceptions informed participants' decisions in engaging with services. Within the overarching areas of interaction with services, categories described participants' need for language support, past experiences of health services, perceptions of shortcomings in service provision and means of addressing these shortcomings. As narrative analysis progressed, participants' stories of their personal health and experiences of health services added depth to these categories, revealing cross-category linkages that had not been initially apparent and providing new insight into the manner in which participants understood their position within UK health services.

8.2 Health Narrative 1: Injury and the search for support

8.2.1 Context

To understand the significance of this narrative, it is vital to first understand the circumstances that led Malgorzata, the narrator, to engage with Roma Support Group health advocacy services. She was homeless at the point of first contact and living with a friend. Unable to access benefits systems (as adding a second benefits recipient at her temporary address would reduce her friend's rate of payment), Malgorzata was in a state of financial desperation and could not afford the bus fares to attend her medical appointments. From this point I met with Malgorzata in numerous advocacy sessions, first attempting to reinstate her pass allowing her to use London public transport free of charge and, failing that, visiting her local council's offices to see what assistance they might be able to provide. Upon meeting with a council representative, we were informed that, without a valid address, Malgorzata was ineligible for any support. As we left the office with the feeling that we had exhausted our options for resolving this situation, Malgotzata voiced her sense of resignation, saying, ‘It’s like they don’t see me.’

When Malgorzata told me her story, the narrative itself was relatively brief, focused on her experience of badly breaking her hand. The decision to recount this story seemed to arise from a desire to make sense of her experiences and the environment around her. Her narrative was, to an extent, emotionally fraught, but it was also a firmly bounded experience; she did not feel the need to elaborate on the wider circumstances of her life.

8.2.2 A badly broken hand

Foremost in Malgorzata’s mind were the direct and tangible circumstances of her injury as she launched into her story of the preceding months. There was no mention of her experience of homelessness and the administrative barriers to access formal support; rather, she emphasised the physical development of symptoms after breaking her hand:

> *When I fall down at home in Poland this happened. I think I’m just, I’m not feeling too much pain. I’m feeling clicking inside, because when people fall down they don’t . . . but maybe that’s why I’m not feeling all my pain. When I go into hospital they say I have broke my two bones and they said is very difficult broke[n], and after this I can get some problems, but I didn’t know how big.*

First she noted the physical manifestations of the break – clicking in her bones and a lack of sensation – yet she was careful to stipulate that the pain had not yet set in. Malgorzata foreshadowed the onset of more serious problems, describing the initial consultation regarding the broken bone, and then offering a cryptic reference to her initial unawareness of how serious her problems would become.

The fall occurred approximately two weeks before Christmas, and Malgorzata moved on to describe how the Christmas holiday passed before she received any further medical input on her condition; meanwhile, severe pain began to set in. She attributed this deterioration to the temporal distance between the initial injury and the point at which she was able to receive formal medical attention, as well as medical professionals’ seeming dismissiveness of the severity of her condition. Against a backdrop of increasing concern over physical symptoms, Malgorzata revealed how no one provided her with any clear information about her prognosis and instead offered her empty reassurances:

> *When I am in plaster I am not feeling too much because… Feeling something wrong with my fingers, but no one told me… 'ah, you just thinking, it is no problem'. You got problem here, but the nerve is coming here, so I am not using hand and feeling too much.*

It was only upon seeking input from a specialist that Malgorzata gained a fuller understanding of the nature of her condition. She then underlined the consequences of delayed treatment:

> *The doctors said I have to move my fingers and I tried to move my fingers and colour change and swelling is coming, and now it's nearly two months. I saw two different doctors but they working together. One told me he's the right one and if I need the operation he, he do operation for my arm. So first they have to see my nerves.*

Her narrative ordering mirrored her personal discovery of medical information, thereby providing me with insight into her emotional progression through the process of diagnosis.

Once she understood the nature of her injury, Malgorzata entered into a phase of rapid learning about her treatment options and prospects for recovery:

> *And after this they said they have to do some injection in my bones, they have to put sleep me and they see what they can do. Maybe operation, but anyway, if the frac[ture]'s here and pressing nerve, they have to remove.*

Malgorzata revealed some of the medical knowledge she has gained through her interactions with health professionals, outlining a step-by-step treatment process. This pragmatic, measured description can be read as an attempt to impose a sense of meaning on circumstances that she struggled to understand. She then expanded on this struggle to obtain information about her condition:

> *In hospital, in Poland, they said I have the frac[ture]s and I knew about this, but they said if you need, if you feel not comfortable, they have to remove for you, but they didn't tell me.*

By drawing connections between health services in Poland and health services in the UK, Malgorzata implied that Polish health services afforded her only a partial understanding of her condition and long-term treatment options.

After highlighting the communication issues with health services in Poland, Malgorzata elaborated on an additional dimension of limitations on her communicative abilities, this time in the context of UK services:

> *I have an appointment in March, so I have to ring them because this is so important, so I have to get interpreter because I can get some questions. The thing is, my mind is in Polish language, and*

> *I try to make the words in English, but it is different way. It's really not easy. The thing is, if I'm talking about everything, it's different language, but if I go to hospital, it's hospital language. Very different.*

Although this was not her first contact with health services, yet she found it jarring to suddenly have to learn new medical vocabulary in order to understand what health professionals were explaining to her:

> *And first time I broke my hand – I never broke nothing in my life – so new words. I know something about diabetics, about heart problems, about blood pressure, but this is…*

With this overview of the health problems she had already experienced, and it seemed notable that she chose to construct a narrative around a relatively commonplace injury and not the more severe health problems she had previously experienced. Perhaps this was due to the immediacy of the injury to her present circumstances; more than her other health issues, this was the one that has had the greatest emotional impact. This could be the consequence of the pain it caused her, the circumstances of her life at the time of injury or the simple fear that accompanied loss of sensation and uncertainty over whether feeling would ever return.

After discussing the medical details of her injury, the tone of the narrative shifted from a relatively pragmatic discussion of diagnosis, treatment and interactions with medical professionals to an emotive reflection on the life changes that have arisen from being constantly in pain:

> *And I'm very tired and it's very difficult for me to speak, to talk about… you know, because I'm not sleeping well. And my brain is no working like before. I'm tired. It's nearly three months and maybe seventh of March, three months, so it's really too long. Before I'm crying but now I stop crying because it's not a help. So I'm just waiting when the story's ending. I'm just thinking, okay, the hand can stay like this, no problem, just no pain.*

With this expression of frustration and helplessness, Malgorzata gave an indication of her reason for telling this particular story at this point in time: she had reached a breaking point, and she seemed comfortable in disclosing this sensitive information to me in light of my advocacy role. The significance of the narrative did not lie in the nature of the injury, but rather in the pain, the exhaustion and the emotional changes that she has observed as a result. She was frustrated that she has waited so long without any hope of resolution. Then, repeating for the third time that she was tired, Malgorzata reflected on the physical changes that came about through her injury:

> *Because I'm really tired. Before maybe I'm thinking different but now it's really too much. Everybody says my eyes change, my face change, you know? Just my mum, she said 'I look better*

> *than you, I wear better clothes than you', because really I'm… I can't get anything that give me happiness now, it's nothing.*

Malgorzata revealed a sense of dissociation, of detachment from her former sense of self. She once took pride in her appearance, yet had since been plunged into a state in which she no longer felt the emotional strength to project her former public face. Although she did not specifically state that she was suffering from depression, the symptoms that she named do indicate that she was experiencing difficulties with her mental health.

Yet after describing her hardship and exhaustion, the narrative concluded with an expression of cautious optimism and perseverance:

> *Anyway, I'm strong. I pray every day, maybe 10, 15 times, I pray because, you know, sometimes I don't know what I can do.*

Describing prayer as a response to uncertainty and a source of strength, Malgorzata's discussion of religious faith conveyed the fruitlessness of seeking support from other sources. While much of the narrative detail emphasised her interactions with health professionals, Malgorzata ended the narrative with a reflection on self-reliance. Professionals had been unable to provide her with answers, and so she concluded that she could only build a sense of security within herself.

8.2.3 Connections to grounded theory categories

Malgorzata's narrative reached across grounded theory categories to reflect the challenges of navigating health services across national borders, managing the challenges posed by language barriers and ultimately developing an understanding of diagnostic information. With her discussion of the initial – and inconclusive – diagnosis that she received in Poland, Malgorzata's narrative shed light on differing perceptions of health services in the UK and participants' countries of origin. She placed her trust in UK health services, as it was only upon her return from Poland that she discovered that her symptoms were the product of nerve damage. She nonetheless noted how constant internal translations between English and Polish created a barrier to seamlessly expressing her concerns. Underlying this surface-level commentary on interactions with health services, however, were deeper indications of mental ill health. She presented changes to her emotional state through the lens of external perceptions – focusing on her mother's observation of the dramatic changes to her physical appearance – and thereby adding dimension to the grounded theory categories of family expectations and feelings of shame. Malgorzata expressed how physical changes stemming from pain-induced sleeplessness – which could be a further manifestation of depression – made her the subject of criticism, as she was no longer able to present an outward image of strength. Her strength, she concluded, was internal.

8.3 Health Narrative 2: Misdiagnosis and diminishing trust

8.3.1 Context

After establishing initial contact with Katarzyna through assistance with a disability benefits claim form, I asked her whether she could elaborate on her impressions of the disability benefits system. At the conclusion of this longer narrative, she offered a brief vignette focusing on a past medical crisis and the resulting contact with health professionals. Her pathway through the disability benefits system highlighted professional disrespect for claimants' individual circumstances, and this segued into a discussion of similar experiences within health care institutions. Perhaps because she knew me in my advocacy capacity, she was particularly open in her criticisms of health professionals, selecting details that captured a sense of confusion and diminishing trust.

8.3.2 A grave diagnosis and a search for answers

Katarzyna had earlier described how the lengthy process of claiming disability benefits had set off panic attacks, and she expanded on this discussion of her emotional state with descriptions of the desperation that came with a diagnosis of cancer. She opened this segment of the narrative with a reference to her contact with health professionals, thus attributing her emotional unrest (at least in part) to a perceived failing on the part of professionals to provide her with adequate support:

> *I had a really bad experience with the doctors, also, it was in 2003 or 2004 they told me that I have breast cancer. And when I was feeling really good, they told me they have to do an operation, that I have breast cancer, and all my life just break, and from that time I had a panic attack because I was so much worry. I have two kids, they're just growing up and now I'm going to die. What's going to be happen with them? I have no brother, no sister.*

In this emotional appeal, Katarzyna conveyed fear and devastation, focusing not just on herself, but also on the future implications of cancer for her children. She treated death as a matter of certainty and foresaw a future in which her children would have no family to care for them.

As the narrative moved forward, Katarzyna described how she was set to undergo surgery to have her tumour removed. When the operation was about to begin, however, she received shocking information about her condition:

> *Just five minutes before operation, before they give me anaesthetic, the doctor, she came, and she said, 'can I just have a look in which place we going to do operation' and I said yes, and when she was checking and checking for half an hour, and she was like 'Katarzyna, you have no' … how you call… the bubble… the lump. And so they took a biopsy, and five minutes before operation there's no more lump? So that was strange for me. They done again scan, and they say, we don't know what's going on, but the lump disappeared.*

By detailing that she first underwent a biopsy and a scan, Katarzyna seemed to impose a sense of clarity and order on an otherwise disorienting situation. In doing so she shifted the tone of her narrative from one of fear and helplessness to indignant disbelief. This narrative construction was also present in Malgorzata's narrative, as she detailed medical information in what can be interpreted as an attempt to stave off emotional distress.

After the panic of her initial diagnosis, it was notable that Katarzyna did not describe any sense of relief in discovering that she did not have breast cancer. Instead she doubted the credibility of her care providers:

> *Yeah, I just wanted to know what happened, but when I went to see the doctor again who give the reports, he couldn't say anything. And the nurse said 'I'm so sorry', and the interpreter, she was like in shock, and say maybe I should sue them, and I'm like, 'no, I'm not going to.'*

Katarzyna highlighted various professionals' responses to her situation, describing the doctor's silence, the nurse's apologies and the interpreter's recommendation that she take legal action. By including these varying responses in her narrative, Katarzyna presented the doctor as largely detached from the emotional distress that his diagnosis caused, while the interpreter and the nurse were presented as significantly more sympathetic. This juxtaposition of reactions set off Katarzyna's thinking about questions of professional competence, as the professional with the highest level of qualification was able to offer the least reassurance.

Unable to gain any clear explanation of the way in which the diagnostic error occurred, Katarzyna described her personal means of constructing meaning:

> *And this was like something, a miracle, you know? Maybe I was praying too much.*

As Malgorzata from the previous section described prayer as a source of solace when she felt unable to cope with distress; Katarzyna prayed when she felt overwhelmed by her cancer diagnosis. Both references to religion are very brief, seemingly offhand remarks, which may simply reflect a view that prayer does not require further elaboration.

In this vein, Katarzyna resumed her discussion of interactions with health services, specifying how she now seeks the opinions of multiple professionals before trusting in the accuracy of a diagnosis:

> *I still remember the doctor's name. And now the doctor, he's really famous and he has his own clinic in central London. And now when I'm going to doctor, I'm not, like, sure that they're going to give me a good decision, like what to do, what kind of illness I have. Now I'm not going to see one doctor, I'm going to see like two or three doctors to make sure I'm always asking now for second opinion, because I'm not trusting anymore.*

Katarzyna alerted me to the contradiction between the doctor's professional success and his flawed diagnostic practices, calling to mind her earlier discussion of the contrast between DWP assessors' professional authority and neglectful assessment practices. In Katarzyna's view, professionals can gain success regardless of the hardship they inflict on their patients, with patients' concerns going unaddressed if they contrast with professional opinion. She attempted to subvert this inequality by taking charge of her health situation and actively seeking second opinions after diagnosis.

8.3.3 Connections to grounded theory categories

Katarzyna's narrative offered insights into the grounded theory concepts of social distance between patients and professionals, and the manner in which this connects to perceived inadequacies of service provision. As she grappled with the impacts of misdiagnosis, Katarzyna drew my attention to medical professionals' lack of transparency, first in communicating the nature of misdiagnosis and then in clarifying the manner in which such an error occurred. She emphasised how she no longer bases her trust in conventional indicators of professional competency. This presented a contrast to Malgorzata's characterisation of health professionals in the previous narrative, in which she highlighted the difficulties arising from language and communication barriers, but overall expressed trust in professional input. By comparing these differing views of professional competency, new dimensions of the concept of trust emerge. According to participants' narratives, trust is neither implicitly held nor lost, but rather is variable and dependent on the patient's sense of the professional's displays of respect and communicative openness. This suggests a dimension of personally mediated racism, in which participants perceive professionals' behaviour to run directly counter to their wellbeing; yet it could also suggest the beginnings of internalised racism, in which participants' self-confidence in accessing services is eroded through repeated unproductive contact with professionals.

8.4 Health Narrative 3: Clashes with professional authority

8.4.1 Context

Beata is a Polish Roma woman, who sought assistance from RSG health advocacy to obtain assistance with her mother's application for disability benefits. I had not had contact with her prior to interview, as she was fluent in English and rarely required the assistance of RSG's health advocacy services. Even so, she encountered challenges in navigating the complexities of the disability benefits system. While the meeting initially centred around the completion of the benefits application, conversation turned to Beata's personal health related experiences and interactions with health services. When I asked her about her past contact with health professionals, she launched into a narrative about a difficult pregnancy and the way in which this permanently altered her perceptions of health services.

8.4.2 A cycle of worries and reassurances

As the narrative opened, Beata described the onset of concerns about her pregnancy, stipulating that she was proactive in seeking out medical information:

> *In that time I was pregnant and my contact was with the hospital and with the GP. That was where my contacts was, and, um, from the beginning I was not feeling too well, which I informed my GP that I am feeling unwell and I think there is something wrong with the pregnancy and they calm down me and tell me that is very often like that in the beginning, don't worry, going to*

> *be everything fine, and, okay, I was thinking, fine, maybe it is something different because every pregnancy is different: I understand that; I have already three children.*

Beata was explicit about her concerns: she believed that her general feeling of being unwell indicated a problem with the pregnancy, and she presented her experiential knowledge in direct juxtaposition to her GP's reassurances. She made a point of stating that she has three children, and through these three former pregnancies, she gained the knowledge of what to expect when she is pregnant. Despite her past experiences of pregnancy, she conceded that perhaps she could be mistaken; perhaps her unexpected symptoms could be the result of healthy variations from pregnancy to pregnancy, yet ultimately these efforts were overshadowed by her physical symptoms of pain.

Beata described repeated GP and hospital appointments, during which she continually reiterated her concerns about her pregnancy. The health professionals offered reassurances, yet Beata interpreted these attempts to mitigate her concerns as challenges to the knowledge and authority she has gained through the course of past pregnancies:

> *She [GP] make some examination or something else, you know, to check what is going on. She was telling me, 'don't worry, it is the beginning; there is always pain there,' and, um, I was feeling that she don't treat me properly because, um… she was – how do I explain – she was treating me like, like that was first child mine and I doesn't know what is going on . . . At that time I was… 37 years, my age… not too young.*

Not only did Beata reiterate that she has been pregnant in the past, but she also mentioned her age, which added further weight to her assertions and conveyed her expectation of personal autonomy in determining the nature of medical attention she believe she should receive. By focusing on interactions with health professionals, Beata called attention to perceived limitations on her personal autonomy, substantiating her belief that professionals were not treating her with sufficient respect.

Beata was careful to note the precise stage at which different interactions with health professionals occurred, conceivably to highlight the long delays in receiving adequate responses. With this focus on the passage of time and the developments (or lack thereof) in her pregnancy, she conveyed her growing sense of urgency in uncovering substantive answers to her concerns:

> *I was three months pregnant then – three and a half months – and I wasn't feeling the movement of the baby, which in that stage, with the other problems of before, I wasn't really feeling. And, you know, I was worried, really. Then I go again to my GP and was telling, 'listen, I*

> *don't feel movement of my child, is something wrong.' Because in that stage I should feel the movement of the baby. And she was telling me, 'No, that is… you are not too high in the pregnancy to feel the movement,' and I was watching her, and I was telling that is not my first child, is three baby I have already, then I know how I should feel when I pregnant.*

Once again repeating the detail that she had three children already, Beata emphasised the GP's perceived dismissiveness in maintaining that there was no cause for concern. With these consistent repetitions of detail, Beata reflected her feeling of being caught in a cycle of concerns and empty reassurances.

She began to question whether her fears were merited, or whether she should place her trust in professionals' assertions of the pregnancy's normal progression:

> *Yes, exactly, and you know, still you think, okay, then maybe I been confused, maybe the doctor is all right. Yeah? But still maybe you have the thinking somewhere behind that is something wrong, and every visit I repeat my worries.*

Despite her momentary doubts, she ultimately remained firm in the conviction that her concerns should inform the direction of treatment:

> *And they don't treat me seriously when I was asking them about something else. Because I want to make scan to see that is everything right; they don't make the scan. They make the blood test and after one month they send me letter and was telling me that – I don't remember exactly – but was something wrong with the blood test, you know.*

Beata interpreted health professionals' denial of her request for a scan as a sign of dismissiveness. However, upon receiving abnormal blood test results, the doctors were willing to act on Beata's requests for further diagnostic investigations. As she waited for a conclusive result, she noted that her condition deteriorated substantially:

> *And the doctor was watching me and he was telling me 'okay, I go to make for you the appointment for the scan.' I show up after two weeks. In that time, in the last two weeks, I was feeling really terrible sometimes. And of course the doctor make the scan and he was telling, 'I'm sorry to tell you but you were right; the child is dead.' Is not moving at all. I was six and a half months pregnant.*

With a further reflection on this devastating result, Beata emphasised her sense of injustice in having been made to wait so long for a conclusive answer to her concerns.

She did not immediately describe the emotional impact of discovering that her child had died, but instead offered a pragmatic, step-by-step account of what happened next. Perhaps in an effort to impose a sense of order on a situation that felt beyond her control, Beata explained how she was given pills to induce labour and sent home. What follows is a harrowing account of delivering a dead foetus, alone in the bathroom of her home:

> *Yeah, and I go home, and in the night time, something around 11, in the evening actually, maybe around 12 o'clock, I was starting to feel the pain. Of course I was so crazy, so stupid, that I go to bathroom and I tell no one and I give birth in the bathroom. I was bleeding very heavily; I have no strength at all to come from the bathroom or to call someone because in that time the children had been small, and every time when I tried to go from the bathroom. And you know, I was there in the bathroom some half-hour, maybe more. I was bleeding very heavy, and thank god I am quite a strong, you know, mentally as well and I been used to that, that I did everything myself and I put cold water, to sit in the cold, because I know that the cold is keeping the blood tighter and you don't bleed too much.*

Her family was home as she gave birth, yet Beata emphasised that she told not one what was happening. Alluding to a combination of physical weakness and mental strength underlying her decision not to call her family for help, Beata implied that her self-sufficiency may have been misguided, yet also suggested a sense of personal pride in her ability to handle this situation on her own. Beata persevered through the pain and bleeding, exerting her will and exercising control over a situation in which health professionals had largely left her powerless.

It was only after she had described the ordeal of giving birth that Beata mentioned the emotional release that came after months of waiting to understand what was wrong with her pregnancy. Still hoping for answers, she took the foetus to the hospital in a glass, demanding that the doctors run tests to determine how the death had occurred:

> *I take that what I give birth in a glass. And I bring that to the hospital on that appointment [unintelligible] And I was crying and telling them 'listen, I give birth in the bathroom, and please could you check what was wrong with my child because I want to know what was wrong.' And then tell me 'yes, of course, we going to tell you, we going to send you letter with the result from the examination.' They take all my documentation from the pregnancy with them, straight away, and every letter from them that I got, they take away, and they clean everything, you know, and they tell me, okay, fine, you can go home. And that was, that's it.*

Despite assurances that the hospital would soon contact her with the test results, Beata received no further information about the death of her child.

This constituted a final violation of trust, and Beata emphasised the long-term emotional impacts of her experience:

> *After two or three months I go to the hospital and I was asking them in the reception, I was telling them in short way what was the story and that I was waiting for the letter with the result of the examination. And they tell me, 'we don't have anything in the computer system.' And then, you know, I give up because, to tell you the truth. I have enough to worry about and I start to feel very depressed, and after that I got very big depression and I have very high dose.*

The conclusion of Beata's narrative conveyed a sense of exhaustion and resignation, yet she did not elaborate on her experience of depression (perhaps because she had only met me earlier that day, and did not feel comfortable in disclosing sensitive personal details). She again mentioned the passage of time, highlighting how she waited months for an answer from the hospital, and in doing so she again revealed her sense of disbelief in waiting so long for medical professionals to act on her requests. Although her ordeal had been a fixture of her life for so long, she rather abruptly closed the narrative with her decision to 'give up', stipulating that she did not abandon her search for answers because it was no longer important to her, but rather because she felt that she was powerless and would not get the justice she deserved.

8.4.3 Connections to grounded theory categories

Beata's narrative focused on clashes between medical professionals' assertions and individual perceptions of health. She made repeated references to the idea of professional respect for patients' knowledge of their health, which added dimension to the grounded theory categories related to communication with professionals and, ultimately, responses to inadequacies of service provision. Taken as a whole, the bulk of Beata's narrative described her repeated, unsuccessful requests for further diagnostic investigation, which were summarily disregarded by a range of GP practice staff and hospital doctors dealing with her case. She reflected at length on the way in which health professionals failed to take her concerns seriously, and thus traced the development of her sense of internalised racism. Although she began her journey through health services with a degree of confidence and clear expectations of the way her treatment should proceed, she found her efforts at obtaining diagnosis repeatedly pushed back Despite her assertiveness in requesting additional medical input, she was powerless in addressing the inequalities and potential racism implicit in professionals’ responses to her situation. This, as she describes it, was a contributing factor in her descent into deep depression.

8.5 Health Narrative 4: Medical errors and an altered life

8.5.1 Context

Kristina is a Slovak Roma woman, who came to the UK to pursue employment prospects that had been largely closed off to her in her native Slovakia. Upon arrival, she found work as a cleaner in a hotel and enjoyed the independence that came with being consistently employed, but her life changed abruptly with the onset of chronic health problems. Suddenly unable to care for herself, she was entirely reliant on friends and family to carry out basic daily living tasks. Although she was single and her adult children had moved away, she maintained a close extended family network and lived next door to her parents. She approached RSG health advocacy services seeking assistance in filing a medical negligence lawsuit following a surgical error, and from this point on, I became heavily involved in her case. I helped her to track down evidence for her claim and meet with solicitors, and generally provided reassurance when she felt overcome by frustration at the lack of improvement in her health situation. She felt deeply wronged by the health professionals who had dealt with her case, and this sense of injustice guided her narrative as she described her protracted medical crisis and an elusive recovery.

8.5.2 A prolonged medical crisis and a changed life

Kristina’s narrative opened with an overview of the early stages of her illness, when she was working and began to experience severe abdominal pains. Finding painkillers to be ineffective in managing the pain, she sought medical attention, when it was then discovered that she had a cyst on her kidney:

> *Then after some period started pain worse, and worse. So I’m going to GP and cyst was growing. Then he send me to specialist to see, so was like 14-15 centimetre big, so was quite a lot, yeah. So this time I can’t bending; I can’t do proper, you know, my work, so I start with infected everything, so many times I be receiving urine infection, so I was on antibiotic and it was a lot of pain. So I have to stay home; I can’t go into my work. So this continue, continue, and some x-rays*

> *I have to done, always. So nearly every month, nearly twice, I have urine infection. It was very painful, so I can't walk and this. I got problem in the job, because I want to go back.*

In this early stage of the narrative, Kristina emphasised how her main goal was to continue her work, yet she ran up against barriers arising both from physical inability to perform required tasks and her manager's resistance to accepting sick notes provided by Kristina's GP.

Following her diagnosis, Kristina received a referral to hospital for the surgical removal of the cyst:

> *So one day I'm going to Whitechapel hospital – my GP referred me to do laparoscopic remove cyst from my kidney. These people tell me, 'this is just simple operation; this is simple cyst. We just do removing. Laparoscopic is nothing to worry.' So I went there and they do this operation.*

She highlighted the doctors' reassurances – the promises of the simplicity of the procedure and the limited potential for complication – and with this detail expressed her unconcerned frame of mind as she went in for the operation.

Upon waking up after the operation, Kristina was in extreme pain; she says it was of greater intensity than the pain experienced in giving birth to her three children. Yet despite her severe discomfort, she still considered that perhaps these were normal effects of the surgery she had undergone, and input from medical professionals only served to reinforce the conviction that her symptoms were no cause for concern:

> *So nurse coming all the time, give me painkillers and this, check my temperature. So I'm shouting, I'm screaming of pain, and people say everything is fine. Doctor coming and saying 'everything is okay, everything is fine, so tomorrow you can go home.' So next day they let me go home. I was on a lot of tablets – painkiller, antibiotic, and I feel very, very pain.*

Kristina juxtaposed the intensity of her pain – which caused her to shout and scream in discomfort – with the doctor's seeming nonchalance in assuring her that her recovery was progressing normally and that she could go home.

Elaborating on her condition upon discharge from the hospital, Kristina outlined her gradual process of understanding that a surgical error had occurred:

> *My belly was, after operation, like nine months pregnant. I can't breathe; I can't go in toilet properly, and I take these painkillers every two hours – supposed to be every six hours – I have to take often, often. I'm vomiting; I can't hold this pain. Then when I was sitting, and I have three*

> *holes in my belly (because there was laparoscopic done), start leaking hot water – proper hot, like you boil in a kettle – from these three holes, out on my pyjamas, on my bed. It was just running and running. I was screaming of pain, screaming. I take tablets; I'm changing; my mum put some towel on this – all the time just running.*

Despite the gravity of her symptoms, Kristina struggled to obtain a conclusive answer as to the precise nature of her condition. She went first to the GP, where she was prescribed antibiotics, yet these were ineffective in mitigating her symptoms. She then called a local hospital for advice and was informed that she should return to the hospital where the operation took place.

By this point in the narrative, Kristina's condition had deteriorated dramatically, and she contacted her friends in a panic, asking that they take her immediately to the hospital:

> *I can't drink even; I was thirsty; I can't drink. I was full-up with water. Full-up. My face was proper, like, yellow. . . So I call to my friends 'please take me to hospital because I'm dying.' So these people take me to hospital; I even don't know where I am, of pain, lot of pain . . . So they take me to the room, change me, and straight away take me to the room where is done operation, and put me on the table – I can't lie down on my bed because of lot of pain. So these people hold me from one side to other side, and five minutes wait, and put me like five centimetre down, again, five centimetre down. So I can't lie down because of lot of pain. They give me in the wing this strong medication – morphine – plus give me in the mouth, and it doesn't help, doesn't stop. So straightaway, can't wait, and put me to this big hole with drain to my kidney, and take nearly six litre water out. And I feel everything; I feel everything. These people – one man behind me doing like this: 'don't worry, darling, don't worry; just five minutes more, just five minutes.' I was crying, screaming.*

In this tense sequence of events, Kristina's vivid selection of detail – the jaundice in her face, the gradual lowering onto the hospital bed and the removal of six litres of water from her body – reflected her fear and uncertainty in the midst of medical crisis. Amid these descriptions of suffering, she also included the voice of professional reassurance in the background, telling her once again that she need not worry.

Kristina left the hospital with a drain in her kidney, which she needed to monitor for approximately a month and a half, after which a stent was inserted. She was careful to stipulate that, throughout her treatment, she was provided with no information about her distinct diagnosis or of her future prospects for recovery. It came as a surprise when she received an appointment letter from University College

London Hospital (a hospital she had never before visited) inviting her for a consultation with one of their senior members of staff. It was during this consultation that she was informed of the medical error underlying her symptoms:

> *And this man – this is old man, more than 60 years old – and he's professor. So when we sit down he told us open, and listen, he told me 'I'm looking your whole file. You know what these people done to you? These people by mistake cut your kidney, and these people don't know what he can do with you; he can't do nothing. He send you to us; we can fix this.'*

Kristina highlighted the new doctor's age and level of professional qualification to underline the gravity of a situation that would require a referral to a doctor of this calibre. Furthermore, by paraphrasing the professor's description of her condition, she emphaised the negligence of the hospital staff where the operation took place.

Kristina's disbelief in learning of the medical error quickly transformed into frustration:

> *I was shocked. I was shocked. And he say 'so, we have to make soon as is possible operation.' I say 'listen, I don't want to. If I don't want to, what happens?' 'You can die,' he told me, 'you have to.' I say 'okay, so this is my last operation. If I do this operation, I don't want to do any more; is enough.' So I told him, 'if this kidney is so sick and cutted and this, please take this kidney out. I have one more; I can live with this.' He told me, 'you're still young, so we can save this kidney.' I say, 'listen, if you open me, and if you see any reason, so you can't do, or something, something is worse, just don't wake up me again and do again [unintelligible]; just take out.' He said, 'okay.' So I signed everything.*

With this segment of dialogue, Kristina seemed to explore treatment options as an act of bargaining. She conveyed a loss of trust in medical professionals, yet when she learned that the damage to her kidney could be fatal if left untreated, she searched for a more conclusive solution to the problem – a solution that would require no further surgeries.

In expressing her preference for removal of the kidney over an operation to repair the damage, Kristina revealed her lack of confidence in efforts to restore her kidney's former function. She then moved on to express how this scepticism was validated:

> *So after two months, after operation, start growing my left side again. I'm going to Professor N [the professor referred to previously]; I'm going to hospitals; I'm going to my GP. All the time I'm show them, all the time after operation. I go twice a month minimum. Infection. I'm like I was*

> *before operation, on antibiotic, and now I feel worse. So, this is, I don't know what's going on. Everybody tell me everything is fine. My left side is growing, you see this properly – is growing, and swollen, worse and worse. My belly is like nine months pregnant – still. So I don't know what's going on.*

With this vivid description of the changes to her body, Kristina grounded her frustration with medical professionals in her inability to live her life as she previously had. She characterised her life post-surgery as a series of medical appointments, all providing inconclusive information about her condition and what to expect from the future.

Reflecting on the changes to her life resulting from the medical error, Kristina placed the blame squarely on the professionals who dealt with her case:

> *So these people spoil my life properly. I can't have normal life; I can't have friends; I can't have sex properly. How I can live this life now? How? I'm… my urine is leaking; I'm on the pads. Who can stay with me? How I can live now? On medication – if I don't take medication, I can't walk. If I don't take antibiotic, always in the urine infection. So how can I live like 3-4 years on the antibiotic only?*

Kristina intertwined her physical symptoms with their social impacts, creating a picture of a life put on hold by medical trauma. She selected hard-hitting details that seem reflective of the fact that she knew me not as a detached researcher, but as an advocate. By the point at which she told me her story, I had already helped her to make numerous complaints to health services and to find a solicitor to deal with her medical negligence claim. There is no detail included in this section of Kristina's narrative that she had not disclosed at a previous point in time, yet by repeating her concerns, she emphasised her search for answers and her perception that I may be able to help. She then moved on to detail a range of activities in which she could no longer partake as a result of her pain:

> *I can't go out like my friends go and enjoy life – going to cinema, going to pubs, sit down, talk, or somewhere walking out. I can't go because of lot of pain. I'm shamed when people ask me 'how are you? How you feel?' I'm shamed to explain them again, 'I feel a lot of pain.' So, tell me, how I can live?*

Elaborating on life limitations, Kristina presented her condition as a burden to others and as a source of questions that she feels she cannot answer. She then directed her final rhetorical question at me, the listener, asking that I consider the seeming impossibility of continuing with her life in its current form and drawing me in to her sense of despair.

Yet this expression of hopelessness gave way once again to indignation as Kristina considered her desire for compensation for her suffering:

> *So I want to, these people to pay for this, because they spoil my whole life for one crazy thing: he cut my kidney. And make me, I nearly die if I don't go after this first operation quickly to the hospital; I can die at home because is lot of fluid going to my tummy, and if I don't do this drainage I don't know how I can… if I'm alive today. Because my belly was like this [gestures outward] – hard, like stone. I can't breathe; I can't drink water. I can't – is hot water leaking from my body. So, somebody left just like this and want to kill me? No, I don't live like this.*

This summary of events again emphasised the doctor's negligence and conveyed Kristina's disbelief that she was sent home when the doctors were aware of the error.

As the narrative drew to a close, Kristina expressed her increasing frustration with the professor who had taken over her case, exploring indicators of professional dismissiveness:

> *I don't want to just see somebody – I go to central London – and for two seconds he see me; everything is fine. That's it? For what reason am I going there? Nothing. Even one day coming with me, you go mad. My friends take me with car – one and a half hour minimum when is no traffic; sometimes we going three hours. I swear, three hours in the car. Always clinic is late, always. One hour we wait because doctor is late. Take me for two minutes, I swear, two minutes, everything is fine. 'You just going for blood test and urine sample – that's it; you can go.' Nothing. If I don't make ten times CT scan, renal scan, nuclear scan – everything; everything is fine.*

She focused on the discrepancy between the amount of time she must allocate to attend an appointment in central London and the length of her appointments, implying service providers' lack of consideration for her personal circumstances.

She then tied these signs of the inefficiency of health services to disrespectful treatment she had received from professionals:

> *I'm asking: why is pain? 'I don't understand these things; you [University College Hospital professor] are doctor – explain what happened? Why is pain?' He say, 'you are fat.' I say, 'what?' I stand up and I'm going out. I'm going out; I don't want to any more go. I don't have words to speak to these people; I can start swearing. And these people tell me, 'we don't have*

> *appointments' or 'we don't receive'… I don't know, what can I do? It's enough. Enough. I'm just human. I don't know, what can I do?*

Already aggrieved by professionals' lack of transparency with regard to their errors, Kristina felt further anger and frustration when doctors criticised her weight instead of offering pain management strategies. As she closed her narrative, Kristina juxtaposed indignation against hopeless as she considered her future with a chronic illness.

8.5.3 Connections to grounded theory categories

Kristina's narrative cut across the grounded theory categories related to interactions with services and communications about health issues, providing insight into the degradation of confidence in services that follows mishandling of a medical crisis. She consistently expressed a sense of personally mediated racism, recalling her distinct interactions with health care providers as direct precursors of her changed life. She expanded on the category of cross-service communication, revealing how services may communicate with each other but deprive patients of access to these communications, thus creating situations in which patients only learn of vital diagnostic information at the point of crisis. She moreover expressed the feelings of anger that came with inadequate service provision, and her sense of powerlessness and helplessness as she was shuffled from one service to another. She was offered little clarity in either diagnosis or prospects for recovery. These issues of transparency in her engagement with services – ranging from professionals' initial failure to communicate the potential risks of laparoscopic surgery to their failure to disclose potentially fatal damage to her kidney – reveal the basic injustices behind her sense of anger, disbelief and desire for retribution.

8.6 Health Narrative 5: Interpreting errors and a sense of injustice

8.6.1 Context

Tomas and Eva are a Slovak Roma couple. Tomas works as a cleaner at a school, and Eva stays home and looks after their two children, one of whom is autistic and has extensive support needs. They sought assistance from the RSG health advocacy service after deterioration in Eva's health led her to make a claim for private insurance[10], which was refused on the grounds that she had failed to disclose a pre-existing mental health condition to the insurance company. Having never suffered from mental health problems, Eva was surprised to learn of this decision, and she thus requested a copy of her medical records from her GP to see whether they contained an indication of past mental distress. Eva's records stated that she had previously attempted suicide and been hospitalised in a psychiatric hospital in Poland, all of which was incorrect. Her records furthermore stated that her preferred language is Polish, although she is a Slovak speaker and understands only very basic Polish.

Upon reading this information, Eva remembered the appointment during which the incorrect information had been entered. A Polish interpreter had been present, and Eva struggled to communicate with the interpreter. She nonetheless decided to proceed with the appointment, as she did not want to wait another few weeks to be rebooked with an interpreter who spoke the correct language. She had shown the doctor scars on her wrists – the result of carpal tunnel surgery – and she believes that this triggered the assumption that she had made a suicide attempt. The source of the information about hospitalisation in Poland – a country where Eva had never lived – remains unclear. I first met Tomas and Eva when they came to RSG with a request for assistance in rectifying the error in Eva's medical records. I assisted them in writing multiple complaint letters, first to the GP practice and later to the Parliamentary and Health Services Ombudsman, all of which were met with refusals to amend the records. As Tomas and Eva told me their story, they talk to me as an advocate and ally in their case. What emerged was a scathing indictment of the credibility of health professionals and a picture of a health system that directly disadvantages patients from non-English-speaking communities.

8.6.2 The wide-reaching consequences of an interpreting error

The narrative opened with a description of the appointment during which incorrect information was entered into Eva's medical records:

> ***Tomas:*** *My wife was at the GP – the appointment – and the GP asked the translator if she was from another country and was using another language, and they make a big mistake because they translate to doctor, or something, that my wife was in the psychiatric clinic in Poland. We were never before living in Poland. Different country, different language.*

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[10] I did not enquire during advocacy sessions or interview as to Eva and Tomas's reasons for purchasing private life insurance.

Eva recalled how the GP noticed that she and the interpreter appeared to be speaking different languages, yet the appointment proceeded even in light of the increased likelihood of miscommunication and misdiagnosis. Not only does this raise questions from an ethical perspective, but it also takes on particular relevance later in the narrative, as GP practice staff would go on to contest the basic fact that an interpreter had been present at all.

Eva left the appointment with a prescription, which she believed to be for sleeping tablets, and she went directly to the pharmacy to collect the medication. As she spoke to the pharmacist, she was cautioned against taking the medication, as it had significant side effects and could be risky in light of the fact that Eva had recently given birth. It was only at this point that Eva suspected that the medication was not what she believed:

> ***Tomas:*** *She have small baby, you know. I was in the home. When she bring back the prescription on the reception, she said something is wrong, because I do not have psychical illness. And they take back the prescription.*
>
> ***Eva:*** *This prescription these ladies give me was for good sleeping, because, you know, I'm not sleeping, I have problems with sleeping. Only I'm asking for some small tablet, small, because I have baby.*

Realising that she had in fact been prescribed anti-depressants, Eva immediately returned to the GP practice to request that they cancel the prescription, and at this point it seemed that the issue was resolved.

The question of incorrect attribution of mental illness resurfaced multiple years later, when Tomas and Eva sought to make an insurance claim:

> ***Tomas:*** *After that, we left it, but few years ago, my wife have the health problems and she get disability. She was on the disability. But she had the contract with insurance company. When we make the claim, because she start in the highest group of the disability, we want to make a claim for the compensation from the insurance company, and the officer said we can't claim nothing because 'you give the wrong information to our systems. You didn't say that you are mental sick, you was in the hospital in Poland.'*

This set the stage for protracted conflict with the GP practice over the nature of information included in the medical records and how such inaccurate information was entered.

Upon seeking answers from the GP, Eva and Tomas received information that directly contradicted their understanding of reality:

> ***Tomas:*** *Then because we tell to doctor that this interpreter is not in our language, and doctor said [they] don't make mistake because your husband was your interpreter. Is not true because I was home with three or four months baby. Yeah, they said I was there. Yeah, I'm coming there, because my wife call me there and say how you can say I was there when I was in the home, and that time I doesn't speak English. Because it was short time in England.*

By explaining that he was at home with the baby at the time of the appointment, and moreover that he would have been unable to serve as an interpreter because he did not yet speak English (though he later attained a high degree of English proficiency), Tomas challenged the GP's claims that he was assisting with interpreting during the appointment.

The idea that authorities place greater trust in medical professionals' accounts than in patients' explanations recurred throughout the narrative, and Tomas proceeded to provide examples underlining this fact:

> ***Tomas:*** *There was a lot of people that make mistakes, but now, exactly, in the future, [unintelligible] to my wife, she is like mental sick person. She can't, for example, do the driving licence anymore because she is mental sick.*

Not only did Eva find her life chances limited by her alleged mental health problems, but the entire family also suffered from the effects of the incorrect medical records. In this vein, Eva and Tomas recounted an instance in which their son suffered from an attack of Bell's palsy, leading to the paralysis of half his face, yet they found themselves again unable to make an insurance claim:

> ***Tomas:*** *Bell's palsy: his face is fall down, and we lose the opportunity, the way to ask for the claim in the insurance company saying we don't pay money because you give the wrong information. But wrong information give the GP. We was many time asking that they took it out from the system because they are not our fault; we didn't do mistake. GP arranged the interpreter; GP put the information inside. We didn't do something wrong, but they don't want to talk with me and my wife.*

Expressing his sense of injustice, Tomas insisted that he and Eva had done nothing wrong, creating a sense that their futures were at the mercy of professionals who refused to engage in the search for a mutually acceptable solution.

He reinforced how the insurance company was unwilling to engage with them after they supposedly withheld key medical details:

> ***Tomas:*** *They don't want to talk. Now my wife can't take the new insurance for life insurance because she have the wrong information inside. The insurance company, everyone, I say, if you want to be insured you have to took out information because they are wrong. It is not true.*

As Tomas understood the situation, the only way to secure his family's future is to remove the incorrect information from the medical records. He also understood by this point, however, that he and Eva had become enmeshed in a complex web of bureaucratic restrictions, and that their accounts of the reality of the situation were unlikely to hold much weight.

After approximately two years of making repeated complaints to the GP practice, and ultimately contacting the Parliamentary and Health Services Ombudsman, Eva and Tomas were granted a meeting with the practice manager and one of the lead GPs to discuss her case. They entered into the meeting with the hope that the practice would agree to remove the incorrect information from Eva's records, and Eva envisioned this as a straightforward process:

> ***Eva:*** *Some doctor, this manager, not putting some information. One, he does not say, okay, this way, this way, and my way. I'm doctor, I'm manager, and I'm writing, 'she's not from Poland; I see her passport. She's from Slovakia. She gives me these documents, these documents.'*

Appealing to an idea of common sense, Eva reflected on how preposterous she finds the practice's misrepresentation of her nationality and language preferences. She imagined that the doctor and the practice manager would look at her passport, see the error in providing a Polish interpreter and amend the records accordingly.

As Tomas goes on to explain, the meeting did not proceed at they had hoped:

> ***Tomas:*** *The first feeling was surprise, because the professional doctor had some unprofessional behaviour. Second was there was a lot of people inside but he was again upset, very noisy; his voice go up. He don't give the truth and he don't give the opportunity to say, like, the opinion to my wife. She want to say something to him but she was very scared because his sound go up; he was very smashing with the hands. She was scared; she was sitting; she was quiet, and finally she signed this paper, which was putting in the system. But she knew because she was scared. And he was scared of my wife as well . . . because he said, 'if you want something, you go to*

> *court, but you need a lot of money.' What is mean, 'you need a lot of money'? She was under pressure.*

The GP appeared to use intimidation tactics during the meeting, raising his voice and pounding his fists to effectively silence Eva. Tomas repeated multiple times that Eva was 'scared' by the GP's behaviour and therefore had been pressured into agreeing to the GP's terms in making a superficial amendment to the record. Yet Tomas also expressed how he and Eva were able to reverse some of the power imbalance by threatening legal action against the practice. Although the GP attempted to dissuade them with a reminder of the substantial legal fees that such a process could incur, Tomas and Eva perceived this as yet another intimidation tactic and remained firm in their plan to pursue the issue further. Ultimately the GP practice agreed to amend Eva's records by including a copy of her initial complaint letter to the practice, yet Tomas and Eve remained aggrieved. Not only had they been unsuccessful in their efforts to prompt the removal of the incorrect information, but their meeting with the GP also solidified their suspicion that he was not looking after their best interests.

As she reflected on the conflict between the GP's priorities and their own, Eva described a further instance in which her GP's actions seemed at odds with her efforts to seek support in managing her health issues:

> ***Eva:*** *I have some claim for disability – this is not PIP; before this is Disability [Living Allowance]. And when I had before disability some question sent straight away to GP, and writing GP, you know – I have this home, copy – too many years. And here is some question about bathing… why is he not writing – never – about these tablets about mental health? This is my question.*

Despite the grave representation of mental health issues in her GP records, the GP's supporting letter for her application for disability benefits notably left out any reference to her alleged suicide attempts and psychiatric hospitalisation.

Tomas then added his perspective on the omission of mental health details from the GP's letter, positing that the GP wantonly misrepresented information for his own benefit:

> ***Tomas:*** *He is using this information if it is good for him. You know, if it is something good for another one… he manipulate with information.*
>
> ***Eva:*** *PIP is big one, you know, doctor, GP must be putting normal information. When he is inside, writing, why is he not putting same information? When is putting same information to insurance company?*

> ***Tomas:*** *He manipulate the information.*

After Tomas expressed his view that the GP was manipulating information, Eva expanded on this notion, suggesting that the doctor himself was aware of the inaccuracies in her medical records, and that he would not include these inaccuracies in official correspondence with a government agency. Although these ideas are speculation, they were vital in representing Tomas and Eva's loss of confidence in medical professionals and their perception that professionals' words – regardless of accuracy – have greater public legitimacy than theirs.

Tomas reiterated this idea of conflict between patient and practitioner accounts with a final reflection on the practical and emotional impacts of the error in medical records:

> ***Tomas:*** *Yeah, but this is not the way to give me two version: your version, my version. And anyone can choose which one is good. Same as like with this DLA, you know, they writing she's mental sick, then writing she's okay. He is manipulating the information how is good for him and how is good for medical centre. He is manipulator. My opinion is that he know he is doing a mistake, and if he said, yes, our medical centre make the mistake, we could ask for compensation because it has affect our insurance money; it has affected her life. . . because this is six years, and six years she always thinking about all the troubles. The doctors took six years of her life.*

As the narrative drew to a close, the sense of disillusionment ran strong, as Tomas reflected on the consuming impacts of medical records errors on his wife's life. Yet while this could be read as resignation to the existing state of social power structures, there is also an undertone of defiance, as Tomas reflected on the possibility of seeking compensation for the financial and emotional damages arising from professional error.

8.6.3 Connections to grounded theory categories

On the most fundamental level, Eva and Tomas's narrative explored the grounded theory concept of shortcomings of language support provision, highlighting an extreme case of the challenges that can arise from an inability to communicate effectively with health professionals. Perhaps more than any other narrative, Eva and Tomas's story revealed how participants' sense of personally mediated racism can develop. As they expanded on the far-reaching consequences of inadequate language support, their narrative emphasised manipulative and self-serving behaviour on the part of professionals. Their narrative adds depth to the concept of language support provision by establishing the connection between effective language support (or lack thereof) and sense of trust in professionals. They selected narrative details that first portrayed the GP practice's seemingly conscious refusal to provide an interpreter in their native language, and then explored the personal impacts of interpreting errors. As they ran up against faceless bureaucratic frameworks, which seemed to always be operating to their disadvantage, Tomas and Eva's narrative explored the concept of social distance between patients and professionals. This is perhaps most striking in their representation of the lead GP at their practice, in which Tomas's insistence that he is a 'manipulator' who only works for his own personal gain revealed how a lack of professional empathy can have lasting damage on patients' sense of trust in health services.

8.7 Narrative synthesis: Commonalities across narratives

Taking a holistic look at the narratives included in this chapter, it is illuminating to consider each participant's unique motivation in choosing to tell one particular story at a particular point in time. Some participants – like Malgorzata, Tomas and Eva – were enmeshed in addressing the challenges outlined in their narratives, and this likely served as a deciding factor in their decisions to tell these particular stories. For other participants, the events described in their narratives had occurred years previously, yet had lasting impacts on participants' physical and emotional wellbeing, trust in professionals and understanding of their position within UK health systems. In every case, the narrative development was tightly bound with expressions of a sense of injustice, as participants struggled to come to terms with injuries, medical errors and perceptions that professionals had failed to act in their best interests.

8.7.1 Characterising mental health issues

Mental health arose as a key concept in the majority of the narratives in this chapter, and narrative analysis revealed that disclosure of mental health issues often occurred at the end of narratives of trauma and distress, portrayed as a natural response to the emotional turmoil that participants had faced. In Beata's narrative of pregnancy, for example, she seemed to draw a direct cause-and-effect relationship between the events described in her narrative and the onset of mental health issues. She only disclosed her battle with depression in the final sentence in her narrative, summing up the long-term impacts of professionals apparent unconcern for her trauma. Malgorzata’s narrative of breaking her hand and Kristina’s narrative of medical error followed a similar structure, in which they alluded to mental health issues as a direct consequence of wider experiences of distress. Katarzyna’s narrative of cancer misdiagnosis represented a structural outlier – with her disclosure of mental health issues occurring at the opening of her narrative – yet she also presented her experience of emotional breakdown as a direct result of a distinct diagnosis. By establishing these linkages between mental health and their wider health and social circumstances, the frequently stigmatised topic of mental health appeared to take on a degree of social acceptability.

8.7.2 Perceptions of power imbalances and diminishing trust

Diminishing trust in health services also arose as a prominent recurring theme in narrative analysis, as participants described the power imbalances that constrained their efforts to access necessary support. Discussions of lost of trust in health care providers were woven through the narratives, becoming more pronounced as the stories drew to a close. In Katarzyna’s narrative of cancer misdiagnosis and Beata’s narrative of pregnancy, the loss of trust in health services took the form, broadly, of health professionals’ reluctance and inability to provide clarity on pressing health questions. Participants viewed the lack of open communication as a lack of transparency, and their accounts suggest that they, as members of a minority community, are forced into a barrier-ridden path through health services, with limited opportunity for recourse when their rights to equitable access are challenged. Kristina’s narrative of medical error and Tomas and Eva’s narrative of interpreting error took this degradation of trust a step further, as they considered legal action to gain compensation for their suffering. Participants’ accounts – with their descriptions of medical professionals alleged manipulation of personal data and lack of transparency in providing diagnostic information – suggested a deep awareness of the power imbalances that permeate their access to health services, and by expressing their impulse towards retribution, they sought to overturn the unequal power structures that characterised their engagement with health services.

8.8 Summary

By tracing the development of participants' narratives of health and engagement with services, this chapter provided insight into the processes that inform participants' understanding of their position within UK health systems. Each narrative outlined participants' perceptions of their relationship with health professionals, and furthermore offered a view of the social, cultural, political and ecological precursors of participants' health communication. Narrative analysis then allowed for elaboration on categories and concepts identified through grounded theory analysis, adding nuance and depth to the categories of mental health, communication with professionals, responses to inadequacies of service provision and social distance between patients and professionals. The narratives included in this chapter explored inequalities and power differentials that arose when Roma participants engaged with health services and attempted to exercise their will in making health decisions. In nearly every case, these efforts at rectifying power imbalances brought about opposition from service providers, whether in the form of direct refusal to address their concerns or more subtle dismissals of requests for additional diagnostic input. This, in turn, reflected what can be seen as endemic discrimination against migrant communities in health services, and a more specific antagonism against Roma.

Chapter 9: Discussion and conclusions

9.1. Purpose of the study

In light of European reports of the barriers faced by the Roma in accessing health services, this study sought to investigate these issues in a UK context. Set against a backdrop of destabilisation in Roma migrants' immigration status following the Brexit vote, this study looked at direct interactions between Roma individuals and health services, and also at impacts of broader social and political factors on Roma health. Roma cultural beliefs and communication methods clashed with rigid health system operating procedures, and all the while, more subtle forces of discrimination and inattention within public policy shaped the experiences of Roma populations in accessing health and benefits systems.

This study proceeded according to the following objectives:

- To assess whether and how language and communication barriers issues influence Roma community members' health service use and interactions with health professionals.
- To understand Roma community members' experiences of claiming disability benefits and the significance of social support to their conceptions of stability and security.
- To assess the health system structure outlined in the Health and Social Care Act of 2012 in light of the needs of Roma communities.
- To ascertain whether and how the institutional and bureaucratic structures of UK health and welfare institutions create power differentials between Roma community members and service representatives.
- To understand whether and how wider socio-political factors – including immigration, discrimination and racism – influence Roma community members' conceptualisations of their position within UK social institutions.

9.2 Synthesis

9.2.1 Summary

The results of grounded theory and policy analysis posited that four interconnected spheres of action and interaction shape Roma health experiences in the UK: 1) a foundational policy climate, 2) intra-community communication within Roma groups, 3) engagement with health services and 4) contact with a wider public service environment. These interacting factors embodied power differentials, which in turn defined the ways in which Roma individuals conceptualised their health and their position within UK institutions. Roma individuals could become either empowered or disempowered as they interact across these different societal spheres, as language barriers (and acquisition), development of systemic knowledge, attitudes of agencies and providers and impacts of past discrimination either inhibit or facilitate their abilities to gain access to their desired services and support. Overlaying these analytical frameworks with participants' personal narratives, the narrative analysis component of this study then explored how Roma individuals constructed narratives of injustice in describing their interactions with health and benefits systems.

9.2.2 Policy analysis

Chapter 5's analysis of national health policy frameworks and local health needs assessments revealed a policy climate that effectively disregards the specific experiences of Roma migrants. Although Roma migrants do receive a degree of attention in the National Inclusion Health Board's publications, these documents put forth a representation of Roma as a 'vulnerable' group, which could erase the complexities of discrimination and unconscious bias faced by Roma across a range of social and socioeconomic positions. Classification as 'vulnerable' is particularly unhelpful, for example, in the case of participants profiled in Chapter 8. These participants spoke English, navigated health services independently and indeed were active in seeking out their desired treatment options. Yet their experiences within health care environments revealed gradual loss of trust in services' ability to meet their needs, leading to constructions of service providers as opponents in their efforts to enhance their personal wellbeing. By reducing these complex experiences to a simple designation of patients' 'vulnerability', the frameworks outlined by the National Inclusion Health Board do not address the pressing issue of unconscious bias against Roma patients, regardless of the extent to which they exhibit typical markers of vulnerability.

Inattention to the distinctive profile of Roma became increasingly apparent in the review of JSNAs, which largely failed to distinguish Roma from Gypsies and Travellers, and thus neglected key health determinants related to language, migration experiences and discrimination in their countries of origin. There was furthermore no apparent correlation between Gypsy/Roma populations (as reported in school census data) and inclusion of GRT in health needs assessments. As the Health and Social Care Act makes no specific provision for ensuring policy attention to specific groups – even when those groups face disproportionate health inequalities – Roma appeared to gain inclusion in JSNAs through research reports or activity of community groups. Because Roma often lack a voice in advocating for attention to their needs, the health situation of the Roma seemed to fall largely outside policy makers' notice. Notably, JSNAs for each of my research sites displayed irregular attention to the needs of Roma, including them in one round of assessment and then omitting them in the next. I argue that this irregularity stems from the lack of a framework for ensuring that all population groups receive equal attention under local commissioning decisions, and propose that greater accountability of local authority areas to both national monitoring bodies and local community groups would result in the development of better strategies for promoting equal access to services. In the current climate, however, service-level recognition of Roma needs is variable, laying the foundation for subsequent results chapters' discussions of Roma experiences as they interacted with health services.

Grounded theory analysis shed light on the lack of targeted services for Roma migrant communities (Romanes interpreting and health mediation programmes, for instance), emphasising the concrete impact of this seeming oversight on participants' perceptions and use of services. Although Roma received incremental attention through the CCG-sponsored GP training programme in Newham, it must also be noted that the programme was a short-term project with no potential for renewal. Such programmes appear to be effective in raising providers' awareness of Roma patients' needs (Roma Support Group, 2017b), the lack of inclusion of Roma in Newham's JSNA suggests that similar programmes are unlikely to be prioritised for future funding.

9.2.3 Grounded theory analysis

Against the background of policy inattention to Roma health needs, Chapter 6 presented the results of grounded theory analysis, exploring the three key thematic areas of 1) dimensions of the UK social environment as it impacts on Roma participants; 2) patterns of health-related communication and understanding in Roma communities; and 3) challenges of direct engagement between Roma patients and health care institutions. The idea of social distance between Roma participants and service providers was pronounced throughout these thematic areas, ultimately revealing the overarching theme of Roma individuals' social powerlessness in their interactions with UK public service systems.

This section opened with a brief discussion of immigration insecurity, exploring the issue of refused benefits applications on the basis of a purported lack of right to reside. In the ensuing discussion of claims for disability benefits, I explored how participants grappled with complex claim forms and documentation requirements, lack of transparency in the process for assessing applications for social support and rejections of applications without adequate statement of reason. As participants struggled to access benefits systems and communicate with assessors, their accounts revealed a combination of internalised racism (manifested in the lack of confidence in their ability to successfully make benefits claims) and personally mediated racism (manifested in perceptions of assessors' direct hostility). Inability to access benefits systems served as a destabilising factor for many Roma participants, minimising their social power and their future abilities to exercise their rights.

After addressing these broader dimensions of Roma participants' experiences, I focused on the topic of health, looking first at how Roma participants shared health information and developed their understanding of health issues. Here the social environment came into focus, bringing accompanying connotations of institutional racism as participants revealed the lack of alignment between health service operating procedures and Roma cultural modes of health communication. Mental health occupied a key place in this discussion, offering a case study in Roma participants' public communication about a traditionally stigmatised issue and their decision-making processes in seeking out mental health support. These issues with health communication tie in to wider discussions of cultural competence of health professionals, suggesting a need to commission specific cultural awareness training programmes or to create Roma health mediator positions within services.

Moving on from this discussion of health perceptions and communication, I provided an overview of the dynamics that arose when Roma participants made contact with health services. This centred on the impacts of language and interpreting service provision, difficulties of navigating service frameworks and perceptions of the shortcomings of service provision, all of which reflected participants' perceptions of professional dismissiveness and service inefficiency. While there were some instances in which participants highlighted positive experiences of engaging with health professionals, they more often described engagement with health services as a source of degradation and disempowerment. This discussion suggested an underlying issue of institutional racism manifested in the lack of attention to Roma-specific needs within JSNAs and commissioning decisions. Without provision of support in health services that reflects Roma patients cultural and language profiles, participants' account suggested development of internalised racism as they found their communicative confidence and self efficacy in seeking health information impeded by service-level unawareness of the distinctive needs of Roma patients.

Grounded theory analysis offered insight into the multi-dimensional issues faced by Roma participants in their access to health services and, more broadly, in their efforts to inject a sense of security and stability into their lives in the UK. Over the course of analysing interview transcripts, I identified storytelling as a significant means by which Roma participants' conveyed health information, yet grounded theory analysis did not serve as an effective approach to meaningfully presenting individual narratives. With this in mind, I undertook narrative re-analysis of a select set of interviews focusing on experience of health and welfare, using grounded theory categories as a guide for identifying key concepts in participants' stories.

9.2.4 Narrative analysis

Chapter 7 elaborated on the first thematic area identified through grounded theory analysis – namely the immigration and benefits dimensions of Roma migrants' experiences in the UK. Opening with a discussion of the impacts of a changing environment for EU migrants in the wake of the Brexit referendum, the first segment of the chapter did not lay out any distinct participant's narrative, but rather traced the narrative of my time in the field. I assessed participants' responses as the government gradually released information related to EU migrants' future settlement rights, and Roma feared that their educational disadvantage and precarious work situations would prevent them from maintaining residence in the UK. Following on from this discussion of fear and uncertainty, I explored a further dimension of participants' insecurity with four narratives outlining applications for disability benefits. These narratives explored concepts related to assessors' failure to account for vital medical information[11]; lack of provision for language and communication support[12]; misleading information presumptive responses to assessment questions and lack of transparency from DWP representatives[13]; and mental health as a motivator for claiming benefits[14]. Participants' collective accounts produced an image of the disability benefits assessment as a system aimed at summarily denying their needs, which came particularly to the fore in light of their status as members of a disadvantaged migrant community.

Building on this foundation of mistrust towards UK bureaucratic systems, Chapter 8 presented five participants' narrative of health and engagement with health professionals. These expanded on the concepts of professional negligence and diminishing trust in services[15]; frustrated efforts to receive person-centred care and reliance on individual will to manage health conditions[16]; and the life-limiting impacts of serious illness, degradation of perceived social standing and mental health[17]. Participants drew repeatedly on the concept of self-sufficiency, conceivably as a response to their perceptions that health services have failed to address their needs. This was apparent when Katarzyna resolved to always seek out second and third opinions after receiving a diagnosis, when Beata delivered a stillborn foetus in the bathroom by herself, and when Kristina, Eva and Tomas decided to take legal action against their GP. Underlying these signs of resolve were frequent references to severe mental distress – sometimes explicitly stated as a diagnosis of mental illness and at other times implicit in allusions to the overwhelming burden of ill health. Every participant had experienced some form of trauma, and they framed their distress in terms of immediate and pressing life concerns, enabling them to explain their emotional responses not only to themselves but also to their wider community.

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[11] Elzbieta, Paulina, Maria, Katarzyna
[12] Elzbieta, Maria, Katarzyna
[13] Elzbieta, Paulina, Maria, Katarzyna
[14] Elzbieta, Maria, Katarzyna
[15] Katarzyna, Beata, Kristina, Eva and Tomas
[16] Beata, Kristina, Eva and Tomas
[17] Katarzyna, Malgorzata, Kristina

9.2.5 Theoretical and methodological reflections

Running through the grounded theory concepts of communication, social interaction and official decision-making is the concept of power differentials and the idea that institutional rules, regulations and negligence places Roma participants in a position of disadvantage relative to health and public services. While grounded theory analysis alerted me to these issues, narrative re-analysis added depth to my critical perspective, revealing the power of stories to 'serve as correctives or even frontal attacks on the world-view circulated by those in power' (Price, 2010, p. 158). When investigating participants' narratives of benefits systems, the present analysis echoed Humphris's (2017) finding that Roma migrants' sense of uncertainty in UK benefits systems could call to mind past experiences of racism, thus perpetuating an understanding of oppositional relationships with public service providers.

Incorporating discussion of health perceptions and access to services, the analysis went on to reflect Janevic et al.'s (2011) categorisation of personally mediated, internalised and institutional racism. Particularly in the implications of mental distress apparent across many participants' narratives, this could also suggest a degree of intergenerational trauma (Sangalang & Yang, 2017; Lehrner & Yehuda, 2018) and an internalised expectation that of discriminatory treatment from professionals (Janevic et al., 2011; Aiello et al., 2018). Roma participants in this study began their interactions with services from a position of relative powerlessness, and their personal narratives emphasised how their attempts to obtain meaningful information from service providers went unanswered. This is also the case in efforts to obtain benefits, as rigid institutional restrictions on eligibility and complex pathways to completing applications effectively excluded participants from obtaining the support they required. Participants were overwhelmingly and unabashedly critical in their characterisations of health and benefits systems, underlining their sense of grievance with vivid – and sometimes harrowing – descriptions of inadequate professional support and lack of transparency in disclosing prognoses and medical errors. Approaching this data from a critical race theory perspective revealed a conflict between the dominant group's assertions of blamelessness and the racialised ethnic minority's efforts to dial back professionals' perpetuation of hierarchies that silence Roma patients' voices within health services.

9.2.6 Comparisons to other studies

UK-specific studies of the health situation of migrant Roma tend to present Roma health experiences either as case studies in more general narratives of migrants' access to health services, or as a component of broader enquiry into the social position of Roma in the UK. While there is a fairly substantial body of European research addressing the health of Roma populations – some of which reflects my findings related to discrimination in health services – it largely does not focus on migrant Roma communities (Cook et al., 2013; Cretan & Turnock, 2008; European Commission, 2014; Fesus et al, 2012; Foldes & Covaci, 2012; Hajioff & McKee, 2000; Idzerda et al., 2011; Janevic et al., 2012; Jarcuska et al., 2013; Kolarcik et al., 2009; Kosa & Adany, 2007; Koupilova et al., 2001; Masseria et al., 2010; Ringold, 2000; Roman et al., 2013; Zeman et al., 2003). Similarly, research on Gypsy and Traveller health in the UK addresses cultural conceptions of health, discriminatory treatment within health services and the impacts of material deprivation on health status. With their focus on indigenous Gypsy or Traveller groups, however, these studies do not offer insight into language and communication barriers, the challenges of understanding foreign institutions or the insecurities in status arising from the UK's hostility to migrant communities.

UK-specific studies specifically analysing the health of Roma migrant communities include a series of health needs assessments for Slovak Roma in Sheffield, the evaluation of the Roma Support Group's Mental Health Advocacy Project and an analysis of Roma health in Leeds (Gill, 2009; Moore, 2010; Ratcliffe, 2011; Roma Support Group, 2012; Willis, 2016; Warwick-Booth et al., 2017). The Sheffield needs assessments offered in-depth analyses of Roma community members' health status and experiences of services, though incorporated less attention to the broader social determinants of health. The RSG mental health project evaluation honed in on the specific area of mental health, yet did not offer an in-depth look at the social context in which mental health issues occur. Warwick-Booth et al. (2017) investigated barriers to health care from the perspective of Roma communities – looking also to the social determinants of health – yet did not incorporate in-depth interviews with Roma community members and thus did not capture the holistic look at individual perceptions that this study sought to achieve. In the context of benefits, there is a small body of work exploring the instability and uncertainty of Roma migrants' access to UK benefits systems (Dagilyte & Greenfields, 2014; Dagilyte & Greenfields, 2015; Humphris, 2017), yet these do not make specific reference to Roma individuals' experiences of claiming disability benefits.

Other studies focusing on migrant Roma in the UK offer only brief descriptive overviews of Roma health issues but do not look specifically at questions of health status, perceptions and accessibility of services (Brown, Scullion & Martin, 2013; Brown et al., 2017; Craig, 2011; European Dialogue, 2009). Employing survey, focus group and policy analysis methodologies, these studies make reference to health-related issues and concerns – such as difficulties of accessing services due to language barriers, perceptions of low standards in UK health services and a preference to travel back to their countries of origin to use health services – and present these in the context of wider Roma experiences in the UK. These studies do not, however, interrogate Roma individuals' perceptions of these limitations on access or explore the dynamics of intra-community health communication that shape decisions to access support.

There is also a small body of UK-specific research that includes Roma health as a component of broader enquiries into the health needs of other migrant and disadvantaged groups. Like my study, these research projects employed partnerships with Roma community organisations as a means for making contact with Roma participants, yet their overall aims and presentation of data differ significant from my research. The 2010 Pacesetters Programme – which involved partnership working between the Department of Health, the NHS and local community groups – sought to improve access to services for GRT groups experiencing disproportionate health inequalities. While a core component of this project involved implementation of interventions aimed at improving access to health services for Roma patients, the broader focus was on Gypsies and Travellers. The programme's evaluation report discussed low levels of awareness of available health services, low levels of provider awareness of Roma health needs, cultural barriers to open discussion of health issues and importance of trust in increasing engagement with health services (Van Cleemput et al., 2010). Although my findings also echoed these general trends, yet Pacesetters report emphasised greater all-out restrictions on service accessibility than was revealed through the results of my study.

A further study conducted in conjunction with NHS Barking and Dagenham focused on Polish, Lithuanian and Albanian migrant communities in East London and included a section on Roma to gain additional insight into the disproportionate health inequalities affecting disadvantaged migrant groups. The resulting data on Roma health highlighted issues with interpreting service provision in health services, lack of accessible health information and past experiences of discrimination as a contributor to mental health issues (Tobi, Sheridan & Lais, 2010). My findings also reflect these themes, yet the overall presentation of my study differs fundamentally in the sense that the Barking and Dagenham research presents Roma health experiences as part of an amalgamation of broader Eastern European migrants' impressions of UK health services, looking to common themes in issues of access yet not focusing on the historical and social position of the Roma.

9.3 Strengths and limitations

9.3.1 Community-based data collection

Employing community partnerships as my central data collection strategy was integral to facilitating access to subject groups and building trust with individuals who may approach research projects with a degree of hesitation and mistrust. While this is not the first study to build on engagement with Roma community organisations to recruit potential research participants, it was novel in its incorporation of health advocacy work. This allowed me to demonstrate a personal commitment to participants' areas of concern, thereby reinforcing to participants that my research was driven not by an inflexible agenda or a set of pre-conceived notions about Roma experiences. Most interviews were preceded by health advocacy sessions, which enabled me to gain a preliminary understanding of participants' health concerns and life circumstances before engaging them formally in interview. Perhaps even more critically, I directly assisted participants in accessing health services, fostering tangible associations between my research and reductions in barriers to care. Not only was I present in the field, but participants also came to view my presence as useful.

In addition to facilitating contact with Roma participants, my health advocacy activities had the unanticipated effect of expanding my knowledge of the ways in which health systems operate. Requesting interpreters for GP appointments, for example, alerted me to the stark discrepancies in interpreter provision in primary care settings, with some GP surgeries readily providing interpreters and others refusing outright. Such activities enabled me to view health services from Roma patients' perspectives, providing me with direct insight into the frustrations and limitations of access stemming from inability to communicate with health care providers. It was also through my involvement with community organisations that I was able to make contact with local health service commissioners and managers, which afforded insight into the mechanisms by which health services and commissioners become aware of Roma needs and develop strategies to meet these needs. Access to meetings with health service decision makers became possible through my depth of involvement with partner organisations, and in these meetings I was well-placed to provide perspectives on health services delivery to Roma patients on the basis of my preliminary research findings. In this sense, my fieldwork activities not only allowed me to discern the conditions of health services' thinking about Roma health in a challenging funding environment, but also afforded me opportunities to directly affect the ways in which service development reflected the needs and concerns of Roma patients.

As I had not had contact with Roma communities prior to undertaking this research, my fieldwork strategy necessitated that I access pre-existing networks of community engagement and advocacy service provision. Furthermore, fieldwork physically occurred within the relatively narrow frame of Roma community centres. Although this approach to data collection proved effective, it nonetheless raised questions of how the depth of my involvement with community organisations influenced my results and how results might have differed if data had been gathered in different settings. I was only able to meet participants who accessed the services of each of my partner organisations, yet it remains unclear whether these individuals' experiences are representative of the broader experiences of Roma populations in their respective areas. It is very possible that there are more disadvantaged segments of local Roma populations that remain unaware of the support mechanisms available to them. Conversely, there likely are segments of the Roma population that do not require the services of community organisations and have attained a degree of knowledge of UK institutions that my findings do not capture.

My two partner organisations had widely different profiles and operating procedures, and this resulted in differing capacities to oversee my health advocacy volunteer work, to facilitate interviews and to provide interpreting support. The Roma Support Group had a long history of collaborating with researchers and a set of pre-determined frameworks for supporting researchers' involvement in the organisation. As such, I had a clear understanding of organisational expectations of my dual roles as a volunteer and researcher, as well as how my involvement with the organisation would develop over time. The Luton Roma Trust, however, was in the early stages of operating as a registered charity when we began our partnership, and in many ways I was individually responsible for determining the structure of my volunteer work. This was valuable in affording me flexibility in my activities and allowed me to engage in a wider range of organisational activities than was possible at the Roma Support Group, yet I also found that members of Roma communities in Luton had limited prior experience with formal research projects as compared with Roma communities in London. Where participants in London readily understood what I meant when I said that I was doing a research project at a university, participants in Luton tended to express a degree of confusion upon initially hearing about my study, which in some cases manifested itself in reluctance to engage in an interview.

The Luton Roma Trust furthermore had only two part-time members of staff (as opposed to the Roma Support Group's ten), which not only affected the times when I was able to volunteer, but also limited the capacity to provide language support during my interviews. These differences in organisational capacity resulted in a weighting of my results toward the experiences of Polish and Slovak Roma communities in London. Thus, although I had initially intended to engage in comparative analysis of data from each research site, the organisational structure of Luton Roma Trust offered lesser potential for immersion in the field. Instead of serving its intended purpose of facilitating comparative analysis, adding the second site in Luton served to validate and offer new perspectives on concepts that were emerging through my more intensive fieldwork in London. While increased time in the field would likely have allowed greater engagement with the Roma in Luton, I was bound by time restrictions stemming from requirements of my PhD programme. By the time I entered the third year of my research, I would have ideally continued to recruit for interviews in Luton, yet I ultimately deemed my time to be more effectively spent if I shifted my focus towards analysis of my data and writing up of my results.

9.3.2 Consideration of participatory approaches

Even with careful attention to the need to represent community voices in my research, I recognised that I occupy a socially advantaged position compared with most participants in my study, and that taking the lead in analysis of their experiences has the potential to perpetuate patterns of social domination (Durose et al., 2016; Ryder, 2015; Ladson-Billings & Donnor, 1994; Young, 1990). I furthermore remained conscious of the contention that many – though not all – academic texts on the Roma were produced not by Roma, but rather by external researchers with varying levels of community involvement and varying agendas in conducting their research (Ryder, 2015). Historically, this has produced a preponderance not only of 'hierarchical research approaches but also forms of scientific, racial and cultural racism' (Ryder, 2015, p. 8). Yet even when research takes a more neutral, scientific approach to analysis, Roma individuals still find that non-Roma researchers' interpretations of data fail to take Roma frames of reference into account (Ryder, 2015). With this comes the potential for researchers to propagate stereotypes and stock narratives of disadvantage, which are unrepresentative of the range of different life situations in the community, and moreover produces limited tangible outcomes for members of Roma communities themselves (Ryder, 2015; Ladson-Billings & Donner, 1994).

In light of these challenges of representation, research with Roma communities has increasingly adopted methods of 'co-production', in which research aims and methodologies are agreed upon with community members, and data is jointly analysed by communities and researchers (Durose et al., 2016; Ryder, 2015; Ladson-Billings & Donnor, 1994). Especially in research involving marginalised groups, the relationship between researchers and community members is effectively equalised, with community members removed from the traditional role of informant and instead taking on the roles of 'commissioners' and 'mandaters' (Durose et al., 2016, p. 9). Roma involved in co-production of research can offer interpretations of data that counteract some of the stereotypical representations arising from more hegemonic research methodologies, and can furthermore strengthen attention to the real and concrete concerns of Roma communities within policy development frameworks (Ryder, 2015). While co-produced research can be criticised for veering too closely towards activism – and thus failing to provide impartial portrayals of research subjects – critical methods of co-production have inbuilt checks on this potential for departure from objectivity, incorporating intersectional perspectives to capture 'not only external and structural forms of exclusion centred on gender, race, socio-economic and institutional factors but also forms of oppression which exist internally within Roma communities (Ryder, 2015, p. 16).

The central tenets of participatory research and co-production informed the early development of my fieldwork engagement strategy, which proceeded with a commitment to long-term and impactful involvement with grassroots Roma organisations. In practical terms, however, undertaking a fully participatory approach was unfeasible in the context of my study. Limitations on time and resources made it impractical to train participants in research methods, and language barriers also presented a substantial impediment to meaningfully involving participants in data analysis. I was furthermore working on an extremely limited budget and would have been unable to offer Roma co-researchers compensation for their time. My involvement with Roma community centres did, however, provide me with repeated and consistent contact with study participants, through which I could discuss concepts that were arising over the course of analysis and thus increase the representation of Roma perspectives in my results. As I am not a Roma community member, asking participants for informal feedback on my findings offered perspectives on my results that I may not have otherwise considered and ensured that my representations of community members' experiences remained sensitive to their personal understandings of these events.

9.3.3 Addressing language barriers

I did not share a first language with my Roma participants, and this constituted a significant challenge in recruiting participants for my study and conducting interviews. As Tremlett (2009b) noted in her discussion of language acquisition during her fieldwork with Hungarian Roma communities, conducting research in settings where English was not the primary language could limit what I was able to claim that I 'know' about the field. I was not privy to the content of many informal discussions that took place around me, and this mean that my impressions of Roma participants' views and experiences were largely limited to more formal interviews. Furthermore, I was unable to access participants language use and vocabulary, which prevented me from validating claims from the literature highlight Roma individuals' limited vocabulary related to health conditions and parts of the body.

When conducting interviews, I was in some cases able to speak English with participants; in other cases, I depended on bilingual staff members of my partner organisations to assist me in conducting interviews and explaining the nature of my study. I was fortunate that they volunteered their interpreting services free of charge (as I did not have the funds to employ professional interpreters), yet their prior relationships with participants may have influenced the nature of the data I was able to collect. In some cases, the presence of a familiar and trusted advocacy worker seemed to enhance participants' confidence in engaging in interviews. In other cases, however, participants' communicative openness may have been limited by the presence of community centre staff. Even when I explicitly stated that my interview questions focused on interactions with health professionals and experiences of using services (and not on the details of health conditions) some participants were reluctant to discuss these issues in the presence of a third party, particularly given that the interpreter was someone previously known to them and with whom they were likely to have future contact.

Some participants expressed a preference to proceed with their interviews without the involvement of an interpreter, and as a result, a significant proportion of my interviews than expected were conducted in English. I was furthermore conscious when asking community centre staff to assist me with interpreting that I was taking time out of their working days, and this provided a further reason for conducting interviews in English when possible. Interviews only proceeded in English after I confirmed that participants were sufficiently confident in their language skills to answer my interview questions, and participants were always made aware that they could stop the interview if they found that they were unable to develop responses. While acknowledging that conducting interviews in English likely limited the representativeness of my sample, it also allowed for direct communication between participants and myself, helping to ensure that the content of my interview questions was not lost in translation. Many of these interviews yielded rich data (perhaps because there was no interpreter present, and they could thus proceed as open conversations), yet I nonetheless understood that participants were not speaking their native language and that this somewhat impeded their capacity to express themselves.

9.3.4 Hybridising methodological approaches

This study is methodologically novel, and is the first to present Roma migrants' narratives of health experiences and disability benefits in a UK context. By building my approach to narrative inquiry from a foundation of grounded theory analysis, I was able to direct my analysis of distinct narratives towards topic areas that were shared across my participant group. I had, for example, identified mental health as a key concept through grounded theory analysis, yet it was only upon looking at participants' complete narratives that I understood the development of personal conceptions of mental health, participants' understanding of life circumstances as a key precursor for mental distress and the role of family and community in shaping mental health. By taking a holistic view of individual narratives, I was able to demonstrate the significance of events and perceptions in the context of participants' lives. Moreover, participants' narratives expanded on their interactions with health services, and by tracing individuals' accounts, I captured the sense of injustice running through the narratives. This arose as a vital theme of my study, revealing the discrimination, racism, disregard and disrespect that characterises Roma community members' disadvantage in the realm of public services.

In addition to analysis of participants' narratives, I also harnessed narrative analytical techniques to explore my own personal narrative journey as a researcher in a field that was subjected to substantial political changes. By taking a holistic look at the story I told through my fieldnotes, I developed perspectives on the ways in which the Brexit referendum fundamentally altered the environments in which I conducted my fieldwork. Immigration did not arise as a fundamental concern through grounded theory analysis, yet as I looked holistically at my own narrative of the field, immigration and wellbeing seemed to no longer occupy distinct spheres. I became increasingly involved in advocacy activities aimed at ensuring that Roma migrants receive fair treatment once the UK leaves the EU. As I worked to publicise case studies alerting public officials to the challenges that Roma will face in securing their post-Brexit immigration status and assisted with organising focus groups to inform community members of pathways to maintaining legal residence in the UK, I became increasingly attuned to the fears the permeated the Roma community.

While I found narrative re-analysis to be invaluable in reframing my perceptions of participants' experiences and my understanding of the field, it is worth noting that I did not initially set out to conduct a narrative study, and interviews therefore did not have a uniformly narrative character. Narratives arose spontaneously over the course of interview, but as I was not intentionally stimulating participants to tell their personal stories (especially in the early stages of fieldwork) I was somewhat limited in the accounts that I could select for analysis according to a narrative framework. My interviews did not uniformly take the form of narrative accounts, and it would have been ineffectual to apply narrative analytical techniques to interviews that followed a semi-structured model. While it could be argued that my three-pronged analytical approach (encompassing policy, grounded theory and narrative analysis) undermined the consistency of my results, I maintain that it allowed me to represent facets of the social environment that would have been obscured had I adhered to a single analytical framework.

9.3.5 Recruitment of health professionals

Recruiting health professionals for interview was far more difficult than originally expected, and ultimately I was unable to engage any primary care providers in my research. Despite repeated emails and phone calls to practice managers at GP surgeries where participants were registered, my efforts at making contact went largely unacknowledged. Only one GP expressed initial passing interest in participating in my study, yet he did not respond to any of my attempts to follow up. The professional perspectives represented in my study include those from psychologists, interpreters, equality and diversity managers and patient participation leads, and while they offered valuable insight into the functioning of health systems and efforts to promote equality in treatment, the majority of professionals interviewed had very limited contact with Roma patients. They were thus unable to offer impressions of the distinct experiences of health professionals working with Roma patients, which could have provided deeper insight into the service provision concerns raised by Roma interviewees.

9.4 Reflections and learning

Much of the first year of my study was spent grappling with terms commonly applied to the Roma – exclusion, inclusion, integration, mainstream, etc. – and gradually coming to understand that my early impressions of their meanings captured none of the nuance and complexity implicit in these broad characterisations of social interactions and processes. In those early days, applying the term ‘mainstream’, for instance, seemed to provide an apt and convenient means of comparison between the Roma and other groups. Yet upon deeper interrogation of the significance of the term, it became readily apparent how relative the concept of the ‘mainstream’ actually is, and how its use reflected an inadvertently hegemonic assumption of the normality of my own culture and experiences in comparison to the foreignness of those of the Roma. It was only through this process of questioning my early assumptions that I was able to begin to develop a rudimentary conception of Roma identity. As my observations from the field came to supplement my reading about the Roma, my understanding of this group and its position within wider social contexts took on new and sometimes unexpected dimensions. Ideas of social exclusion and its accompanying disadvantages were replaced by observations of the richness of networks of support within Roma communities and the resolve that individuals demonstrated in combatting external hostility. I cannot claim to understand the full complexity of Roma identity and the dynamics of interactions between the Roma and external institutions, yet the process of questioning the assumptions with which I approached this project was invaluable in developing a stronger foundation on which to explore my subsequent impressions.

As I entered the field, I gave substantial consideration to questions of reflexivity and the ways in which elements of my personal identity influenced the type and quality of data I was able to collect. As a general rule, women were much more willing to participate in interviews than men, and their responses to interview questions tended to be significantly more detailed. It is notable that the vast majority of personal narratives I gathered were from women, as they likely felt more comfortable disclosing intimate details of their personal lives to a woman. Men were substantially more reticent in their discussions of health, and tended to focus on superficial difficulties of obtaining language support and receiving appointments in a timely manner. I suspect that this was connected to my status as a young woman. In once case, for example, an older male interviewee made vague reference to a negative experience in undergoing cancer treatment, yet when I asked if he could expand on this topic he explained that he feared his answer would offend me and declined to provide any further information. In addition to the gender dimensions of reflexivity, I also came to see my position as a community advocate as a key determinant of the details that participants included in their interviews. Many were unreservedly critical of health and benefits systems, and I posit that they were comfortable in exposing these criticisms because they saw me to be, essentially, an ally in their conflicts with services.

Also fundamental to the development of my perceptions of the field was my analysis of health policies and service provision strategies. This analysis occurred concurrently with fieldwork, and thus, as I was investigating participants' direct and practical difficulties of accessing health services, I was also analysing strategies aimed at improving equality of access for disadvantaged groups. One of the fundamental findings of my policy analysis was that migrant Roma are dramatically underrepresented in local health needs assessments, and this lack of awareness amongst service providers was borne out in my fieldwork. When I enquired with a local interpreting service provider, for instance, about the availability of Romanes-speaking interpreters, I was met with basic questions of who the Roma are and why they require specialised language support provision. At the time of fieldwork, Roma were included in the needs assessments for both of my research sites (though information about Roma was omitted in subsequent JSNA updates), yet the state of provider awareness did not reflect the status of Roma as a target group in health promotion strategy. As I considered the shortcomings in aligning health (and benefits) service provision with Roma community needs, I gradually developed a set of recommendations for research, policy and practice aimed at ensuring more meaningful official attention to situation of Roma migrant communities in the UK.

9.5 Recommendations for research, policy and practice

Table 4: Recommendations for research, policy and practice

Area	**Recommendation**	**Implementation measures**
Research	Expand and update research on Roma health perceptions,	• Devise an ethnographic study exploring public

	especially regarding mental health	and private mechanisms of Roma health communication • Devise and ethnographic study investigating contact between Roma communities and mental health services, focusing on community members' impressions of formal mental health input • Consider the impacts of social determinants of health on health communication and mental health
	Explore the representation of Roma migrants across a broader range of UK public institutions	• Devise co-produced studies investigating Roma migrant communities' contact with broader benefits systems, social care, housing and homelessness services • Investigate the impacts of prejudice and discrimination in determining the nature of contact with services
	Establish the state of providers' knowledge of Roma health	• Engage primary care providers in interviews regarding their knowledge and experiences of providing services to Roma patients • Compare providers' responses to their Roma patients impressions of service provision

		• Evaluate the impact of Roma cultural awareness training for health professionals
Policy	Improve national data on Roma health, distinguishing between Gypsies, Roma and Travellers	• Carry out a national, government-funded survey of the health needs of Roma communities • Add ‘Roma’ as a distinct category in the next census • Add ‘Roma’ to the NHS Data Dictionary • Disaggregate ‘Gypsy’ and ‘Roma’ categories in school census data
	Expand engagement of community stakeholders in JSNA development	• Engage partners from Roma community organisations in JSNA development to facilitate meaningful attention to Roma migrants’ needs
Practice	Apply integrated care frameworks to streamline health care provision for individuals with complex needs	• Establish community ‘hubs’ bringing together representatives from a range of services to look after the health needs of vulnerable members of the Roma community • Incorporate input from Roma community groups in developing these care frameworks • Give special attention to the mental health needs of Roma communities and methods for

		facilitating access to mental health support
	Improve provision of language and communication support	- Create a system for recording shareable records of patients' language support needs, which would allow automatic booking of interpreters when a patient makes an appointment - Provide cultural awareness training to non-Roma interpreters - Train Romanes-speaking interpreters

9.5.1 Expanding research on Roma health perceptions

While this study makes reference to the ways in which Roma participants conceptualise health conditions and communicate about health in both public and private settings, this does not present a comprehensive picture of Roma health perceptions and suggests a need for more detailed research in this area. I make this suggestion in response to a perceived discrepancy between the literature presenting health as a taboo subject and my findings revealing a much greater degree of openness in discussing issues related to health. Further research could involve ethnographic research into the nature of Roma health communication in family and community settings and compare this to health communication in health care environments, thus expanding on my preliminary observation that health communication seems to take on a significantly greater degree of openness outside of the presence of other Roma individuals.

Religion is a further topic area that could be explored in significantly more detail. Although passing references to prayer and religious beliefs did appear in a small set of interviews, I did not ask participants to expand on this topic, as the focus of my interviews was on distinct interactions with health and public service providers. A detailed study of the impact of religious beliefs on Roma individuals’ use of health services could explore questions related to stoicism and fatalism, which arose in the literature review but were not borne out by my interviews or field observations. By providing insight into the dynamics of Roma health perceptions and decisions, this could form a basis for more effective guidance for health professionals working with Roma patients and could lead to improved provision of culturally appropriate health information.

Deeper investigation of mental health could reveal how Roma community members perceive and act on what has traditionally been a highly sensitive issue, and could also explore the impact of a broader range of social determinants on health and wellbeing in Roma migrant communities. This study offered a preliminary look into the ways in which participants discussed mental health issues, and suggested that many were encountering significant challenges to their mental wellbeing. It was outside the scope of this study, however, to provide an in-depth look at the ways in which Roma individuals understand mental health issues, communicate about mental health within and outside the community, and make decisions to seek out formal mental health support. This could be the subject of future ethnographic research, perhaps incorporating a component of participant observation as Roma community members make contact and engage with mental health services.

9.5.2 Exploring Roma representation in public services

On a conceptual level, this study raised questions of the idea of Roma integration and its utility in bringing about substantive changes in the circumstances of both UK and European Roma populations. Despite the pervasiveness of this concept in political discussions of the situation of the Roma in Europe, my field observation did not reflect the presumed isolation from other groups that seems to be implicit in the concept of ‘integration’ as a priority area in social policy. While some individuals I encountered in the field did display a preference to socialise predominantly with other Roma, this did not preclude engagement with public services or, more broadly, a desire to be seen as an active contributor to UK society. Participants’ narratives of health and welfare suggested sensitivity to discrimination and abuses of their rights, and when offered an opportunity to exercise these rights (for example, by making a complaint about disrespectful treatment by health care providers), they eagerly pursued these avenues for expressing dissatisfaction with their treatment.

These observations run counter to the narratives of isolation so common in public discussions of the Roma, revealing a willingness amongst Roma to actively engage with public institutions. This suggests a scope for further research into the engagement of Roma within broader systems of benefits, social care and housing and homelessness services, as well as the interacting forces of discrimination and empowerment in determining the quality of their engagement. Research could be conducted within Roma community organisations, exploring the ways in which Roma migrants seek information about public services, the nature of their interactions with services officials and the outcomes of their involvement. Instead of propagating the notion of the Roma as fundamentally separate from other groups, their situation could be more effectively addressed with attention to the numerous ways in which the Roma already engage in UK society.

9.5.3 Establishing the state of providers' knowledge of Roma health

Given that primary care providers did not engage in my study, questions remain about how they perceive their interactions with Roma patients and their depth of knowledge about issues in Roma health. Without this input from primary care providers, it remains unclear whether providers' specific knowledge of Roma culture has an impact on Roma patients' perceptions of the quality of care they receive, or whether Roma participants' dissatisfaction with service stemmed more from administrative inefficiencies. These service-level considerations could inform research questions as to whether a provider's understanding of Roma culture has an effect on the quality of a medical consultation. Beginning by identifying health services with known Roma patients, health care providers working within these services could then be surveyed or interviewed to establish their self-reported knowledge of Roma health and culture. This data could be compared against Roma patients' impressions of providers' cultural sensitivity and overall quality of care, perhaps focusing on Roma patients with health conditions commonly associated with cultural stigmas.

To gain further insight into providers' knowledge of Roma culture and to establish the effectiveness of methods for increasing provider knowledge, research could also be directed at evaluating Roma cultural awareness training programmes for health professionals. Anecdotal evidence from this study (discussed in Chapter 6) suggested that cultural awareness training could enhance professionals' knowledge of Roma health inequalities and minimise barriers to communication with providers. It would be valuable to establish providers' pre-training, baseline knowledge of Roma and then to conduct post-training follow-up interviews to gain insight into changes that they made to their practice as a result of training. Impressions from Roma patients could then be gathered to further establish whether training had a perceptible impact on providers' communication and behaviour, especially with reference to sensitive topics within Roma culture. The resulting data could be employed in developing more effective mechanisms for facilitating communication between health service providers and Roma patients, and could furthermore inform local policy makers' development of strategies for addressing Roma health needs.

9.5.4 Improving national data on Roma health

Existing UK data on Roma health tends to take a highly localised perspective on Roma individuals' interactions with services. This can be seen as a corollary of the trend towards localism in health service provision, with the quality of local Roma populations' health experiences reflecting the services and support mechanisms that are locally available, yet it can also be argued that it closes off lines of enquiry into broader trends in Roma health inequalities. Studies conducted in specific UK regions suggest similar issues in accessibility of services – i.e. language barriers, difficulties of obtaining referrals and limited awareness of available services – yet there are no data to confirm whether these accessibility issues exist across the UK (Gill, 2009; Moore, 2010; Tobi et al., 2010; Roma Support Group, 2012; Willis, 2016; Warwick-Booth et al., 2017; McFadden et al., 2018). Furthermore, research into Roma health tends to be concentrated in a relatively narrow set of geographical areas – London, Leeds, Sheffield – and as such, there are likely large segments of UK Roma with health needs that remain unidentified. In light of the gaps in data on the health experiences of Roma in the UK, a national, government-funded study assessing Roma health needs would provide valuable insight into large-scale consistencies and disparities in local barriers to accessing health services, and could also help to assess the feasibility of developing national initiatives aimed at reducing Roma health inequalities.

Arguments have been made in favour of national data collection on Roma populations as the best method for establishing population size, areas of population concentration and, by extension, areas of need (Brown, Martin & Scullion, 2014; Craig, 2011). With more complete information on these populations, local governments would be more able to assess the depth of attention they should give to GRT communities in health strategy development. This could be achieved, for example, through the inclusion of 'Roma' as a distinct census category, as well as through disaggregation of 'Gypsy' and

‘Roma’ categories in school census data. When including Roma ethnicity as a component of national ethnic data collection, however, it will also be vital to ensure that this is accompanied by increased cultural awareness training for staff working directly with these communities. National monitoring of marginalised communities could create fears of heightened discriminatory practices (hence the commonly reported reluctance to self-ascribe as Gypsy, Roma or Traveller), yet it is only through official government recognition of these groups that frameworks can then be developed to ensure attention to their needs (Bartlett, Benini & Gordon, 2011; Craig, 2011).

In a health policy context, there is a need to move away from health needs assessments that erase the distinctions between Gypsies, Roma and Travellers. In the case of the Roma, it is furthermore vital to ensure that any future health service development initiatives account for the deprivations and disadvantages that they face both in their countries of origin and in the UK. Addressing the impacts of Roma communities’ migrant status in their use of UK health and public services could provide key insight into the intersecting factors of Roma community language profiles, past experiences of discrimination and expectations of health services, which could in turn inform more nuanced guidance for service providers working with Roma migrants.

9.5.5 Engaging stakeholders in JSNA development

In assessing JSNA responses to inequalities faced by GRT communities, it is worth noting that the complex social determinants at the root of Roma health likely require action beyond the scope of CCGs’ and local authorities’ expertise and funding. Through partnership working with Roma community groups, however, Health and Wellbeing Boards would be better equipped to capture the specific concerns of local Roma groups in their JSNAs. As the WHO’s Health in All Policies approach emphasises, non-governmental stakeholders can bring to the process of policy development specialist knowledge of communities to the process of policy development, and can potentially help to maximise the efficiency of programmes for reducing health inequalities (World Health Organization, 2014a). Taking proactive measures to involve members of local communities in commissioning decisions could help to promote the development of services targeted at GRT needs and ensure that these services operate at maximum efficiency. Crucially for Roma, stakeholder engagement could also help to ensure that their needs are no longer overlooked or absorbed into broader discussions of Gypsy and Traveller concerns (which fail to capture the migrant profile of Roma). When engaging Roma organisations as stakeholders, however, it is important that commissioners not simply delegate responsibility for delivering Roma health improvement programmes without offering community partners support and funding to undertake such activities. Like CCGs and local authorities, Roma organisations are constrained by funding and personnel limitations, and it is only through collaborative working and sharing of resources that stakeholder engagement programmes could operate to the benefit of all involved parties.

9.5.6 Applying integrated care frameworks to Roma health

Many Roma participants in this study displayed complex need related not only to their health situations, but also to conditions of poverty, housing insecurity and limited access to benefits. Responding to the sometimes 'disjointed' nature of support across health and social care services, recent NHS developments have sought to address complex need through 'integrated care' frameworks (NHS England, 2018). These models of service provision potentially bring together general health, specialist and social care services to holistically meet the needs of groups facing particular vulnerabilities (NHS England, 2018). In an example of integrated services, 'community hubs' have been established in Kent, which bring together GPs, community nurses, social care workers, mental health professionals, pharmacists and health and social care coordinators (The King's Fund, 2018).

If developed through meaningful consultation with Roma and delivered with sensitivity to Roma socioeconomic and cultural profiles, integrated care frameworks could provide a powerful means for meeting the needs of some of the most marginalised individuals. The joined-up approach to integrated care could address challenges associated with navigating pathways between primary and secondary care, obtaining consistent language support and ensuring that Roma individuals have access to their full entitlement of local authority assistance. Integrated care could furthermore offer particular opportunities in the area of mental health. As mental health can be a sensitive topic within some segments of Roma communities, individuals may avoid seeking out mental health support out of shame or lack of knowledge of available services. If mental health services are linked up with a wider package of support, however, Roma individuals could be afforded a better understanding of professional input into their mental health and could thereby feel more comfortable in accessing support.

9.5.7 Developing language, interpreting and advocacy support

Roma participants made frequent references to the shortcomings language support provision in health services, highlighting the difficulties of requesting interpreters and uncertainties over whether requested interpreters would be present at their appointments. In light of this need for more streamlined provision of language support services across health systems, health services could take steps to centralise information about patients' language support needs. This could take the form of a central database recording patients' language support needs, which would be shared across NHS services and could lead to automatic booking of an interpreter when a patient registered on the database makes an appointment. A system of this type would eliminate the existing irregularities in procedures for requesting language support and would furthermore take the onus off patients in ensuring that they are able to communicate with health care providers.

There is also scope for substantially expanding cultural awareness training for interpreters, as many come from the majority population in Roma community members' countries of origin, and thus may be unaware of Roma patients' specific cultural and communication needs. To further eliminate cultural barriers between Roma patients and interpreters, interpreting services could recruit and train Romanes-speaking interpreters, thereby providing Roma patients with the option of communicating in their first language. These measures could also be supplemented by the development of health information materials in pictorial or audio formats, which would allow patients with limited literacy to exercise greater autonomy in gathering health information and determining which services are most appropriate for their needs.

9.6 Conclusions: the wider applicability of this study's findings

This study began as an investigation of the health inequalities faced by Roma communities, with an interest in understanding whether European reports of disproportionate issues in health service accessibility would be replicated in a UK context. Interviews and field observations proceeded with an initial focus on the interactions between Roma participants and health services, which rapidly revealed that inequalities faced by Roma communities run deeper than direct contact between patients and services. In fact, barriers to UK health services seemed seldom to reflect direct discrimination on the part of providers, yet they do appear to reflect unconscious bias towards patients from migrant and deprived backgrounds. Roma participants were in most cases able to gain basic levels of access to health services, yet the complexities of health system bureaucracy and irregularities in provision of language support and health advocacy prevented them from obtaining their desired levels of care. As these systemic underpinnings of inadequate access to health services became clear, they brought forward further considerations of the wider socio-political environment of public service provision in the UK and the challenges that Roma participants encountered in their efforts to establish a sufficient level of stability in their post-migration living situations.

In this sense, the experiences of Roma migrant communities in the UK can be seen as an example of the ways in which intersecting influences of discrimination, material deprivation and migration experiences can make them invisible within public service institutions. Targeted needs analyses reveal service priorities, and in this case, the widespread omission of Roma is telling. Roma participants’ impressions of UK health services revealed a picture of services stretched to their limits – a situation experienced across numerous non-Roma patient groups – and for Roma, the overwhelming message seemed to be that services lack the capacity (and the motivation) to attend to their specific needs. Within this environment, it was often the most vulnerable patients with the most complex needs who faced the greatest barriers to obtaining adequate support. The experiences of Roma participants outlined herein serve to reinforce this observation. Addressing this issue will require attention not only to discrete patient-provider interactions within health services, but also to the social inequalities, political decisions and wider public service frameworks that underlie power imbalances between UK public institutions and disadvantaged and marginalised populations.

This study adds to existing research on Roma health by offering a critical perspective on the ways in which Roma individuals experience health and public services in the UK, as well as the ways in which institutional operating framework can restrict Roma individuals’ ability to take full advantage of public services. This study is furthermore novel in incorporating discussions of recent developments in UK immigration policy from the perspectives of Roma migrants, positing that immigration instability erodes Roma community members’ sense of life chances in the UK. With this comes concern over entitlement to benefits systems and fears that inability to work due to long-term health conditions could restrict future right to reside in the UK. When confronted with perceived challenges to their rights in both health and benefits contexts, Roma participants responded with a sense of injustice and indignation, which was also underpinned by a sense of helplessness and uncertainty as to where they could turn. In developing a theory of the ways in which power differentials arose between Roma individuals, health service providers and representatives of public services, my study lays the groundwork for further enquiry and action in addressing the social inequalities faced by Roma migrants in the UK.

Focusing on individual narratives of health and benefits systems, this study sought to shift the focus of much of the current research on UK Roma health from surface-level descriptions of barriers to accessing health services and to reveal how personal histories of subjugation can inform Roma migrant communities' perceptions of health and benefits systems. By presenting narratives that highlighted participants' acute sense of injustice in contemplating their interactions with health and benefits systems, this study challenged common narratives of Roma as victims of their social environment. Participants were not passive in their expressions of having been wronged, and their decisions to tell their stories revealed an active desire to bring about change in the way that health and benefits systems treat Roma community members. Health professionals, public service providers and policy makers alike could benefit from a more nuanced understanding of the historical, social and cultural profiles of Roma communities, thus allowing them to incorporate sensitivity to experiences of discrimination and unconscious bias against Roma into their practice. This holds the potential to bring about dramatic changes in the manner in which professionals and policy makers understand and address the situation of Roma migrant groups, and could in turn provide a foundation for models of service delivery that take a more holistic approach to the challenges they face in accessing adequate support mechanisms.

Appendices

Appendix 1: Participant Consent Forms

Durham
University

Participant Consent Form

The experiences of the Central and Eastern European Roma in accessing UK health services
Version 4: 15/5/2015

Participant Identification Number:

1. I confirm that I have read and understand the participant information sheet for this study. I have had the opportunity to think about this information and have been given a chance to ask questions about any details I do not understand.	Yes	No	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	Yes	No	
3. I understand that any information included in study reports will not include my name or reveal my identity.	Yes	No	
4. I understand that taking part will not affect my access to health services or my involvement with the Roma Support Group.	Yes	No	
5. I understand that other study participants may assist in analysis of results, but none of my identifying information will be shared with them.	Yes	No	
6. I agree to information that will not include my name or reveal my identity being stored at Durham University for up to 5 years after completion of this study.	Yes	No	
7. I would like to receive a summary of findings at the end of the study.	Yes	No	
8. I agree to take part in this study.	Yes	No	
9. If I am unable to answer survey questions in English, I agree to allow a family member to serve as an interpreter.	Yes	No	N/A

Name of participant Date Signature

____________________________ ______________ ____________________________

Name of Researcher

____________________________ ______________ ____________________________

Participant Consent Form

The experiences of the Central and Eastern European Roma in accessing UK health services
Version 4: 7/5/2015

Participant Identification Number:

1. I confirm that I have read and understand the participant information sheet for this study. I have had the opportunity to think about this information and have been given a chance to ask questions about any details I do not understand.	Yes	No	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	Yes	No	
3. I understand that any information included in study reports will not include my name or reveal my identity.	Yes	No	
4. I understand that taking part will not affect my access to health services or my involvement with the Luton Roma Trust.	Yes	No	
5. I understand that other study participants may assist in analysis of results, but none of my identifying information will be shared with them.	Yes	No	
6. I agree to information that will not include my name or reveal my identity being stored at Durham University for up to 5 years after completion of this study.	Yes	No	
7. I would like to receive a summary of findings at the end of the study.	Yes	No	
8. I agree to take part in this study.	Yes	No	
9. If I am unable to answer survey questions in English, I agree to allow a family member to serve as an interpreter.	Yes	No	N/A

Name of participant　　　　Date　　　　Signature

______________________________　　_______________　　_____________________________

Name of Researcher

______________________________　　_______________　　______________________________

Durham
University

Participant Consent Form

The experiences of the Central and Eastern European Roma in accessing UK health services
Version 1: 15/5/2015

Participant Identification Number:

1. I confirm that I have read and understand the participant information sheet for this study. I have had the opportunity to think about this information and have been given a chance to ask any clarifying questions I may have.	Yes	No
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	Yes	No
3. I understand that information included in study reports will not include my name or reveal my identity.	Yes	No
4. I agree to fully anonymised data being stored at Durham University for up to 5 years after completion of this study.	Yes	No
5. I would like to receive a summary of findings at the end of the study.	Yes	No
6. I agree to take part in this study.	Yes	No

Name of participant	Date	Signature
____________________________	______________	___________________________

Name of Researcher		
____________________________	______________	____________________________

Appendix 2: Participant Information Sheets

Participant Information Sheet for Interviewees

The experiences of the Central and Eastern European Roma in accessing UK health services

Invitation to take part

You are being invited to take part in a project aimed at improving health service for Roma in the UK. This study will look at how you view health and health care, and how you understand the health of your community.

Why am I being invited?

This study seeks to understand how the Roma view health services and how these views affect health service use. You are being invited because you have expressed an interest in sharing your thoughts on health service use, or because another participant in this study has suggested that you may be interested in taking part.

What will I need to do if I take part?

Interviews will take approximately 1 hour, and questions will focus on your experiences in using UK health services. There are no right or wrong answers – we simply want to better understand your opinions and experiences. If you agree, the interview will be audio recorded. Otherwise, I will take notes. None of your personal identifying details will be included in written reports.

If you are unable to answer interview questions in English, I will ask if it is possible for a family member to serve as an interpreter.

Do I have to take part?

No, it's entirely voluntary. You do not have to take part, and you can end participation at any time. If you would prefer not to take part in this interview but would still like to be involved in the RSG's mental health project, this is not a problem. Participation in one project will in no way affect participation in the other.

Will my decision to take part affect my use of Roma Support Group services?

No, taking part will not affect your use of Roma Support Group services. I will not discuss your answers to interview questions with any members of the organisation. However, if you mention concerns about health, discrimination or other areas where you may need support, I will give you information for contacting a member of staff who will be able to help you.

If you are also part of the RSG's mental health project, nothing you tell me in this interview will in any way affect your participation in the mental health project.

What are possible benefits of taking part?

By agreeing to take part in this study, you are helping me to better understand your community and your beliefs. I will then use this information to write a report on access to health services in UK Roma communities. Doctors and policy makers may then use this information to provide better services to Roma communities.

What are possible disadvantages of taking part?

Some of the questions asked during the interview may be about your health problems and experiences of discrimination, which may make you feel uncomfortable. If the interview becomes too upsetting, you are free to stop at any time. If you decide after the interview that you do not want your answers included in this study, please let me know within 24 hours.

What happens after the interview?

At the end of the study, I will host an open meeting for you, other participants and other community members to discuss the findings. If you are uncomfortable with attending a meeting, results of the study will be available online and in short written reports available at the RSG offices.

Results from this study may be published in journals for health professionals and researchers and presented at conferences.

Will information be kept confidential?

Yes, reports will not include your name or any information that could identify you. Recordings and transcripts will be stored securely for a period of 5 years and then destroyed.

After data collection, I will ask study participants if they are interested in assisting with analysis of results. None of your identifying information will be shared with other participants, and no one from this location will be involved in analysing your interview transcript.

Nothing you tell me in this interview will be used in any way in the RSG mental health project I am coordinating.

Who is in charge of the study?

This study is a PhD project at Durham University. The researcher is a student who is supervised by a team of experienced researchers.

Contact details:
Sarah Zawacki
Telephone: 0191 33 40837
Email: s.g.zawacki@durham.ac.uk
Address: Sarah Zawacki, Room E113A, Wolfson Research Institute, Stockton on Tees, TS17 6BH

Durham University

Participant Information Sheet for Health Professionals

The experiences of the Central and Eastern European Roma in accessing UK health services

Version 1: 7/5/2015

Invitation to take part

You are being invited to take part in a project aimed at improving health service for Roma in the UK. This study will look at the relationship between Roma communities and health care providers, with the goal of better understanding how health services address the needs of Roma patients.

Why am I being invited?

This study seeks to understand how the Roma view health services and how these views affect health service use. My partners in Roma community organisations have suggested that you may have experience and expertise in working with Roma individuals, and for this reason I would like to hear your thoughts on the ways in which current service provision strategies meet their needs.

What will I need to do if I take part?

Interviews will take approximately 1 hour, and questions will focus on your interactions with members of UK Roma communities. There are no right or wrong answers – I simply want to better understand your opinions and experiences. If you agree, the interview will be audio recorded. Otherwise, I will take notes. None of your personal identifying details will be included in written reports.

Do I have to take part?

No, it’s entirely voluntary. You do not have to take part, and you can end participation at any time.

What are possible benefits of taking part?

Taking part will allow you to share your thoughts about the ways in which health systems serve Roma patients. This could help to shape the development of future strategies for addressing Roma health needs and could also help policy makers to better address the needs of the Roma.

What are possible disadvantages of taking part?

There will be a slight time disruption (approximately 1 hour).

What happens after the interview?

After data has been collected and analysed, I will host open dissemination meetings where you and other participants can discuss findings. Summaries of results will also be available online and in the offices of my partner organisations.

Results from this study may be published in journals for health professionals and researchers and presented at conferences.

Will information be kept confidential?

Yes, reports will not include your name or any information that could identify you. Recordings and transcripts will be stored securely for a period of up to 5 years and then destroyed.

Who is in charge of the study?

This study is a PhD project at Durham University. The researcher is a student who is supervised by a team of experienced researchers.

Contact details:
Sarah Zawacki
Telephone: 0191 33 40837
Email: s.g.zawacki@durham.ac.uk
Address: Sarah Zawacki, Room E113A, Wolfson Research Institute, Stockton on Tees, TS17 6BH

Participant Information Sheet for Community Workers

The experiences of the Central and Eastern European Roma in accessing UK health services

Version 1: 7/5/2015

Invitation to take part

You are being invited to take part in a project aimed at improving health service for Roma in the UK. This study will look at the relationship between Roma communities and health care providers, with the goal of better understanding how health services address the needs of Roma patients.

Why am I being invited?

This study seeks to understand how the Roma view health services and how these views affect health service use. As Roma community organisations play an important role in shaping community members' health experiences, your work with community members and health professionals offers insight into the nature of the patient/provider relationship.

What will I need to do if I take part?

Interviews will take approximately 1 hour, and questions will focus on your interactions with members of UK Roma communities and health professionals. There are no right or wrong answers – I simply want to better understand your opinions and experiences. If you agree, the interview will be audio recorded. Otherwise, I will take notes. None of your personal identifying details will be included in written reports.

Do I have to take part?

No, it's entirely voluntary. You do not have to take part, and you can end participation at any time.

What are possible benefits of taking part?

Taking part will allow you to share your thoughts about the ways in which health systems serve Roma patients. This could help to shape the development of future strategies for addressing Roma health needs and could also help policy makers to better address the needs of the Roma.

What are possible disadvantages of taking part?

There will be a slight time disruption (approximately 1 hour).

What happens after the interview?

After data has been collected and analysed, I will host open dissemination meetings where you and other participants can discuss findings. Summaries of results will also be available online and in the offices of my partner organisations.

Results from this study may be published in journals for health professionals and researchers and presented at conferences.

Will information be kept confidential?

Yes, reports will not include your name or any information that could identify you. Recordings and transcripts will be stored securely for a period of 5 years and then destroyed.

Who is in charge of the study?

This study is a PhD project at Durham University. The researcher is a student who is supervised by a team of experienced researchers.

Contact details:
Sarah Zawacki
Telephone: 0191 33 40837
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Appendix 3: Interview topic guides for Roma participants

Topic guide version 1

Interview Topic Guide: The experiences of Central and Easter European Roma in accessing health services

General Information

- Where do you live? London or Luton? Area of city? How long have you lived in this area?
- Age range

Icebreakers

- How would you describe the Roma community in your city?

Health experience

- Do you consider yourself to be generally healthy? Why or why not?
- What do you do when you have health problems?
- What do you think are the main health problems in your community? What could be done to fix these problems?
- What do you do first when you or a family member is sick?

Access and use of health services

- What experiences have you had using health services in the UK? Best experience? Worst experience?
- Are you registered with a GP (physician)? If not, why?
- If registered, when do you visit your GP?
- When do you use A&E services? Specialist services?
- Have you had problems in trying to use health and social services? If so, what were these problems? Do you feel that you received enough support in solving them? Why/why not?
- What things have made it easier for you to use health services services?
- What can providers do to improve health services for you?

Communication with service providers

- Have you ever had trouble communicating with health care providers?
- Have you previously requested interpreter services? What were your experiences?
- Have you used in-person interpreters, telephone interpreters or both?
- Which type of service do you believe leads to the best results? Why?

Prevention

- What do you do to keep yourself and your family healthy?
- Do you know about preventive services like NHS Health Checks?
- Do you use health-screening services? (Give examples if necessary)

Impact of lifestyle on health

- Do you feel that your current living situation has an impact on your health? If so, is it positive or negative? Why?
- Could discuss accommodation, general physical environment

Knowledge

- Whom are you most likely to ask for information about your health? Family? Friends? Health professionals? Another source?
- When looking for health-related information, whom do you trust?

Beliefs

- What health advice would you give a family member?
- Do you feel that health care providers understand your needs?

(Based on Parry et al. 2004 and Tobi et al. 2010)

Topic guide version 2

Interview topic guide for Roma community members

Version 5

Health experience

- Could you tell me about the last time you had any health problems?
- How did you deal with these health problems? What do you do first when you or a family member gets sick?
- What do you think are the major health concerns in your community? What could be done to fix these problems?
- Do you feel that health care providers understand your needs? Do you feel that they make an effort to understand your culture?

Access and use of health services

- Are you registered with a GP? If not, why? (Don’t know how? Don’t want to?)
- If registered, when do you visit your GP?
- What problems have you experienced in trying to use health services (GP, specialist, etc.)?
- Has anything been done to make it easier for you to use these services? (For example, double appointments, easy access to interpreters)
- What has been your best experience in using health services? Worst experience?
- Have you ever had trouble communicating with health care providers?
- Have you used interpreting services? What are the benefits/drawbacks of working with interpreters?
- Have you ever returned to your home country to use health services? Why or why not?

Health benefits environment

- Have you claimed any health-related benefits? (PIP, ESA, DLA)
- How did you feel about the questions on the forms? (Confusing/straightforward/easy to answer/hard to answer)
- What were your experiences in attending the assessment?
- Did you feel that the assessor treated you with respect? Why or why not?
- Were you satisfied with the outcome of your health benefits claim?

Impact of environment/life circumstances on health

- Do you feel that your current living situation has an impact on your health? If so, is it positive or negative? Why?

Knowledge

- Who are you most likely to ask for information about your health? Family? Friends? Health professionals? Another source?

Appendix 4: Interview topic guides for professionals and community workers

Topic guide for professionals

Interview topic guide for health professionals

The experiences of the Central and Eastern European Roma in accessing UK health services

General information

Location (London or Luton)

In what position are you currently employed? How long have you been working here?

Do you have a background in serving disadvantaged/ethnic minority communities?

Providing services to Roma patients

How many Roma patients do you serve? (If you are unsure, give your best estimate.)

How frequently do you see these patients?

What have been your experiences in interacting with these patients?

Have you observed any particular challenges in providing services to Roma patients?

How do you feel that your colleagues respond to the needs of Roma patients?

Do you think that there are steps that could be taken to improve services for Roma patients? If so, what would you recommend?

Topic guide for community workers

Interview topic guide for community workers

The experiences of the Central and Eastern European Roma in accessing UK health services

General information

Location (London or Luton)

In what position are you currently employed? How long have you been working here?

What services does your organisation provide to Roma communities? Do you focus exclusively on Roma or do you work with other groups as well?

How would you say the situation of Roma communities in the UK compares to that of other marginalised and minority ethnic groups?

Providing services to Roma

How many Roma does your organisation serve?

What have been your experiences in interacting with Roma communities?

Have you observed any particular challenges in providing services to Roma?

How do you feel that your colleagues respond to the needs of Roma?

Do you think that there are steps that could be taken to improve services for Roma? If so, what would you recommend?

Appendix 5: Grounded theory analysis

Table of grounded theory codes

OPEN (LINE-BY-LINE) CODES	AXIAL (SENSITISING) CODES	THEORETICAL CODES
Need for language support	Language barriers and access to health services	Challenges in interacting with UK health services
Difficulties of requesting interpreters		
Unwillingness of services to provide interpreters		
Unreliability of interpreters		
Bi-lingual health advocacy		
Inconsistencies in English proficiency and functionality in a health context		
Difficulties in making appointments	Navigating administrative barriers	
Need for double appointments		
Dismissiveness from reception staff		
Navigating referral mechanisms		
Opaque referral mechanisms		
GPs’ reluctance to make referrals		
Trust in health professionals	Relationships with health professionals	
Fragility of trusting relationships		
Professional failure to provide desired information		
Comparisons to countries of origin		
Intra-community health discussions	Family, gender and barriers to communication	Intra-community transmission of health information and its influence on service use/expectations
Discussions of health issues with family members		
Understanding of health issues	Developing treatment preferences	
Perceptions of medications		
Perceived over-prescription of paracetamol		
Self-sufficiency in using services		
Expectations of treatment		
Use of emergency services	Service selection	
Use of GP services		
Making decisions about service use		
Desire for onward referrals from primary care		
Identifying and naming mental	Coming to terms with mental	

health issues	health issues	
Coping mechanisms for mental health issues		
Descriptions of mental health services		
Intra-community transmission of mental health information		
Inadequacy of housing conditions in light of health needs	Social determinants of health and wellbeing	Interactions across the social spheres of immigration and welfare
Providing care for family members		
Conditions of financial insecurity		
Immigration status and anxiety		
Completing application forms for disability benefits	Navigating disability benefits systems	
Undergoing assessments for disability benefits		
Language barriers in benefits assessments	Shortcomings of communication in application process	
Inadequacies of language support in benefits assessments		
Difficulties in understanding assessment questions		
DWP staff omitting information from assessment reports	Perceptions of disability benefits assessment procedures	
Comparison of DWP assessment and court tribunal appeal		
DWP staff’s dismissive behaviour during assessment		
Perceived lack of communication from assessors		

Excerpt from coded fieldnotes entry

6/10/15 - London

My first day of working in advice went surprisingly well, considering that I don't necessarily consider myself qualified to advise on health care access matters (a sign of just how impractical academic study can be when you're suddenly thrust into the real world of real problems). H. had forgotten about his appointment, so I was available to take walk-in clients, so to speak. G. mentioned that A. was in the office to discuss another issue, but she was also having issues with securing interpreters for her hospital visits. As I began my meeting with her, I was surprised to find that she spoke such good English that we were able to carry out the advice session almost entirely without K.'s help (the only point at which we had to enlist her interpreting services was when discussing medical terminology – spinal cysts and related terms).

A. was noticeably distressed – even tearing up at some points – as a result of her experiences in trying to communicate with health care providers about back pains. About three or four years ago, she went to her GP with complaints of severe pain in her lower back. She was prescribed painkillers, which were only moderately effective, prompting her to return to her GP and request that they take a different course of action. She was eventually referred to a pain clinic, where she was expecting to receive and MRI but did not. As a result of the perceived ineffectiveness of the UK health system, A. returned to Poland to receive an MRI, where it was found that she had spinal cysts. She underwent an operation in Poland to remove the cysts, but was still experiencing pain upon her return to the UK. When she visited her GP to seek treatment for this pain, her doctor expressed disapproval of her decision to receive treatment in Poland.

Language barriers; requesting interpreters

Language barriers; level of English proficiency

Language barriers; level of English proficiency

Indicators of emotional distress

Use of GP services

Perceptions of prescriptions

Understanding/describing health problems

Navigating referral mechanisms

Preferences for services in country of origin

Expectations of treatment

Fragility of trust in professionals

Excerpt from coded interview

I: If you have any health problems or you're feeling sick, what is the first thing you do? Do you go to a doctor; do you ask family and friends for advice?	
015: Sometimes if something is not very serious we [my family and I] talk between each other, women, but if something is serious I go to see GP or maybe emergency. If we can't make appointments we go there.	Understanding of health issues Discussion of health issues with family members Selection of services Difficulties in making appointments
I: Do you think it's better to go to A&E than to go to a GP if there is a serious problem?	
015: Yes, because there are more doctors and specialists.	Preference for emergency services
I: When you go to A&E, do you feel that you get seen really quickly and that what the doctors do is in line with what you need?	
015: So, it depends. If, because you have to go to the reception desk to see doctor or nurse, they will ask you what's the problem, so sometimes you have to wait very long, but when my husband was very ill, you know, there was, like, water in his lungs and he couldn't breathe, so the reaction was straight away, we didn't have to wait.	Difficulties in making appointments; long waiting times Understanding of health issues
I: And when you use these emergency services, are there interpreters there for you?	
015: No interpreters.	Shortcomings of language support
I: Then how do you communicate?	
015: In my case, for example, in my situation, my son speaks English.	Family and language support
I: And do you find that it's ever a problem to have your son be an interpreter for you?	
015: If I've got arm pain or headache, I can say, but women things, this I cannot say.	Barriers to discussing health issues with family members

Sample theoretical memos

Analysis of 13/10/15 Fieldnotes (written 6/11/16)

In this early case of navigating the system for making interpreter requests, I notice for the first time how convoluted this system can be. What I observed was hospitals and GPs passing responsibility from one to another, both claiming that it is the job of others to make interpreter requests. This indicates a lack of communication and coordination amongst providers, which is further complicated by the fact that there is no overarching procedure for requesting interpreters. Each service sets its own rules, which may work as long as a patient stays with one service, but in the case that a referral is made to another service, this system seems to quickly break down. Some hospitals will provide interpreters after a phone call request; others provide them automatically based on the fact that need for language support was previously flagged up in the system; others still will only provide an interpreter if the referring GP makes the request.

The lack of transparency creates substantial problems for patients who do not speak English and moreover have limited experiences with UK health systems. This extends beyond the simple concept of language barriers to encompass more complex issues of patient-provider and provider-provider communication. To request an interpreter requires quite a nuanced understanding of each service's requirements. Yet in the cases where different providers' restrictions serve as a barrier to making a request, even fluency in English will not ensure that a request will be made. A non-English-speaking patient must effectively navigate two levels of communication simply to secure appropriate language support for a consultation: first engaging effectively in face-to-face communication with the service provider and then communicating through the system bureaucracy to secure future language support.

Analysis of 2/11/16 Fieldnotes (written 3/11/16 and 6/11/16)

After attending the NELFT Equality and Diversity manager's meeting, the question remained as to what E&D mangers actually do. Does their role have some connection to the concept of acknowledging and respecting diversity, while taking care to treat all groups equally? Or is the goal to treat all individuals equally? Is there a difference between respecting diversity between groups and respecting diversity between individuals? Efforts to promote equal treatment of the Roma, for example, tends to take the form of cultural awareness training, yet I am well aware that one of the contentions of this training programme is that it unavoidably presents the Roma as something of a monolithic entity, which failing to fully express the variation in Roma culture. To focus too much on variation, however, would lead to a training programme in which we essentially say that you can't really know anything for sure about the Roma community because there is no one Roma community, at which point health professionals would criticise the impracticality of such advice.

The E&D managers were quite satisfied with our short training presentation, likely because we help them to fulfil their Equality Act requirements. It's no secret that they value these box-ticking exercises, yet I can't say whether there's any real follow through after the boxes have been ticked. The baseline concept here is that service providers interact with local communities as a means of meeting national targets, yet this needs to be taken a step further to reveal that in many cases the engagement never extends beyond listening to community representative. There are limitations on engagement.

Appendix 6: Sample narrative analysis

	Participant's account	**Analysis**	**Narrative linkages**
Context		The participant is a Slovak Roma woman who came to the UK to seek work and to escape discriminatory treatment in her country of origin. Prior to the onset of her health problems, she was satisfied with her life in the UK and had attained a degree of independence through her full-time work as a cleaner in a hotel. She lives next door to her parents and regularly spends time with her cousins. Her three adult children live away from home, and she is separated from her former partner, though she does not talk about the relationship.	
Temporality	And I say just one month, no maybe even one week done this operation, two weeks, and is nothing better; I feel worse and worse.	The narrator creates a sense of temporal confusion in presenting widely variant periods of time since she underwent the operation, which perhaps reflects her disorientation during that time of intense pain.	
	So then on 9th of July 2015, I think, he do this big open operation, Dr M. It was eight and a half hours operation, and I was two weeks in the hospital.	By specifying the date that the operation took place, the narrator conveys the significance of the surgery in her memory.	
Plot	The narrator is working as a cleaner and begins to feel pain in her abdominal region.		
	The narrator is diagnosed with a cyst in her kidney.		
	The narrator undergoes a routine surgery to remove the cyst.		
	She wakes up from the surgery in extreme pain but is still discharged from the hospital.		
	(detail omitted for brevity)		
	The specialist informs her		

	that a laceration to her kidney occurred during the surgery to remove the cyst, and that she will have to undergo a further surgery to correct the error.		
	The narrator expresses anger that she is no longer to live independently and pain-free.	At this point the narrative departs from a chronological structure to allow for the narrator's reflection on the life changes that occurred since the onset of her health problems.	Link to HN2: narrators in both stories depart from the sequential organisation of their stories to pause for reflection on change.
People	A range of unnamed doctors and nurses at hospitals and the narrator's GP practice		
	Professor M.	Of the many health professionals in this story, this is the only one whose name is mentioned, perhaps to convey his significance to the narrative, and also in a reflection of his professional credentials.	
Selection of detail/narrative editing	I was working, like, housekeeping in a hotel; I was cleaning rooms. And I feel a lot of pain, starting pain, and I just start taking painkillers. Then I'm going to visit doctors, and I find out I've got a large cyst on left kidney, and he told me that this is simple – simple cyst – so there's nothing to worry; they don't need to do nothing. Before it no start properly pain, strong pain. Still I was managing because I take painkillers sometimes, and I don't want to leave my work. I'm loving my work, so I don't want to leave.	The narrator contextualises the onset of her health problems with a discussion of her last job and her enjoyment of her work, thus creating the sense that she has something to lose. She describes her diagnosis early in the narrative and creates a narrative tension between the doctor's assertion that there is 'nothing to worry about' and her experience of severe pain. This tension between concrete symptoms and medical professionals' reassurances continues throughout the narrative.	Link to HN1: both narrators highlight the discrepancy between the perceived severity of their health problems and doctors' insistence that there is no cause for concern.
	Then after some period started pain worse, and worse. So I'm going to GP and cyst was growing. Then he send me to specialist to see, so was like 14-15 centimetre big, so was quite a lot, yeah. So this time I can't bending; I can't do	The narrator interweaves her discussion of worsening symptoms with comments on the practical impediments that this creates in carrying out activities of daily living. By interspersing descriptions of physical pain with references to her work	

	proper, you know, my work, so I start with infected everything, so many times I be receiving urine infection, so I was on antibiotic and it was a lot of pain. So I have to stay home; I can't go into my work. So this continue, continue, and some x-rays I have to done, always. So nearly every month, nearly twice, I have urine infection. It was very painful, so I can't walk and this. I got problem in the job, because I want to go back.	situation, she reinforces her desire to stay in her job, conveying that she is only out of work due to severe physical distress.	
	So one day I'm going to Whitechapel hospital – my GP referred me to do laparoscopic remove cyst from my kidney. These people tell me 'this is just simple operation; this is simple cyst. We just do removing. Laparoscopic is nothing to worry.' So I went there and they do this operation.	The narrator does not describe a resolution to the issue of her inability to work, and instead moves abruptly on to a discussion of the medical procedures she undergoes to remove the kidney cyst. She recounts the health professionals' reassurances that the procedure is routine and thus sets the stage for a discussion of complications and her sense that she was provided with inadequate information about the risk associated with the procedure.	
	When I wake up I was in the room, so I feel very, very pain. It was crazy. It's worse than delivering baby, because I deliver three babies. So this pain, you can't explain what I have after this operation. And they give me tramadol, give me morphine; I don't know what. And I think this pain has to be like this, because after first operation, I don't know how I can feel after this.	The narrator highlights her personal experience of delivering children in the past to emphasise the intensity of the pain she felt after surgery.	Link to HN1: both narrators make references to previous experiences to shed light on their suspicions that health professionals were not disclosing the full severity of their health problems.

Appendix 7: Data on participants

ROMA COMMUNITY MEMBERS (INTERVIEWEES)							
Participant Identification Number	**Pseudonym (if applicable)**	**Date of interview**	**Gender**	**Age range**	**Location**	**Country of origin**	**Language of interview**
001	N/A	07.12.2015	Male	50-59	London	Poland	Polish with interpreter
002	N/A	07.12.2015	Female	40-49	London	Poland	Polish with interpreter
003	N/A	22.01.2016	Male	60-69	London	Poland	Polish with interpreter
004	Malgorzata	22.02.2016	Female	40-49	London	Poland	English
005	N/A	19.04.2016	Female	40-49	London	Poland	English
006	Katarzyna	19.04.2016	Female	40-49	London	Poland	English
007	Elzbieta	22.04.2016	Female	40-49	London	Poland	Polish with interpreter
008	N/A	26.04.2016	Female	40-49	London	Poland	English
009	Maria	01.07.2016	Female	40-49	London	Poland	English
010	Paulina	05.07.2016	Female	20-29	London	Poland	English
011	N/A	08.07.2016	Female	30-39	London	Poland	English
012	N/A	22.07.2016	Female	40-49	London	Poland	English
013	N/A	25.07.2016	Male	40-49	Luton	Bulgaria	English
014	Beata	27.07.2016	Female	40-49	London	Poland	English
015	N/A	01.08.2016	Male	30-39	Luton	Romania	Romanes with interpreter
016	N/A	01.08.2016	Male	30-39	Luton	Romania	Romanes with interpreter
017	N/A	08.08.2016	Female	30-39	Luton	Romania	English
018	N/A	29.09.2016	Male	60-69	Luton	Romania	Romanes with interpreter
019	N/A	29.09.2016	Female	60-69	Luton	Romania	Romanes with interpreter
020	N/A	19.01.2017	Female	50-59	London	Poland	Polish with interpreter
021	N/A	23.01.2017	Female	50-59	Luton	Romania	Romanes with interpreter
022	N/A	23.01.2017	Male	50-59	Luton	Romania	Romanes with interpreter
023	Kristina	30.01.2017	Female	40-49	London	Slovakia	English
024	N/A	30.01.2017	Female	40-49	London	Slovakia	English

025	N/A	03.02.2017	Female	50-59	London	Poland	Romanes with interpreter
026	Tomas	16.06.2017	Male	40-49	London	Slovakia	English
027	Eva	16.06.2017	Female	40-49	London	Slovakia	English

IMMIGRATION FOCUS GROUP PARTICIPANTS (London – 20.07.2018)			
Participant Identification Number	**Gender**	**Age range**	**Country of origin**
001	Male	50-59	Poland
023	Female	40-49	Slovakia
025	Female	50-59	Poland
027	Female	40-49	Slovakia
028	Female	40-49	Poland
029	Female	40-49	Poland
030	Female	40-49	Romania
031	Male	40-49	Romania
032	Male	30-39	Romania

PROFESSIONALS AND COMMUNITY WORKERS				
Participant Identification Number	**Date of interview**	**Location**	**Profession**	**Country of origin**
CW001	22.04.2016	London	Advocacy worker	Poland
CW002	10.07.2016	London	Advocacy worker	Poland
CW003	23.01.2017	Luton	Advocacy worker	UK
P001	07.11.2016	Luton	CCG staff	UK
P002	24.11.2016	London	Equality and Diversity Lead	UK
P003	08.12.2016	London	Psychologist	UK
P004	30.01.2017	London	Medical interpreter	Poland
P005	02.01.2017	London	People Participation Lead	Africa (country unspecified)
P006	02.01.2017	London	People Participation team	UK
P007	02.02.2017	London	Psychologist	Ireland

Appendix 8: Policy analysis data

JSNA 2016 Data – Health

N/A = No data/not relevant to GRT

Local authority	Title	Year	Acknowledgement of CEE Roma (Y/N)	Direct engagement with GRT communities (Y/N)	Health profile	Health service use	Barriers identified	Recommendations
NORTH EAST								
Darlington	Darlington Health and Wellbeing Strategy	2013	N	N	General reference to health inequalities faced by Travellers	N/A	N/A	N/A
Durham	County Durham Joint Health and Wellbeing Strategy; Gypsies and Travellers (2008); Gypsy, Roma, Traveller Strategic Action Plan (2014)	2014	N	N	Poorer health compared with other socially deprived groups, excluded groups and ethnic minorities; male life expectancy 10 years less than settled population, female 12 years less (2008 data)	N/A	N/A	Break down cultural barriers in access to services; improve housing conditions
Gateshead	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Hartlepool	Hartlepool JSNA: Travellers	2013	N	N (consultation undertaken with professionals)	Life expectancy 10 years lower than national average; infant mortality rate 20 times higher than national average; low levels of immunisation due to mobility; lack of continuity of care and lack of specialised health visitors; domestic abuse; low rates of cervical screening; high maternal mortality; high rates of premature death from cardiac diseases among men	N/A	N/A	N/A
Middlesbrough	Traveller JSNA 'under development'	N/A	N	N	N/A	N/A	N/A	N/A
Newcastle upon Tyne	N/A	N/A	N	N	N/A	N/A	N/A	N/A
North Tyneside	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Northumberland	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Redcar and Cleveland	Redcar and Cleveland JSNA: Travellers	2013	N	Y (consultation with travelling community led to reopening of Haven site)	Life expectancy 10 years lower than national average; infant mortality 20 times higher than national average; low levels of immunisation; domestic violence; low uptake of cervical screening; risk of premature death from cardiac diseases among men	Difficult to establish level of need due to mobility of population; tendency to go to A&E rather than GP	N/A	Change people's opinions of Gypsy and Traveller community to increase integration

South Tyneside	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Stockton-on-Tees	Travellers	2013	N	Y (Tees Valley G/T Accommodation Needs Assessment)	High rates of self-reported anxiety; high suicide rates; low self-esteem and depression, particularly amongst women; mental health stigmatisation; high levels of alcohol consumption associated with mental health issues; high levels of drug use; lack of knowledge about healthier lifestyles; high infant mortality; life expectancy 10 years less than general population; low immunisation rates (due to high mobility, lack of continuing care, lack of specialist health visitors); more likely to be caring for a dependent relative	Low uptake of immunisation and screening programmes; lack of confidence and knowledge about how to access local services; lack of cultural awareness amongst service providers	Lack of confidence about using services; lack of knowledge of healthier lifestyles, possibly due to illiteracy; external agencies considered culturally unaware; racism and discrimination	Tackle wider determinants of health and well-being, particularly accommodation, employment and education; encourage Gypsy and Traveller communities to access mainstream services; improve community knowledge of mental health issues; develop awareness of Gypsy and Traveller culture among health providers; tackle domestic violence issues
Sunderland	N/A	N/A	N	N	N/A	N/A	N/A	N/A
NORTH WEST								
Blackburn with Darwen	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Blackpool	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Bolton	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Bury	Joint Strategic Needs Assessment	N/A	N	N	Most at risk health group in the UK with lowest life expectancy and highest infant mortality	N/A	N/A	N/A
Cheshire East	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Cheshire West and Chester	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Cumbria	Health Needs Assessment: Cumbria Gypsy Travellers	2009	Y	Y (surveys and focus groups with GRT researchers and respondents; 3 European Roma participants)	Poor health status and more self-reported symptoms of ill health; high prevalence of mental health problems (70% reported themselves to be suffering from depression or nerves); disparity in immunisation uptake; some prefer to use emergency services; one in five Gypsy Traveller women has experienced death of a child, compared with 1% of settled population; poor council housing, fear of identification, feelings of containment and cultural/social isolation	Ethnic group least likely to be registered with a GP; low expectations of health services and misinformation; some registered with GPs in another area because of difficulties of registering locally; 53% of GPs reported known contact with Travellers	Reluctance to register Travellers with no permanent address; practical problems of access while travelling; complex and variable appointment systems; differing expectations; poor literacy; mistrust of authority figures; communication barriers; inability of health services to cope with a mobile lifestyle; lack of ethnic data	Provide services to caravan sites; Health Trainers on each authorised site; introduction of multi-agency care pathways for Travellers; mandatory cultural awareness training; better ethnic monitoring; patient-held records; network for good practice in primary care; production of culturally specific resources and information (including audio and visual materials)
Halton	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Knowsley	Knowsley Joint Strategic Needs Assessment	2011	N	N	N/A	N/A	N/A	N/A
Lancashire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Liverpool	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Manchester	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Oldham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Rochdale	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Salford	Gypsy Roma Traveller Action Research Project	2014	Y	Y (Czech Roma families engaged in action research)	High prevalence of mental health issues, domestic violence and smoking	Difficulties in obtaining information from health services can limit use	Feeling amongst participants that professionals do not understand GRT culture; difficult for community members to find out what extra support is available from services; low levels of literacy; language barriers for migrant Roma; fear of authority due to previous experiences of safeguarding	Training in cultural competence for health professionals; development of community advocacy programmes; outreach needed to improve access to services; need to engage GRT children who have not transferred to secondary school
Sefton	N/A	N/A	N	N	N/A	N/A	N/A	N/A
St. Helens	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Stockport	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Tameside	Tameside Joint Strategic Needs Assessment	2013	N	N	Low vaccination uptake	N/A	N/A	N/A
Trafford	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Warrington	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Wigan	Chapter 1: Population Profile	2011	Y	N	N/A	N/A	N/A	N/A
Wirral	Joint Strategic Needs Assessment	2014	N	N (though Anglia Ruskin report includes interviews with GRT)	Cites Anglia Ruskin University report of Gypsy, Roma and Traveller inclusion in NRIS; more likely to have a long-term illness, health problems or disabilities; at greater risk of diabetes; higher rates of stillbirth and neonatal issues	Late presentation and more acute use of services	Cultural pride and other barriers	N/A
YORKSHIRE AND THE HUMBER								
Barnsley	Barnsley JSNA	2016	N	N	Health problems between 2 and 5 times more common than in settled community; more likely to be anxious (women more so than men) and to have breathing problems and chest pain; more likely to suffer from stillbirths, miscarriages, death of young babies and older children	N/A	N/A	N/A
Bradford	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Calderdale	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Doncaster	N/A	N/A	N	N	N/A	N/A	N/A	N/A
East Riding of Yorkshire	N/A	N/A	N	N	Links to FFT G/T reports	N/A	N/A	N/A
Kingston Upon Hull, City of	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Kirklees	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Leeds	Leeds JSNA	2015	N	N	G/T identifed as having 'specific needs'	N/A	N/A	N/A
North East Lincolnshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
North Lincolnshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
North Yorkshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Rotherham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Sheffield	Slovak Roma Health Needs Assessment	2016	Y	Y (Roma community researchers conducted interviews with members of Roma migrant communities)	Lower life expectancy; high levels of obesity; high rates of hepatitis B; high risk of tuberculosis; high rates of hearing loss; higher rates of primary congenital glaucoma; diagnosis rates for mental health issues likely underrepresents actual numbers	Difficult to quantify because of lack of ethnic monitoring in health systems; limited data on diagnoses; vulnerable patients more likely to present at GP surgeries; higher usage rates of A&E services; high rates of non-attendance at appointments	Poverty as an overarching challenge; low levels of health literacy; lack of awareness of healthy diet and benefits of physical activity; limited data on medical history	Need for face-to-face (not telephone) interpreters; Roma health mediator programmes including outreach components; training of Roma community members to serve as advocates; health impact assessment of housing conditions; need for more data to develop culturally appropriate responses to health inequalities; cross-agency collaboration
Wakefield	N/A	N/A	N	N	N/A	N/A	N/A	N/A
York	N/A	N/A	N	N	N/A	N/A	N/A	N/A
EAST MIDLANDS								

Derby	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Derbyshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Leicester	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Leicestershire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Lincolnshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Northamptonshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Nottingham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Nottinghamshire	County JSNA	2012	N	Y (study of G/T health needs in Newark and Sherwood)	More likely to suffer from lung cancer, COPD, CHD and mental illness; more likely to experience accidents	Less likely to access preventative health care; poor experience of health service	N/A	N/A
Rutland	N/A	N/A	N	N	N/A	N/A	N/A	N/A
WEST MIDLANDS								
Birmingham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Coventry	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Dudley	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Herefordshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Sandwell	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Shropshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Solihull	Solihull JSNA	2012	N	N	N/A	N/A	N/A	Need to develop immunisation programmes
Staffordshire	Staffordshire Enhanced Joint Strategic Needs Assessment	2013	N	N	Low immunisation rates; measles outbreaks	N/A	N/A	Commission additional health visiting staff to increase immunisation rates
Stoke-on-Trent	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Telford and Wrekin	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Walsall	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Warwickshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Wolverhampton	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Worcestershire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
EAST OF ENGLAND								
Bedford	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Central Bedfordshire	Gypsy and Traveller Communities in Central Bedfordshire		Y	Y (local study conducted in G/T communities)	Same illnesses and problems as general population, but lower health status than the lowest socioeconomic group; life expectancy 10-12 years less than UK average; women 20 times more likely to have experienced death of a child	All but homeless or highly mobile were permanently registered with a GP, but not all who have access use primary care	Inadequate health promotion materials (not culturally competent); poor literacy skills; enforced mobility; lack of transport; inflexible systems; discrimination, marginalisation, lack of trust; poverty, homelessness, distrust; 'poor memory' for navigating service pathways, 'lack of self-esteem and self-confidence leading to helplessness that is continually reinforced and therefore learned'	Review ethnic information and the way it is collected; assign ethnic codes including Romany Gypsies, Roma and Irish Travellers; ensure access to outreach services; use health champions to develop culturally competent health improvement programmes; source culturally specific health education materials; social marketing pilot to increase immunisation uptake

Cambridgeshire	Joint Strategic Needs Assessment: Cambridgeshire Travellers	2010	Y	N (decided not to consult with communities as a result of evidence already available through Pacesetters programme)	Lower life expectancy, higher infant mortality, poorer health outcomes and poorer access to preventative care; 40% reported long-term illness compared to 18% of settled community; higher rates of smoking and obesity, low uptake of immunisation, contraception and cervical screening; higher smoking prevalence; higher prevalence of mental health problems (3 times more likely to suffer from anxiety and twice as likely to be depressed)	Lack of confidence in accessing health services; 'Self-reliance when suffering from ill health often resulted in delayed access to services; lack of understanding of health problems can reduce compliance with treatment	Issues of self-identification; lack of cultural awareness; literacy problems (lack of information in appropriate non-text formats; active and unintentional discrimination (economic exclusion, communications); reluctance of GPs to register Traveller patients; difficulty of obtaining permanent registration	Improve providers' cultural awareness; increase ethnic monitoring; drop-in clinics; vocational and literacy courses; produce CD/DVD materials; increase early intervention and prevention, immunisation, maternal health service, male health services, more support around complex needs, training GRT health champions
Essex	Essex Joint Strategic Needs Assessment - Countywide Report	2013	N	N	N/A	N/A	N/A	N/A
Hertfordshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Luton	Luton Joint Strategic Needs Assessment	2011	N	Y (Carried out GRT Health Needs Assessment through surveys and focus groups)	Access to healthcare, mental health services and drug and alcohol services highlighted as specific issues	N/A	N/A	Develop a shared health action plan; improve access to primary and secondary care; support families who are undergoing 'transitional' life changes; improve health literacy and encourage healthy behaviours; ensure mandatory cultural competency training for all health staff who work with GRT
Norfolk	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Peterborough	Peterborough JSNA - Demographic Population Facts, Figures and Trends Chapter	N/A	N	Y (Traveller Needs Assessment)	Lower life expectancy, higher infant and maternal mortality rates and generally poorer health outcomes than age-sex matched comparators; more self-reported symptoms of ill health; chest pain, respiratory problems and arthritis more prevalent; high rates of miscarriage, stillbirth and perinatal death	N/A	N/A	N/A
Southend-on-Sea	Southend Joint Strategic Needs Assessment	2008	N	N	N/A	N/A	N/A	N/A

Suffolk	The Joint Strategic Needs Assessment for Suffolk	2011	N	Y (survey of travelling community in Kessingland)	Lifespan 10 years lower on average, 12 years lower for women; more prone to heart disease than the settled community; 'smoking and alcohol related problems are highest amongst the Gypsy and Traveller community'; domestic violence; low immunisation rates; poor diet	Often not registered with GP so access care via A&E; late presentation and lack of early intervention services	Literacy issues; fear of discrimination; lack of knowledge and understanding of available services; lack of information in an accessible format; transport issues; transcience of the community	N/A
Thurrock	N/A	N/A	N	N	N/A	N/A	N/A	N/A
LONDON								
INNER LONDON								
Camden	N/A	N/A	N	N	N/A	N/A	N/A	N/A
City of London	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Hackney	Health and Wellbeing Profile	2012	Y	Y (Children Travellers' Health Needs Assessment, 2009)	Poorer health outcomes; high rates of maternal mortality, infant mortality, perinatal death, low birthweight, child accidents, infectious disease; low rates of immunisation and breastfeeding; high rates of anxiety and depression; high levels of smoking and alcohol consumption; domestic violence	Most registered with GP	Marginalisation and exclusion; poor literacy; racism and lack of understanding of GT needs by health professionals	N/A

Hammersmith and Fulham	Child Poverty in Hammersmith and Fulham, Kensington and Chelsea, and Westminster	2014	N	N	Particularly at risk of poor health outcomes (correlated with poverty); children more likely to experience early death, poor childhood development and limited uptake and access to health services	N/A	N/A	N/A
Haringey	Roma and Irish Traveller Needs Assessment	2013	Y	Y (panel focusing on GRT men's health)	Worse health; lower life expectancy; higher rates of limiting long term illness; poor access to maternity and antenatal provision; higher fates of teenage pregnancy; low uptake of immunisation; poor oral health; poor access to health services; focus on outcomes (maternal health, illness, life expectancy, immunisation, mental health, substance misuse, oral health); draws connections between movement and health	Less likely to engage with primary care services; more likely to present late in maternity services; tendency to view minor health complaints as insignificant and self-medicate; importance of word of mouth and reliance on trusted relationships	Reluctance to self-identify due to fear of discrimination; issues of registering without a permanent address; lack of trust; language barriers; health professionals' behaviour; literacy issues and inability to fill in forms; more recent migration of CEE Roma may make it particularly difficult to access services	Retain and develop a culturally sensitive 'whole family' approach; increase interagency collaboration; require all council systems and hospitals to record data on Roma and Irish Travellers; provide a handbook for recording medical information; raise cultural awareness among health care staff; commission a dedicated Roma and Irish Traveller primary health care focused service
Islington	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Kensington and Chelsea	See H&F	N/A	N	N	N/A	N/A	N/A	N/A
Lambeth	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Lewisham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Newham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Southwark	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Tower Hamlets	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Wandsworth	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Westminster	See H&F	N/A	N	N	N/A	N/A	N/A	N/A
OUTER LONDON								
Barking and Dagenham	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Barnet	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Bexley	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Brent	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Bromley	Gypsies and Travellers and Travelling Showpeople Accommodation Evidence Base Paper	2014	N	N	N/A	N/A	N/A	N/A
Croydon	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Ealing	JSNA: Ealing Population Characteristics	2014	Y	N	N/A	N/A	N/A	N/A
Enfield	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Greenwich	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Harrow	Harrow Joint Strategic Needs Assessment	2015-20	N	N	Gypsy Traveller children less likely to be vaccinated	N/A	N/A	N/A

Havering	Havering Joint Strategic Needs Assessment	2012	N	N	N/A	N/A	N/A	N/A
Hillingdon	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Hounslow	Summary of Health and Wellbeing Needs in Hounslow: Joint Strategic Needs Assessment	2014	N	N	N/A	N/A	N/A	Need for increased monitoring of local health inequalities
Kingston upon Thames	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Merton	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Redbridge	JSNA: Demographic Change and Deprivation		N	N	Travellers suffer disproportionately from health inequalities associated with income, level of education and work status	N/A	N/A	N/A
Richmond upon Thames	Gypsy and Traveller Health Needs Assessment	2016	N	Y (semi-structured interviews with Gypsies and Travellers)	Lower life expectancy (though may be closer to general population life expectancy in areas where GT have access to secure permanent sites and adequate medical care); higher frequency of chronic conditions; depression and anxiety common - stigma associated with mental illness; higher suicide rates; more children than age-sex matched comparators;	Reluctance to engage with services where there is a lack of continuity; reliance on television and word of mouth for health information; tendency to use A&E while travelling	Cultural tendency not to seek service for conditions deemed 'minor'; stigma attached to certain conditions; lack of knowledge of preventative services	N/A

					lifestyle health risk factors; low expectations of good health; poor uptake of preventative services			
Sutton	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Waltham Forest	N/A	N/A	N	N	N/A	N/A	N/A	N/A
SOUTH EAST								
Bracknell Forest	Gypsy, Roma and Traveller People	N/A	N	N	Poorer health status and more self-reported symptoms of ill health than other UK resident English speaking ethnic minority groups and economically disadvantaged white UK residents	N/A	N/A	Engage the traveller community within its own environment
Brighton and Hove	Brighton and Hove JSNA	2013	N	Y (2012 health needs assessment)	Life expectancy 15-25 years less than general population; infant mortality rate is 1 in 20; 38% have a long-term illness; higher levels of anxiety	Poor access to health services	N/A	N/A
Buckinghamshire	Joint Strategic Needs Assessment	2010	N	Y (interviews carried out as part of accommodation needs assessment)	Low uptake of childhood immunisation; epidemic of measles and mumps; worse self-reported health	80% registered with a GP; fewer than 50% registered with dentist; often use A&E as a result of difficulties with registering with local practices	N/A	N/A
East Sussex	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Hampshire	Gypsies and Travellers	2013	N	N	Health inequalities when compared with other deprived or excluded groups; estimated that G/T die 10-12 years younger than the majority population; no robust local data on prevalence of illness and lifestyle; high prevalence of long-term conditions; higher prevalence of risky lifestyle behaviours; higher levels of domestic abuse; higher levels of dental health problems and fewer dental check-ups; increased risk of preventable childhood infectious disease; high proportion of learning disabilities	N/A	N/A	County-wide strategic partnership to oversee and enable reduction of modifiable inequalities; improve outcomes in education; provide appropriate accommodation; tackle hate crime; improve access to employment
Isle of Wight	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Kent	Kent Gypsy, Roma and Traveller Population JSNA Chapter Update 2014	2014	Y	Yes (interviews conducted with GRT population, with members of the Gypsy population trained as community researchers)	Exceptional level of social exclusion; poor levels of health compared with other marginalised groups; high infant mortality rates; difficulties in accessing healthcare; low childhood immunisation	Cultural pride in self-reliance; a tolerance of chronic ill health;fear of terminal diagnoses; avoidance of screening; more trust in family carers than professional care; word spreads	Lack of trust; poor quality of care (leading to disinclination to use services); preference for treatment at home; receptionists assume that everyone can read and write	Introduce services to change lifestyle; improve coverage in ethnic monitoring; improve access to dental services

					uptake; admission to hospital with cardiovascular disease, respiratory disease	about experiences in health systems		
Medway	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Milton Keynes	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Oxfordshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Portsmouth	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Reading	Joint Strategic Needs Assessment for Reading Borough Council	2013	N	Y (2012 Gypsy, Roma and Traveller health survey)	Arthritis, diabetes and asthma; mental health issues; lifestyle and losing weight	Concerns with continuity of care	Difficulties with reception staff; temporary residency a concern when registering	N/A
Slough	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Southampton	Southamption JSNA - Inequalities Profiles: Gypsies and Travellers	2014	Y	N	Significant inequalities in health outcomes, particularly life expectancy (10-50% lower than general population), infant mortality and maternal mortality; reported higher rates of bad or very bad health	N/A	Poor access to health services	N/A

Surrey	JSNA Chapter: Gypsies, Roma and Travellers	2011	Y	Y (needs assessment conducted; Surrey Gypsy, Roma and Traveller Community Relations Forum set up in 1998; Gypsy Liaison Officers employed through borough council)	Health problems associated with stress or challenges of site provision; smoking, high blood pressure, anxiety/depression ; poor health compared to other disadvantaged groups; lower life expectancy; asthma, diabetes, bronchitis significantly higher than among the general population	Anecdotal reports of reluctance among a handful of practices - does not address how GRT communities use services	Institutional discrimination and' lack of meaningful engagement with the GRT community'; shortage of accommodation; lack of cultural sensitivity among service providers; use of inappropriate written communication; transient lifestyles; low expectations of health; isolated locations of GRT sites	Cultural awareness training for frontline staff; address the health, social and educational needs of GRT children and young people; need to focus on wider determinants of health and social wellbeing (in particular accommodation); joint working between statutory organisations, voluntary organisations and the GRT community
West Berkshire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
West Sussex	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Windsor and Maidenhead	Joint Strategic Needs Assessment	2012	N	N	N/A	N/A	N/A	N/A
Wokingham	Joint Strategic Needs Assessment for Wokingham Borough Council	2012/13	Y	Y (2012 Gypsy, Roma and Traveller health survey)	Worse health outcomes, poorer health status than disadvantaged white residents; more problems with mobility, self-care, usual activities, pain or discomfort and anxiety and depression	Increased use of emergency services; need for support in asking the right questions in health care settings	seems to be access problems to primary care services'; difficulties with reception staff in GP practices; low availability of GP appointments	N/A

SOUTH WEST								
Bath and North East Somerset	Travellers and Gypsy Travellers		Y	Y (use of community interviewers)	Poorer health than age-sex matched comparators; higher occurrence of anxiety/depression, respiratory problems, heart disease, diabetes and arthritis; more carers; mortality rate up to one and a half times that of the settled population; smoking, anxiety and depression main health concerns	30% of respondents would only use a doctor/hospital if someone in their family was seriously ill or injured; 21% would visit a GP while using alternative medicine at the same time; men less like to visit GP than women; unwillingness to discuss subjects such as sexual health and substance (mis)use; issues with GP registration on unregistered sites	Continuity of care for mobile communities; lack of understanding and clashes over compliance with treatment; challenges of working on sites/towpaths; lack of health service provider confidence in dealing with communities; lack of practitioners' cultural knowledge; poor knowledge of where and how to access specialist advice; lack of fixed address; requests to see a same-sex doctor not taken seriously	Health card to be provided to travellers to indicate a need for help with filling forms; cultural awareness training for frontline staff; better advice for registering patients with no fixed abode; train community health advocates; development of culturally appropriate health resources; in-reach services to sites and towpaths; training for health professionals on engaging service users; hand held medical records; specific attention to domestic abuse and substance misuse
Bournemouth	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Bristol, City of	N/A	N/A	N	N	N/A	N/A	N/A	N/A

Cornwall	Health Equity Audit: Access to Primary Care for Black and Minority Ethnic Groups and Migrant Workers	2011	N	Y (Gypsy and Traveller Survey)	Health inequalities more pronounced than any other socially deprived or excluded groups; greater number of colds and minor infections among children; problems with nerves, arthritis, asthma, heart disease, chest pain, chronic cough, anxiety and depression	Attending follow-up appointments comes second to search for accommodation; use of A&E as a result of late reporting of illness; GP registration high among GT with permanent accommodation; frequent non-attendance of appointments; reluctance to undertake cervical cancer screening	Problems with registering without documentation; access to transport; language and literacy; lack of interpreters	N/A
Devon	N/A		N	N	N/A	N/A	N/A	N/A
Dorset	Joint Health and Wellbeing Strategy for Dorset	2013-2016	N	N	Higher mortality rate, including maternal and infant mortality	N/A	N/A	N/A
Gloucestershire	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Isles of Scilly	N/A	N/A	N	N	N/A	N/A	N/A	N/A
North Somerset	Joint Strategic Needs Assessment: Gypsies and Travellers	N/A	N	Y (questionnaire survey on health needs)	Considerably poorer health status; higher rates of infant mortality; higher maternal death rates; more problems across 5 indicators; higher prevalence of respiratory problems; higher prevalence of depression and anxiety; outbreak of measles in Gypsy Traveller population; stroke,	Lack of interest in offers to engage in preventative services; high level of registration with GPs but less with dentists; home care for terminally ill preferred to hospital care; difficult to ensure continuity of care to mobile population	N/A	Engage community with existing services by training staff in culturally appropriate service provision; know local numbers of GT families; increase registration with dentists and optometrists

					cancer, diabetes less common; higher prevalence of eye problems; higher smoking rates			
Plymouth	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Poole	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Somerset	N/A	N/A	N	N	N/A	N/A	N/A	N/A
South Gloucestershire	South Gloucestershire Joint Strategic Needs Assessment	2013	N	N	N/A	More likely to experience poverty than other groups	N/A	N/A
Swindon	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Torbay	N/A	N/A	N	N	N/A	N/A	N/A	N/A
Wiltshire	Joint Strategic Needs Assessment: Wiltshire	2013	N	N	Methods for meeting increased health needs can affect inequality	N/A	N/A	N/A

JSNA 2016 Data – Social determinants

N/A = No data/not relevant to GRT

Local authority	Descriptions of GRT culture/history	Housing	Education	Employment	Community safety
NORTH EAST					
Darlington	N/A	No socially rented or unauthorised pitches; living in a trailer or council site associated with illness; size of accommodation often unsuitable for family size	N/A	N/A	N/A

Durham	N/A	Conditions on sites can have detrimental effects on health; lack of amenities had a direct impact on health concerns	N/A	N/A	N/A
Gateshead	N/A	N/A	N/A	N/A	N/A
Hartlepool	N/A	No socially rented or unauthorised pitches; living in a trailer or council site associated with illness; size of accommodation often unsuitable for family size	Often drop out between 11 and 13 years of age; less than 10% of GT children obtained five GCSEs A*-C grades (including English and maths), compared to a national average of 53%; elective home education	Self-employment common	Underreporting of hate crime
Middlesbrough	N/A	N/A	N/A	N/A	N/A
Newcastle upon Tyne	N/A	N/A	N/A	N/A	N/A
North Tyneside	N/A	N/A	N/A	N/A	N/A
Northumberland	N/A	N/A	N/A	N/A	N/A
Redcar and Cleveland	Expectation for males to be economically active at a young age and for females to care for the home and children	Living in a trailer or council site associated with illness; size of accommodation often unsuitable for family size; RECOMMENDATIONS: fund all site maintenance costs, increase number of authorised encampments, allow residents to assist in design of community facilities	Often drop out between 11 and 13 years of age; less than 10% of GT children obtained five GCSEs A*-C grades (including English and maths), compared to a national average of 53%; elective home education	Self-employment common	Underreporting of hate crime
South Tyneside	N/A	N	N/A	N/A	N/A

Stockton-on-Tees	Domestic violence is common; 'more likely to experience social exclusion'	Shortage of appropriate accommodation; those living in trailer or on council site more likely to have long-term illness; larger than average size families often live in unsuitable accommodation	Poor school attendance and high illiteracy rates; often drop out of full-time education between 11 and 13 years old; les than 10% obtained 5 GCSEs compared to national average of 53%; more likely identified as having special educational needs	Low employment rates; high poverty; income reliant on self-employment	Focus on unauthorised encampments
Sunderland	N/A	N/A	N/A	N/A	N/A
NORTH WEST					
Blackburn with Darwen	N/A	N/A	N/A	N/A	N/A
Blackpool	N/A	N/A	N/A	N/A	N/A
Bolton	N/A	N/A	N/A	N/A	N/A
Bury	N/A	One authorised site, with more families living in permanent accommodation; unauthorised sites	N/A	N/A	N/A
Cheshire East	N/A	N/A	N/A	N/A	N/A
Cheshire West and Chester	N/A	N/A	N/A	N/A	N/A
Cumbria	Self-reliance and stoicism; specific gender roles with males seen as providers; women tend to take responsibility for family health; illiteracy seen as inevitable consequence of travelling way of life; stigma attached to mental health issues	Just over half lived in permanent housing (59 in houses/flats v. 43 in caravans/trailers); health professionals tended to identify them by address; highest levels of depression, stress and anxiety reported by Travellers living in permanent accommodation; perception that most Travellers live in caravans led housed Travellers to feel 'invisible' to health services and local authorities	Bullying commonly cited as a reason for not attending secondary school; boys tend to work with their fathers from the age of 12; pupils who need additional attention may move on before they can receive help	N/A	N/A

Halton	N/A	N/A	N/A	N/A	N/A
Knowsley	N/A	No current provision of pitches; planned provision for future pitches	N/A	N/A	N/A
Lancashire	N/A	N/A	N/A	N/A	N/A
Liverpool	N/A	N/A	N/A	N/A	N/A
Manchester	N/A	N/A	N/A	N/A	N/A
Oldham	N/A	N/A	N/A	N/A	N/A
Rochdale	N/A	N/A	N/A	N/A	N/A
Salford	Trust in professionals working with families is vital; men reluctant to engage with health services	Difficulties in finding suitable housing can result in delays in accessing education	GRT parents place their trust in schools and school staff to provide a safe environment; context of poor past experiences of education; reluctance to move on to secondary education	Effectiveness of work experience for GRT young people	N/A
Sefton	N/A	N/A	N/A	N/A	N/A
St. Helens	N/A	N/A	N/A	N/A	N/A
Stockport	N/A	N/A	N/A	N/A	N/A
Tameside	N/A	N/A	N/A	N/A	N/A
Trafford	N/A	N/A	N/A	N/A	N/A
Warrington	N/A	N/A	N/A	N/A	N/A
Wigan	N/A	64 caravans in the borough	N/A	N/A	N/A
Wirral	N/A	N/A	N/A	N/A	N/A
YORKSHIRE AND THE HUMBER					
Barnsley	N/A	N/A	N/A	N/A	N/A
Bradford	N/A	N/A	N/A	N/A	N/A
Calderdale	N/A	N/A	N/A	N/A	N/A

Doncaster	N/A	N/A	N/A	N/A	N/A
East Riding of Yorkshire	N/A	N/A	N/A	N/A	N/A
Kingston Upon Hull, City of	N/A	N/A	N/A	N/A	N/A
Kirklees	N/A	N/A	N/A	N/A	N/A
Leeds	N/A	N/A	N/A	N/A	N/A
North East Lincolnshire	N/A	N/A	N/A	N/A	N/A
North Lincolnshire	N/A	N/A	N/A	N/A	N/A
North Yorkshire	N/A	N/A	N/A	N/A	N/A
Rotherham	N/A	N/A	N/A	N/A	N/A
Sheffield	Overview of origins in India, experiences of discrimination in Slovakia and motivations for settling in the UK; stigmatisation of mental health issues	High rates of overcrowding, with small homes shared by extended family groups; poor conditions in rental properties	Discrimination, stereotyping and racially motivated abuse at school, which are linked to high rates of school exclusion; high percentage in special needs education, largely due to high rates of hearing loss; gaps in education due to frequent returns to Slovakia	Difficulties of obtaining employment in Slovakia	N/A
Wakefield	N/A	N/A	N/A	N/A	N/A
York	N/A	N/A	N/A	N/A	N/A
EAST MIDLANDS					
Derby	N/A	N/A	N/A	N/A	N/A
Derbyshire	N/A	N/A	N/A	N/A	N/A
Leicester	N/A	N/A	N/A	N/A	N/A
Leicestershire	N/A	N/A	N/A	N/A	N/A
Lincolnshire	N/A	N/A	N/A	N/A	N/A
Northamptonshire	N/A	N/A	N/A	N/A	N/A
Nottingham	N/A	N/A	N/A	N/A	N/A
Nottinghamshire	N/A	Need for more permanent pitches; lack of sanitary facilities	N/A	N/A	N/A
Rutland	N/A	N/A	N/A	N/A	N/A

WEST MIDLANDS					
Birmingham	N/A	N/A	N/A	N/A	N/A
Coventry	N/A	N/A	N/A	N/A	N/A
Dudley	N/A	N/A	N/A	N/A	N/A
Herefordshire	N/A	N/A	N/A	N/A	N/A
Sandwell	N/A	N/A	N/A	N/A	N/A
Shropshire	N/A	N/A	N/A	N/A	N/A
Solihull	N/A	Shortage of sites	N/A	N/A	N/A
Staffordshire	N/A	N/A	N/A	N/A	N/A
Stoke-on-Trent	N/A	N/A	N/A	N/A	N/A
Telford and Wrekin	N/A	N/A	N/A	N/A	N/A
Walsall	N/A	N/A	N/A	N/A	N/A
Warwickshire	N/A	N/A	N/A	N/A	N/A
Wolverhampton	N/A	N/A	N/A	N/A	N/A
Worcestershire	N/A	N/A	N/A	N/A	N/A
EAST OF ENGLAND					
Bedford	N/A	N/A	N/A	N/A	N/A
Central Bedfordshire	Variations in travelling patterns and decision to travel	Increase in number of caravans locally, though percentage of caravans on authorised sites is half that of the overall region; data on numbers living in houses is not available; tenancy management and applying for housing/site vacancies difficult for Gypsies and Travellers (confusion about process, communication difficulties, poor literacy skills and lack of personal documentation); strategy for meeting unmet housing needs	Attainment significantly lower than general population - based on national statistics (local figures not available); higher absence rates (local figures include a Gypsy/Roma category); two part-time education liaison officers employed	Development of All Age Skills Strategy to ensure that employers' needs are met by local provision, while also meeting needs of individuals and communities	N/A

		in development			
Cambridgeshire	Living in a house associated with long-term illness and higher rates of anxiety; despite tradition of travelling, not all GRT groups currently travel	Different accommodation needs; those in settled housing may face challenges in maintaining tenancy, lack of support, racism and isolation; homelessness, forced eviction, mobility; overcrowding; poor housing conditions often associated with other forms of deprivation, including unemployment, ill health, poor education and social isolation; RECOMMENDATIONS: assess site provision, promote site management	All known Gypsies and Travellers access education at some point in the year; parental decision not to register children with a school; 'The decision not to register with a school is often actively taken by parents. These children and young people are being excluded from the opportunity to develop skills and knowledge that will equip them to participate fully and equally in society.'	Preference for self-employment; employment opportunities are limited due to lack of agricultural jobs	Underreporting of hate crime in the Traveller community
Essex	N/A	Has become common for Gypsy and Traveller families to live in more formal style housing; most living in caravans live on authorised public or private sites	N/A	N/A	N/A
Hertfordshire	N/A	N/A	N/A	N/A	N/A
Luton	N/A	N/A	N/A	N/A	N/A
Norfolk	N/A	N/A	N/A	N/A	N/A
Peterborough	N/A	Reports health status by site type (private authorised, unauthorised, council and no planning status specified)	N/A	N/A	N/A

Southend-on-Sea	Cultural preference for living in caravans; either pursue a nomadic way of life or have given up this way of life	Most live on sites that are either authority managed or private	N/A	N/A	N/A
Suffolk	N/A	N/A	N/A	N/A	N/A
Thurrock	N/A	N/A	N/A	N/A	N/A
LONDON					
INNER LONDON					
Camden	N/A	N/A	N/A	N/A	N/A
City of London	N/A	N/A	N/A	N/A	N/A
Hackney	Nomadic way of life; lack of cultural context for management of long term conditions	N/A	Vulnerable to not achieving best possible academic outcomes (due to mobility)	N/A	N/A
Hammersmith and Fulham	N/A	50+ families living on a K&C site, with more housed	20% fail to transfer from primary to secondary school	N/A	N/A
Haringey	Not a homogenous group; many maintain aspect of Romani language; purity rules, importance of family relationships; recommendation to promote Gypsy Roma Traveller History Month; encourage self-identification when accessing services	Overcrowding; significant numbers in bricks and mortar accommodation; low recorded numbers in social housing	Haringey has highest level of Roma students in London; low school attendance and participation in secondary education (product of bullying and discrimination); survey of head teachers; workshops and events to address misconceptions; many eligible pupils do not claim Free School Meals; tend to have higher levels of special educational needs	Number of Roma and Irish Travellers with qualifications of any kind is low; increased competition for work because of influx of migrants; discrimination from employers; little business start-up support; A2 restrictions	Youth Offending Roma caseload has doubled in the past year; evidence that petty criminal behaviour is higher
Islington	N/A	N/A	N/A	N/A	N/A
Kensington and Chelsea	N/A	N/A	N/A	N/A	N/A
Lambeth	N/A	N/A	N/A	N/A	N/A
Lewisham	N/A	N/A	N/A	N/A	N/A

Newham	N/A	N/A	N/A	N/A	N/A
Southwark	N/A	N/A	N/A	N/A	N/A
Tower Hamlets	N/A	N/A	N/A	N/A	N/A
Wandsworth	N/A	N/A	N/A	N/A	N/A
Westminster	N/A	N/A	N/A	N/A	N/A
OUTER LONDON					
Barking and Dagenham	N/A	N/A	N/A	N/A	N/A
Barnet	N/A	N/A	N/A	N/A	N/A
Bexley	N/A	N/A	N/A	N/A	N/A
Brent	N/A	N/A	N/A	N/A	N/A
Bromley	Culturally there is a strong onus placed upon self sufficiency	Lack of halting sites has led Gypsies and Travellers to settle, often in social housing	Boys encouraged to leave school early and work in the family business	N/A	Outlines enforcement measures for encampment sites
Croydon	N/A	N/A	N/A	N/A	N/A
Ealing	N/A	Deficit of caravan sites and rapid eviction from roadside sites	N/A	N/A	N/A
Enfield	N/A	N/A	N/A	N/A	N/A
Greenwich	N/A	N/A	N/A	N/A	N/A
Harrow	N/A	N/A	N/A	N/A	N/A
Havering	N/A	N/A	Children from travelling families less likely to attend school	N/A	N/A
Hillingdon	N/A	N/A	N/A	N/A	N/A
Hounslow	N/A	N/A	Those with Traveller heritage have lower levels of educational attainment	N/A	N/A
Kingston upon Thames	N/A	N/A	N/A	N/A	N/A
Merton	N/A	N/A	N/A	N/A	N/A
Redbridge	N/A	N/A	N/A	N/A	N/A

Richmond upon Thames	Stoicism and self-reliance; travelling a crucial part of community identity; family provide essential support mechanism	Difficult to assess housing needs	Low levels of literacy and education (nomadic lifestyle, financial deprivation, low aspiration for children's academic achievement poor attendance and bullying)	Preference for family-based employment and self-employment	N/A
Sutton	N/A	N/A	N/A	N/A	N/A
Waltham Forest	N/A	N/A	N/A	N/A	N/A
SOUTH EAST					
Bracknell Forest	Strong sense of identity, cultural traditions and family	Majority live in privately-owned or rented accommodation; others live on council sites	Majority of known school-age children attend school, small number educated at home; work to support families in the transition to secondary education	N/A	N/A
Brighton and Hove	N/A	2/3 live in settled housing; lack of suitable stopping places; higher heating costs and inability to claim winter fuel allowance	Lower GCSE attainment	Higher employment rates locally than nationally	N/A
Buckinghamshire	N/A	N/A	Many drop out of education before beginning secondary school	N/A	N/A
East Sussex	N/A	N/A	N/A	N/A	N/A
Hampshire	N/A	3/4 live in bricks and mortar accommodation, with 25% living on authorised local authority or private sites	Reports national education figures	N/A	N/A
Isle of Wight	N/A	N/A	N/A	N/A	N/A
Kent	Reluctance to disclose ethnicity for fear of discrimination	Approximately half of population estimated to live in housed accommodation (but data on these communities, particularly Roma, is still a problem)	N/A	N/A	N/A

Medway	N/A	N/A	N/A	N/A	N/A
Milton Keynes	N/A	N/A	N/A	N/A	N/A
Oxfordshire	N/A	N/A	N/A	N/A	N/A
Portsmouth	N/A	N/A	N/A	N/A	N/A
Reading	N/A	N/A	N/A	N/A	N/A
Slough	N/A	N/A	N/A	N/A	N/A
Southampton	N/A	Poor accommodation	Poor access to education; Gypsies and Irish Travellers had the highest proportion with no qualifications	Gypsies and Irish Travellers had lowest proportion of respondents who were economically active; over half of those who were economically active were employed, 20% were unemployed; elementary occupations most common type of employment	N/A
Surrey	Strong cultural identity, which allows development of social capital and existing community assets; strong sense of fatalism; cultural attitudes about vaccinations and immunisations can lead to health problems	Significant shortage in accommodation	Low school attendance and high levels of illiteracy; significant gaps in educational attainment	GRT Strategy describes workforce development	N/A
West Berkshire	N/A	N/A	N/A	N/A	N/A
West Sussex	N/A	N/A	N/A	N/A	N/A
Windsor and Maidenhead	N/A	N/A	Increased substance abuse risk associated with lower educational attainment	N/A	N/A
Wokingham	N/A	Gives statistics on numbers of caravans	N/A	N/A	N/A
SOUTH WEST					

Bath and North East Somerset	Distinct culture, lifestyle and traditions	Relatively high levels of satisfaction with living conditions (lower among Gypsies); problems with access to water and heating	0.01% of primary and secondary students' ethnic classification in B&NES was Gypsy/Roma; more likely to have special educational needs	N/A	N/A
Bournemouth	N/A	N/A	N/A	N/A	N/A
Bristol, City of	N/A	N/A	N/A	N/A	N/A
Cornwall	Nomadic; males tend not to talk about health issues	N/A	N/A	N/A	N/A
Devon	N/A	N/A	N/A	N/A	N/A
Dorset	N/A	Four designated sites	N/A	N/A	N/A
Gloucestershire	N/A	N/A	N/A	N/A	N/A
Isles of Scilly	N/A	N/A	N/A	N/A	N/A
North Somerset	Stoicism and fatalistic acceptance of health conditions; living in bricks and mortar accommodation culturally unacceptable	Need for additional residential pitches; lack of sites leads to overcrowding	Particular issues with pre-school provision and secondary school retention; lower formal education after primary school	N/A	N/A
Plymouth	N/A	N/A	N/A	N/A	N/A
Poole	N/A	N/A	N/A	N/A	N/A
Somerset	N/A	N/A	N/A	N/A	N/A
South Gloucestershire	N/A	N/A	Lower educational attainment	N/A	N/A
Swindon	N/A	N/A	N/A	N/A	N/A
Torbay	N/A	N/A	N/A	N/A	N/A
Wiltshire	N/A	Funding to increase number of pitches	N/A	N/A	N/A

Appendix 9: 2018 Policy analysis update

JSNA 2018 Data – Health

N/A = No data/not relevant to GRT

Local authority	Gypsy/Roma population in schools	Inclusion in JSNA (Y/N)	Extent of JSNA inclusion	Acknowledgement of CEE Roma (Y/N)	Health profile
NORTH EAST	**740**				
Darlington	124	Y	JSNA section	N	Poorer self-reported health; lower educational attainment; low levels of economic activity
Durham	117	Y	JSNA section	N	Lower life expectancy; lower educational attainment; high levels of anti-GRT hate crime; lack of data on GRT population
Gateshead	16	Y	JSNA section	N	Impacts of changes in planning policy on Traveller sites
Hartlepool	2	Y	1 sentence	N	No 'unmet needs' identified
Middlesbrough	114	N	N/A	N	N/A
Newcastle upon Tyne	294	N	N/A	N	N/A
North Tyneside	5	N	N/A	N	N/A
Northumberland	13	Y	JSNA section	N	None identified; provide data on population and caravan count
Redcar and Cleveland	16	N	N/A	N	N/A
South Tyneside	0	N	N/A	N	N/A
Stockton-on-Tees	35	Y	N/A	N	Shortage of appropriate accommodation; lack of confidence in using services;

					lack of data on GRT population
Sunderland	4	N	N/A	N	N/A
NORTH WEST	**1,111**				
Blackburn with Darwen	32	N	N/A	N	N/A
Blackpool	47	Y	JSNA section	N	Lack of site provision; overcrowding in bricks and mortar accommodation
Bolton	91	N	N/A	N	N/A
Bury	45	N	N/A	N	N/A
Cheshire East	83	N	N/A	N	N/A
Cheshire West and Chester	42	N	N/A	N	N/A
Cumbria	66	Y	1 sentence	N	None identified; included G/T in equality impact assessment
Halton	8	N	N/A	N	N/A
Knowsley	2	N	N/A	N	N/A
Lancashire	164	N	N/A	N	N/A
Liverpool	48	N	N/A	N	N/A
Manchester	200	Y	Included in BME JSNA chapter	Y	General health inequalities; higher rates of lung cancer in Roma communities; difficulties of accessing interpreters
Oldham	141	Y	1 sentence	N	None identified; mentions Gypsy/Roma population size
Rochdale	19	Y	1 sentence	N	Lack of data on Traveller population
Salford	29	Y	JSNA chapter	Y	Lack of professional understanding of GRT culture; low levels of literacy; difficulties of communicating via interpreters
Sefton	4	Y	1 sentence	N	Harder to meet G/T needs
St. Helens	9	N	N/A	N	N/A
Stockport	4	Y	1 sentence	N	None identified; G/T identified as a vulnerable group

Tameside	11	Y	1 sentence	N	Low immunisation uptake
Trafford	9	N	N/A	N	N/A
Warrington	18	N	N/A	N	N/A
Wigan	37	N	N/A	N	N/A
Wirral	2	N	N/A	N	N/A
YORKSHIRE AND THE HUMBER	**3,026**				
Barnsley	34	Y	JSNA section	N	Poorer health than population averages; higher levels of breathing problems, anxiety and chest pain
Bradford	651	N	N/A	N	N/A
Calderdale	81	N	N/A	N	N/A
Doncaster	254	N	N/A	N	N/A
East Riding of Yorkshire	35	N	N/A	N	N/A
Kingston Upon Hull, City of	58	Y	2 sentences	N	Isolation of communities; poorer self-reported health
Kirklees	45	N	N/A	N	N/A
Leeds	467	Y	1 sentence	N	Makes reference to 'specific needs'
North East Lincolnshire	7	N	N/A	N	N/A
North Lincolnshire	31	N	N/A	N	N/A
North Yorkshire	145	Y	JSNA chapter	N	Poorer self-reported health; lower life expectancy; higher rates of chronic disease
Rotherham	346	Y	1 sentence	Y	None identified; Roma identified as largest 'Other White' community
Sheffield	794	Y	Dedicated Slovak Roma Health Needs Assessment	Y	Lower life expectancy; high levels of obesity; high rates of hepatitis B; high risk of tuberculosis; high rates of hearing loss; higher rates of primary congenital glaucoma; diagnosis rates for mental health issues likely underrepresents actual

					numbers
Wakefield	41	N	N/A	N	N/A
York	37	N	N/A	N	N/A
EAST MIDLANDS	**1,193**				
Derby	430	Y	1 sentence	N	Insufficient planning permission for G/T sites
Derbyshire	36	N	N/A	N	N/A
Leicester	189	N	N/A	N	N/A
Leicestershire	77	Y	JSNA chapter	N	Low levels of educational attainment; low knowledge of healthy diet, sexual health, immunisation and cancer screening; high levels of anxiety, depression and suicide
Lincolnshire	78	N	N/A	N	N/A
Northamptonshire	93	N	N/A	N	N/A
Nottingham	135	Y	5 sentences	Y	Lower likelihood of accessing health services; high rates of teenage pregnancy; insecure tenancies and poor housing standards
Nottinghamshire	155	Y	JSNA section	N	Lack of data on G/T population; higher rates of lung cancer, respiratory disease and mental illness; more likely to access health services 'inappropriately'
Rutland	0	N	N/A	N	N/A
WEST MIDLANDS	**1,886**				
Birmingham	534	N	N/A	N	N/A
Coventry	270	N	N/A	N	N/A
Dudley	71	N	N/A	N	N/A
Herefordshire	39	Y	1 sentence	N	None identified; G/T identified as largest 'Other

					White' community
Sandwell	48	N	N/A	N	N/A
Shropshire	59	N	N/A	N	N/A
Solihull	11	Y	1 sentence	N	Shortage of authorised G/T sites
Staffordshire	112	N	N/A	N	N/A
Stoke-on-Trent	90	N	N/A	N	N/A
Telford and Wrekin	20	N	N/A	N	N/A
Walsall	80	N	N/A	N	N/A
Warwickshire	129	N	N/A	N	N/A
Wolverhampton	145	N	N/A	N	N/A
Worcestershire	278	N	N/A	N	N/A
EAST OF ENGLAND	**1,588**				
Bedford	34	Y	1 sentence	N	Carers from G/T communities are not known to services
Central Bedfordshire	85	N	N/A	N	N/A
Cambridgeshire	316	Y	JSNA section	N	Need for greater monitoring of access to health services, early intervention, health promotion and mental health; carers from G/T communities are not known to services
Essex	237	N	N/A	N	N/A
Hertfordshire	196	N	N/A	N	N/A
Luton	116	Y	1 sentence	N	Low levels of immunisation amogst G/T children
Norfolk	147	N	N/A	N	N/A
Peterborough	160	Y	1 sentence	N	None identified; G/T acknowledged as part of 'Other White' group
Southend-on-Sea	15	N	N/A	N	N/A

Suffolk	235	Y	JSNA chapter	Y	Lower life expectancy; high rates of long-term illness; experiences of racism and discrimination; mistrust of wider population; limited data on European Roma health
Thurrock	47	N	N/A	N	N/A
LONDON	**1,051**				
INNER LONDON	**239**				
Camden	4	N	N/A	N	N/A
City of London	0	Y	1 sentence	N	None identified; very small population size
Hackney	24	Y	1 sentence	N	None identified; important for local councillors to engage with Traveller communities
Hammersmith and Fulham	13	N	N/A	N	N/A
Haringey	80	Y	JSNA chapter	Y	Reported largest Roma population in London; low levels of educational attainment; poorer health and lower life expectancy than other groups; low levels of engagement with primary care and maternity health services; overcrowding in housing
Islington	6	N	N/A	N	N/A
Kensington and Chelsea	3	N	N/A	N	N/A
Lambeth	11	N	N/A	N	N/A
Lewisham	13	N	N/A	N	N/A
Newham	63	N	N/A	N	N/A
Southwark	9	N	N/A	N	N/A
Tower Hamlets	5	N	N/A	N	N/A
Wandsworth	6	N	N/A	N	N/A
Westminster	2	N	N/A	N	N/A
OUTER LONDON	**812**				

Barking and Dagenham	107	N	N/A	N	N/A
Barnet	4	N	N/A	N	N/A
Bexley	94	N	N/A	N	N/A
Brent	35	N	N/A	N	N/A
Bromley	94	Y	JSNA section	N	G/T tend to experience poorer health outcomes; provides data on G/T accommodation
Croydon	39	N	N/A	N	N/A
Ealing	32	Y	JSNA section	Y	Limited site provision; evictions from encampments; identifies migration and language profiles of European Roma migrants
Enfield	45	N	N/A	N	N/A
Greenwich	61	N	N/A	N	N/A
Harrow	11	Y	1 sentence	N	G/T children less likely to be vaccinated
Havering	29	Y	JSNA section	N	None identified; data provided on caravan counts
Hillingdon	29	N	N/A	N	N/A
Hounslow	24	N	N/A	N	N/A
Kingston upon Thames	26	Y	JSNA chapter	Y	Poorer health and lower life expectancy compared to other ethnic minority groups; low childhood immunisation rates; high rates of life-limiting long-term illness; high levels of illiteracy; poor quality accommodation; lack of knowledge of mainstream services
Merton	23	N	N/A	N	N/A
Redbridge	87	N	N/A	N	N/A
Richmond upon Thames	5	N	N/A	N	N/A
Sutton	20	N	N/A	N	N/A
Waltham Forest	47	N	N/A	N	N/A

SOUTH EAST	**3,215**				
Bracknell Forest	18	Y	JSNA chapter	N	Poorer self-reported ill health; lack of national data on G/T health; need to engage the community 'within its own environment'
Brighton and Hove	6	Y	JSNA chapter	N	Poorer health than general population; lower life expectancy; difficulties of accessing health services; low levels of education attainment; high levels of unemployment; stresses related to social stigmatisation of identity
Buckinghamshire	106	N	N/A	N	N/A
East Sussex	128	N	N/A	N	N/A
Hampshire	309	N	N/A	N	N/A
Isle of Wight	2	N	N/A	N	N/A
Kent	1,248	Y	JSNA chapter	Y	Lower life expectancy; higher infant mortality and maternal mortality; poorer self-reported health; higher rates of respiratory disease; lower childhood immunisation rates; lack of data on Roma migrant communities
Medway	152	N	N/A	N	N/A
Milton Keynes	16	N	N/A	N	N/A
Oxfordshire	71	N	N/A	N	N/A
Portsmouth	27	N	N/A	N	N/A
Reading	5	Y	JSNA chapter	N	Poorer health; lower life expectancy; impact of accommodation insecurity on physical and mental health; racism and discrimination
Slough	130	N	N/A	N	N/A
Southampton	34	N	N/A	N	N/A

Surrey	494	Y	JSNA section	N	Underreporting of G/T population; high rates of infant mortality; young marriages
West Berkshire	51	Y	JSNA chapter	N	Poorer health outcomes; higher rates of self-reported ill health; low levels of access to maternity, GP, sexual health, smoking cessation, dentistry, mental health, drug and alcohol services; high rates of long-term health conditions; low levels of educational attainment; need for GRT to be included in JSNAs for **all** local authorities
West Sussex	244	Y	JSNA section	N	Review of accommodation needs assessment; travelling and moves into bricks and mortar accommodation can be both beneficial and detrimental to health
Windsor and Maidenhead	81	Y	JSNA chapter	N	Poorer health status and more self-reported symptoms of ill health; high rates of respiratory disease; high rates of mental ill health; difficulties accessing GP; services; review of accommodation needs assessment; discontinuation of health visiting services to G/T communities; low levels of educational attainment
Wokingham	93	Y	JSNA chapter	N	Lower life expectancy; poorer mental health and higher rates of suicide; poor infant and maternal outcomes; high rates of long-term illness; high rates of respiratory disease; high prevalence of diabetes
SOUTH WEST	**767**				
Bath and North East Somerset	2	Y	JSNA chapter	N	Lack of service provision; barrier to health service registration arising from no fixed address; high rates of

					mental health issues; high rates of mobility issues; low levels of educational attainment; low levels of literacy
Bournemouth	5	N	N/A	N	N/A
Bristol, City of	39	N	N/A	N	N/A
Cornwall	80	N	N/A	N	N/A
Devon	83	N	N/A	N	N/A
Dorset	50	N	N/A	N	N/A
Gloucestershire	167	N	N/A	N	N/A
Isles of Scilly	.	N	N/A	N	N/A
North Somerset	30	N	N/A	N	N/A
Plymouth	11	N	N/A	N	N/A
Poole	19	N	N/A	N	N/A
Somerset	121	N	N/A	N	N/A
South Gloucestershire	19	Y	JSNA section	N	None identified; cites population and caravan count data
Swindon	12	Y	1 sentence	N	GRT experience bias and hostility
Torbay	0	N	N/A	N	N/A
Wiltshire	129	N	N/A	N	N/A

Comparisons of 2016 and 2018 JSNA Data

Local authority	Inclusion of GRT – 2016	Inclusion of GRT – 2018	Acknowledgement of CEE Roma – 2016	Acknowledgement of CEE Roma – 2018
NORTH EAST				
Darlington	Y	Y	N	N
Durham	Y	Y	N	N
Gateshead	N	Y	N	N
Hartlepool	Y	Y	N	N
Middlesbrough	Traveller JSNA 'under development'	N	N	N
Newcastle upon Tyne	N	N	N	N
North Tyneside	N	N	N	N
Northumberland	N	Y	N	N
Redcar and Cleveland	Y	N	N	N
South Tyneside	N	N	N	N
Stockton-on-Tees	Y	Y	N	N

Sunderland	N	N	N	N
NORTH WEST				
Blackburn with Darwen	N	N	N	N
Blackpool	N	Y	N	N
Bolton	N	N	N	N
Bury	Y	N	N	N
Cheshire East	N	N	N	N
Cheshire West and Chester	N	N	N	N
Cumbria	Y	Y	Y	N
Halton	N	N	N	N
Knowsley	Y	N	N	N
Lancashire	N	N	N	N
Liverpool	N	N	N	N
Manchester	N	Y	N	Y
Oldham	N	Y	N	N
Rochdale	N	Y	N	N
Salford	Y	Y	Y	Y
Sefton	N	Y	N	N
St. Helens	N	N	N	N
Stockport	N	Y	N	N
Tameside	Y	Y	N	N
Trafford	N	N	N	N
Warrington	N	N	N	N
Wigan	Y	N	Y	N
Wirral	N	N	N	N
YORKSHIRE AND THE HUMBER				
Barnsley	Y	Y	N	N
Bradford	N	N	N	N

Calderdale	N	N	N	N
Doncaster	N	N	N	N
East Riding of Yorkshire	Links to FFT G/T inclusion reports	N	N	N
Kingston Upon Hull, City of	N	Y	N	N
Kirklees	N	N	N	N
Leeds	N	Y	N	N
North East Lincolnshire	N	N	N	N
North Lincolnshire	N	N	N	N
North Yorkshire	N	Y	N	N
Rotherham	N	Y	N	Y
Sheffield	Y	Y	Y	Y
Wakefield	N	N	N	N
York	N	N	N	N
EAST MIDLANDS				
Derby	N	Y	N	N
Derbyshire	N	N	N	N
Leicester	N	N	N	N
Leicestershire	N	Y	N	N
Lincolnshire	N	N	N	N
Northamptonshire	N	N	N	N
Nottingham	N	Y	N	N
Nottinghamshire	Y	Y	N	N
Rutland	N	N	N	N
WEST MIDLANDS				
Birmingham	N	N	N	N
Coventry	N	N	N	N
Dudley	N	N	N	N

Herefordshire	N	Y	N	N
Sandwell	N	N	N	N
Shropshire	N	N	N	N
Solihull	Y	Y	N	N
Staffordshire	Y	N	N	N
Stoke-on-Trent	N	N	N	N
Telford and Wrekin	N	N	N	N
Walsall	N	N	N	N
Warwickshire	N	N	N	N
Wolverhampton	N	N	N	N
Worcestershire	N	N	N	N
EAST OF ENGLAND				
Bedford	N	Y	N	N
Central Bedfordshire	Y	N	Y	N
Cambridgeshire	Y	Y	Y	N
Essex	Y	N	N	N
Hertfordshire	N	N	N	N
Luton	Y	Y	N	N
Norfolk	N	N	N	N
Peterborough	Y	Y	N	N
Southend-on-Sea	Y	N	N	N
Suffolk	Y	Y	N	Y
Thurrock	N	N	N	N
LONDON				
INNER LONDON				
Camden	N	N	N	N
City of London	N	Y	N	N
Hackney	Y	Y	Y	N

Hammersmith and Fulham	Y	N	N	N
Haringey	Y	Y	Y	Y
Islington	N	N	N	N
Kensington and Chelsea	N	N	N	N
Lambeth	N	N	N	N
Lewisham	N	N	N	N
Newham	N	N	N	N
Southwark	N	N	N	N
Tower Hamlets	N	N	N	N
Wandsworth	N	N	N	N
Westminster	N	N	N	N
OUTER LONDON				
Barking and Dagenham	N	N	N	N
Barnet	N	N	N	N
Bexley	N	N	N	N
Brent	N	N	N	N
Bromley	Y	Y	N	N
Croydon	N	N	N	N
Ealing	Y	Y	Y	Y
Enfield	N	N	N	N
Greenwich	N	N	N	N
Harrow	Y	Y	N	N
Havering	Y	Y	N	N
Hillingdon	N	N	N	N
Hounslow	Y	N	N	N
Kingston upon Thames	N	Y	N	Y
Merton	N	N	N	N
Redbridge	Y	N	N	N
Richmond upon Thames	Y	N	N	N
Sutton	N	N	N	N

Waltham Forest	N	N	N	N
SOUTH EAST				
Bracknell Forest	Y	Y	N	N
Brighton and Hove	Y	Y	N	N
Buckinghamshire	Y	N	N	N
East Sussex	N	N	N	N
Hampshire	Y	N	N	N
Isle of Wight	N	N	N	N
Kent	Y	Y	Y	Y
Medway	N	N	N	N
Milton Keynes	N	N	N	N
Oxfordshire	N	N	N	N
Portsmouth	N	N	N	N
Reading	Y	Y	N	N
Slough	N	N	N	N
Southampton	Y	N	Y	N
Surrey	Y	Y	Y	N
West Berkshire	N	Y	N	N
West Sussex	N	Y	N	N
Windsor and Maidenhead	Y	Y	N	N
Wokingham	Y	Y	Y	N
SOUTH WEST				
Bath and North East Somerset	Y	Y	Y	N
Bournemouth	N	N	N	N
Bristol, City of	N	N	N	N
Cornwall	Y	N	N	N
Devon	N	N	N	N
Dorset	Y	N	N	N

Gloucestershire	N	N	N	N
Isles of Scilly	N	N	N	N
North Somerset	Y	N	N	N
Plymouth	N	N	N	N
Poole	N	N	N	N
Somerset	N	N	N	N
South Gloucestershire	Y	Y	N	N
Swindon	N	Y	N	N
Torbay	N	N	N	N
Wiltshire	Y	N	N	N

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