

**Gypsies and Travellers accessing primary health care:
interactions with health staff and requirements
for 'culturally safe' services.**

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TABLE OF CONTENTS

Abstract	vii
Acknowledgements	viii
CHAPTER 1 Introduction	
1.1 Background. My position and starting point as a researcher	1
1.2 Epistemological and Methodological background	3
1.3 Aims of the Thesis	4
1.4 Thesis structure	4
1.5 Pseudonyms and Anonymity	5
CHAPTER 2 Gypsies and Travellers in British Isles: Ethnic Identity	
Introduction	6
2.1. Who are Gypsies and Travellers?	6
2.1.1 Terminology and demography	6
2.1.2 Legal definitions	7
2.1.3 Gypsies and Travellers: current Numbers	8
2.1.4 Geographical distribution and types of accommodation	9
2.2 Social policy pertaining to Gypsies and Travellers	10
2.3 Debates about ‘Race’, Ethnicity, culture and health	11
2.3.1 ‘Race’	12
2.3.2 Ethnicity	16
2.3.3 Ethnic Identity	19
2.3.4 Culture	21
2.4 Gypsies and Travellers –Ethnic identity	26
2.4.1 Historical origins and notion of descent	26
2.4.2 Group identity and culture	36
2.4.3 Power and agency and tackling racism	40
2.4.4 Processes of exclusion and assimilation	41
2.5 Conclusion	46
CHAPTER 3 Health Inequalities	
Introduction	47
3.1 Definitions and meanings of health inequalities	47
3.2 Measurement and monitoring of health inequalities	51
3.3 Identification and classification of social groups	54
3.3.1 Socioeconomic classifications	54
3.3.2 Indices of deprivation	56
3.4 Explanations of health inequalities	58
3.4.1 Artefact explanations	58
3.4.2 Theories of natural or social selection	59
3.4.3 Cultural or behavioural selection	59
3.4.4 Material or structuralist selection	59

3.5	Social determinants of health	60
3.5.1	Psychosocial environments: income inequality social position, and social cohesion	62
3.5.2	Psychosocial environments and illhealth: biological mechanism	64
3.5.3	Early experience and life course effects on health	66
3.5.4	Social exclusion	68
3.5.5	Social inclusion	72
3.5.6	Discrimination and racism	74
3.5.7	Health beliefs and health-related behaviour	77
3.5.8	Access to health care	81
3.6	Tackling health inequalities	83
3.7	Health of Gypsies and Travellers in UK and Ireland	86
3.7.1	Cultural lifestyle impact on Gypsy and Traveller maternal and child health	88
3.7.2	Gypsies and Travellers: access to health care	90
3.8	Conclusion	93
CHAPTER 4 Interpersonal Communication: Relationships between Health Care Staff and Patients		
	Introduction	95
4.1	Communication processes	97
4.1.1	Models of medical care	97
4.1.2	Models of nursing care	100
4.1.3	Power Relations	101
	Concepts of powerlessness and empowerment	101
	Why Empowerment? the drivers	103
4.1.4	Obstacles to empowerment	105
4.2	Communication outcomes for staff and patients	111
4.2.1	Doctor-patient relationships	111
	Continuity	115
4.2.2	Nurse-patient relationships	116
4.2.3	Health Visitors	117
	Empathy	119
	Trust	119
	Respect	120
4.2.4	Receptionist-patient relationships	120
4.2.5	Primary health care teams	121
4.3	Errors & misunderstandings	122
4.4	Narratives in health care	124
4.5	Intercultural communication	125
4.6	Communication training for health staff	129
4.7	Conclusion	135
CHAPTER 5 Methods		
	Introduction and overview	136
5.1	Study background	136
5.2	Ontological and epistemological position	137
5.3	Phase1: Relationship between Gypsies' and Travellers' cultural beliefs, attitudes and health perceptions and their access to health care	140

5.3.1 Method	140
5.3.2 Researcher/ researched relationship	141
5.3.3 Sampling	141
Achieved sample	142
Access to participants	142
5.3.4 Data collection	144
Topic Guide Phase1 study	144
5.3.5 Thematic analysis of qualitative data	145
5.3.6 Validation	145
5.4 Phase 2: Communication Barriers between Gypsies and Travellers and health staff	146
5.4.1 Background and Rationale	146
5.4.2 Research Strategy	147
5.4.3 Methodology: a participatory approach	147
5.4.4 Participatory Action Research (PAR)	150
5.4.5 User involvement in health and social care	152
5.4.6 User Involvement in research	153
5.4.7 Negotiation over methods options	154
5.4.8 Reference group	155
5.4.9 Proposed Multi method approach	156
Group interviews- Focus group method	156
Proposed fieldwork stages	156
Narratives - group sessions using a Stories Template	157
5.4.10 Ethics and Research Governance	159
Obtaining informed consent	160
Feminist ethical model	160
5.4.11 Fieldwork	161
Gypsy and Traveller participants	161
Health staff participants	162
5.4.12 Research meetings: chronology and structure	163
5.4.13 Data analysis	164
Thematic analysis	165
Narrative analysis	166
Quality and Rigour	168
5.5 Conclusion	169
CHAPTER 6 Phase 1 Results: Relationship between Gypsies and Travellers' Cultural Beliefs, Attitudes and Health Perceptions and their Access to Health Care	
Introduction	171
6.1 Culture and identity	171
6.1.1 Identity	172
6.1.2 Racism and discrimination	174
6.1.3 Nomadism	175
6.1.4 Kinship – family ties	177
6.1.5 Privacy and shame	180
6.1.6 Cleanliness, appearances and pollution concerns	184
6.1.7 Self-reliance and control	187

6.1.8 Education	190
6.1.9 Religion	191
6.2 Health beliefs and attitudes	193
6.2.1 Attitudes to illness and health	193
6.2.2 Attitudes to screening and diagnosis	195
6.2.3 Attitudes to health services	198
6.2.4 Lay referral, health seeking behaviour and family care	202
6.3 Communication and encounters with health staff	206
6.3.1 Health visitor advocacy role	209
6.3.2 Staff awareness of cultural factors	210
6.3.3 Continuity and GP registration	212
6.3.4 Discrimination and racism	214
6.3.5 Lack of knowledge and understanding among Gypsies and Travellers	216
6.3.6 Appointment systems	218
6.4 Conclusion	220

CHAPTER 7 Phase 2 Results: Communication with health staff: Gypsy and Traveller perspective

Introduction	223
7.1 Trust: confirmation of existing themes	224
7.1.1 Anxiety and access to health care	224
7.1.2 Diagnostic certainty	225
7.1.3 Respect	229
7.1.4 Discrimination & prejudice	230
7.2 Self-reliance and avoidance of health staff encounters	233
7.2.1 Strategies to obtain required health care	235
7.3 Elaboration on the importance of identity and shame	238
7.3.1 Shame: devalued identity	238
7.3.2 Shame as humiliation	240
7.3.3 Concealing identity	243
7.3.4 Shame and cultural values	244
7.3.5 'Being a good mother'	247
7.4 New insights: Cultural competence in health staff	248
7.5 Responses to Preliminary Feedback	251
7.5.1 Relationships with health staff and health staff views	253
7.6 Interim feedback	255
7.7 Conclusion	256

CHAPTER 8 Phase Two Results: Communication with Gypsies and Travellers: Health Staff Perspectives

Introduction	258
8.1 Staff Expectations of Gypsy and Traveller patients	258
8.1.1 Past experience	258
8.2 Cultural awareness, equality and diversity	262
8.2.1 Attitudes to cultural awareness	262
8.2.2 Attitudes to equality and diversity	265
8.3 Organisational Pressures	269
8.4 Staff roles	271

8.4.1 Public role status	272
8.4.2 Role autonomy	273
8.4.3 Exposure to public gaze	274
8.5 Service Delivery	275
8.5.1 Organisation settings	276
8.5.2 Organisation structure	277
8.5.3 Organisation culture and ethos	280
8.5.4 External policy context	285
8.7 Responses to feedback	288
8.7.1 Preliminary feedback	288
Rowan surgery	288
Elm surgery	289
8.7.2 Interim feedback to Rowan surgery	290
8.8 Conclusion	290
CHAPTER 9 Communication between Gypsies and Travellers and health staff	
Introduction.	292
9.1 Gypsy and Traveller perspectives: racialised identities, mistrust and low expectations	292
9.2 Health staff: some parallel preconceptions	293
9.3 Common patterns	294
9.4 Marxist perspectives on power and control	295
9.5 Agency, identity and social control	297
9.6 Health staff experience of power and control	298
9.7.1 Managing social identities- Gypsies and Travellers	299
9.7.2 Managing social identities- health staff	300
9.8 Cultural identity: inequality, inclusion and exclusion	302
9.9 Impact of shame social inequality and exclusion on communication	305
9.10 Understanding interpersonal communication: value of a dialogical approach	308
Story 1	310
Story 2	312
9.11 Implications of findings for primary health care service delivery	317
9.12 Implications for training	318
Table 1 Key Features of health care settings	324
CHAPTER 10 Conclusions	
Introduction	326
10.1 A PhD journey	327
10.2 Methodological implications and limitations	329
10.3 Conclusions and ways forward	332
The role of a racialised and devalued identity in communication barriers	332
The shaping of health staff reactions to Gypsies and Travellers	333
The theoretical synthesis of broad social control and managing identities at interpersonal level	335
10.4 Implications for further research	337
10.5 Wider implications	338
APPENDICES	

Appendix A: Critical appraisal of reviewed papers on Gypsy and Traveller health	339
Appendix B: Full research questions Phase 1 and Phase 2 -	342
Appendix C: Phase 1 -Sampling grid and characteristics of interviewees	343
Appendix D: Phase 1 -Topic guide	344
Appendix E: Phase 1 - sample(part) of data coded under one heading	345
Appendix F: Action research typology (adapted from Hart and Bond by Meyer)	347
Appendix G: Phase 2 -Reference group membership	350
Appendix H: Phase 2 -Gypsy and Traveller and health staff participants	351
Appendix I: Chronology and format of stages of Fieldwork	352
Appendix J: Phase 2 -sample of initial coding	354
Appendix K: Characteristics of Study Phase 1 Interviewees by ID code	355
Appendix L: Story One in Labov's grid (over 3 pages)	356
Appendix M: Story 2 in Labov's Grid (over 2 pages)	359

BIBLIOGRAPHIES

Bibliography in citation order (Vancouver Style)	361
Bibliography in alphabetical order by author (Harvard style)	396

This thesis explores the barriers to accessing primary care health service provision for Gypsies and Travellers in England. Research took place in two phases. The first was a qualitative study of Gypsies' and Travellers' cultural beliefs, attitudes, perceptions of and access to health care. Findings included low expectations and poor experience of services, as well as many examples of communication barriers between Gypsies and Travellers and health staff. The second phase built on these findings, by adopting participatory action research (PAR) methods, to explore communication processes from both staff and Gypsy and Traveller perspectives. The aim was to elicit understanding with a view to exploring how barriers might be overcome.

Both phases of research show how Gypsy and Traveller experiences of discrimination and racism contribute to a sense of devalued identity, characterised by feelings of shame and humiliation. Shame and attempts to ward off shame are central features of relationships and encounters with health staff as personal reactions to these experiences can produce mutual mistrust and poor relations between staff and the Gypsy and Traveller patients. At the same time, health staff reactions are shaped by pressures related to role, status and setting. By focusing on processes of co-constructed communication, I identify specific patterns of tension and mistrust.

In conclusion, I argue that a reflective and collaborative staff approach in primary care, based on effective leadership and a shared team ethos, can provide the empathic focus needed as a starting-point for trust and effective communication. I also argue that acquisition of good communication skills and development of experiential cultural awareness, whilst essential, are insufficient to guarantee cultural competence. A reflexive approach, focussing on personal qualities, values, beliefs and attitudes, is also essential for cultural safety. I outline the specific staff training implications of these findings, in terms of ensuring culturally safe health care for Gypsies and Travellers.

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1.1 Background: My Position and Starting Point as a Researcher

“Why have you come to work with us, couldn’t you get a proper job?”

Nita, a young Irish Traveller mother of two, put this question to me when I first took up post as a health visitor for Travellers in 1993. Although it was not the immediate trigger for my research interest, it was the first jolt to my awareness of the suspicions and expectations that Gypsies and Travellers have about attitudes towards them. I had worked as a health visitor with people from all classes and different ethnicities for nearly 20 years prior to this, but it was the first time I had experienced such a pervasive sense of low worth in the eyes of others. The reactions of many colleagues and acquaintances to my decision to work exclusively with this group of people justified Nita’s impression of others’ negative attitudes towards them.

Working with Gypsies and Travellers, I became increasingly aware of their alienation from the general population. This was illustrated by the hostile attitude of a local resident who complained to the health team (GP, health visitor and administrative assistant) about provision of a mobile health clinic service to Gypsies and Travellers who were staying on waste ground near his housing estate. I also became aware of the high level of morbidity among Gypsies and Travellers in my area and the dearth of available evidence to contextualise this anecdotal experience. Although there were descriptive reports about the health of Traveller populations and their difficulty in accessing primary and secondary health care, there were no published studies using valid and reliable health status measures.

I visited Ireland to study health service provision to Travellers and was inspired by the outcomes of a health status study of Irish Travellers.¹ The study findings, specifically the inequalities identified by mortality statistics, were the impetus behind policy measures to address the poor health of Travellers in Ireland. I was aware that, in the absence of similar local and current evidence, it would be difficult to persuade policy makers of the need for targeted measures to meet specific needs in the UK. This was my

stimulus to seek research funding. The importance of researching the health status of Gypsies and Travellers in the UK was highlighted for me by the response of a leading public health practitioner that Gypsies and Travellers' health experience would be no different to that of any other group who experienced poverty.

In 1998 I conducted a pilot study² to test the hypothesis that Gypsies and Travellers have a higher ratio of self-reported health problems and lower quality of life than a similar white British or Irish population. This study not only showed statistically and clinically significant differences in some aspects of health status between Gypsies and Travellers and matched comparators, but also indicated a need to understand the associated factors from the perspectives of Gypsies and Travellers. There was no substantial qualitative element to the pilot study, except for two brief open-ended questions allowing respondents to add comments about their health and ways that they dealt with health problems.ⁱ However, some of these comments suggested that environmental and cultural factors were possible influences on health outcomes and access to health care:

“You're much healthier when you're travelling about.”

“it's these houses which kill you know.”

“It's got to be really necessary to go to the doctor.”

“I just deal with it, I just leaves it.”

These pilot study findings led me to conduct a qualitative study to explore the contextual factors of the health status of Gypsies and Travellers in England.ⁱⁱ

This first phase of work informed a second phase concerning the specific theme of communication barriers between Gypsies and Travellers and health staff. I also draw on this first phase of the research in the interpretation of the subsequent findings.

ⁱ The two open ended questions in the pilot study were :

Q17. What else would you like to tell me about your health or health problems in general?

Q18. Did you get treatment from GP or hospital for the problems you have mentioned, or did you find another way of dealing with them? Please explain your decision.

ⁱⁱ I carried out this first phase of the research as an arm of a multi-centre study of the Health Status of Gypsies and Travellers in England. (see Chapter Five)

My health visitor practitioner background, with a role in seeking out health needs and influencing policy, led to my early interest in active lobbying for changes to social policy and legislation that were detrimental and/or discriminatory towards Gypsies and Travellers. In the initial research phase I had to become reflexively aware of the need to ensure that this role did not conflict with my research role. I was increasingly aware that my research could be suspected of bias if I continued to pursue both roles simultaneously. However, my ultimate goal is that the research findings will be used by Gypsies and Travellers and health staff, who have been enabled and informed by their involvement, to lobby for change.

1.2 Epistemological and Methodological background

In seeking to understand the self-perceived needs of Gypsies and Travellers and to explore their health beliefs, attitudes and derived meanings, I adopted a 'subtle realist' research strategy. In other words although I hold that there are real social phenomena which exist independently of the ways in which they are represented, our understanding of them is shaped by social, political and cultural circumstances and values and the meaning of such phenomena is therefore socially constructed. In seeking to understand the inverse relationship between Gypsy and Traveller health needs and use of services, and the specific role of communication barriers, I draw upon an interpretivist epistemological position. This is appropriate, given my wish to understand how both health staff and Gypsies and Travellers construct their social worlds, and to recognise the potential impact of my own role in the research process.

This position is consistent with my desire to explore these questions in partnership with Gypsies and Travellers, and to adopt a participatory action research approach. I was drawn to a participatory approach because Gypsies and Travellers are frequently the 'subjects of research' and many are jaded and disillusioned by the experience - not least because they have rarely seen any benefits from previous research. This has reinforced their experience of unequal power relations within wider society, where their voice appears to be unheard or unheeded. The place of health staff differs in this respect and I do not work in partnership with them in the same way. I will give a fuller explanation of my interpretivist stance and participatory approach in Chapter Five.

1.3 Aims of the thesis

The initial aim of the first phase of my research is to understand the health and health care experiences, beliefs, and attitudes of Gypsies and Travellers, as well as to understand perceived barriers to service access. The specific aim of the second phase of the research is to understand communication processes between Gypsies and Travellers and primary health care staff, with a view to exploring how perceived barriers might be overcome. My ultimate goal is to contribute to a body of research that will underpin improved access to health care and health service provision for Gypsies and Travellers, and will facilitate improvements in their health status.

1.4 Thesis structure

As I am working within a health services research context to explore this complex topic, it is necessary to draw on insights from a number of disciplines and perspectives. In Chapters Two to Four I therefore review the literature in a number of relevant areas. Firstly, in Chapter Two, I commence with an overview of the historical and contemporary context of the position of Gypsies and Travellers in the UK. My objective is to explore the discourse and theories of identity and ethnicity in relation to health, prior to exploring the debate on the ethnic identity of Gypsies and Travellers. The intention is to investigate the relationship of the ethnic identity of Gypsies and Travellers with health, and specifically how this relates to their experience of communication barriers, with reference to experiences and expectations of racism and discrimination among other factors. I also examine theoretical perspectives on racism and social exclusion and their relationship to social policies pertaining to Gypsies and Travellers. Here, I explore issues of power relations and agency, in relation to Gypsies' and Travellers' experience of communication processes.

In Chapter Three, I explore the evidence on health inequalities and the impact of health and social policies designed to reduce them. My focus on Gypsies and Travellers, who are self-identified as ethnic groups, also led me to explore the health beliefs and models of health as they relate to different ethnic groups and the influence that these have on health inequalities and access to health care.

In Chapter Four I explore the evidence on interpersonal communication between health staff and patients to discover what is already known and to identify the gaps in

knowledge that this thesis aims to inform. I conducted my research in two phases, both with a participatory focus. I describe and discuss the methods I used for both phases in Chapter Five.

Several themes relating to the health and health care experience of Gypsies and Travellers emerged from first phase of my research. In Chapter Six I present three of these themes, concerning culture and identity, health beliefs, and access barriers to health services. All relate closely to the prominent issue of communication barriers, fundamental to all aspects of health care experience.

In Chapters Seven to Nine I present the results of the second phase of the study in which I explore, from both perspectives, the various contextual influences on communication between Gypsy and Traveller patients and health staff. In Chapter Seven, I present the Gypsies and Travellers' perspective and, in Chapter Eight, the health staff perspective. I draw together the data from these two separate perspectives in Chapter Nine and situate the findings in the broader literature of health care, social divisions and contemporary policy and discuss the implications for practice and for training. Finally in Chapter Ten I include reflections and critique of the research process as I present the conclusions to this thesis. I finish by considering the wider implications of the study findings.

1.5 Pseudonyms and Anonymity

Gypsy and Traveller participants:

In accordance with ethical and participatory principles, I asked each participant individually whether or not they wanted anonymity. Participants in the first phase of the study wished to be anonymised and the initials used to identify quotes do not refer to their real names. Each participant in the second study phase was happy to be identified by their real name in the acknowledgments and for their real initials to be used to identify quotes.

Health staff participants:

I decided to preserve the anonymity of all health staff participants, because some but not all were happy to be acknowledged by name. I have simply described the role of each person following quotes.

Research Locations and settings:

All place names and the names of the GP surgeries are fictitious.

Introduction

In this chapter I begin by describing the historical and contemporary context of the position of Gypsies and Travellers in the UK, with a brief explanation of terminology followed by demographic information. I then explore the debates concerning ‘race’, ethnicity and culture before situating Gypsy and Traveller ethnicity in these debates. I continue by outlining my argument that Gypsies and Travellers have a racialised ethnic identity and explaining how this is socially constituted and strengthened. Finally I describe the impact of this identity for the social position of Gypsies and Travellers in the UK.

2.1 Who are Gypsies and Travellers?***2.1.1 Terminology and demography***

Records show the existence of groups of people in England, commonly known today as Gypsies, or Travellers, since the 15th century. The variable meanings of the term Gypsy have been “a semantic problem, not of the Gypsies’ making”³(p1). Worldwide there are more than 100 groups who collectively form part of a wider Romani population, estimated at 12 million people⁴ (p xvii). In the UK, distinct groups, commonly known as English Gypsies, Welsh Gypsies, Irish Travellers and Scottish Gypsy Travellers have been identified – and have identified themselves – as having different languages and certain different cultural traditions but also many common features of lifestyle and culture that unite them collectively as distinct from the rest of UK society. Their own use of specific terminology to describe the rest of UK society, i.e. ‘non-Gypsies or Travellers,’ emphasises the sense of a separate collective identity. They use varied terms to describe others: English and Welsh Gypsies commonly use the term ‘Gorgers’, (with various spellings)ⁱ, Irish Travellers use ‘Country people’, Buffers, or ‘Settled people’,

ⁱ Gorger is the closest spelling to the usual way that the word is pronounced by English and Welsh Gypsies. It is variously spelt by different authors as Gorgio, Gajo, Gadge, or Gaujo

and Scottish Travellers use 'Flatties'. European Romani also commonly refer to non-Romani people as gadze (with various spellings).

Whenever I refer to Gypsies and Travellers I am referring to these groups collectively, but am excluding, unless specified, the groups of people who are known as 'new age' or 'new' Travellers. The latter group, who do not constitute an ethnic group in the usual sense, are not the focus of this thesis. UK resident, European, Roma are also excluded from this study. Although some of their experiences and difficulties in access to health care may be similar, there are many differences that make it inappropriate to include these groups here. In each of the groups the term Traveller or Gypsy may be used to describe themselves. For clarity therefore, I use the two terms Gypsy and Traveller to include all those in the groups described.

2.1.2 Legal definitions

Different legislative definitions of Gypsies and Travellers have been used over time and this has resulted in a lack of shared understanding of who is included when health needs are being considered. The first legal definition, established for the purposes of planning law in the 1968 Caravan Sites Act,⁵ emphasised the cultural tradition of nomadism but ignored ethnicity as it defined Gypsies (sic) as "persons of nomadic habit of life whatever their 'race' or origin." This definition was subsequently amended and narrowed by case law to state that travelling must be for work purposes. It has been used to good effect to refuse planning permission to old or infirm Gypsies and Travellers; for planning purposes they cannot be considered as Gypsies. A new definition contained in the 2006 Government circular 'Planning for Gypsy and Traveller Caravan Sites' is now used for planning purposes⁶:

persons of nomadic habit of life whatever their 'race' and origin, including such persons who on grounds only of their own or their family's or dependents' educational or health needs or old age have ceased to travel temporarily or permanently, but excluding members of an organised group of travelling show people or circus people travelling together as such.

This definition falls short of the new broader housing definition for accommodation assessment purposes under the Housing Act 2004⁷, and which is intended to enable local authorities to understand the possible future accommodation needs of all Gypsies and Travellers; not just of those travelling. There was a twelve week consultation period on the broad definition preferred by the Government that did not exclude travelling

show people or circus people and had the crucial extension: “and all other persons with a cultural tradition of nomadism and/ or caravan dwelling.” This broader definition is a great improvement on the planning definition and is appropriate in a policy measure to address accommodation needs; many Gypsies and Travellers have previously experienced discrimination as a result of earlier definitions. However, as a result of the responses to the consultation, a variation of the definition was finally recommended ⁷ to show more clearly the distinct groups who are covered and to explicitly include travelling show people and circus people whose needs may have continued to be overlooked by the original option:

“gypsies and travellers” means:

- (a) persons with a cultural tradition of nomadism or of living in a caravan; and
- (b) all other persons of a nomadic habit of life, whatever their race or origin, including:
 - (i) such persons who, on grounds only of their own or their family’s or dependant’s educational or health needs or old age, have ceased to travel temporarily or permanently; and
 - (ii) members of an organised group of travelling show people or circus people (whether or not travelling together as such).

It could be questioned why there should be separate definitions for planning processes and for accommodation needs, but this has to be considered within the context of a wider policy framework and the ways in which policy is used and interpreted. There is a rider within the 2006 consultation document stating that adoption of either of these new definitions will not affect the ethnic status of Gypsies and Irish Travellers as enshrined in law for the purposes of the Race Relations Act. Romany Gypsies and Irish Travellers gained legal recognition as distinct ethnic groups in England and Wales in 1988 and 2000 respectively.ⁱⁱ

2.1.3 Gypsy and Travellers: current numbers

Numbers of Gypsies and Travellers in the UK can only be estimated; these estimates are usually based inadequately on the biennial caravan counts carried out by local authorities in England. Estimates vary between 90,000 and 120,000 in England and a further 2,000 in Wales,^{8,9} but an unknown number also live in houses, accounting for other total estimates of 300,000 in England.¹⁰ This latter estimate puts the population at

ⁱⁱ The Court of Appeal ruled that Romany Gypsies are an ethnic group in *CRE v Dutton* (1988) A County Court reached a similar decision in respect of Irish Travellers in *O’Leary and others v Allied Domecq* (2000)⁸

an equivalent size to Britain's Bangladeshi population.¹⁰ It is equally difficult to know the accurate breakdown of different ethnic groups among Gypsies and Travellers. However the Irish Traveller Movement in Britain suggests that 15,000 Irish Travellers live in England. This figure is additional to the 25,000 who comprise 0.5% of the total population in Ireland.¹¹

2.1.4 Geographical distribution and types of accommodation

The situation of Gypsies and Travellers living in the UK today remains as it has done throughout their history; they are marginalised and their presence is invariably resented wherever they appear in caravans or wherever a caravan site is proposed. The frequency of sensational newspaper headlines such as "Gipsy[sic] invaders"¹², "Stamp on the camps"¹³, "Travellers' camps cost £300,000 each year"¹⁴ both illustrate and fuel this reaction. The problem of relations between Gypsies and Travellers and society as a whole is intensified by the lack of suitable and available accommodation, and successive policies aimed at addressing these problems have not yet met with success. I will examine the reasons for this later.

Those Gypsies and Travellers, estimated as a third of the total number, who are living in caravans (commonly known as 'trailers') are distributed across the UK, but disproportionately high concentrations live in certain geographical areas, such as Kent and East Anglia. A high proportion of those living in trailers do not have a place on an authorised site; approximately one fifth of the 15,746 caravans counted were on unauthorised sites in the biennial count of January 2006. This figure is only 330 fewer than two years previously, despite an apparent increase in provision indicated by 700 more caravans counted on authorised sites.¹⁵ This indicates several possibilities: the number of families requiring accommodation is increasing; the level of increased provision is progressively failing to meet rising demand; there is and will be increased pressure to move into housed accommodation in response to the shortfall. However, one of the key findings of the Review of the Gypsy Caravan Count system is that the count is inaccurate; with variations in accuracy between local authorities.¹⁶ The same review estimated that by 2007 between 2,500 and 4,000 extra pitches would be required for caravans on residential and transit sites. This does not take into account that approximately half of the existing socially rented authorised sites are unsuitable for use because of hazardous or unacceptable environmental conditions (such as very close proximity to motorways, railways, rubbish tips, industrial sites or sewage works).¹⁶

2.2 Social policy pertaining to Gypsies and Travellers

Social policy pertaining specifically to Gypsies and Travellers in the last century has focused almost exclusively on the issue of caravan site provision. However, many other policies prior to such legislation, whilst not necessarily targeted at Gypsies and Travellers, have had the cumulative effect of restricting their ability to lead a nomadic lifestyle through reduced availability of stopping places and planning restrictions.¹⁷

As a result, more families were forced to resort to unauthorised camping; a situation that led to successive legislation to control such growth, i.e. 1960 Caravan Sites and Control of Development Act, 1968 Caravan Sites Act, 1994 Criminal Justice and Public Order Act.¹⁷ Crawley has highlighted the absence of any long term or adequate planning measures to meet the accommodation needs of Gypsies and Travellers:¹⁰

this reflects...the absence of any clear, widely understood national policy towards accommodation for Gypsies and Travellers (p14).

In contrast, a similar situation in Ireland led to eventual recognition of the interrelatedness of accommodation with other factors influencing the relationship between Irish Travellers and the 'settled community.' An Irish government Task Force was established to address accommodation and the whole range of other factors in the context of this relationship. In the 1995 report¹⁸ this link is specified:

The relationship between the Traveller and 'Settled' communities in Ireland today is complex. It is influenced by a number of factors including lack of contact and knowledge on the part of each community about the other, social exclusion of Travellers by the settled community, lack of provision of appropriate accommodation facilities for the Traveller community and incidents of inappropriate behaviour. Incidents of social exclusion and discrimination against Travellers include hostility and aggression and segregation in the provision of facilities (p5).

Crawley made a similar observation in her report on accommodation provision for Gypsies and Travellers in the UK:¹⁰

one of the key concerns throughout this report has been the need to address the tension that exists between Travelling and settled communities.(p55)

However, as she observes, successive governments have resisted taking action to address these underlying problems; instead, there have been attempts to impose control

in an apparent response to the popular view that Gypsies and Travellers are the cause of the problems: ¹⁰

it is clear that at all levels of the political spectrum there is a lack of political will to tackle the marginalisation of Travellers and Gypsies in society...The discourse is one of enforcement and eviction rather than provision and Travellers and Gypsies are viewed by many as a problem rather than a social group in need of support. Underlying this is a failure to accept the nature of the nomadic lifestyle and provide services which suit it (p55).

In recent years, Gypsy and Traveller organisations and others, have been lobbying for law reform, in respect of accommodation needs, with the result that an All Party Parliamentary Group for Traveller Law Reform was formed.¹⁹ Since the Institute of Public Policy Research (IPPR) report ¹⁰ was published, the present government has introduced various policy measures to include Gypsies and Travellers within mainstream policies, in response to continued pressure to address their accommodation needs. For example, the statutory requirement under the Housing Act 2004⁴ for each local authority to produce an accommodation needs assessment now specifically includes an assessment of Gypsy and Traveller accommodation needs and also a requirement to produce a Gypsy and Traveller accommodation strategy. It is too early to report on the outcome of these recent measures. I also review and discuss the health and social impact of this demographic information and aspects of social policy concerning health inequalities in Chapter Three.

First, however, I explore and review theoretical perspectives concerning 'race', ethnicity, culture and health; I also discuss debates about Gypsy and Traveller identity, in order to contextualise questions of accommodation needs and social policy responses.

2.3 Debates about 'Race', Ethnicity, culture and health

Various definitions of ethnicity highlight the confusion concerning terminology, most particularly with the often synonymous use of the term ethnicity and 'race'. In the USA some academics, such as House and Williams,²¹ writing about health inequalities, appear to acknowledge the confusion and synonymous use of the terms by referring to "race / ethnicity" and "racial / ethnic characteristics." Senior and Bhopal²² state that the terms 'race' and ethnicity are used interchangeably in the context of health research:

with an inference that variations in the prevalence of disease between ethnic or racial groups is due at least in part to genetic differences (p327).

Both 'race' and ethnicity are now widely accepted as categories that are socially constructed,²³ but when used they are often poorly defined. I will commence with 'race': although the concept is discredited, because it is important for an understanding of the concept of racism.

2.3.1 'Race'

Macionis and Plummer²⁴ define 'race' simply as "a category of people sharing biologically transmitted traits"(p260), but warn that differences, usually noted as physical characteristics, are superficial and that individuals of all 'races' are members of a single biological species, possessing a variety of physical traits as a product of migration and intermarriage over the course of human history. Bhopal²⁵ expands the definition:

a group a person belongs to as a result of a mix of physical features, ancestry and geographical origins, as identified by others or, increasingly, as self identified (p1970).

Historically the definition of 'race', based on physical or biological differences, has been associated with the interpretation that certain 'races' are superior to others. Blumenbach, in 1775, was the first anthropologist to coin the word 'race' when he classified humans into five categories: Caucasian, Mongolian, Ethiopian, American and Malay.²⁶ There is still debate among some scientists; Risch, for example, continues to argue for a concept of 'race' based on biological differences. However, such definitions, based on a concept of biological differences, have now largely been discredited by geneticists such as Rosenberg et al²⁷ and Lewontin.²⁸ Their respective studies have shown that as much 85% to 93-95% of genetic variation occurs among individuals and as little as 3 to 8% is accounted for by 'racial' differences. Most anthropologists today agree that 'race' is a discredited construct according to the following statement by the American Association of Physical Anthropologists²⁹:

The peoples of the world today appear to possess equal biological potential for assimilating any human culture. Racist political doctrines find no foundation in scientific knowledge concerning modern or past human populations (p569).

Bhopal argues that belief in the superiority of white 'races' in the 19th century led to justification of racist policies such as eugenics.³⁰ He quotes Kuper in stating that:

Humans are one species: 'races' are not biologically distinct; there is little variation in genetic composition between geographically separated groups, and the physical characteristics distinguishing 'races' result from a small number of genes that do not relate closely to either behaviours or disease (p1755).

I share Eriksen's view³¹, that the term 'race' should be abandoned in favour of ethnicity because hereditary fixed traits do not follow clear boundaries. He makes a crucial point that one does not have to believe in the validity of the concept of 'race' to acknowledge its importance, in that socially, the notion of 'race' both exists and informs people's actions. The blurring of the distinction between 'race' and 'ethnicity' is reinforced by common use of the term racism to describe discrimination on ethnic grounds. Legal definitions in the UK reinforce this confusion. The Race Relations Act 1976³² describes its function as making it unlawful to treat a person less favourably than others on racial grounds but proceeds to describe those grounds as covering 'race', colour, nationality (including citizenship) and national or ethnic origin. The Race Relations (Amendment) Act 2000³³ has not amended the term 'race' in its title.

Mason³⁴ suggests that the persistent synonymous use of the terms 'race' and ethnicity, in research, policy and in lay terms, is rooted in British colonialism and the subsequent discrimination against 'New Commonwealth' immigrants, in contrast with the largely unquestioning acceptance of white immigrants. Bradby²³ also points to the importance of the historical context in shaping current concepts, and suggests that values that supported racial discrimination and slavery continue to influence current thinking about human diversity. Changing the terminology does not necessarily change the racialised thinking that underpins some uses of the term ethnicity, particularly when used as a variable in research. Where ethnicity is not clearly defined, research results can be used to reinforce negative assumptions that 'racial' or genetic differences are responsible for variations, rather than examining the range of confounding factors that may result from being a member of an ethnic minority. Back and Solomos³⁵ argue that in order to avoid accusations of racism, the terms 'difference' and 'culture' are often substituted for 'race', but that in such situations the qualities of the social groups are still portrayed as fixed rather than dynamic. Bhopal³⁶ appears to differ from Eriksen in that he does not

argue for abandoning the term 'race'. He sees a modern concept of 'race', as used frequently in the USA, which emphasises its social rather than biological origins. However he does argue that:

the term 'race' should be used with caution for its history is one of misuse and injustice. In the study of racism, however, the concept is central (p442).

In this sense I accept the validity of Bhopal's view, as, like Eriksen, he acknowledges that the social concept of 'race' persists and must therefore be addressed. However as he warns above, there is an intrinsic risk of perpetuating the historical concept of biological differences through continued use of the term.

There are various concepts and uses of the term racism which do not all refer to the perceived superiority or inferiority of groups based on their presumed 'race'.³⁷ An internationally accepted definition of racism is:

Any distinction, exclusion, restriction, or preference based on 'race', colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment, or exercise, on equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural, or any other field of public life.³⁸

Back and Solomos refer to the concept of a pseudo-biologically defined culturalism, as they point out that in the 1990s theories about 'race' and racism have been simultaneously linked with wider controversies about culture and identity. By referring to Goldberg's work on racist culture, they describe a central feature of this process as being the way in which social formations are seen in terms of patterns of 'belonging' in terms of 'race' or culture.³⁵ The concept of 'race' is less relevant than an understanding of why various groups become racialised at particular points in time and in particular locations. In other words it is the historical and socio-political context rather than the overall concept that is important.³⁵

Brah et al³⁹ indicate that the debate about the use of the category 'race' in reference to racialised social groups has led to the more frequent use of the term racialisation. Racialisation is a preferred term for the process of ranking people on the basis of their presumed 'race' and is described as being at the heart of a system of inequality and social exclusion.²⁴ Karlsen and Nazroo⁴⁰ argue that external influences such as a common experience of exclusion lead people from ethnic minority groups to recognise

their ethnic status as one that has been racialised by the ethnic majority. They highlight the difficulty in measuring the extent of a person's experience of racism as being one of the problems in establishing the connection between racial discrimination and health.⁴¹ Nevertheless, they do identify some studies which have found a positive association between racism and ill-health.⁴²⁻⁴⁶ Karlsen and Nazroo report no similar studies on white racialised groups.⁴¹ This would seem to reflect the perception that people are categorised on the basis of their colour and that 'Black' people are 'other' whose identities predominantly become racialised on that basis, while 'White' groups are considered to be the 'norm'. It can be assumed that it is for similar reasons that comparison groups in research on 'race', ethnicity and health are usually the White majority population.

'Cultural racism' is said to have originated in the social and political crisis afflicting Britain in the 1980s, as part of a defensive response to a perceived threat to a 'British /English way of life' ('us') from foreigners ('them').³⁵ This concept was formulated and described by Barker as 'new racism.'⁴⁷ 'New racism' is seen as a process of racialisation, in which "socially significant groups...are regarded as nationally constituted populations of unequal merit", creating a moral justification for excluding or marginalising such groups on the basis of undesirable cultural characteristics.⁴⁸ Jayasuriya describes this idea of cultural distinctiveness of majority groups, which leads to other groups being accepted or excluded, as the crux of 'new assimilationism.'⁴⁸ It can be seen how notions of citizenship evolve from this view, with certain national cultural characteristics or values deemed as requirements for the rights of citizenship to be conferred. For example in the UK the introduction of a citizenship test in 2003, with its cultural bias, suggests that knowledge of the host country's language and culture is essential to integration and 'belonging'. Whereas proponents of this policy may argue that it is a step towards greater social cohesion, I would argue that it risks promoting assimilation at the expense of social cohesion, instead of recognising and celebrating diversity. As Yural-Davis states: "instead of looking for ways of encompassing difference by equality, we are going back to a view of society in which everyone has to conform to a mythical, homogenous 'British culture.'" ⁴⁹ I will later discuss these concepts in respect of Gypsies and Travellers' experience of racism. The confusion and debate about the terms 'race' and ethnicity, particularly in the field of epidemiology, continue but Bhopal ³⁶ makes a crucial point that categories are only labels:

that need to be recognised as shorthand for potentially important information. Authors should be describing the characteristics of the populations they are referring to (p 442).

So, although in European research the concept of 'race' has largely been abandoned in favour of ethnicity, as Bhopal acknowledges, we have seen how the concept is important for an understanding of racism. We have seen too how both concepts can be used to construe difference and inferiority on an essentialist basis and lead to exclusion on 'racial' or ethnic grounds. I now explore the concept of ethnicity itself.

2.3.2 Ethnicity

The interchangeable use of the terms 'race' and ethnicity is often due to the lack of agreed definitions and shared understandings of the term ethnicity. I begin here by discussing the legal definitions before discussing the various models of ethnicity that are in use. Since 1983, following a test case to confer ethnic status on Sikhs, a legal definition of an ethnic group has used the Mandla criteria⁵⁰, drawn up by the House of Lords for the purposes of the 1976 Race Relations Act. According to these, the essential characteristics that define an ethnic group are first, a long shared history, of which the group is conscious as distinguishing it from other groups, and the memory of which it keeps alive; and second, a distinct cultural tradition, including family and social customs and manners, often but not necessarily associated with religious observance. Both Gypsies and Irish Travellers gained legal recognition as ethnic groups by meeting these criteria. Scottish Gypsy/ Travellers are also to be "regarded as an ethnic group" by recommendation of the Scottish Parliament.⁵¹ This recommendation is a clear acknowledgment of the Mandla criteria and allows recognition of Scottish Travellers' ethnicity in terms of policy measures in the absence to date of a legal test case that allows for recognition under the Race Relations Act 1976. Clark argues the case for Scottish Gypsy Travellers ethnicity in some detail in terms of the essential characteristics of the Mandla criteria, whilst emphasising the fluid nature of ethnicity in the 21st century.⁵² The Mandla criteria definition very much views ethnicity as an identity, as discussed by Nazroo, who talks of three competing paradigms when describing ethnicity: 'untheorised' ethnicity, ethnicity as a structure, and ethnicity as identity.^{40; 53}

‘Untheorised’ ethnicity is the model that often pathologises ethnicity, with genetic and cultural differences portrayed as fixed, while appearing to be empirically driven. Differences are often assumed on the basis of racialised stereotypes. Nazroo refers to examples, such as the idea that Asians have a higher incidence of diabetes due to their evolutionary history involving adaptation to surviving periods of famine.⁵³

An ‘untheorised’ model of ethnicity is apparent amongst those for whom ethnicity remains a ‘race’- based concept of a visible minority. For example much health research, by reifying and essentialising ethnic categories, suggests that ethnicity is a cause of health differences.⁵⁴ This idea is reinforced by the fixed-response census categories of ethnic groups which are used in a variety of survey and ethnic monitoring situations. Bradby²³ points to the problematic use of these categories by highlighting the lack of a theoretical rationale for determining the range listed, which are based on a mix of nationality, colour, continental origin, racialisation and ethnicity. Although there is now a census option for self-assessment of one’s ethnicity, this illustrates the complexity of the concept. Rankin and Bhopal⁵⁵ gave an example from a study that compared respondents’ identification of their ethnicity using the census question in an open question about their self-described ethnicity. Only 62% of those who chose Indian as their ethnic category in the census question used that term as their ethnic self-identity. The use of the terms White, European, Western and Caucasian are similarly criticised by Bhopal and Donaldson⁵⁶ when used as comparisons for research purposes, as such inconsistent and heterogeneous labels are misleading. Use of such terminology reinforces Mason’s view that the history and influence of colonialism is responsible for the view in some quarters that a category of people must show a visible and significant degree of difference to be designated as an ethnic group. This view gives rise to stereotypical assumptions that downplay any acknowledgement of the white British having an ethnicity and reinforce the view that white is the norm. Mason³⁴ suggests that this view of seeing ethnicity as only being applied to ‘others’ underlies assimilationist assumptions.

The concept of ‘ethnicity as a structure’ focuses on socioeconomic position as an explanation for health inequalities.⁵⁷ Failure to explore structural factors, such as the inter-relationship between ethnicity and class, and inequalities within ethnic minority groups, can contribute to exclusionary practices associated with racialisation of ethnic minority groups. This in turn can lead to, or exacerbate any existing socioeconomic disadvantage. Socioeconomic position cannot easily be disaggregated from ethnicity; as

Nazroo has shown, there are higher concentrations of people from ethnic minority groups in poor social circumstances than their majority counterparts.⁵⁷ Research which focuses on ethnicity as an explanation for health differences to the exclusion of factors such as racism that may have contributed to their social position reinforces the institutionalised nature of racism. Eriksen wrote of the probable high correlation between ethnicity and class in that people in particular ethnic groups may also belong to specific social classes, but he equally indicated that class and ethnic differences “must be distinguished from one another analytically”³¹ (p36). This is not easily accomplished, as we see in Chapter Three where I examine socioeconomic classification. Nazroo points out that with a few notable exceptions, including his own research into the health of Britain’s ethnic minorities, class is largely absent as a variable in investigations into the relationship between ethnicity and health.⁵⁸ Nazroo also argues that structural approaches generally focus on certain, specific material explanations for inequalities, while other elements of the structural disadvantage faced by ethnic minority groups, such as their experiences of racism or concentration in particular geographical locations, are often ignored.⁵⁷ This criticism could apply to some Marxist approaches.

Karlsen and Nazroo⁵⁹ have argued for an understanding of ethnic identity as multi-dimensional, in relation to health. Their analysis of the Fourth National Survey of Ethnic Minorities identified five broad underlying dimensions of ethnicity that could contribute to a sense of identity. They warn of the dangers of over-reliance on the findings, as these are based on combining heterogeneous groups into ‘quantitatively determined ethnic categories.’ and this may possibly obscure some important inter-group differences. However, they conclude that the processes of ethnic identification are similar across the different ethnic groups explored. A set of questions were used to determine the importance of five dimensions of identity. These processes were summarised as self-description, self-presentation and behaviour, membership of ethnically specific organisations, perceptions and experiences of racism and a sense of cultural assimilation. For example Jenkins’ definitions of nominal components of ethnicity⁶⁰ are included with questions concerning the importance of nationality and ‘ethnicity/ race.’ The virtual components of ethnicity, or factors associated with an internal sense of identity, are included with questions pertaining to the importance of traditional customs or behaviours, membership or affiliation to ethnically specific organisations and the sense of being a member of a racialised group. Structural factors,

including perceptions of racism, experience of racism and the impact of being a member of a minority cultural group, were shown to be particularly important in the development of an ethnic identity. I discuss these implications of ethnicity as structure as they pertain to Gypsies and Travellers in section 2.4.3. and 2.4.4. First however, a more detailed exploration is required of the concept of an ethnic identity.

2.3.3 Ethnic Identity

Karlsen and Nazroo⁴⁰ maintain that it is only through exploring ethnicity as an identity that the dynamic and multi dimensional nature of ethnicity can be truly understood. We have seen how the structural dimensions of ethnicity contribute to the development of an ethnic identity. This model fits closely with Bradby's²³ and Okely's⁶¹ emphases on the need for self-ascription of ethnicity to reflect one's own identity. Jenkins⁶⁰ emphasises that social identity in general, including ethnicity, involves the twin processes of self-definition through group identification and social categorisation by others: 'ethnicity depends on ascription from both sides of the boundary' (p22). Identity consists not only of a name or label, but also of the experience of what that name or label means – in other words, our experience of how others see us is important to our construction of our own identity and is inextricable from how we see ourselves. Similarly, Mason³⁴ has observed that 'the concept of ethnicity is an attempt to replace the emphasis on physical difference with a stress on cultural or social variation' (p11). He points to Smith's definition of an ethnic unit as 'a population whose members believe that in some sense they share common descent and a common cultural heritage or tradition and who are so regarded by others.' (p11). One of the first questions asked of another Gypsy or Traveller when they first meet is 'who are you from' or words to this effect. This was evident in this study when Gypsies from Medham and Norville came together and found a common family link.

Jenkins⁶² argues that ethnicity is relational and cannot be unilateral. A sense of ethnicity can only arise in the contexts of relationships and interaction with others i.e. "between people who are seen to be different as well as between those who are seen to be the same" (p120). I have earlier described how ethnicity and 'race' are often used synonymously; as Bhopal⁶³ argues; both terms serve a useful function with regard to identity and belonging. His definition of ethnicity³⁶ highlights the synonymous use of the concept:

the social group a person belongs to and either identifies with or is identified by others, as a result of a mix of cultural and other factors, including language, diet, religion, ancestry and physical features traditionally associated with 'race' (p443).

However, as he also emphasises, ethnic boundaries are fluid and definitions will vary according to situational requirements. A recent contributor to the letter pages of the Guardian ⁶⁴ illustrated this fluidity: "I am of Indian origin and grew up in England. I am happy to be classed as Indian, English, British Indian or perhaps Indglish, but not Asian." Identity is not only relational but political and strategic; people may choose either to demonstrate or to hide specific differences or attributes, according to their immediate situation and objectives. People do have multiple ethnic identities and Mason illustrates how they may choose to emphasise different ethnic identities, for example either English or British or European ethnic identity, depending on the circumstances.³⁴ In the context of wider discussions about postmodernism and 'late modernity', it has been suggested that identity should be viewed as fluid as well as multi-dimensional. Giddens, among others, has proposed that reflexive self identity is a socially contingent and distinctly modern phenomenon,⁶⁵ This is a matter of debate, however and I take Jenkins's ⁶⁰ standpoint that such concerns about identity cannot be new but simply take a specific form in the present:

there is something distinctive about every time and place...but there is nothing to gain from annexing notions of selfhood, identity and reflexivity as definitively modern (p13).

The most important feature, when considering the role of ethnicity and culture in relation to attitudes and beliefs and effects on health, is the specific context and the mix of influences on people's lives. I will discuss the concept of culture in more detail in the following section, but Bradby ²³ suggests that because ethnicity is so culturally and historically specific, and is so closely related to other variables, it cannot be used as a coverall term for a universal phenomenon. In other words there is no agreed definition of ethnicity that allows for meaningful comparisons to be made through time and across cultures. Recognition of the fluid nature of ethnicity leads her to share Nazroo's view that:

inadequacies in the measurement of ethnicity are the main limitation hampering investigations in to ethnic inequalities in health and how they might be structured through social and economic disadvantage (p10).

The relational nature of ethnicity also brings into question the central issue of power; of who sets and defines ethnic boundaries. Nazroo ⁵³ agrees with Solomos that identity “confers a sense of personal location and provides a stable core of individuality”, but suggests a need to understand the role of action and struggle in forging and transforming a dynamic collective social identity. I will return to the issue of power and agency in the specific context of Gypsies’ and Travellers’ ethnic identities in section 2.4.3.

We have seen how ethnic groups can become racialised and how this experience can strengthen a sense of ethnic identity. It could be argued that research concerning ethnicity could be seen as ‘racist’ because it might contribute to processes of victim-blaming. For example, Nazroo ⁵⁸ describes how an explanation for lack of interest in exercise is viewed as a consequence of a pathological (minority) culture, whilst high rates of smoking are not viewed as a problem arising from white ethnicity. However, this is not an argument against the relevance of cultural factors in relation to explanations of health status, rather, it emphasises the need to examine the context in which they operate and to explore other explanatory factors such as socio-economic inequalities, which may be decisively relevant. Having raised the issue of cultural factors in the context of ethnicity, I now explore the concept of culture itself.

2.3.4 Culture

‘Culture’ also has many definitions and, like ethnicity, needs to be understood in relation to class, gender and social, political and historical context. In common with the concept of ethnicity, a failure to recognise the dynamic nature of culture risks the error of emphasising cultural differences at the expense of exploring other factors that influence behaviour and the construction of identity. In relation to social identity Jenkins ⁶⁰ admits to avoiding the use of the word culture, where possible:

because of the multiplicity of contested meanings attached to the word, because of its capacity for reifying everyday lived experience, and in a desire to avoid the culture/society dichotomy... (p187).

However, whilst I am aware of the risk of portraying culture as a fixed characteristic of a group, the concept of culture is important in the context of this thesis as Gypsy and Travellers themselves explicitly spoke of the need for health staff to have more cultural awareness “so they’d know a bit more about Travellers...” (see p228). It is in the same context that Papadopoulos ⁶⁶ quotes Henderson in explaining that:

culturally sensitive research is not research about a culture but research done with a raised consciousness concerning the impact of culture on the person (p83).

Barth ⁶⁷ conveys the complex nature of culture:

although ethnicity takes cultural differences into account , we can assume no simple one-to-one relationship between ethnic units and cultural similarities and differences (p14).

As Eriksen ⁶⁸ illustrates, there is the possibility of deep ethnic differences without correspondingly different cultural differences, such as within Bosnia, and examples of cultural variations without ethnic boundaries, such as between social classes. Eriksen ⁶⁸ aligns himself closely to Barth as he too argues that ethnicity is not synonymous with culture, and that the relevance of culture is in its symbolic difference and situational implied meaning in the formation of identity:

Ethnicity is the enduring and systematic communication of cultural differences between groups considering themselves to be distinct. It appears whenever cultural differences are made relevant in social interaction, and it should thus be studied at the level of social life, not at the level of symbolic culture. Ethnicity is thus relational, and also situational: The ethnic character of a social encounter is contingent on the situation. It is not, in other words, inherent (p 44).

Brah et al ³⁹ write about identity in a similar vein and suggest that the concept of culture “has become a central theme in a wide range of debates concerning social change within social and human sciences” (p1), with an increased interest in how it is used to produce meaning in social life. The concept of culture as the practice of producing meaning is one of three usages that Clarke ⁶⁹ describes in relation to social policy. He also describes the use of culture “as a field of difference” as I have described it earlier in connection with ‘new racism.’ This use of the concept of ‘culture’ risks denial of the dynamic nature of culture or ‘culture-a-process.’ He refers to a similar essentialist and damaging

use of the term where he argues that culture is described as 'not-structure'; that is, when social problems are deemed to result from the cultural characteristics of a group rather than from poverty or unemployment. Instead, Clarke argues for the importance of the contextual nature of culture, as he states, with reference to Hall's view that social life cannot be conceived of without meaning: "all social action is - at the very least - mediated by culture" (p79).

Helman ⁷⁰ uses the term 'cultural lens' to describe how individuals perceive and understand their world, as he defines culture as "a set of inherited guidelines (both explicit and implicit)" (p2). The implicit level is explained, with reference to Hall: there are three different levels of culture and that the deepest level is one in which the 'rules' are so taken for granted that they are almost beyond awareness and are the most stable and resistant to change. This implicit level of culture becomes part of one's identity that is transmitted through upbringing. McNair ⁷¹ illustrates the importance of upbringing and socialisation for the process of transmitting culture with a quote from Mark Twain:

Mohammedans are Mohammedans because they are born and reared among the sect, not because they have thought it out and can furnish sound reasons for being Mohammedans; we know why Catholics are Catholics; ...why Republicans are Republicans and Democrats, Democrats. We know that it is a matter of association and sympathy, not reasoning and examination; that hardly a man in the world has an opinion on morals, politics, or religion that he got otherwise than through his associations and sympathies (p16).

This description of the partly conscious and partly unconscious learned experience, known as enculturation, is what is probably being referred to in statements by Gypsies and Travellers when explaining their lifestyle, such as 'I was born a Gypsy; I didn't choose this way of life'. However, although cultures are dynamic and do adapt, people can also choose to adopt other cultures or become acculturated. McNair ⁷¹ describes the difference and points to the trauma of acculturation that is imposed rather than chosen:

Acculturation...is the imposition of systematic cultural change carried out by a dominant and often alien culture. One culture can borrow from another without being acculturated. But when a dominant culture through direct contact between individuals imposes, for example, language, habits, and values on other cultures, acculturation has happened. Acculturation more often than not brings about cultural loss and trauma (p41).

This describes the process of cultural assimilation whereby a group is absorbed into the dominant culture and loses its specific cultural characteristics. I elaborate on this in section 2.4 with specific reference to the ethnic identity of Gypsies and Travellers.

Karlsen ⁷² suggests that the choice element in adopting aspects of other cultural lifestyles is determined by the extent of power available to the dominant culture. With reference to Hall's assertion of the "effective hegemony of 'English' as representing itself as the essential dominant British culture, over Scottish, Welsh, and Irish" she argues that those with power and authority, and therefore with less threat to their identity, "can restrict the action and identities of the less empowered"(p114). She uses this argument, with David Beckham as an example, to explain how a white person from the dominant majority culture can adopt a 'black' lifestyle without losing his/ her original identity in the eyes of self or others, but argues that the reverse does not occur in ethnic minorities with threatened identities. The extent of this choice and power is contingent on the felt sense of threat to the identity of minority groups in terms of assimilation by the dominant culture.

However, within each culture there are also different social groupings, such as men, women, children, elderly kinfolk, and kith, each with their own distinctive cultural attributes. While maintaining the importance of cultural background as an influence on many aspects of people's lives such as their beliefs, behaviours, attitudes to illness and family structure, Helman ⁷⁰ also acknowledges that it is only one of a number of other influences on behaviour and attitudes. He lists these other influences as individual, educational, socioeconomic and environmental factors; all of which will vary in their significance depending on the context. In other words cultures are no more homogeneous or static than ethnicity and generalisations that seek to explain attitudes and behaviours should be avoided as they can as easily lead to stereotyping. Helman points to the subtle difference between the 'unwritten rules or 'codes of practice' of a culture which govern how a person should think and behave, and how they actually behave because of the many other influences and differences between people within cultures.

Many studies have been conducted on health meanings, beliefs, values, and practices and their impact on health amongst different cultural groups. Radley and Billig ⁷³

criticise the implied assumptions in many such studies, that health beliefs on a number of issues are fixed and held over a long term. They maintain that people:

construct their state of health as part of their ongoing identity in relation to others, as something vital to the conduct of everyday life (p221).

In taking this position they suggest that people's views about health are best understood as accounts rather than beliefs and that such accounts go beyond describing one's individual condition to articulating a person's situation and how they will be held accountable to others. This is a similar conceptual argument to Cornwell's ⁷⁴ description of the difference between public and private accounts of health or illness. 'Public' accounts, usually offered in formal situations, are deemed to be legitimising accounts that present the self in a favourable light. In contrast 'private' accounts, which are more likely to be offered in informal settings where trust has developed, reflect personal beliefs and are often constructed in terms of stories of personal experience.

In summary, to give undue emphasis to either culture or ethnicity in isolation risks perpetuating and even reinforcing other factors that may have a detrimental effect on people's life chances. There is a need to be wary of the use and interpretation of ethnicity as a variable and to be precise in defining and determining ethnicity in relation to the study question. At the same time it is important not to avoid the study of ethnic variations in health and well-being simply because of possible interpretations by others who may use ethnicity as a weapon for victim blaming. There are many good reasons for studying ethnic variations in health, as Chaturvedi ⁷⁵ explains:

those who would deny the value of ethnic group comparison studies may also be turning their backs on important work exploring equity in access to health care and public health interventions (p926).

Bhopal ³⁰ also agrees that research into ethnicity and 'race' should not be abandoned but that the purpose and emphasis should change from seeking to use it to "unlock the secrets of the causes of disease to being a tool for assessing needs and inequality and guiding practical action"(p1754). He makes some significant recommendations intended to improve the understanding of ethnicity as an epidemiological variable that include consideration of socioeconomic differences as an explanation of differences in health between ethnic groups.

I argue that racism should also be a variable in health services research. Parker ⁷⁶ argues that categorising by ethnicity without explaining the meanings of such categories is to disregard the impact of racism. A recent report on ethnic disparities in health and social care, commissioned by the Department of Health's Equality and Human Rights Group ⁷⁷ reinforces this view by stating:

while ethnic disparities in health continue to be attributed to genetic and non-specific cultural explanations in some areas of medical research, the emerging evidence base suggests that socio-economic factors and the experience of racism may be amongst the most important causes of these disparities (p4).

These structural factors are relevant to the position of Gypsies and Travellers and their situation as an ethnic group in a society that is largely hostile towards them. I will now explore these ideas further in relation to the ethnic identity and socioeconomic position, of Gypsies and Travellers and the influences of social attitudes towards them.

2.4 Gypsies and Travellers – Ethnic identity

Although Gypsies, Irish Travellers, and pending a test case in law, Scottish Gypsy Travellers, ⁵² have gained recognition under Race Relations legislation as ethnic groups, in contrast with other ethnic groups in the UK, their ethnic status is still the focus of debate – both in academic contexts, and in relation to policy and research initiatives. In particular, issues of authenticity and entitlement are rarely far from the surface with reference to Gypsy and Traveller identity. The key issues in discussions and debates about Gypsy and Traveller identity have revolved around inter-related themes of historical origins; ethnicity by descent; cultural identity; perspectives on group acceptance of identity and perspectives on legislative ethnic identity in the context of political influences. I will now review these arguments, first covering the linked areas of historical origins and notion of descent, then questions of group identity and culture.

2.4.1 Historical origins and notion of descent

Debate about possible historical origins in Britain is greater among Gypsy scholars than among many Gypsies and Travellers themselves. Ni Shuinear ⁷⁸ states that “Gypsies and Travellers everywhere are supremely indifferent to their own origins” (p60).

However, although this is understandable in that Travellers “have a name for themselves as a group, and they know exactly who does and does not belong to it and why” ⁷⁸(p59), this suggested indifference to their origins would appear to undermine

recognition of their ethnic identity by the dominant majority. My experience is similar; most Gypsies and Travellers that I have worked with are indifferent to their historical origins, but in contrast they have a very strong sense of their family heritage and of their identity as members of their 'family line' of Gypsies or Travellers. Gay-y- Blasco speaks of the strong sense of identity among the Gypsies she has worked with in Spain, referring to their sense of commonality.⁷⁹ The Gitanos, or Spanish Gypsies, have undergone similar experiences of control and assimilation to Gypsies and Travellers in the UK and experience the same difficulties of living in a society that is hostile towards them. Gay y Blasco found a similar model of their sense of identity; it is not dependent on place and they do not see communal harmony with other Gypsies and Travellers who are not their kin as crucial to their identity. Yet they conceived all Gypsies everywhere as one people, but

a scattered aggregate of persons, of undefined size, origin and location, who are similarly positioned vis a vis the rest of the world and who uphold the Gitano laws (p7).

The importance of extended family support in such a hostile world is similarly important among UK Gypsies and Travellers. As O'Connell⁸⁰ argues, denial of Irish Travellers' cultural identity contributes to an assimilationist ideology and to their low social status in Irish society. In a political context the importance of historical origins is clear, and Ni Shuinear⁷⁸ illustrates this when describing one school of thought in respect of Irish Travellers:

the more distant their origins in time and space, the more "real" we must concede the Travellers to be, and treat them accordingly (p73).

Reid,⁸¹ a Scottish Gypsy Traveller, writes of three theories of Gypsy Traveller origins in Scotland: indigenous origins, Indian origins and fusionist theories. Although he is referring specifically to Scottish Gypsy Travellers, these theories are also familiar elsewhere. The 'Indian theory' is most frequently mentioned with reference to English and Welsh Gypsies. Hancock⁴, in common with many, refers to the notion of a 'shared Indian origin' of Romanies but seems to concur with Ni Shuinear about the relative insignificance of this for their sense of identity as he states:

while the knowledge of our Indian origins is important...it is not a body of knowledge that is kept in mind on a daily basis. In fact most Romanies don't even know about it (p78).

Reid ⁸¹ supports Ni Shuinear's arguments about the connection between origins and authenticity, as he argues for the right for Scottish Travellers to define their own identity, and as he decries the political use of origins by Gorgers to distinguish those who they decide are 'true Gypsies':

As a Gypsy/ Traveller myself I am made painfully aware that we have always been defined by outsiders. Countless names and descriptions have been foisted upon us. The language used to describe Gypsies/Travellers is constantly changing and has more to do with Government policy than ethnic identity (p32).

Among Gypsies and Travellers, a national identity appears to be secondary to the notion of an ethnic identity. Stewart ⁸² refers to the conventional ideal of national identity as a "near mystic assimilation of territory, language and people" and comments that Gypsies in Europe have not thought of themselves as a diaspora population. He hints at the ways in which Gypsies and Travellers are seen as disrupting prevailing ideas about identity and classification:

Lacking even the desire for a shared territory, the basis of a nation, Gypsies constitute a kind of awful historical mistake, a blot on the parsimonious schema of 'one people, one state' with which we try conceptually to order Europe today...(p85)

In recent times, in a period of increasing globalisation, there has been an increase in nationalisms, with many regions or territories within existing states currently striving for independent states, for example Catalonia, Scotland, and Quebec.⁸³ There is a similar political awareness and ethnonationalism among Gypsies or Roma, the Romani Movement, as they seek political status of a Romani people at national and international levels.⁸⁴ Fraser describes Gypsy groups in Europe as being "part of a larger entity" but equally recognises the distinctiveness of different groupings.³ He suggests that:

the attitudes of different Gypsy groups to each other are a contributory factor in the unending debate among outsiders over who should and should not be designated a true Gypsy (p8).

and refers to the breakdown of a simple dichotomy between 'them'(Romani) and 'us'(Gadje). However he argues that a rise in Gypsy national organisations in the latter

half of the 20th century, as a self defence against “policies of rejection and assimilation”, has led to a “new awareness of the historical and cultural ties that Gypsies share” (p9). At an international level, Gheorghe and Mirga⁸⁴ describe this recent ‘ethnic awakening and mobilisation within the Romani community’ and the concept of the symbolic existence of a Romani nation, with its members dispersed worldwide. In order to differentiate between the traditional concepts of nation, characterised in large part by its territory, and the Romani concept, various Romani intellectuals have used terms such ‘stateless nation, nonterritorial, transnational to signal that they are seeking “a broader political framework in which to address their cause” (p11). These Roma activists involved in international Romani organisations; the International Romani Union and Romani Advisory Council, also add weight to the points made earlier about the ways in which ethnic identities can be strengthened through adverse social relations; they attribute the ethnic awakening within the Romani community to the collapse of communism and associated anti-Roma behaviour.

Clark and Dearling⁸⁵ pose the question of whether Gypsies and Romanies are one ethnic group, Romani, or many, as they name some of the “long and complex list that is defined by both Romanies and outsiders”(p2). These include, for example, Tsiganes in France, Zigeuner in Germany, and Minceir in Ireland, Sinti, Manouches and Jenische. While questioning whether narrow and ethnically exclusive definitions of Gypsies and Travellers can provide an efficacious basis for campaigning for their human rights, and arguing that the debate should be reconceptualised, they emphasise that they do not discredit the significance of Romani/ Gypsy identity; its history and its culture. It could be argued that a focus on exclusive definitions could be detrimental to collective human rights campaigns, but as Clark and Dearling argue, support for the shared human rights of all Gypsy and Traveller groups should not be at the expense of ‘retaining difference.’ Gheorghe and Mirga⁸⁴ refer to a “mosaic” type of Romani culture and society, which is complex, multi-layered and characterised by both differences and commonalities. They point to the history of migration and nomadism as survival strategies for Roma to explain the different cultural heritages and histories and various levels of cultural adaptation of various Romani populations to their current ‘territories.’

From a different perspective, Belton⁸⁶ has also developed an analysis of the emergence and definition of Gypsy and Traveller populations. He argues that “a significant number of people might have been obliged to take up what might be seen as Gypsy

habits and therefore become Gypsies by repute”(p77). He sees this as a result of people being uprooted in various political and economic upheavals shaping Europe from the period of the English Civil war in the 17th century to the industrial revolution in the 19th century. He broadens his argument by referring to Willems’ view that throughout Europe, “a historical process has merged various travelling groups who have travelled for economic reasons rather than an ethnic drive or racial urge into one all-embracing category - Gypsies” (p65). However, I argue that this viewpoint plays down the role of self-ascription identified by Jenkins ⁶⁰, Nazroo ⁵³ and others, whereby the group sees itself as distinct from others, and vice-versa . We see below how Gypsies and Travellers define their ethnic boundaries for group membership and readily differentiate between those whom they accept and recognise, as opposed to ‘outsiders’ such as ‘new travellers’ with a similar travelling lifestyle. Whereas ‘new travellers’ share many of the same problems of marginalisation and lack of toleration for their choice of accommodation in caravans, and some Gypsies and Travellers would argue for their rights to a nomadic lifestyle as well as their own, they do not accept that ‘new travellers’ share their ethnic identity. Although now disbanded, with previous member groups now divided between separate federations, the Gypsy and Traveller Law Reform Coalition, which included new travellers, was formed in a united effort to campaign for law reform for all Gypsy and Traveller groups. Unity of political purpose, however, does not equate to shared ethnic group membership.ⁱⁱⁱ

Many Gypsies and Travellers deem themselves to be heterogeneous members of one worldwide group of people, sometimes referring to a shared common language and a common geographical origin, or implying this with common association and reference to Gypsies in Europe and elsewhere.^{4, 87-89} This is sometimes brought into question when the common language of Irish Travellers is examined. Gammon or Cant is not recognised as a dialect of Romani and nor, according to Ni Shuinear ⁷⁸, is it a ‘scrambled’ form of the Irish language, although it is spoken by Irish Travellers in both Britain and Ireland and also by those who emigrated to the United States in the 19th century. It could be argued that Irish Travellers are not part of the same worldwide group. However, this view also ignores a fundamental aspect of ethnicity as a cultural phenomenon, in that the group regards itself and is regarded by others as distinct from

ⁱⁱⁱ A description of different Gypsy and Traveller groups can be seen on the Travellers in Leeds web site: http://www.travellersinleeds.co.uk/_travellers/travCommsNewTravellers.html and in chapter one in Here to Stay: The Gypsies and Travellers of Britain²⁶

Gorgers. Gypsies and Travellers have long seen themselves as separate from Gorgers and have been seen by them as a separate group, despite evidence of intermarriage. It was as a result of concern about the projected loss or decay of the Gypsy language and culture that the Gypsy Lore Society was initiated (by Gorgers) in the 19th century.⁹⁰ Although the motive for the Lorists was to preserve a romanticised and questionable notion of a 'pure race', Gypsies too distinguished themselves in this way, borrowing the notion of a 'pure Romany race' to avoid the negative attitudes afforded to them as an itinerant population. This distinction led to a hierarchical distinction between the ascribed 'true Gypsies', known as Romanies, and others who were considered 'diluted' and less respectable and were termed derogatively as 'didakais', 'mumpers' or 'posrats'. The latter were condemned as criminal and scapegoated accordingly.

In referring to many studies of "Gypsies" on several continents (and she includes Irish Travellers as well as groups more commonly described as Romani), Okely⁶¹ points out that the Travellers or Gypsies invariably differentiate themselves from the 'Gadje.' She highlights some of the common features or characteristics emerging from these studies:

many are found to have pollution beliefs...There is usually an ideology and practice of self-employment and occupational flexibility. Many groups exploit geographical mobility, although not all could be labelled nomads (p27).

She discusses the 'sub-classification' of groups of Gypsies and Travellers and suggests some reasons for the emphasis on what she describes as a "mythical Indian origin" to distinguish between 'real' Gypsies and others, such as 'Tinkers' or Irish Travellers. A Hungarian theology student, Stephan Valyi, who noticed similarities between the Indian Sanskrit language and the language spoken by his neighbouring Romany labourers first suggested the connection between Romanies and India in 1760.⁴ The Indian origins theory of the Romani language was further developed by Rudiger, a trained philologist, in the late 18th century.⁹¹ Hayward, who has compiled a Romany dictionary, traces the historical derivation of the current English Gypsy language.⁹² and Matras provides a full discussion of the scholarly debate on the existence and origins of the Romani language.⁹³ Although these discussions are beyond the scope of this thesis, Matras explains the importance of the debate as he challenges the arguments put forward by Okely and Willems which suggest that there is no Romani language with an Indian origin. He argues that by denying the existence of the language, and thereby denying the territorial origins, they are challenging the proponents of the Indian origins

theory. He suggests that these proponents interpret Gypsy and Traveller ethnic identities in linguistic- territorial terms because they are more familiar to mainstream society and politically useful. Okely⁶¹ suggests that Gypsiologists^{iv} equated language with 'race' and that the theory of a supposed single exotic origin persists today as a "mythical charter for selective acceptance of members, usually a minority, of a potentially threatening group" (p12). Fraser³, whilst not wholly disputing the origins of the Romani language, strongly contests the extent to which this can be equated with the origins of the Romani speakers;

historical linguistics cannot determine the racial and ethnic origin of the early Romani-speakers. There is no inherent or necessary link between language and 'race': there are indeed many well-attested cases of whole ethnic groups switching language through time (p22).

Nonetheless he, like Hancock⁴ goes on to discuss other possible evidence for links to an Indian origin, including suggestive genetic evidence. He concludes though, that the Romani language and its speakers "have been exposed to a multitude of historical, demographic and sociolinguistic influences over the centuries; so too have the languages and populations of India"³(p32). Although he is also seeking to prove a single unifying Indian origin, he does veer from this position when, in discussing groups such as Irish and Scottish Travellers, he too contests biological determinism, stating:

It is a futile task to look for precise categorisation among such groups, particularly if the aim is to rank them in order of genuineness (p297).

Len Smith⁸⁸, a respected English Gypsy author, in his informal, but well-researched history of the New Forest Gypsies, points out that the first recorded Gypsies in England also had their own reasons for exploiting 'exotic origins' as 'Egyptians.' He refers to evidence of Gypsies being in Persia in AD 900 and further deduction that they began wandering westwards, splitting in different directions into Europe in the 15th century before their first recorded existence in Scotland and then England in the 16th century. He explains that warrants of safe conduct, granted by kings and nobles to "some duke or earl of little Egypt" that these early Gypsies carried, gave "an air of mystery about it so far as Europe was concerned and what better than to claim an origin thence?" (p23). He

^{iv} Okely does not explicitly identify the Gypsiologists in this context although she mentions Irving Brown as one highly respected Gypsiologist who was unable to find a link with language when searching for evidence of Indian culture among European Gypsies (p11)

adds that they had a cover story: the Pope had sent them on a seven-year pilgrimage (dates of which were constantly being revised in different places) and that during this time they were not to sleep in beds, but on the ground only. This resourceful explanation for self-description as Egyptians, which initially enabled them to survive as nomads in Europe, did not give these medieval Gypsies lasting protection and security; once they arrived in great numbers legislation was introduced in 1530 that allowed for capital punishment or deportation of 'Egyptians.'⁹⁰ The death penalty remained in place until 1783.⁶¹ Hancock⁴ writes that other itinerant groups used similar ploys to make themselves acceptable and non-threatening as 'outsiders' but that Gypsies throughout Europe soon became subject to harsh laws of suppression. In several countries, including England, it became an offence, punishable by death or deportation, just to be a Gypsy. There are various explanations put forward for such extreme suppression. Smith suggests that in England it coincided with the growing population of "masterless men"^v in a period of great political change and led to a historical need for English Gypsies to conceal their identity.⁹⁰ He also suggests that the law against importing Egyptians is an explanation for the tendency for Gypsies at that time to assume the English names of landed gentry as proof of their native birth. He recounts this historical persecution to explain that:

those attitudes, typical of Tudor times, were to persist, and from that time until the present date, the popularity and social acceptance of Gypsies in Britain has waxed and waned across great extremes (p26).

This is relevant to present-day debates about the cultural characteristics that mark Gypsy and Traveller identity as an ethnic identity. Okely⁶¹ controversially suggests several alternative theories for the 'Egyptians' gaining recruits to their group from disenfranchised indigenous people, for example dispossessed peasants following the land enclosures, and that a second 'secret' Creole language may have been adopted to consolidate a novel identity. Belton⁸⁶ makes similar claims about origins, but the context for Okely's view is in questioning the assumption that an ethnic group needs to be defined by its 'foreign' origins. Although there are sometimes heated debates among academics about the origins of Gypsies there is a general consensus that the existence of a distinct group, known then as Egyptians, was first recorded in the UK in the fifteenth century, and they exist today as Gypsies with a unique history and culture.^{3;4;61;88;94}

^v Smith gives the reference for this term from 'Masterless Men, the vagrancy problem in England 1560-1640' by AL Beier³⁵

Common descent has also been proposed as a basis for defining Gypsy and Traveller ethnicity, alongside notions of shared historical origins (see section 2.3.2 re Mandla criteria). Okely⁶¹ has referred to the principle of descent as:

a self-ascriptive mechanism for continuity. It restricts entry into the group and offers the means for survival. Among Gypsies or Travellers it is the most socially relevant and the one necessary condition for being a Gypsy (p67).

Smith⁸⁸ also accepts the importance of the principle of descent, and in acknowledging evidence of marriage outside the group (i.e. with Gorgers), he does not see this as 'diluting' Gypsy Traveller identity:

Gypsy history from Europe at [Tudor] times is clear that marriage outside the culture ...was forcefully discouraged. Despite these taboos against intermarriage with the gorjis, I think we can be certain that some did occur, which would have been a good thing in genetic terms, providing an influx of new blood into a small ethnic group (p26).

The process of Gorger individuals being accepted into Gypsy Traveller families in Britain has accelerated over the centuries and he argues "we can be sure the Gypsy is moulded from a variety of clays" (p27). He also explains that the principle of descent does not necessarily imply biological inheritance but that ethnic group membership can be 'handed down' by those who already 'possess' it, provided there has already been group acceptance of that ethnic group membership.(private email 6.8.2003). He explains this further by stating that however mixed the heritage, a Gypsy or Traveller who is accepted as such by the group can pass on that group membership to his/ her descendents.

Belton⁹⁵, strongly influenced by Willems, also takes a social constructivist approach to understanding how notions of difference (including ethnic difference) arise and are shaped in specific social, economic and political contexts. He argues that some claims for ethnic minority status by Gypsies and Travellers have relied on simplistic and sometimes romantic appeals to notions of historical origin, cultural tradition and blood-line; his view is that these are fragile indicators of Traveller ethnicity and that they impose an appearance of homogeneity on an actually diverse range of Gypsy and Traveller groups. This leads him to argue that:

Travellers should be understood as being a heterogeneous population, developing out of and reflecting the social and economic situation in which it exists (p144).

However, in my view, this is true for all populations. As Evans⁹⁶ states:

[all] cultures are a blend of nationalities and global influences, the product of invasion, immigration and colonisation, of trade, travel and communication... contemporary Traveller culture is the product of generations of influence and interaction (p2).

Belton⁹⁵ states that his concern is not to deny the existence of distinct Gypsy and Traveller communities, or their sense of belonging, but to analyse and comment on the significance of the ways in which discourses concerning ethnicity have evolved in relation to Gypsies and Travellers. In particular, his view is that a simplistic notion of ethnicity undermines efforts to tackle inequality and marginalisation by favouring a socio-cultural response rather than a wider socio-political response. This argument is made in the context of his specific focus on a link between homelessness and caravan-dwelling. In terms of empirical analysis, the evidence he presents to suggest that there is a link between the size of the caravan-dwelling population and post-war housing shortages is consistent with his points about population movements in the early stages of industrialisation. His conclusions from these analyses have provoked a very critical response, particularly from other Gypsy and Traveller authors. Smith alludes to the concept of group ascription as he specifically refutes Belton's argument that the Gypsy and Traveller population has come to include some non-Gypsies who took to caravan-dwelling due to homelessness and unemployment in the post war period, adopted a Traveller identity, and thus became defined by society as Gypsies. Smith speaks of all the many "travelling folki" he came across in those times in the London area who he describes as:

Gypsies by any test! I can't imagine that in the very few years since the war ended that they all 'learned' this way of life and language. Certainly, back then, these Londoners would not have been integrated into Gypsies so easily, and would have stood out like sore thumbs if they had been around. (private email 2005)

We can see that references to historical origins and common descent have both been used to define ethnic boundaries, and their relative importance depends on the situation and who is contesting those boundaries. The principle of descent is particularly

important for group acceptance, but we have seen how this can be metaphorical or 'conferred' and allows for intermarriage; it does not imply a 'pure blood line.' Okely⁶¹ comments that Gypsies and Travellers use the term 'blood' in this context as a metaphor for ethnic continuity. However both these features can be contested by 'others' who attempt to set ethnic boundaries by refuting ethnic identity, as I will now describe.

2.4.2 Group identity and culture

Despite agreement for the purposes of the Race Relations Act 1976 that Romany Gypsies and Irish Travellers fulfilled the Mandla criteria, with reference to shared histories, cultural traditions and practices, we have seen that the legal definitions used for the purposes of site provision have not always differentiated between 'real' Gypsies and Travellers and 'other' groups adopting a travelling lifestyle. As Evans⁹⁶ argues, in refuting their cultural identity as 'proper Gypsies' it becomes easier to dismiss them politically as vagrants or dropouts. Assimilationist references continue to surface periodically, as illustrated by Jack Straw, speaking as Home Secretary, in a radio interview in 1999:⁹⁷

There are relatively few Romany Gypsies left, who seem to be able to mind their own business and don't cause trouble to other people, and then there are a lot more people who masquerade as Travellers or Gypsies.

Academics^{85;98;99} have challenged such statements, arguing that they appeal to simplistic, static and divisive images of 'authentic' Gypsy and Traveller ethnicity and also that Gypsies and Travellers do meet key criteria for ethnic group status (both in legal and in theoretical terms). English and Welsh Gypsies, Irish Travellers, and Scottish Gypsy Travellers all consider themselves to be ethnic groups and in their counter-arguments they often refer indirectly to the notion of ethnicity as identity. For example, they often compare themselves to other ethnic groups when referring to discrimination that they have encountered. At an empirical level, authors cite evidence of common customs and traditions: for example, Gypsies' and Travellers' strong commitment to the extended family, the importance of economic independence (preferably through self-employment and trade), specific social customs concerning cleanliness and hygiene (mochadi) and other customs and beliefs associated with gender roles, with dealing with death and other practices.^{100;87} Another cited cultural feature is the presence of specific languages for English/ Welsh Gypsies (Romani), Irish

Travellers (Shelta or Gammon) and Scottish Travellers or 'Nawkins' (Scottish Traveller Cant).¹⁰¹

Okely⁶¹ maintains that Gypsy and Traveller identity is reinforced by upbringing in a community, within which aspects of shared culture that the group consider socially relevant to their identity are regularly validated. Referring to Barth's argument that it is socially relevant factors rather than objective differences that are crucial for group membership, she states:

aspects of Gypsy culture may resemble aspects of wider society. But cultural similarity with any non-Gypsy persons does not necessarily weaken the permanent feature in the Gypsies identity; namely their conceptions of themselves as a distinct group (p67).

Smith⁸⁸ agrees, and refers indirectly to the concept of ethnicity as an identity:

The essence of Gypsy-ness is fundamentally based on the culture and way of life, attitude to the rest of the world, and the indefinable sense of 'specialness' that a Gypsy feels about himself (p26).

He asks "where would a negative result leave someone who was convinced of his/her own ethnicity, and could show his descent for some generations back?", when refuting the notion of a blood test for a Romani gene to prove descent (private email 12.12.01)^{vi} In another context he expands on this position: "I do not believe in the concept of 'race'...but I do believe in cultural identity" (private email 13.6.2003). He is in fact refuting the idea that Gypsy or Traveller identity is 'racial', i.e. based on physical features. He is also making the point in the context of a suggestion that a unity or coalition of Traveller organisations may dilute their separateness; he emphasises that all groups may have a cultural identity and that unity does not homogenise the cultural identity of separate groups. O'Connell¹⁰³ discusses the dynamic and relational nature of ethnicity with reference to Irish Travellers. He explains how socio-cultural features are selected and given meaning through interaction between groups, sometimes taking on new meaning through historical associations so that they "symbolise the group's sense of peoplehood and aspirations, like for example, nomadism for Travellers"(p113).

^{vi} The Romani gene was reported in a study in the American Journal of Human Genetics in December 2001 as confirming the ethnic unity of the Roma¹⁰²

Nomadism is viewed as a particular cultural characteristic by Gypsies and Travellers and non-Gypsies and Travellers alike. However, this can become problematic if seen as an essential fixed characteristic, for example when outsiders believe that Gypsies and Travellers no longer belong to their ethnic group if they cease to travel for any reason. McDonagh,¹⁰⁴ an Irish Traveller, describes nomadism as central to Traveller ethnic identity but explains it in this context:

when Travellers speak of Travelling , we mean something different from what country people usually understand by it...For Travellers, the physical fact of moving is just one aspect of a nomadic mindset that permeates every aspect of our lives . Nomadism entails a way of looking at the world, a different way of perceiving things, a different attitude to accommodation, to work, and to life in general (p34).

As conceptions of identity depend on perceptions of similarity and difference, Gypsies and Travellers, in setting their own ethnic boundaries, demonstrate not only who they think they are, but equally, who they think they are not. Okely⁶¹ emphasises the dichotomisation between Gypsies and Gorgios as being continuous, but that the Gypsies' self-ascription is decisive. She highlights the importance of this when she suggests that "a broad definition of Gypsy and Traveller might be 'not Gorgio'" (p66). This implies an important aspect of self-definition by describing a key distinction of members not only perceiving themselves as having a distinctive identity but also emphasising the importance of categorisation by other.⁶⁰ An oral tradition and use of narrative is a cultural attribute often referred to by Gypsies and Travellers; this extract from the poem 'Identity' by Charles Smith⁸⁹, an English Gypsy, brings to life some aspects of this interaction between group identity and social categorisation:

What do you see
When you look at me?
Your idea of identity
Am I the Gypsy
You've read books about?
Am I the Traveller
You heard talk about ?
Will you see the folki
Not in the books?
Will you judge my cousins
Just by their looks?
Will you know the Gypsy who lives in your street?
Or the one in the butchers who serves you your meat?
What of the midwife who helped at the birth of your son

Her parents were Gypsies so she must be one
Then there's the old lady who tends all the graves
She preaches the Bible and claims Jesus saves
You will recognise her son who calls with a bell
The other one's a teacher, you won't know him so well...(p28)

In summary, there is in-depth debate concerning the possible historical origins for different Gypsy and Traveller populations, and the linked issue of shared descent. Reference to common descent appears to be most strongly emphasised, but at the same time, patterns of inter-marriage with Gorgers are acknowledged and not seen as undermining the importance of a sense of common descent. Strong ethnic group boundaries that reinforce a sense of cultural identity are maintained through upbringing. References to distinct ethnic boundaries, partly through strong differentiations between Gypsy or Traveller ethnicity and Gorger status, form one of the ways in which Gypsies and Travellers are able to resist pressures towards assimilation.

Belton's ⁹⁵ general arguments about signs of ambiguity and confusion in discourses about ethnicity, and also his Foucauldian arguments concerning the forms of social control and surveillance embodied in caravan site provision and regulation carry some weight;

Travellers are the 'other' because they represent an alternative to market norms, departing as they do from housing conventions and, importantly, from the accompanying norms of housing that act as a means of observation and control, through known location and patterns of consumption and communication (p143-4).

Nonetheless, whilst there is a case, for Belton's argument ⁸⁶ that Gypsy and Traveller identity is socially constructed, dynamic and shaped by social and political forces, this is also true for other ethnic identities. This argument does not lend any credence to his view that "Gypsy ethnicity, founded on tenuous ethnic and racial markers, is a fragile construct" (p36). In contrast we have seen examples in this chapter that support Barth's and O'Connell's view of the significance of socially relevant factors with symbolic meaning rather than objective differences. In my view, a recognition of distinct Gypsy and Traveller ethnic identities provides the most coherent account of Gypsy and Traveller status, within the 'ethnicity as a social identity' paradigm. Attempts by 'others' to deny Gypsy and Traveller ethnicity and to assimilate them can be seen in the context that their 'way of life', and in particular their nomadism, is perceived as a threat

by the dominant majority. We have seen how the threat of assimilation serves to strengthen an ethnic identity and reinforce their marginalisation and experience of ‘new racism.’ Although all the above authors are concerned about equality, Belton takes a political approach which concerns class and market relations and tends to play down the relevance of ethnicity. Like others,^{40; 58; 80} I find ethnicity more salient, while still recognising the contribution of socioeconomic and class position. Stewart⁸² points to the relevance of ethnic identity as he describes methods of survival in a hostile world:

Gypsies developed a battery of communal devices to protect themselves, summed up in the term ‘Romanes’ – a term which refers to Romani, the Gypsy language and to ‘the Gypsy way of doing things’ (p89).

Throughout this thesis, but specifically in Chapter Three, I highlight the relevance of ethnicity to health inequalities. In this context Nazroo⁵³, whose view pertains closely to the situation of Gypsies and Travellers, states that ‘ethnic identity politics’ is the way forward as he quotes Modood:

Ethnic identity, like gender and sexuality has become politicised. There is an ethnic assertiveness; arising out of the feelings of not being respected...it is a politics of projecting identities in order to challenge existing power relations, of seeking not just toleration ...but also public acknowledgment, resources and representation.

I now discuss this further in relation to power and agency and the political and social context.

2.4.3 Power, agency and tackling racism

O’Connell⁸⁰ refers to the strengthened sense of identity of Irish Travellers as being a political instrument in their struggle for human rights. He explains:

Gaining awareness of the root causes of their oppression has strengthened their sense of ethnicity, partly as a necessary defence in the face of ongoing hostility (p15).

Belton,⁸⁶ in questioning whether a focus on ethnic differences is the soundest route to tackling the injustice experienced by Gypsy Travellers, finds that the concept of ethnicity seems “to be spiralling into the same problems of contradiction in use and

confusion of definition that marked the demise of its theoretical predecessor ['race']” (p186). His argument is that it is better to focus on social justice and thus be able to challenge, the broad range of social and economic conditions and interactions that produce inequalities. However I am persuaded by Mc Donagh and McVeigh¹⁰⁴ who link recognition of oppression to the potential for challenging it:

If Traveller ethnicity is recognised Traveller disadvantage is explained in terms of discrimination and the main priorities for action are tackling this discrimination and ‘celebrating diversity’; if Traveller ethnicity is denied, Traveller disadvantage is explained in terms of pathologising Traveller culture and the main priorities are getting rid of the less respectable culture through sedentarisation, assimilation or other more violent genocidal strategies (p7).

Whilst they too suggest that many Travellers and others see the question of Traveller ethnicity as merely an academic argument, and for Travellers; “the immediate pressing issue is existing Traveller disadvantage”, they contend that:

the question of ethnicity is absolutely crucial in the fight against Traveller disadvantage...the recognition of Traveller ethnicity begins to ...situate Traveller disadvantage in terms of institutionalised anti-Traveller racism (p5).

We have seen how racialisation of groups based on supposed “undesirable” characteristics has led to their exclusion, and we will see in Chapter Three how this contributes to health inequalities. This is just one important factor alongside class or socioeconomic inequality, which I discuss further there. To ignore the question of ethnic identity is to ignore a crucial factor in the quest for equality. Conversely, as we have seen, if ethnicity is denied, ethnic boundaries may be strengthened and further marginalisation may result. Evans⁹⁶ quotes Hilding, a Gypsy, who emphasises the importance of identity:

Travellers today, they are ashamed of who they are because the governments put them down so much... I don't think you should forget who you are because inside you're forgetting yourself. If you forget about your past life, then who are you in the end? (p162).

2.4.4 Processes of exclusion and assimilation

We saw earlier how in the 19th century those Gypsy Travellers who were not classed as ‘real Romanies’ were given the pejorative term ‘didakais’, and that this supposed ‘pure

race' of Romany Gypsies were viewed as separate from the larger group of Travellers and as declining in numbers.⁹⁰ The classifications used before the legislative changes in the 1960s supported the myth of the existence of only a few real Romanies. Okely⁶¹ cites the first government survey of Gypsies in Kent in 1952 as reporting that only 10% of the eleven hundred Gypsies were members of Romany families. She writes that this survey set the tone for other local authorities to condemn the majority of Gypsies in their localities and to justify lack of site provision.

Gypsies' and Travellers' history of self-employment and aversion to wage-labour has historically been symbiotic, filling a niche in local provision of services; their nomadic lifestyle not only suits this cultural preference for economic organisation but is also necessary for its continuation. However, fear and suspicion of nomads has been a constant factor in negative attitudes towards them among the majority populations in most countries and has had a considerable impact on relationships and resulting policies. For example, Godwin¹⁰⁵ writes:

In Europe their persecution by the gadje began quickly with the church seeing heresy in their fortune telling and the state seeing antisocial behaviour in their nomadism (p78).

Monbiot¹⁰⁶ refers to the alienation of Gypsies and Travellers as an "acceptable hatred" as he links their alienation to their nomadism. He associates the hostility and perceived threat of their mobility in part with the difficulty that it poses for control of a nomadic population and points to the forced sedentarisation of the European Gypsy populations. However, he also views envy as the root cause of all racism and suggests that "beneath the enduring hostility to Gypsies lies an ancient envy of the nomadic life." McVeigh¹⁰⁷ refers to anti-nomadism as 'sedentarism' which he defines as:

that system of ideas and practices which serves to normalise and reproduce sedentary modes of existence and pathologise and repress nomadic modes of existence (p9).

He argues that this is a broader concept than racism, and in this description I also share the view that hatred born of fear of nomads is a major cause of their repression. However, in describing the historical transition in civilisation from nomadism to sedentarism it is plausible that there may be a sense of envy in the felt injustice at the

nomads' ability to challenge the dominant sedentary form of existence, arising from a sense of loss of freedom. Although McVeigh argues that sedentarism, which can be directed at any nomadic groups, such as 'new travellers', is not essentially racist, he does suggest that sedentarism takes the form of racism when it is applied to ethnic nomads. I view his point as crucial, that sedentarism does not simply aim to stop nomads from travelling but denies their ethnicity and pathologises them in the process. He argues that sedentarism is structured by class and property ownership as well as 'race'. In arguing that the existence of nomads is a challenge to the legitimacy of land ownership and control he makes an important link with colonialism and the nomadism of indigenous of First Nation people:

Where indigenous peoples were nomadic , prior [land] ownership was denied and the colonised given the status of non-people, uncivilised and incapable of civilisation...Ever since the simultaneous and intrinsically related expansions of capitalism and colonialism, the travelling dispossessed have threatened the established economic and political order (p21).

In this sense there are parallels with Belton's arguments concerning capitalist market structures and class relations, however, here the argument is broader as it also reflects attitudes towards groups based on cultural differences. This historical explanation gives credence to McVeigh's view that nomads threaten the sedentary identity of all non-nomads, or sedentary hegemony, and helps to explain the widespread support for anti-nomadic measures. It also contextualises the 'cultural racism' referred to earlier, that in the UK is a response to the perceived threat to the 'British way of life.'

To return specifically to the situation of Gypsies and Travellers in the UK, the threat of assimilation, however it is couched, is real and seen as a form of ethnic cleansing aimed at who they are rather than how they live.¹⁰⁷ Overt racism is now increasing in the UK after a two-decade period of decline, with hostile media coverage linked to self-reported prejudice against different racialised groups, such as Muslims.¹⁰⁸ A more recent survey of attitudes towards minorities¹⁰⁹ made a similar link, with the media as a key source of people's attitudes. It examined the causes or explanations of prejudice that can, but do not necessarily, give rise to overt racist behaviour. The two main causes of prejudice identified were economic and cultural, with Gypsies and Travellers as groups against whom most prejudice was expressed, closely followed by refugees and asylum seekers. Hostile media reports were also implicated, for example, by citing anticipated rise in

crime, or falls in house prices, in fuelling perceived threats to ethnocentric or 'normal' values. Perceived unfairness is often used to justify prejudicial attitudes and hostility. Irresponsible media reporting can often fuel this perception of unfairness by suggesting that policies, such as site refurbishment grants, are unduly favouring Gypsies and Travellers at the expense of the wider local population.^{vii} This increases division, and reduces the prospect of opportunities for positive social encounters where people can get to know and respect each other.

Negative stereotyping can be extended to Gypsies and Travellers regardless of whether they remain in caravans or move into houses. Discrimination and persecution of Roma in Europe persist even though they have been forcibly sedentarised for decades. The level of prejudice may depend on the extent to which they have been scapegoated as a cause of social ills and to what extent they 'become like 'us' or the dominant 'norm.' The scapegoat theory carries much weight, and the demonisation of Gypsies is described by Ni Shuinear.¹¹⁰ She asserts that Gaujos not only scapegoat Gypsies, but in doing so, distance themselves from their own failings:

Anti-Gypsyism is a moral crusade- and seen as such by those who are active in it. To accept the Gypsy would be to accept everything that decent people reject.... Individual Travellers, in small numbers, may be readily accepted into the fold since their 'conversion' is living proof that our objections to other members of the group are not racist in nature (p52).

This explanation sheds light on the denial of racism in oft-heard assertions that 'it is not the 'real' (i.e. very few) Gypsies I object to.' Straw's earlier comments are a typical example. This theory also partly explains the apparent acceptability of prejudice and racist behaviour towards Gypsies and Travellers. Sir Trevor Phillips, Chair of the CRE, acknowledged the impact of continuing discrimination and hostility¹¹¹, saying: "Discrimination against Gypsies and Travellers appears to be the last 'respectable' form of racism in Britain." Recent examples of such racism include the burning of an effigy of a Gypsy caravan with pictures of family occupants in the window and a registration

^{vii} The following extract from a report in the Sun newspaper on 10.9.2006 is an example of irresponsible media reporting:

"A council was blasted yesterday for buying an illegal gipsy site for £292,000 - spending £1.5million on a luxury upgrade and then inviting back the evicted travellers. The gipsies (sic) now enjoy brick chalets, shower blocks and toilets at the camp in Bristol."

plate PIKEY1 at a public event, and the murder of a 15 year old Irish Traveller boy in what police described as a racist incident.¹⁰

Gypsies and Travellers are no different to other racialised groups in the variety of responses to the hostility and discrimination that they experience. They may sometimes use and accentuate negative stereotypes strategically to their advantage as a warning not to take advantage of them.¹¹² Nonetheless; negative stereotypes can also be internalised as fixed cultural attributes and wittingly or unwittingly perpetuated. The common experience of low levels of formal education attainment can result in a perception that this is the 'norm' for Gypsies and Travellers and that to be educated is to lose cultural identity. Simon Evans warns about the "trap of stereotyping Gypsies/ Travellers as people who are not educated to degree level" and advises that until

cultural diversity truly takes on board the right of Gypsies and Travellers to have their culture and difference recognised, respected and celebrated, a Gypsy with a degree will still be considered an anomaly (Private email 3.3.06).

Whereas there is a tendency, as described earlier, for ethnic boundaries to be strengthened as a result of oppression, the group solidarity of Gypsies and Travellers¹¹² and their unwillingness to be 'assimilated' can be used by others as 'justification' for prejudice, as they are viewed as bringing isolation upon themselves. However, their 'self-segregation' is really no different to that of other ethnic or faith groups who feel their identity to be under threat. We see for example, "white flight", described by Cattle, with 'Black' and 'White' communities living 'parallel lives' in the same neighbourhoods.¹¹³ As Cattle argues, while groups lead parallel lives and have little opportunity to develop any understanding of each other, it becomes easy for stereotypes and false rumours to be spread and believed and for the self-segregation to persist as a defence against such racist hostility.

There is also an alternative protective tendency to hide a Gypsy identity. This expediency may be seen as a form of 'voluntary' acculturation but it can have a traumatic effect of loss on those who feel constrained by their situation to resort to it. Sweeney¹¹⁴ gives an example as she promotes a project aimed at preserving the oral culture of Scottish Gypsy Travellers. She quotes the Traveller project leader, who explains that aspects of the culture were not passed on due to the stigma associated with being a Traveller and that this impacts on the current young generation who want to

“know more about themselves” and ask “Can you tell me why I was deliberately denied my language and culture?”

The various responses to their experience of racism by Gypsies and Travellers serve to illustrate the extent of their social exclusion rather than reduce it. The expectation of racism and discrimination, leading to hidden identity or withdrawal, has a potential profound effect on interpersonal relationships. Lack of personal contact only serves to perpetuate the stereotypes. This is illustrated by 13 year old Gypsy,¹¹⁵ describing the offensive remarks about Travellers made by a school classmate, and adding:

if I told her from the start I was a Traveller , she probably wouldn't even have liked me from the sounds of the way she was saying it. But it just goes to show, she liked me, but because she didn't know I was a Traveller (p79).

2.4 Conclusion

In this chapter I have described the sizeable populations known as Gypsies and Travellers in the UK and suggested some possible reasons for the common popular denial of their legally-recognised ethnic status. ‘Race’ and ethnicity have been used synonymously and loosely in regard to health, but I have argued that, while remaining aware of racism, ethnicity is the appropriate term to use. In particular, it is crucial to address ethnicity as structure and ethnicity as identity.

I have described the social context for an ethnic identity of Gypsies and Travellers, but described how their status remains contested. It is important to recognise the racialisation of Gypsy and Traveller identities and its social impact. There are specific processes of ‘othering’ and stereotyping Gypsies and Travellers that are associated with the reactions of a sedentary majority to groups of people with nomadic identities and lifestyles. These are complex and enduring and need to be recognised if their oppression and inequality is to be tackled effectively. I will explore this further in the following chapter in connection with health inequalities.

CHAPTER 3

Health Inequalities

Introduction

There is a large body of evidence about the level of health inequalities and differences in life expectancy within the UK, and in other European countries. The evidence and some key references are broadly summarised in a European partners' position paper on tackling health inequalities.¹¹⁶ A key contribution to work in this area has been the research by Marmot et al concerning Whitehall civil servants, identifying a social gradient of health inequalities which is strongly associated with unequal social positions.¹¹⁷ I will expand on the various aspects of social position in the section on social determinants of health inequalities below. However, there is a range of debates on the subject of health inequalities, regarding questions of definition, approaches to measurement, and theoretical explanations. Allied debates on how to tackle health inequalities cannot be considered clearly without an understanding of these three sets of issues. Considering these issues is also fundamental to understanding Gypsies' and Travellers' health, in the context of broader current debates on health inequalities. Below I discuss each set of issues in turn.

3.1 Definitions and meanings of health inequalities

The literal meaning of health inequality, and the synonymous term health disparity, is any difference in health status. However there are differing definitions with varying strengths and weaknesses. Kawachi et al¹¹⁸ describe 'health inequality' in its broadest sense as a "generic term used to designate differences, variations and disparities in the health achievements of individuals and groups" (p647), and explain it as a descriptive term that implies no moral judgement. For example, some inevitable health disparities, such as those between young adults and very elderly adults, do not necessarily stem from injustice.

The term health inequity, which is not synonymous with health inequalities, is now used more frequently to differentiate between inevitable health disparities and those that can

be avoided. Kawachi et al ¹¹⁸ describe the concept as referring to “health inequalities that are deemed to be unfair or stemming from some form of injustice” (p647).

Braveman and Gruskin ¹¹⁹ cite Whitehead’s definition of health inequities: “differences in health that are unnecessary, avoidable, unfair and unjust” (p307) - as useful and influential in raising awareness. However, they reasonably argue against avoidability as a separate criterion, as this is implicit if inequity is defined as unjust or unfair. Bambas and Casas ¹²⁰ also suggest the implicit nature of avoidability when stating that avoidability is a key criterion for equity “because if a distribution is not avoidable, it cannot be interpreted to be unfair in a social sense” (p327). They put forward three criteria to establish a situation as inequitable with regard to differences in distributions of health resources or larger determinants of health:

- The differences in distribution must be avoidable
- The difference must not reflect free choice
- The claim must link the distribution to a responsible agent.

These could be seen as broad and generalised criteria, but Bambas and Casas expand on the different areas of avoidability that require consideration prior to any proposals for redistribution; technical avoidability, financial avoidability and moral avoidability. They illustrate the importance of these considerations; for example it would be feasible to address health inequalities through high public expenditure at the expense of other social priorities thus creating other, possibly greater, social injustices.

Braveman and Gruskin ¹¹⁹ suggest that another definition is required for the purposes of measurement and accountability in order to describe the concept more fully:

equity in health can be defined as the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage—that is, different positions in a social hierarchy. Inequities in health systematically put groups of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic, or religious group) at further disadvantage with respect to their health; health is essential to wellbeing and to overcoming other effects of social disadvantage(p254).

Braveman ¹²¹ enlarges on this definition of equity as an ethical principle in relation to the disparities between social groups, stating that relative positions of groups in a social

hierarchy reflect “differences in wealth, power and prestige” (p306). This is the background to her position that

a commitment to health equity, that is to reduce social inequalities in health, rests on ethical values, specifically the principle of distributive justice; it is also consonant and closely related with human rights principles (p307).

This, I would argue, is the fundamental reason for exploring health inequalities; to identify and understand them with the objective of pursuit of social justice by distribution of resources to achieve health equity. However this is a political endeavour which is fraught with potential problems, and hence can result in a lack of political will to tackle such a potentially contentious and possibly crucial vote losing issue.

Kawachi et al ¹¹⁸ highlight the difficulties in identifying health inequities by explaining that this involves:

normative judgement based upon a) one’s theory of justice, b) one’s theories of society, and c) one’s reasoning underlying the genesis of health inequalities (p648).

However in the position paper produced by European Partners for Equity in Health ¹¹⁶ the following examples of health inequities are given:

- health damaging behaviour where the degree of choice of lifestyles is restricted
- exposure to unhealthy, stressful living and working conditions
- inadequate access to essential health and other public services
- health related social mobility... (p2).

I return to the conceptual problems later in the chapter, but ultimately, with a health equity goal, the major challenge is to overcome barriers, including structural factors, to appropriate policy and its implementation. The financial implications of addressing health inequities are a major contributory factor to lack of political will. This is illustrated by the fate of the Black Report on Inequalities in Health in 1980 ¹²²; the Secretary of State failed to endorse the recommendations on the grounds that:

additional expenditure on the scale which could result from the report’s recommendations... is quite unrealistic in present or any foreseeable economic circumstances, quite apart from any judgement of the effectiveness of such expenditure in dealing with the problems identified ... (p16).

However the report was calling for redistribution of resources rather than major additional investment and this suggests that the proposed shift of resources from the most influential and powerful (private sector and hospital consultants) to the less powerful (community sector) was at the heart of the expressed concern around economics. The Secretary of State subsequently added two further objections in challenging the report's explanation for causes of health inequalities and the evidence on unequal access to health services. Townsend and Davidson ¹²² argued that a belief in market values and "the virtue of individualism" underlay the government's approach to health care (p33). In placing emphasis on individual behaviour the government of the day denied the existence of health inequalities in terms of social group disparities; this denial was evident from their subsequent avoidance of the term. The eventual ensuing health strategy, published in 1992, *The Health of the Nation* ¹²³, set several health improvement targets but avoided the concept of health inequalities. The emphasis was on lifestyles, individual responsibility and medical intervention models rather than wider determinants.

It was not until 1994 that there was any acknowledgment of the inequalities concept at policy level, but the term was still avoided. Instead, a report ¹²⁴ from a working subgroup referred to health 'variations' and restricted its focus accordingly. As Wilkinson ¹²⁵ observed at the time:

Political safety was ensured by limiting the discussion to what the NHS and the Department of Health could do. Poverty, housing, job insecurity, the inner cities, the rationing of health services, and other embarrassing problems were left outside... (p1177).

When the New Labour government came to power the concept resurfaced, with the decision in 1998 to set up an independent inquiry into inequalities in health.¹²⁶ The policy documents that followed ¹²⁷⁻¹³¹ acknowledged the wider social causes of health inequalities. It is with this implicit understanding of underlying socioeconomic disparities that I use the term health inequalities to refer to social health inequalities in this thesis, as I expand on the separate specific determinants and their implications. I use the term health equity, adopting Braveman's definition ¹¹⁹, to mean

the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/ disadvantage (p254).

It is possible to categorise people according to their health status without reference to social factors, such as wealth, education and occupation, which may influence that status. However, by using Braveman's definition of health equity, I am acknowledging the associations with social advantage that these features characterise and am seeking to understand Gypsy and Traveller health disparities in this context. I also use the phrase, "underlying social advantage or disadvantage", as Braveman ¹¹⁵ defines it, to refer to "wealth, power, and /or prestige – that is attributes that define how people are grouped in social hierarchies" (p 254).

The use and understanding of definitions of health inequalities has important implications for determining how they are measured. The purpose of measurement is to inform policy and this in turn will be influenced by underlying goals and values that inform concepts of inequality and inequity. Examples are shown below as they are framed in different approaches to measurement and monitoring.

3.2 Measurement and monitoring of health inequalities

Kawachi et al ¹¹⁸ describe two distinct approaches to measuring health inequalities. One method is to measure the distribution of health status across ungrouped individuals in a population. This epidemiological approach, which shows health variation across all individuals in a population, gives a measurement of total inequality. This is often used with the measure of life expectancy at birth for example, to compare health status between geographical areas. This descriptive approach enables international comparisons and comparisons over time and is useful in guiding the use of additional resources to explore and tackle the local health determinants that may influence low comparative health status in identified areas. However this approach does not measure health equity. The more common approach is to measure social group differences. Kawachi et al argue that a "value free" approach is not reasonable as it considers individuals in isolation from their social relations. They add that grouping individuals together on the basis of a shared health profile risks both neglect of the consideration of meaningful social groupings and overlooking investigation into the causes of inequality.¹¹⁸ The two approaches are not mutually exclusive choices and I would argue for both as complementary approaches to measurement and monitoring of public health. However, as Braveman ¹³² argues, if the concern is about health equity it is essential to

study inequalities across social groups. She answers the rhetorical question ‘Why monitor health equity?’ with a fundamental explanation based on human rights:

Priorities for allocation of public resources must reflect the fact that people in more – and less- advantaged social groups experience unequal opportunities to be healthy based on their underlying social disadvantages (p184).

Braveman¹³³ reports that experts in the field use measures of health inequalities in a health equity approach which assume that the most relevant comparisons of health indicators are between better-off and worse-off social groups. These would be pre-selected on the historical basis of those who are considered more or less advantaged in society. This is more appropriate than comparison with the average levels in a population, where the extreme level of good health that is aspired to is masked, and it fits with the human rights principle proposed by Braveman and Gruskin¹¹⁹:

the highest attainable standard of health can be understood to be reflected by the standard of health enjoyed by the most socially advantaged group within a society (p255).

However, although health equity is an appropriate goal, Braveman argues that it is not possible to measure equity directly, as this is a normative concept. Nevertheless, by measuring inequalities between groups, health inequities are likely to be reflected because the inequalities place already disadvantaged social groups at further disadvantage in respect of health and health care.¹³²

To determine the action required to achieve health equity, and to monitor the effectiveness of any policies, appropriate measures are necessary for determining and monitoring social inequalities in health. Braveman¹³² poses three basic sets of questions to be addressed in monitoring health equity:

How do levels of health vary across different social groups?
How do levels of key determinants vary across social groups?
How have both levels of health and health determinants in different social groups and gaps between the groups changed over time? (p186).

Before addressing these questions, a key issue is to identify the appropriate social groups for comparison in the study population. In the UK it is now acknowledged that health equity should be assessed and this is reflected in the policy directive for primary

care trusts to undertake health equity audits.¹³¹ However the lack of reliable social group data, such as ethnic group data, is evident in the reported failure of most Primary Care Trusts (PCTs) to measure inequalities between some of the most disadvantaged groups in society, and instead to opt for 'easier' comparisons where data is readily available.¹³⁴ This helps to explain why there is no reliable evidence of health inequalities between Gypsies and Travellers and other groups. Various factors influence the choice of audit topic, but the views of the local Director of Health and the priorities identified by local strategic partnerships are key factors. The Baseline survey of Health Equity Audits identified the need for suitable updated comparator data, access to methodologies, and sharing of good practice as being crucial to address the avoidance of more difficult audit topics. It also appears important to inform the views of the local strategic partnerships so that they be more inclined to prioritise reduction of health inequalities among the most disadvantaged groups.¹³⁴

Choice of selected groupings reflects different bases on which groups are considered advantaged or disadvantaged in various countries.¹¹⁸ Social position, which equates with social advantage or disadvantage, varies according to economic resources, power and prestige, but is manifested by various indicators such as income, wealth, education, occupation, ethnicity, residential location, religious group affiliation, sexual orientation, and gender. It can be seen that certain individuals will suffer disproportionate social disadvantage by falling into more than one disadvantaged category. For example, a female Gypsy living in a deprived environment will have more obstacles to achieving health equity than a male Gypsy in a comfortable environment.

Historically, in the UK and Europe the usual approach for measuring health inequalities by social group categorisation has been to measure socioeconomic group differences, whilst in the US it has been 'racial' or ethnic differences.¹³³ This may reflect a historical belief in the US, as Braveman suggests, that health disparities result from biological or cultural differences as opposed to underlying social disadvantage. Conversely in the UK, health inequalities are widely understood as reflecting different positions on a socioeconomic scale. I now briefly expand on socioeconomic classifications currently in use in the UK.

3.3 Identification and classification of social groups

3.4.1 Socioeconomic classifications

In the UK, since the early twentieth century, social class has been used as a framework for measuring inequalities in health. The concept of social class is itself controversial; a definition given by Black in his Report on Inequalities in Health ¹²² is:

segments of the population sharing broadly similar types and levels of resources, with broadly similar styles of living and [for some sociologists] some shared perception of their collective condition (p47).

Prior to 1990, social class in Britain has been determined, primarily, by the occupation of the head of a household. The basis for this classification was the varying prestige or social standing associated with the various occupational groups. Although there are a variety of other interrelated social and economic factors involved in defining social class, such as employment opportunities, wealth, education and housing tenure, occupation had been regarded as having the strongest association. ¹²²

Despite the view that occupation was the best measure of social standing for determining health inequalities, there were many identified weaknesses with the early system. For example, by defining a married woman's class on the basis of her husband's occupation, any effect of her status by virtue of gender is negated. Even for a single woman, classified according to her own occupation, her material circumstances, reflected for instance by access to a car or personal income, can be more significant than occupation as indicators of social inequality. ¹³⁵

Until 2001, there were two official socioeconomic classifications used variously in official statistics and in academic research in the UK: social class based on occupations (SC) and socioeconomic groups (SEG). Changes in industry and types of occupations, and continued criticism of the arbitrary nature of these classifications, led to a review in 2001 ¹³⁷, which resulted in NS-SEC, a new replacement social classification. A crucial strength of the NS-SEC measure is that people are classified on the basis of employment relations and conditions of occupations. A category for 'never worked and long-term unemployed' is also included. ¹³⁸ The classification was derived from the 'Goldthorpe schema' which has been used in international comparisons and validated as a good health predictor. ¹³⁶ It accounts for important independent factors known to affect health:

economic security, prospects for advancement, levels of control and work autonomy as well as material rewards.¹³⁷ The NS-SEC classification was introduced for the 2001 census. For the first time, this census also included ethnic data, but there is still much controversy surrounding the relationships and links between the dimensions of social differentiation in the health inequality field. However, although this classification has advantages over its predecessors of being more conceptually clear, covering a wider range of situations in the employment market that may influence health, and being flexible in its use through availability of reduced and simplified versions, it suffers from the same disadvantages as all occupation-based indicators of socioeconomic position. An occupational-based classification of socioeconomic position represents only one important indicator of socioeconomic position and aspect of social inequality.

Social class, social status and socioeconomic status are often used interchangeably as terms to denote social position. I am using the term social position as Bartley defines it; to include social class and status or prestige, and the term socioeconomic position to include these and material assets.¹³⁸ Socioeconomic position is multi-dimensional; different socioeconomic factors can interact with other linked aspects of social differentiation such as ethnic group, gender, sexuality, age or life stage, residential location, and religion, with differing health effects.^{139; 140} A person's socioeconomic position varies according to wealth, power, control and prestige, all of which may be reflected in different degrees by various indicators, and will vary according to the policies or traditions in different societies and over time.¹⁴¹ Braveman et al emphasise the risks of drawing conclusions from research using socioeconomic measures that only measure limited aspects without consideration of the implications of unmeasured socioeconomic factors.¹⁴⁰ There is no single measure that is suitable or applicable for all study purposes and in all settings and points in time.¹⁴²

It is important to be selective in the choice of different socioeconomic measures, considering both feasibility and relevance for the population group in question.¹⁴⁰ For example some researchers have used proxy indicators of socioeconomic position, such as wealth or family size, which for certain groups, such as women who are not the main earners in a household, can be more closely correlated with health outcomes than occupation based measures.¹³⁷ However different proxy indicators may not always be the main explanation for health inequalities. For groups such as Gypsies and Travellers, whose occupations in extended family-based work units are not necessarily the best

indicators of socioeconomic position, proxy indicators such as observable wealth, for example home ownership or car ownership, would be more relevant.⁶¹ Braveman gives an example of injudicious use of proxy indicators, such as education for income level, with evidence of very different income levels between different ethnic groups with similar educational attainment.¹⁴⁰ Income is not only a poor indicator of wealth but measurement of wealth is a sensitive subject and is rarely included in health studies as a variable.¹⁴⁰

Graham and Kelly¹³⁹ argue for consideration of the implications of unmeasured factors such as racism or discrimination. They give the example of socioeconomic disadvantage as a major contributor to the poorer health of certain ethnic groups such as African Caribbean, Bangladeshi and Pakistani, but suggest that exposure to racism is a likely explanation. They illustrate the relative influence of wider social determinants for different ethnic groups; “A Bangladeshi with a degree has the same risk of poverty as a white person with no qualifications” (p5). Interrelated dimensions of disadvantage take a cumulative toll on health and need to be mapped and understood in the context of the health effects of social inequality.¹³⁹

Ecological or area level indicators, known as indices of deprivation, can be used as proxy indicators of socioeconomic position when direct occupation based data are unavailable. However, if area measures are used as a sole proxy measure of individuals' socioeconomic position there is a probable risk of misclassification due to the independent contextual influence of area on health.¹³⁹ For example a study of two separate areas with similar environmental risks from chemical and petrochemical industries found different attitudes towards that risk which was dependent on levels of engagement and trust.¹⁴³ In other words, looking at risk in isolation would be to ignore other contextual influences.

3.3.2 Indices of deprivation

These Indices usually consist of aggregated indicators, derived from census data or other administrative databases, such as the Townsend, or the Carstairs deprivation indices.¹³⁷ Indicators of social position in such measures are non-occupation based and include, for example, housing tenure and car ownership as composite measures of deprivation. Such measures are commonly used to categorise areas on scales ranging from most deprived to most affluent and for health outcomes to be closely correlated.

For example, 88.9% of Sheffield residents reported good or fairly good health in the 2001 Census, but this ranged from 94.4% in the most affluent ward to 82.9% in the most deprived ward.¹⁴⁴ The Jarman underprivileged area score, constructed to measure general practice workload, is derived differently with extra indicators of socioeconomic position. Its indicators include, among eight weighted variables, ethnicity, lone parenthood and residential mobility.¹⁴⁵

However, such measures use indicators about individuals who comprise the population in an area, with no separate information about the environment to suggest independent causal explanations for deprivation or affluence. Various studies have resulted in conclusions about the independent association of area social deprivation and levels of personal deprivation. Carstairs and Morris¹⁴⁶ found in their study of mortality rates in Scottish males that area deprivation effects remained after standardising for individual socioeconomic group. Davey Smith et al¹⁴⁷ found that individually assigned and area-based socioeconomic indicators made independent contributions to several important health outcomes. However, although Sloggett and Joshi¹⁴⁸ also found a clear relationship between deprivation by ward residence and excess mortality, they found that the association disappeared when allowances were made for individual socioeconomic position. They recognised that their study differed from others: it was longitudinal, used a deprivation index different with different composite factors and only measured mortality as a health outcome. However, they suggest that excess mortality in areas designated as deprived on the census based indicators can be wholly explained by a concentration of people with adverse personal socioeconomic factors in those areas. They accept that there are other health outcomes, such as psychological stress, that can be compounded by the ecological effects of living in deprived geographical areas. Nevertheless, they warn of the risk of inequity in policy measures that target such deprived areas at the expense of large numbers of equally disadvantaged people who live outside such areas.

In summary it is important to recognise the limitations of many measures of socioeconomic status used in research or in public health monitoring. They may not be sufficient, relevant or indicative of the social position of different groups within measured populations. On the other hand, the health associations revealed by judicious use of the measures are useful indicators of inequality that point, importantly, to specific factors for further investigation of possible explanatory mechanisms. The

possible causal relationships between different dimensions of social differentiation and wider health determinants such as cultural and environmental factors require more detailed examination.

3.4 Explanations of health inequalities

Here, I will briefly review the debates associated with explanations for socially determined health inequalities, before exploring the evidence base for the impact of different wider social determinants. These include psychosocial factors associated with social status, social exclusion, and life course influences. I have already indicated that the explanations for health inequalities are socially determined. Marmot¹⁴⁹ argues that health inequalities are not inevitable:

a burgeoning volume of research identifies social factors at the root of much of these inequalities in health (p1099).

This explanation lies on one side of the debate that has existed between those who adopt the position of individual responsibility for health and those termed the ‘social determinists’ who believe that most health inequalities between groups reflect unfair distribution of the underlying social determinants of health. I have shown how recent Government policy has shifted from favouring the individual responsibility approach to recognition of the evidence of the social determinists’ position (see page 50). However debates about the nature of the causal relationship between social class and health persist.¹³⁵ Black et al put forward four categories of possible theoretical interpretations to explain why “occupational class” exerts such a significant influence on health in Britain.¹²² Nettleton has reviewed these categories¹³⁵ and I will briefly explore the arguments because of the important policy implications based on varying views of causation and responsibility for good or bad health.

3.4.1 Artefact explanations

This explanation is based on the socially constructed model of health and ill-health, and is used to argue that differences in diagnosis or classification over time are responsible for apparent inequalities arising from statistical artefacts. Statistical artefacts are spurious results which can arise from distorted associations and inferences about the

relationship between variables.¹ For example, this approach to explaining health inequalities could lead to an argument that the relationship between health and class found in the Black report were spurious because they were artificial variables of little causal significance and that the results could be explained by changes in class compositions.¹²² However, this argument does not explain enduring inequalities that have persisted despite reported changes in approaches to measurement.¹²²

3.4.2 Theories of natural or social selection

This argument, also referred to as health selection, is based on the theory that health status influences social position, with those in poor health being downwardly mobile and vice versa. There is some empirical evidence for this argument based on birth cohort studies, although effects were small.¹⁴⁹ Nettleton reports on a study which suggests that social processes discriminate against those in poor health, therefore indicating a plausible explanation for health-related social mobility.¹³⁵

The other two explanations are based on the reverse assumption, i.e. that variations in health status are the result rather than the cause of social class differences.

3.4.3 Cultural or behavioural selection

This explanation emphasises the influence of lifestyle behaviour and suggests that those in lower socioeconomic groups adopt more unhealthy behaviours such as smoking, eating poor diets. Although there is some evidence for this association, the argument can become polarised between those who believe that this is matter of ‘choice’ and personal responsibility and those who believe that ‘unhealthy’ behaviours are largely a result of individuals’ adverse social and economic circumstances.¹³⁵

3.4.4 Material or structuralist selection

The health effects of social structure and environment are the emphasis in this explanation. There is a wealth of evidence for this association.^{116; 117} Social factors have a persistent impact on health after control for smoking and other behavioural factors and this reveals the weakness of the behavioural argument as a sole explanation.¹³⁵

¹ A more detailed examination of statistical explanations can be found in Bartley¹³⁸ chapter 3

To summarise, although it is clear that behavioural and structural factors are not mutually exclusive in explanations of health inequalities, it is important to consider them separately and to avoid ignoring environmental influences that are not manifested through health behaviour. By doing otherwise there is a risk of focusing on behavioural change at the expense of recognition of the need to change the environmental influences that predispose to ‘unhealthy’ behaviours.’ It is important to understand the biological effects of psychosocial environments that underlie behavioural responses, as well as the direct physical health-harming determinant effects such as pollution. In the following section I will consider these effects as wider social health determinants that can also explain health inequalities.

3.5 Social determinants of health

There is a clear conceptual distinction between determinants of health and determinants of health inequalities. Wider determinants include factors that go beyond individual risk factors like smoking, and include income, education, employment, housing, the environment and also healthcare services. Dahlgren and Whitehead illustrate the complexity, range and interrelatedness of social health determinants in a diagrammatic model (see Fig 1). A person’s social position is determined by socioeconomic factors, including for example, gender and ethnicity. However social class and socioeconomic position also indirectly influence intermediary factors, i.e. environmental and health-harmful behavioural factors, which affect health more directly. Environmental factors include physical risks such as pollution or poor housing, and also psychosocial factors, such as chronic stress, that arise from adverse social conditions.¹³⁷

Determinants of health inequalities refer to the unequal distribution of health determinants. The distinction has relevance for policies, as it is quite possible to tackle health determinants without tackling determinants of health inequalities. For example policies aimed at raising educational standards or reducing smoking will focus on overall exposure to health damaging factors. In contrast, targeted policies aimed at reducing health inequality may focus on redistribution of resources.

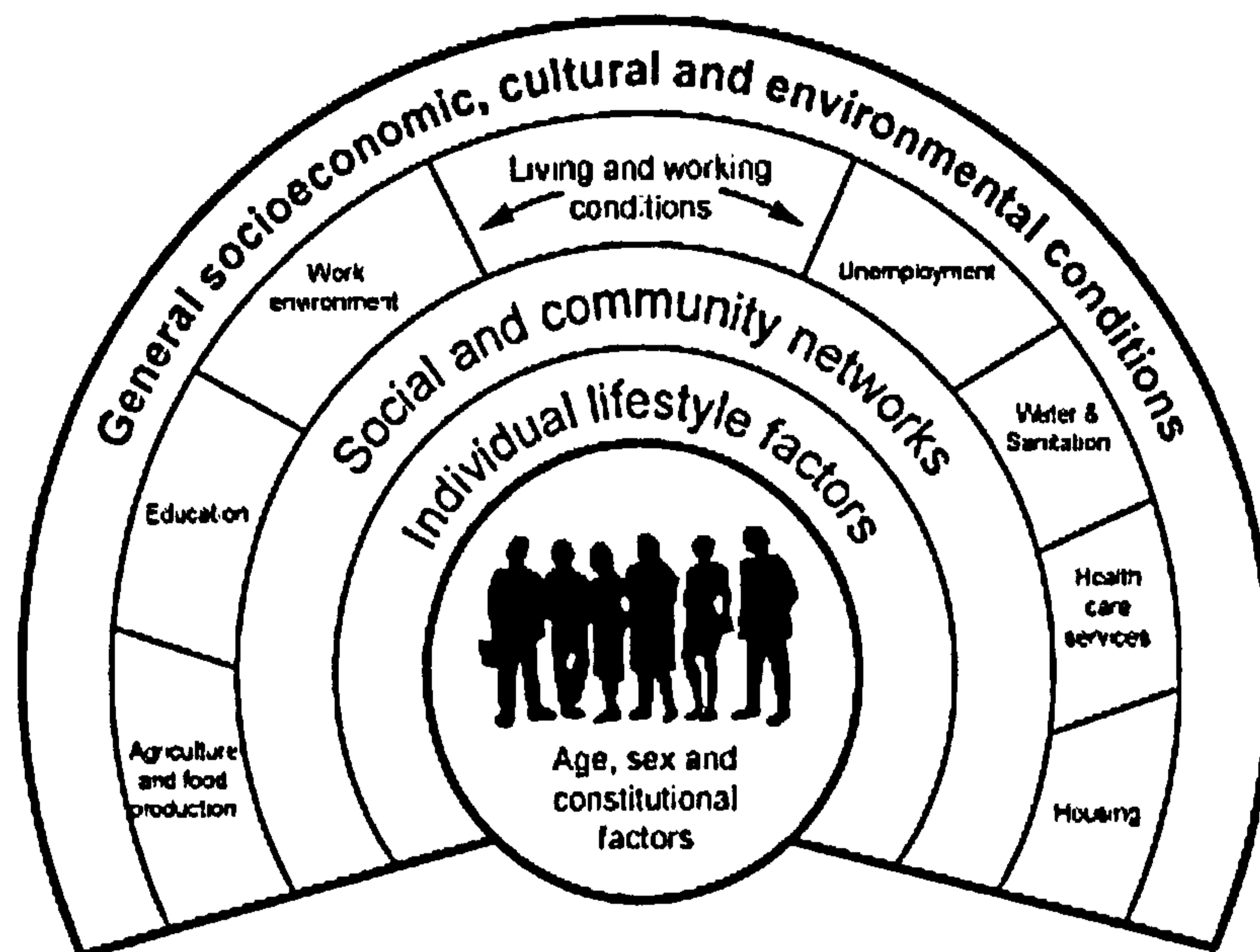


Figure 1 - The main determinants of health (Dahlgren and Whitehead model) ¹²⁶

However, Graham and Kelly also warn that solely focussing redistribution on the most disadvantaged is insufficient; there must also be an inclusive focus on reducing health gradients across the whole social hierarchy.¹³⁹ Inequalities will persist along the social gradient if attempts are made only to improve the health of the most disadvantaged. This leads to an important debate: does health disadvantage in the lowest socioeconomic groups result from a direct effect of lower absolute health determinants, such as pollution or poor housing, or from an indirect effect of the psychosocial circumstances associated with relative social position? If absolute rather than relative poverty or deprivation were the major influence on health inequalities, it would be expected that overall improvement in economic growth would reduce inequalities. The reality is that health inequalities are increasing within European countries despite increased prosperity and overall health improvements.¹¹⁶ Wilkinson has shown that there is greater health inequality in societies with greater income level disparity.¹⁵⁰ He has demonstrated that mortality is more closely associated with relative deprivation than with absolute income and suggests that psychosocial effects of social position have the greatest influence on health inequalities. In the following section I will explore this argument further, as it has particular implications for an understanding of health inequalities relating to Gypsies and Travellers.

3.5.1 Psychosocial environments: income inequality, social position and social cohesion

Graham¹⁵¹ stresses that the mix of health determinants is different for various health outcomes. For example, the physical environment will be a relatively more important factor in health outcomes such as accidents but the social environment will be more crucial in mental health outcomes. Wilkinson¹⁵² refers to the pivotal influence of social position with regard to relative income and poor health in suggesting that

income is related to health not so much through its role as a determinant of material living standards, but rather as a marker for social status (p258).

Wilkinson and Marmot¹⁵³ also explain the link with social position and the psychosocial importance of consumption in serving social, psychosocial and symbolic purposes and expressing identity. They also refer to wealth as a marker for social status and success, and explain the psychological benefits of ‘retail therapy’ that indicate success through possessions that enhance self image. In arguing that social environment is crucial for health Marmot suggests that social position is deemed important for two major related reasons; degree of control over life circumstances and opportunities for full social participation.¹⁵⁴ Wilkinson’s theoretical explanation for the association between income equality and health and social position is that income equality improves social cohesion and therefore reduces social divisions.¹⁵⁵ It is the more egalitarian societies that are the most cohesive. Wilkinson uses Putnam’s definition of social capital to describe the key feature of a cohesive society as the quality of social relations.¹⁵⁶ Social trust, reciprocity, social support, community engagement, sense of belonging or inclusion, self perceived control, power and influence over decisions are all possible indicators of population or community health associated with social capital.¹⁵⁷ Kawachi et al showed that in US states where the income differences were greatest people trusted each other least.¹⁵⁸ Similarly Putnam showed an association between income equality and involvement in community life.¹⁵⁹ Lastly, the association between income inequality and violence points particularly strongly to the harmful related effects of income inequality and lack of social capital.¹⁵⁶ Income inequality is also associated with increased racism and discrimination, with the common feature being exploitation of power over weaker groups who are perceived as inferior or of lower status.¹⁵⁶ The correlation between violent crime and income inequality is so strong and replicated in so many studies that it is used as a proxy measure of social

cohesion.¹⁵⁷ Marmot and Wilkinson¹⁵³ refer to “a culture of inequality which is more aggressive, less connected, more violent and less trusting”(p1234).

Wilkinson proposes a psychological explanation, the human desire for self worth, for the way that inequality manifests itself in poor social relations.¹⁵⁶ He posits that in unequal societies the rich or powerful are seen as valued, superior and socially dominant, in contrast to the poor and less powerful who experience shame and anger as a consequence of their social disadvantage. He suggests that the two major routes to achieving self worth are either social, through being appreciated or valued for contributions to society, or antisocial through competitive means to seeking higher social status. The former route is more open to those who live in egalitarian societies whereas the latter is more likely in divisive societies where there is social dominance. He explains the effects of social dominance and inferior social status:

there is a widespread tendency for those who have been most humiliated, who have had their sense of selfhood most reduced by low social status, to try to regain it by asserting their superiority over any weaker or more vulnerable groups (p225).

This helps to explain why there may be more discrimination and more violence per se among the most shamed and humiliated groups in hierarchical societies. Gilbert¹⁶⁰ suggests that the universal experience of shame is related to judgements of status “of feeling inferior, powerless or bad in comparison to others” (p25). In contrast he refers to studies that suggest that status is not only determined by power but can be achieved by positive reinforcers from others, such as respect, prestige or eminence, which indicate value. Because status is seen as being determined by social attractiveness, automatic behavioural responses are triggered to feelings of shame, i.e. feeling inferior or unattractive to others. Responses can be either submissive or aggressive. Scheff¹⁵² also highlights the significance of shame as “the primary social emotion.” He suggests that those experiencing shame often use alternative expressions such as feeling stupid, insecure, and vulnerable because “shame involves painful feelings that are not identified as shame by the person experiencing them”(p264). He situates violence in this context with reference to the ‘shame rage spiral’; unacknowledged feelings of shame lead to anger and disrespectful communication, thus leading to increased humiliation. He suggests that:

hostility can be viewed as an attempt to ward off feelings of humiliation (shame) generated by inept, ineffectual moves, a sense of incompetence, insults, and a lack of power to defend against insults (p265).

We can see how symbolic expressions of success are also related to the sense of shame in being perceived as inferior without certain 'status symbols'. In Chapters Seven and Nine we see examples of how inequality, manifesting in poor social relations, can influence communication between Gypsies and Travellers and health staff and how, for example, perceived hostility or disrespect can evoke powerful emotions.

In summary, violent outcomes of aggressive behavioural responses are indirect effects of social position, with violence and hostility evident in unequal societies where there is greater income difference, and manifested in power relations down the hierarchical chain. People who are subordinated often try to regain their sense of self worth by asserting superiority or control over those below them. When there are fewer means available to regain self respect there is a tendency to scapegoat or discriminate against vulnerable minorities.¹⁵² These hostile behaviours have clear implications for social relations and health in wider society, and particularly for those who experience the most discrimination. However the psychosocial stresses that precipitate the shame and anger underlying these behaviours also have significant direct physiological health effects on those individuals.

3.5.2 Psychosocial environments and ill-health: biological mechanism

The social environment resulting from a person's social position produces direct psychological effects that influence wellbeing and are implicated in other causes of morbidity and mortality. The ill health effects and physiological mechanisms for these effects are well documented.¹⁶¹⁻¹⁶³ Negative emotions, including depression, anxiety and hostility, that can result from low social status and related psychosocial factors, may not only lead to clinical mental illhealth but can also lead to cardiovascular disease, diabetes and chronic inflammatory conditions such as asthma and rheumatoid arthritis and suppressed immunity. Prolonged neuroendocrine 'fight or flight' responses with raised cortisol levels, are deemed to be responsible for these physiological changes.¹⁵⁰ It has been demonstrated that cortisol levels are only raised in response to performing a difficult task when relative failure is experienced with social comparison introduced into the equation, showing that it is the suggestion of inferiority, not the situation itself that causes most stress.¹⁵² Wilkinson highlights evidence from the 19th century that even

when absolute poverty was a major cause of illhealth, there remained a physical impact of psychosocial stress, as indicated by the enlarged adrenal glands of 'the poor.'¹⁵⁰ Recent evidence shows that social isolation, depression and anxiety and low control at work were the strongest psychosocial factors implicated in coronary heart disease.¹⁶³ Wilkinson¹⁵⁰ summarises the psychosocial stresses and effects of low socioeconomic status:

Hopeless, isolated, anxious and a failure: these feelings can dominate people's whole experience of life, colouring their experience of everything else. It is the chronic stress from feelings like these which does the damage (p215).

Different coping strategies such as smoking, alcohol or drug use in response to psychosocial stresses are also associated with indirect effects of physical health-harming behaviours^{164; 165; 166} Other more useful coping strategies can have a positive mediating effect. These include psychological strategies aimed at appropriate action, finding different meaning in experiences, conflict and stress managing strategies, and developing social ties.¹⁶¹

However, the opportunity to develop healthy behaviours is also context dependent. There are different types of social networks and social relationships that can have a positive influence on health through different mechanisms. Friendships are important social ties that Putnam refers to as 'horizontal relations' as they are relationships between equals, characterised by reciprocity. In contrast he terms hierarchical relationships, characterised by dominance and subordination based on power and coercion, as 'vertical relations.'¹⁵⁹ Regardless of whether these terms still hold true in today's society, we do have evidence of the health benefits of strong social networks.^{167;168} In addition to direct psychosocial and practical benefits of social support and social engagement on self-esteem and morale, it is believed that social networks with friends can both encourage health-seeking behaviour and influence health behaviours such as smoking, exercise and alcohol consumption.¹⁶⁹

The family is a significant context for developing health-enhancing behaviours and I will consider this in the context of the life course and the effects of early experience on health.

3.5.3 Early experience and life course effects on health

Socioeconomic effects on health occur in various ways at all critical stages of the life course, but although the strongest and most critical stages are in early life, the effects are cumulative, with long term implications for health outcomes in later life.¹⁷⁰

The first critical period of early life experience occurs antenatally, with poor socioeconomic circumstances leading to increased maternal risk factors, such as malnutrition and psychological distress. Such risk factors can result in impaired physical development and also impaired foetal cognitive development.¹⁷⁰ Stressful family environments affecting the mother's mood have also been linked to foetal brain development.¹⁷¹ Any of these antenatal effects can be compounded by postnatal experiences. For example, studies on parenting and attachment have shown that if a mother or main carer is severely depressed and unable to develop a positive attachment to her baby in the critical neonatal period, or there is other emotional trauma for the baby arising from family life events at this time, the stress response causes permanent effects on brain development:¹⁷²

Neglect and failure of environmental stimulation during critical periods of brain development may lead to permanent deficits in cognitive abilities (p101).

Other negative effects on brain development include a baby's reduced ability to adapt to stress which can result in him/her being perceived as temperamentally difficult. This can then result in a cycle of stress and stressful responses towards the baby.¹⁷²

Early childhood height has been identified as an indicator of psychosocial and emotional influences in childhood and is seen as a proxy for health in later life; studies show that after control for genetic factors, taller people are healthier and that it is childhood height rather than adult height that predicts social mobility.¹⁵⁰ There is a strong correlation between the early childhood emotional environment and poor health in adult life with lack of secure attachment in early life, domestic conflict, and family instability all implicated.^{150; 152} In turn, we have seen how these factors are more likely among families who experience the psychosocial effects of low socioeconomic status.

We can see that the family social environment is a critical determinant of childhood health and development. Poor social circumstances can result in family life disruption and poor family functioning which can lead to compounding influences on a child's

physical, cognitive and emotional development. This in turn leads to increased risks of aggressive behaviour, poor self control and various manifestations of psychological distress in childhood and is a powerful influence on psychosocial health and functioning in adulthood.¹⁷³ There is also evidence for very poor outcomes in children who have suffered adverse childhood experiences at home, with studies showing associations with raised risks of antisocial or criminal behaviour.¹⁷³

Early adverse influences can predict the future socioeconomic status of that individual. For example, a child with impaired cognitive abilities is more likely to develop behavioural difficulties which can lead to low educational attainment. Low educational attainment is likely to lead to poorer employment opportunities and the increased risk of poor socioeconomic circumstances as an adult. However it is important to note that such outcomes are not inevitable and that the effects of poor social environments on family functioning can be ameliorated by suitable interventions at appropriate stages to support parents and inform their responses.¹⁷⁴

Older children or adolescents are influenced less by the family environment and more by their peer networks and social environment. However the influence of childhood behaviour problems can lead to difficulties in forming good peer relationships, with resulting loneliness or conflict leading to further stress. Studies show that peer rejection is associated with increased aggression and depression.¹⁶¹ Conversely studies have shown that the ability to form supportive peer relationships enables children to gain peer group support in coping through improved self esteem and perceptions of control.¹⁶¹ However there is also evidence of a strong peer influence on health harmful behaviours in adolescence. Taylor et al ¹⁶¹ warn that the effects of peer social environment, although important, cannot be seen in isolation from the family environment. They illustrate the influence of parental style and the family social environment, with an example of peer influence on substance misuse: if the parents also participate in substance misuse or if they have a laissez faire or unengaged parenting style, the adolescent is more likely to mix with peers who misuse substances.

The social skills and coping skills learnt in childhood and adolescence continue to exert their influence in adulthood:¹⁵²

the basic confidence or insecurity which comes from emotional experience in early childhood affects people's vulnerability to the insecurity induced by low social status in the social hierarchy (p 264).

Poor social integration and relationships, characterised by conflict resulting from poor social environments, are closely associated with increased mental distress and decreased immunity.¹⁶¹ These interdependent life course effects of socioeconomic disadvantage do not only extend into old age but, as explained, affect the next generation so that the cycle is continuous.¹⁷⁰

In summary we can see that socioeconomic status arising from poor socioeconomic circumstances has profound and lasting health effects throughout the life course. Childhood is the most critical period, where the effects are not only lasting for the individual child but can initiate a cycle with effects on the next generation. Children raised in poor social environments are at increased risk of different threats to their physical and emotional health, as are their parents. These persistent threats can also influence the ability to cope with stress, with the possibility that maladaptive coping responses can lead to further stress and conflict within the family and wider community; thus producing cumulative effects of a poor socioeconomic environment. Although some of the effects can be ameliorated through specific therapeutic interventions, the need to tackle the structural causes of inequality across the social gradient are paramount if there is to be real improvement in social cohesion and social relations. This is a major challenge in a neoliberalist political era when market relations and competition are dominant ideologies. While socioeconomic inequalities endure, the health damaging effects on disadvantaged individuals of chronic stress, increased morbidity and premature mortality will continue, with consequences for the social environment. The increase in hostility, violence and social divisions will in turn exacerbate the chronic stress experienced by individuals and with the impact on the family environment make it increasingly hard to break out of the cycle. The preceding analysis is connected to the theory that relative poverty is a form of social exclusion. I will now examine the concept and consequences of social exclusion in more detail and explore methods of intervention.

3.5.4 Social exclusion

The term social exclusion is contested and its use varies accordingly.^{175 176} Although the concepts of social closure and social divisions are not new, the term social exclusion is

predominately a political discourse that originated in France in the 1970s, initially to describe those who fell outside state social protection such as the uninsured unemployed. Subsequently the concept of social exclusion became a policy driver for social cohesion.¹⁷⁵ Social cohesion was considered an important goal to avoid any undermining of the state by groups who feel excluded, such as disaffected youth. In Europe the term social exclusion was a response to a changing perception of poverty and it displaced the term poverty in the third EU anti-poverty program, placing more emphasis on social integration of the ‘least privileged in society.’^{177; 178} It increasingly gained political importance and, despite lack of consensus on the interpretation and operative use of the term among EU member states, in 1997 the Treaty of Amsterdam included the reduction of social exclusion as an objective.¹⁷⁸ In the UK the term is prominent in political discourse and Payne describes it as “political shorthand for the consequences of poverty”, with the political focus aimed at providing solutions to these consequences.¹⁷⁹ One of the criticisms of the political discourse on social exclusion is that by incorporating an array of concepts such as poverty, inequality, discrimination and racism, the state distances itself from the policies that would tackle these underlying causes of deprivation.¹⁷⁶ A further criticism is that many and sometimes contradictory interpretations of social exclusion undermine its usefulness as a concept.

Different indicators arise from different discourses on social exclusion and these have implications for policy initiatives aimed at tackling the problems. Levitas questions the concept, meaning and use of the term social exclusion.¹⁴¹ She discusses three competing discourses which give some indication of meaning. Briefly these are a redistributive egalitarian discourse (RED), which emphasises the way in which poverty inhibits social participation or full citizenship; a social integrationist discourse with an emphasis on integration through paid work (SID) and a moral underclass discourse which emphasises moral and cultural causes of poverty and is concerned with dependency (MUD). She simplifies these discourses¹⁸¹ as indicating what is lacking for the socially excluded: “In RED they have no money; in SID they have no (paid) work; in MUD they have no morals”(p2). The former discourse is closest to the government’s stated vision¹⁸² of the need to fund public mainstream services to “to distribute funds more progressively according to deprivation and need” (p12). However full redistribution does not appear to be part of the agenda and this would seem to confirm Shaw et al’s¹⁸³ conclusion that:

Labour politicians do not believe they can be sure of re-election if they raise taxes for the rich and perhaps they think that there are very few votes in reducing unfairness in people's health chances (p183).

I will return to the question of policy initiatives when discussing 'how to tackle health inequalities' but the question of definition is important if health equity is to be achieved. The Government's Social Exclusion web site¹⁸⁴ gives a vague definition:

Social exclusion happens when people or places suffer from a series of problems such as unemployment, discrimination, poor skills, low incomes, poor housing, high crime, ill health and family breakdown. When such problems combine they can create a vicious cycle.

Social exclusion can happen as a result of problems that face one person in their life. But it can also start from birth. Being born into poverty or to parents with low skills still has a major influence on future life chances.

This definition does reflect an acknowledgment that social exclusion arises from deprivation rather than simply arising from material poverty. However, Atkinson¹⁸⁵ argues for a wider interpretation based on three aspects of social exclusion: relativity, agency and the dynamic nature of exclusion. Social exclusion is not dichotomous, in the sense that an individual is either excluded or not. Atkinson argues that to assign an individual or groups of people as socially excluded involves examining the context and the circumstances of those around them, as people can only become excluded in comparison to others in that society. Although material poverty is also relative, an individual is deemed as being in a state of poverty by application of specific income related criteria. Groups of people can be termed 'excluded' on the basis of various criteria, such as living in certain neighbourhoods, irrespective of whether they are 'poor'.¹⁸⁵ As Atkinson argues, one can be poor and not excluded or one can be excluded and not poor.¹⁸⁵

Agency is another important aspect of discourse on social exclusion, with polarised views that the excluded are either to blame for their situation because of their moral values and associated behaviour, or the excluded are those who are victims of political structures and who have little opportunity to participate.¹⁷⁵ Put more simply, people are either excluded as a result of features and systems of society, or they are deemed to voluntarily exclude themselves, as a result of what Ratcliffe appropriately terms 'social pathologisation'¹⁷⁶ (p3). This debate is similar to the accusation of self-segregation and particularly pertinent to Gypsies and Travellers (see section 2.4.4). It can be argued that

social pathologisation leads people to 'self-exclude', but there is little that is truly voluntary about such exclusion.

Atkinson's third component of social exclusion, dynamism, refers to the fact that exclusion is a process and is also particularly pertinent to Gypsies and Travellers as it refers not just to the current status of exclusion, but also to long term prospects. Social exclusion can be cross-generational, and in emphasising the dynamic component of social exclusion the lack of hope for the future that it can engender is highlighted.

A more appropriate definition of social exclusion, one that is both concise and comprehensive, is used by the Centre for Analysis of Social Exclusion (CASE):¹⁷⁵

An individual is socially excluded if a) he or she is geographically resident in a society but b) for reasons beyond his or her control, he or she cannot participate in the normal activities of citizens in that society, and he or she would like to so participate.

Lack of participation, the core feature of this definition, is relative and can be experienced differently on the four key dimensions of consumption, production, political engagement and social interaction.¹⁷⁵ In other words this definition does not just go beyond identifying the socially excluded as merely those who have lack material resources but also allows for a focus on the wider social divisions and multiple causes of deprivation that can contribute to exclusion.

Tomlinson¹⁸⁶ agrees with Levitas that difficulties in defining and explaining social exclusion also lead to difficulties in methods of measuring and monitoring it. The New Policy Institute set out to develop indicators of social exclusion, and constructed a set of 46 indicators "to present a wide view of poverty and social exclusion in Britain."¹⁸⁷ The 1999 Poverty and Social Exclusion Survey, replacing the Breadline Britain surveys of 1983 and 1990, was described as the first national study to attempt to measure social exclusion, by using these indicators. The indicators incorporate some of the multi-dimensional features of social exclusion and a major strength is that it used three dimensions of social exclusion that are distinct from poverty: exclusion from the labour market, exclusion from services (either through unavailability or non-affordability) and exclusion from social relations.¹⁸⁸

However, an aspect that is not adequately addressed is the identification of groups who are stigmatised or marginalised. Shaw et al refer to four aspects of social exclusion¹⁸⁹ which include such marginalisation, two of which have particular relevance for Gypsies and Travellers:

- Failure to supply social goods to groups with particular needs.
- Exclusion from social production, not being able to be an active contributor to society: certain groups may be labelled as undesirable, unacceptable or in need of control (p223).

In view of increasing poverty and social exclusion, whilst still advocating long term redistributive policies in pursuit of improved economic equality, they also advocate specific actions to improve the health of more marginalised communities in recognition of the multi-dimensional nature of social exclusion. However, as Watt argues, this approach comes late in the process and only addresses the 'tip of the iceberg'; it is more effective to tackle the causes of social exclusion through macro solutions than to address the consequences by a more limited targeted approach.^{190; 191} He points to social inclusion and the need to build a more cohesive society through wider population strategies as the way forward. I will now examine some of these approaches in more detail for their relevance in addressing health inequalities.

3.5.5 Social inclusion

As Ratcliffe points out, negation of social exclusion is only one aspect of the process of a socially inclusive society - a concept which he argues is equally as problematic as social exclusion.¹⁷⁶ Levitas also argues that although there is agreement in Europe that social inclusion is a worthy objective because exclusion is unfair and damages social cohesion, there is still no shared interpretation of what is meant by the term. She asks the rhetorical question 'what kind of society is implied by the term social inclusion?' Levitas herself advocates a concept of social inclusion that addresses equality of opportunity in the form of rights and recognition and involvement in decision-making through 'the equalities agenda.'¹⁸¹ In 2003 she argued that the EU approach and New Labour had largely focused on policies to promote employability as a vehicle of social integration and therefore emphasising policies for poverty reduction. However, socio-demographic changes in Europe are also reflected in family policies to tackle the consequences of associated social problems, arising from increased ageing populations,

family breakdown and changing family structures.¹⁹² In the UK such policies include Sure Start, aimed at improving the health and emotional development and increasing the availability of childcare for those children living in disadvantaged areas. However, an additional and undisguised aim is to “support parents as parents and in their aspirations towards employment”¹⁹³ Such policies will vary in their impact according to how included those targeted groups feel and whether they ‘choose’ to participate, but also according to the extent that such policies reach other groups who may wish or need to participate but are excluded by geography. I support Levitas’s wider view of social inclusion:

the idea of an inclusive society potentially forces onto the agenda this larger question of what kind of society we want to live in and indeed the question of who ‘we’ are (p4).

Miliband¹⁸² also speaks as if sharing this vision of a cohesive society based on social inclusion in the wider sense:

Feeling included within society is not just about improving an individual’s income, housing, education or employment. It is not just about having the opportunity to live in a brightly lit but heavily guarded tent. It is about being part of a community and society...experiencing the intangible factors that define inclusion – shared aspirations and hopes, trust and respect between citizens; loyalty and allegiance to the wider community and society (p14).

However these “intangible factors” are the end results of social inclusion. The processes of social participation are more complex, but inextricably linked to social justice in the form of egalitarian policies. The risk of emphasising intangible factors such as shared aspirations and hopes and loyalty and allegiance to the wider community is that they can be associated with or interpreted as negative connotations of citizenship and a perceived route to assimilation.

We can see that the most vulnerable minority groups in society suffer from a double disadvantage; they experience the effects of low socioeconomic status and are more likely to be scapegoated and further excluded from social support structures. This disadvantage is likely to increase feelings of shame and concomitant emotions and effects. Gypsies and Travellers are acknowledged as being among the most excluded minority groups in the UK,^{114, 194} In this context, I find Ratcliffe’s support for the

pluralist model of multiculturalism, based on criteria of cohesion, equality and difference¹⁷⁶, in The Parekh report¹⁹⁵ a compelling interpretation of a model of inclusivity. Mahajan¹⁹⁶ describes multiculturalism as acknowledging the existence of diverse communities, and according positive value to the collective identities of all ethnic communities. In this definition people are included into the nation state as members of diverse but equal ethnic groups. He argues that theories of multiculturalism should ideally provide minorities with a sense of involvement, and that theorists of multiculturalism make a distinction between inclusion and assimilation, with a concept of citizenship seen as a form of assimilation. In contrast he describes group differentiated minority rights as including people both as citizens and as members of specific communities and therefore a non-homogenizing and non-assimilative mode of inclusion.

However multiculturalism in the UK has been criticised, among others, by Trevor Phillips of the CRE¹⁹⁷ for encouraging separateness. Supported by such criticism of multiculturalism, the government has adopted a policy of advocating citizenship classes to aid integration through a common adherence to 'British values'. However, as Cattle argues, the term multiculturalism has become muddled and confused and should not be equated with the homogenised idea of Britishness or a common culture, but instead be concerned with a common sense of belonging.¹¹³ This common sense of belonging necessitates the eradication of discrimination, a respect for and acceptance of difference and diversity, and recognition of the human rights of all citizens as envisaged by Parekh¹⁹⁵. However, the fear of difference has to be overcome and, as Cattle recommends, this requires programmes or policies which allow for increased contact between different communities without moving towards total integration.¹¹³ In this context, discrimination and racism deserve a more detailed exploration. Specifically, among other measures to improve health equity, Shaw et al suggest legislative anti-discrimination policies.¹⁸⁹

3.5.6 Discrimination and racism

We have seen that socioeconomic disadvantage can be compounded by factors such as age and gender. Similarly, multiple forms of discrimination can be experienced, with one of these being discrimination on racial or ethnic grounds, i.e. racism. I will focus on racism in this section, although the experience of discrimination through being a member of any oppressed minority group can have equally devastating and possibly compounding

effects. For example, discrimination on grounds of sexual orientation can negatively influence a person's social position and any such discrimination can compound the effects of racism.

We have seen in Chapter Two how the experience of racism is a social health determinant and a contributory factor in ethnic disparities in health. We have also seen how health can be affected through direct and indirect effects of hostility and violence such as personal injury, psychological damage and socioeconomic disadvantage. Racism can be experienced, however, not only through direct and indirect interpersonal experiences but also through the discriminatory policies of institutions i.e. institutional racism. The concept of institutionalised racism which was given prominence in the Macpherson report ¹⁹⁸ is important because it allows for a focus on the outcome rather than the intent of policies. Institutionalised racism means that individuals can act in good faith but perpetuate discriminatory practices because of the structures and practices of the institution. In this sense ignorance or a lack of deliberate intent to discriminate is no defence for inaction when health disparities are made evident.

It is important to understand the root causes of discrimination that lead to scapegoating and hostility. A survey on attitudes to minorities ¹⁰⁹ showed that prejudices were often linked rather than being exclusive to any one minority group. However the same report showed that the extent to which such prejudices were expressed or manifested depended on the degree to which they were viewed as socially acceptable. It was perceived as more socially acceptable to hold negative views against particular groups if those views were felt to be rationally justified. Different types of prejudice were identified, which ranged in severity of outcome from unintentional prejudice to aggressive prejudice and which varied according to perceived level of threat or justification, as well as perceived levels of social acceptability. Common justifications were based on perceptions of economic threat, i.e. that the minorities in question were depriving others by gaining preferential access to resources such as housing or benefits. Other justifications were based on perceptions of cultural threat of difference, i.e. that certain minority groups do not conform to 'traditional values' and that the majority culture may be undermined as a result. Gypsies and Travellers fitted these culturally and economically based threats as they were viewed stereotypically as groups who do not pay taxes but gained benefits such as site provision at taxpayers expenses, indulged in criminality and who hold no respect for the local environment or community. They were one of the few groups in the

survey who were subjects of aggressive prejudice. Negative encounters and the media were other identified causes of prejudice which contributed to racism. Ignorance through lack of personal contact is a contributory factor in cultural based discrimination. Lack of personal contact was particularly relevant to prejudice towards Gypsies and Travellers and hence a greater reliance on the negative influences of media reports. Whereas negative encounters with individuals resulted in negative generalisations about the wider group, the reverse did not occur i.e. positive encounters with individuals were not generalised in the same way. However the nature of the personal contact was significant and the contact had to be more than superficial in order to break down prejudice. The media plays a significant role in three ways. Press and television provide stories that people can use to justify their existing prejudices because the stories are viewed as accurate and independent. They also encourage latent negative feelings and induce a sense of powerlessness among readers or viewers to affect the issues.¹⁰⁹

These findings have several policy implications for tackling prejudice; the social inclusion agenda is particularly relevant in providing opportunities to bring groups together in situations that encourage more personal positive encounters. As discussed on p74, a pluralist model of multiculturalism as envisaged in the Parekh report is one way forward. Before I discuss the process of tackling inequalities through social participation and other methods, I will briefly explore the various theories concerning health-related behaviour, as I have so far only mentioned these intermediary factors briefly in association with socioeconomic position. The ability to tackle health inequalities effectively is compromised unless there is an understanding of the causes and meaning of health-related behaviour from the perspective of those concerned. It is also presumptuous not to consult and collaborate with those concerned in efforts to improve health equity. This involves listening to their accounts and understandings of how circumstances affect them in their daily lives. In common with all social behaviour, health-related behaviours are enacted on the basis of underlying beliefs and social meaning. Nettleton argues that health beliefs are formed in the context of the sociocultural environment and that health-related behaviour cannot be viewed in isolation from this context.¹⁹⁹ I will now consider health-related behaviour in the context of underlying health beliefs that are shaped by people's social environment.

3.5.7 Health beliefs and health-related behaviour

Earlier in this chapter, I showed the association of harmful health-related behaviours, such as smoking and other forms of substance abuse, with low socioeconomic status. I contested the controversial view that they were a result of unconstrained lifestyle choices and, as such, a matter of individual responsibility. I referred to their use as a coping response to adverse social circumstances beyond the individual's control, and to their association with stressful psychosocial environments, whilst showing that lifestyle factors are one of several inter-related social determinants of health. Graham has shown that, in the face of limited coping strategies available to people in adverse socioeconomic circumstances, smoking is seemingly a logical behaviour and a conscious strategy to improve mental wellbeing.^{164; 200} For example they are less likely to be able to afford leisure breaks or indulge in other stress reduction activities available to those in more fortunate socioeconomic circumstances. Blaxter¹⁹⁹ also makes the cogent point that harmful health behaviours have greatest impact on those already most at risk from other environmental factors, and therefore the relative impact on health outcomes of abandoning behaviours such as smoking, is more limited. In other words there is less leeway for making healthy choices and the decision to do so is also dependent on perceptions of relative health risk. Beliefs about risk are a crucial aspect of beliefs and understanding of health and causes of ill-health, that not only help to explain health related behaviours but also attitudes to seeking health care.

In Chapter Two I referred to Hall's description of three levels of cultural behaviour. Greenhalgh²⁰¹ summarises these as "what people say they do, what they are actually observed to do and the underlying belief system responsible for their behaviour"(p 978) and stresses that the wider context or the socioeconomic environment in which people live must also be considered. Cornwell demonstrated that people's accounts of their beliefs about health do not always predict their health related behaviour.⁷⁴ She showed that people gave 'public accounts' in response to abstract questions to express perceived common views, but different 'private accounts' in the form of personal narratives if discussing their own experience. This can be viewed as a natural desire to avoid negative judgement by presenting the perceived legitimate view. However, meaning will also fluctuate according to the personal experience of different socio-structural situations.²⁰² Social comparison is linked closely to the need for people to legitimise their position. Radley & Billig⁷³ advise that attention should be paid to when and how people need to legitimise their position, pointing out that the need extends across the

spectrum from those in good health to those who are severely ill. They suggest that if healthy people talk of illness they risk being perceived as complainers and for those in ill-health there is the risk of feeling that their personal worth is being challenged.

The issue of health and illness definition is one of language and terminology as well as conceptualisation. Curren,²⁰³ with reference to Parekh's work, commented that language embodies people's cultural assumptions about life. Blaxter²⁰⁴ warns that by asking people to discuss their concepts of health and illness they are being asked to present their social identity. In her study of Aberdeen women, the concept of social identity is relevant in the context of their views on inequality as a health determinant. Radley and Billig⁷³ expand this theory;

any shortfall in health has important implications for other areas of one's life in which people feel that they are evaluated. Accounts of health...articulate a person's situation in the world...and articulate that world, in which the individual will be held accountable to others (p221).

One's social identity can be seen therefore to have a crucial bearing on health-related behaviour. For example, as in Cornwell's study, it can be seen as part of one's cultural identity to be seen to fighting ill-health and to continue working rather than 'giving in to it'.⁷⁴ In this respect a person with such strong beliefs may feel compelled to present a social identity of someone who is strong, tough and healthy and could feel judged for presenting as depressed or unwell. We can see examples of these attitudes in Chapters Six and Seven.

A person's health or illness behaviour depends to some extent on their concept of what it means to be healthy. Blaxter's nationwide study²⁰⁵ of health and lifestyles revealed five main categories: health as 'not-ill,' health as physical fitness, health as social relationships, health as function and health as psychosocial wellbeing. Although in this study she found that people's definitions varied through the life-course and according to gender, in her study of Aberdeen women those in poor socioeconomic circumstances were much more likely to hold a negative concept of health as being 'not ill.'²⁰⁶

Beliefs about causation and responsibility depend partly on whether the emphasis is on health or on illness. Calnan¹⁹⁹ stresses that the concept of health is not the opposite of illness. This leads to varying perceptions of the role of health behaviours, such as healthy diet and exercise, as these could be perceived as contributing to health

maintenance whilst not necessarily factors in ill-health prevention. Interpretations of people's apparent health enhancing behaviours must also be considered in a wider context than their perceived relevance to health. Various meanings that people give to health are related to their socioeconomic circumstances; changes in behaviour are often less to do with improving health than with other life factors such as finance, family problems or appearance.²⁰⁷ Herzlich also found that people's explanations of causes of good health could often be markedly different to perceived reasons for being ill.²⁰² Illness was seen as a by-product of the 'wear and tear of modern life' whereas health was seen as being within the individual. He developed the theory of social representations and suggested that illness can be regarded as the state of the individual, as an object external to people, or as the conduct of the sick person. This latter category relates closely to the moral requirement or duty to be healthy as it includes 'attitude of mind' such as coping and also legitimisation.

The question of responsibility for health, i.e. views on whether the individual can be held responsible for health depends on perceptions of aetiology, or, in psychological terms, on their perception of 'locus of control'. 'Locus of control' is a psychological construct, devised by Rotter, describing concepts of internal or external causes of life chances.²⁰⁸ Those deemed to have an external 'locus of control' would tend to view the causes of ill-health as being situational or outside of their influence and more likely attributed to 'luck', in contrast to those with an internal locus of control who would tend to believe that they could influence their health chances. A belief that good health can be attributed to 'luck' is the basis of a traditional Rom belief in the concept of 'baxt', described by Sutherland.²⁰⁹ Baxt, meaning luck, is regarded as virtually synonymous with health by the American Rom that Sutherland describes. However she also describes ways in which the American Gypsies can bring themselves 'baxt', such as by eating specific foods or avoiding others, observing 'marime' rulesⁱⁱ or also by specific acts of generosity to others. This suggests that their concept of 'baxt' is less outside of their control than a common majority concept of luck. The term 'baxt', translated more commonly as bok or bak⁹² is familiar in a phrase to 'wish one well' among English Gypsies: Kushti bok – meaning literally 'good luck' However, although some of the specific traditional beliefs associated with 'baxt' may have changed among Gypsies and

ⁱⁱ Marime is the word for pollution and is an overarching term for important social rules concerning cleanliness and purity. See detailed descriptions in Sutherland³² and in Okely³³ and also a contemporary description of rules about Mochadi (the more usual term used among English Gypsies) in Spencer's information booklet for health care and other professionals³⁴

Travellers in the UK , the concepts of mochadi and the association with health and hygiene persist (see Spencer).⁸⁷ Studies have shown that those in lower socioeconomic circumstances or with least power tend towards a fatalistic view of causation, symptomatic of an external locus of control.¹⁹⁹ However inappropriate assumptions have been derived from these findings, such as that an external locus of control is associated with an abdication of responsibility and explains the use of health-harming behaviours in terms of ‘instant gratification.’²⁰² In contrast, Blaxter found there was a moral component to people’s concepts of health as ‘not being ill’ in association with a refusal to give in to ill-health or a stoical denial or normalisation of symptoms. If, in spite of doing everything possible within their power to overcome ill-health they still succumbed, then chance or external factors were the logical explanation.²⁰⁵ In this sense she refers to the moral virtue of coping with ill-health whilst simultaneously feeling that falling victim to illhealth is outside of a person’s control.¹⁵⁵ Blaxter has also persuasively argued that the perceived moral duty to be healthy and the stoical concept of health as ‘not being ill’ can explain why people could claim that their health was ‘good’ in spite of obvious disability.²¹⁰ Other studies^{74;211;212} have similarly shown that having an external locus of control or fatalistic outlook on views of illhealth causation does not imply a sense of personal moral irresponsibility to explain health-harming behaviours. Calnan and Johnson²¹² also found that respondents viewed hereditary factors as significant causes of vulnerability to conditions such as cancer and deduced that these views were based on personal experience of incidence within certain families (p97).

The stoical attitudes and responses that I have described , such as ‘not lying down to ill-health,’ afford some sense of agency and pride in coping with circumstances beyond one’s control, that can induce feelings of worth. In addition, by feeling able to claim that they are healthy in spite of disability people are avoiding a negative self-identity that can carry connotations of blame. The crucial predictors of health-related behaviours are people’s social circumstances, and any health-related decisions should be viewed within this context and along with the underlying meanings attached to them. There is not always a straight dichotomy between views on causation; interpretations and actions based on them will vary according to social circumstances and life stages. However, as I have indicated, beliefs related to health maintenance and coping with ill-health carry implications for health seeking behaviour. I now consider these aspects of health beliefs in the wider context of access to health care.

3.5.8 Access to health care

Decisions to seek medical help depend on several factors. An initial step in the decision-making process is to decide on the perceived significance of a symptom. I have already indicated that in the concept of health as 'not being ill' there is a tendency to normalise symptoms. However the perception of significance is dependent on the impact of symptoms on self and on others. Bury²¹³ refers to symptoms of chronic illness as an assault on a person's identity, or 'biographical disruption', with two separate types of meaning. There is meaning which has practical consequences for the individual, such as the extent to which they are able to continue to carry out everyday activities, but there is also symbolic meaning with consequences for how the individual is regarded by others, with implications for social relations. For example, certain symptoms may be denied or hidden if perceived to be indicative of stigmatising conditions. Bury gives an example of patients with early symptoms of multiple sclerosis being misunderstood and their symptoms perceived as indicative of mental illness, malingering, or of being drunk.²¹³ If a patient perceives that his symptoms may be viewed in this way he or she is more likely to keep them hidden. With a felt need to defy illness by 'not giving in' to symptoms, there is a risk of being judged negatively by others for apparently succumbing to a 'sick role.' Equally though, there can be a concern about being viewed negatively by medical staff for 'wasting their time' over symptoms that may not be deemed as serious.²¹² For certain groups, such as mothers, there are further influencing factors that can pose constraints on adopting a 'sick role.' For example, it is seen as imperative to be able to carry out responsibilities as a parent, with the priority of children's health and care possibly conflicting with any need for personal health care.²¹¹

I have briefly referred to both the biological and social significance of symptoms or signs of ill-health. Dingwall²¹² uses a model of illness action that goes beyond a rational cost-benefit analysis and emphasises the influence of lay health knowledge and official health knowledge. He distinguishes between biological events or symptoms, and their meaning, and describes how a biological disturbance affects the predictable relationship between a person and their body. Goffman describes the effects of stigmatising conditions, such as hearing loss, on a person's social identity; this can create an awareness of lack of acceptance by others as a result of the condition. He describes the various means a person will employ in an attempt to present an impression of normality.²¹⁴ Dingwall argues that the disruption of 'normal identity,' which people need to present to others, leads to a series of interpretive and assessment processes that

are involved in the decision-making process to repair the disruption.²¹² The nature of the disturbance and the contextual meaning will affect the extent to which the influence of ‘lay others’ or official health knowledge are brought to the process. Whether a person decides to ignore symptoms, wait or see, or seek help, is dependent on these influences.

The social environment is not the only way in which access to health care is socially determined. It is also socially determined by means of service provision and delivery, in the UK as well as in other countries. This is despite the recommendation by the Independent Inquiry into Health Inequalities¹²⁶ that provision of equitable access to health care in relation to need should be a governing principle of all health policies. Wilkinson¹⁵⁰ shows that, historically, medical interventions have had far less influence on mortality rates than socioeconomic factors. Also, because tertiary medical care in particular is a reactionary downstream determinant, it will have much less scope for impact beyond remedial effects. He refers to evidence that medicine is not a key determinant, even for contemporary health issues such as cancer and degenerative diseases. Yet Bunker²¹⁴ argues that health care is an underestimated health determinant and refers to evidence that medical care has made substantial contributions to life expectancy in the latter half of the last century, adding up to five years life expectancy of the total twenty five years increase in the last century.

However, health and social care are intermediary health determinants that do have particular impact at primary health care level in terms of preventive health care and in public health measures.¹³⁹ A range of evidence exists to show that the inverse care law persists, with people in better socioeconomic positions receiving more services in relation to need at primary and tertiary care level.¹⁸³ Le Grand also argues that this is the case and agrees with Tudor Hart, who first coined the term ‘inverse care law’, that where medical care is exposed to market forces through market led reform, such inequalities in health will widen.²¹⁶ Inequalities in health care arise in different ways; unequal distribution of resources such as health service centres, and different treatment offered to groups with the same health needs are implicated, as well as structural access problems such as culturally inappropriate models of service delivery.²¹⁷ Access to health care therefore needs tackling at several levels to ensure equity of choice in health care treatment; at organisation level to ensure equitable service provision, through to service delivery level to ensure quality of interaction between clinicians and patients.

To conclude, we have seen the impact of psychosocial pathways on health and health inequalities in addition to exposure to material disadvantage. Difference in relative income rather than absolute income; an indication of social status, is most closely correlated with health. We have also seen how it follows that those societies with greater income disparity, leading to greater socioeconomic status disparity, suffer greatest health inequalities, both through direct psychosocial effects of low status and also through poor quality of social relations within such hierarchical societies.

I have described the unequal distribution of a wide range of social health determinants responsible for continued and widening inequalities in health in the UK today. I have also explained the socially determined nature, and importance, of unequal access to health care. I now give a brief summary of strategies to tackle health inequalities before describing what is known about health inequalities experienced by Gypsies and Travellers.

3.6 Tackling health inequalities

The importance of socioeconomic gradients and relative health disadvantage, as well as links between absolute poverty and deprivation with poor health gradients, shows that health inequalities need to be tackled at different levels. In recognition of the continuum, Graham suggests that policies need to address the three levels from absolute poor health of the poorest groups, the gap between their health status and those who are most well off, and the wider health gradient.¹³⁹ A differential rate of improvement is required at the third level so that health improvement is progressively greatest for those who are at the lowest end of the scale. This indicates a need to tackle those social health determinants that are responsible for such wide differences in people's life chances and social positions, and to provide additional services for those in greatest need as well as broad population-based interventions. For example targeted services can be provided such as provision of citizen's advice clinics based in GP surgeries. More generally it is important to weight the provision of primary care services according to need so that there are disproportionately larger numbers of health visitors, and GP practices in areas of higher socioeconomic need. The World Health Organisation²¹⁸ promotes this equity approach above a focus on absolute poverty or disadvantage by stating:

Pro-poor approaches limit intervention to the end of the social production chain that creates health or sickness: they tend to leave untouched the core social processes that generate health inequities, including gender and ethnicity (p482).

They also emphasise the need to involve other departments and organisations in order to address the social determinants of health as well as focussing on delivery of health services. They have long emphasised this requirement however and included it the Alma Ata declaration in 1978:²¹⁹

Health is a fundamental human right whose realisation requires the action of many other social and economic sectors in addition to the health sector.

It could be argued with some authority that the UK Government is committed to tackling health inequalities. They set health inequality reduction targets for the first time in 2001, in relation to infant mortality and in life expectancy at birth, with two key broad aims of ‘closing the gap’ between those in lowest socioeconomic groups and the whole population.²²⁰ Although these were two specific targets, they were chosen to encompass strategies for addressing “all of the major health inequalities, including wider determinants of health, including gender, race, age...” They recognised that the NHS alone could not address the wider socioeconomic determinants of health, and, following a health inequalities review across government departments, a wider policy agenda was agreed with a strong focus on local strategic partnerships between the NHS, local authorities, and voluntary and community sectors. These partnerships had a remit to set local health inequalities targets and were seen as key to improving social cohesion through neighbourhood renewal. The NHS was also responsible for improving access to health care and for delivering programmes to reduce health inequalities.²²¹ The Department of Health, in conjunction with other central Government departments, have combined to produce policies aimed at three major goals:

- Reducing inequalities and promoting equality of opportunity, with respect to the key determinants of good health.
- Focussing on the needs of citizens from threats to health and well-being, over which they have little control.
- Providing modern efficient public services which make sense to users at the point of delivery. (p7)

Policy targets have been set in six recommended areas for action: housing, education, transport, planning and environment, community involvement, and social care. They fall

under three broad themes of supporting families, mothers and children, engaging communities and individuals, and addressing the underlying determinants of health.¹²⁹ Specific policies have aimed at child poverty reduction, improving education, reducing unemployment differentials in the most deprived areas and, within disadvantaged groups, reducing crime levels in deprived areas, and improving social housing.²²¹ We can see that some of the key determinants of health inequalities are being tackled, such as addressing the unequal distribution of social health determinants alongside strategies to improve social cohesion, that in combination, can have a positive outcome on psychosocial health and ultimately on the life course to the next generation. These measures have a range of indicators built into the policies to ensure that the targets are being reached.

However what is less evident is whether policies aimed at ‘closing the gap’ between the lowest socioeconomic groups and the rest of the population do target all of those who experience low social status. Ultimately the measures do not tackle the underlying social determinant of overall relative income differences, the adverse effects of a capitalist system. Whilst this income inequality persists, so too will the effects of lower social status. As Bambra et al assert “the extent of state’s involvement in minimising the adverse effects of capitalism can have a vital impact on health inequalities”²²² (p571). It is appropriately argued that health policies too often focus on mid-level social health determinants which means only addressing the immediate effects of inequality rather than tackling the root causes through macro policies aimed at reducing income inequalities.^{222,223} However, as Bambra et al argue, Western neoliberalist systems are not conducive to tackling health inequalities, and the reality is that UK Government policy does not make any policy connections between health inequalities and national economic policy.²²² For example, as they point out, trade policy, defence policy, foreign policy and international development were all absent from examination in the UK Treasury’s 2002 Cross Cutting Spending Review on Health Inequalities.²²⁴ A study of different types of welfare state programmes has demonstrated that those with universalist policies covering the whole population were most effective in tackling the socioeconomic gradient and reducing income inequalities.²²⁵ We have already seen, from Wilkinson, that these are the societies where there is less health inequality.¹⁵⁰ It appears that some strategies conflict, with the result of widening inequalities. For example the emphasis on responsibilities of citizenship in an attempt to improve social relations in effect ‘put the cart before the horse’ and exclude those who feel unvalued by

society and who therefore may resist measures expected of them to merit inclusion. We have seen how trust is very fragile among those with low social status ¹⁵⁸, and unless initial measures to reduce such psychosocial effects are put in place some of the policies may be unsuccessful in reducing inequalities, particularly those that emphasise behavioural change.

A study reviewing the impact of current government policy initiatives aimed at poverty, inequality and exclusion concluded that although there have been some overall improvements, for example in health and in educational achievement; there has not been a similar improvement in reducing inequalities. ²²⁶ Those who are most disadvantaged are falling further behind. Some improvements in reducing relative poverty have occurred, notably a reduction in relative childhood poverty. However, it noted that there was no aim to reduce overall income inequality, and so unsurprisingly with incomes and earnings having risen fastest for those in the highest bracket, the gap between them and the lowest income groups have increased. Crucially, regarding health inequalities, they found little evidence of narrowing gaps, noting that the main thrust of NHS policy is on overall health improvement and on NHS spending. Ethnic inequalities were reported as remaining large in many dimensions and some vulnerable groups, for example asylum seekers, were noted to be specifically excluded from the inclusion agenda. However, Gypsies and Travellers were not included in these examples.

I have now set the scene and context for the studies relating to the health status of Gypsies and Travellers in the UK. Before concluding this review of health inequalities I will briefly summarise the existing evidence.

3.7 Health of Gypsies and Travellers in UK and Ireland

As I reported in the introductory chapter of this thesis, there were no published studies of Gypsy and Traveller health status in the UK using valid and reliable health status measuresⁱⁱⁱ when I first became aware of the high level of morbidity among Gypsies and Travellers locally. However, a national study of Travellers' health status in Ireland ¹ published in 1987, showed a higher mortality rate for all causes in the Gypsy Traveller

ⁱⁱⁱ There are many criteria for choosing health status measures; such as the acceptability and appropriateness of the measures for use with the study population, but reliability, and validity are two crucial aspects of rigour (consistency and reproducibility and measuring what it is intended to measure) that are assessed by forms of construct validation. See detailed information about Patient-Reported Health Instruments (health status measures) on <http://phi.uhce.ox.ac.uk/instruments.php> ²²⁷

population. Life expectancy of Irish Traveller women was 11.9 years less and of Irish Traveller men 9.9 years less, than women and men in the non-Traveller population in Ireland.

The lack of reliable research evidence on the health of Gypsies and Travellers in the UK has been widely acknowledged.²²⁸⁻²³¹ In 2002 Doyal et al's²²⁸ comprehensive review of studies concerning the health of Gypsies and Travellers in UK and Ireland, used search methods that included five databases in addition to a range of relevant grey literature sources. Overall they concluded that most studies in the review were small scale and anecdotal and the search yielded only thirty-two articles that had collected any primary data. They not only found weak methodological foundations of the data in many of these studies, but also found that the studies had a narrow focus, centring mainly on infectious diseases or maternal and infant health. Further, they noted that there had been no studies that had attempted any systematic comparison of health status of Travellers with the wider population. A literature review of Roma health issues in 2003, which included Gypsies and Travellers in the UK and Ireland as well as Roma in wider Europe, yielded no new primary studies in the UK.²³¹ These authors found that over 50% of these wider European studies focussed on genetic characteristics. This confirmed the authors' findings in an earlier review in 2000²³⁰ of the almost complete absence of research on non-communicable disease in Roma people; although they concluded that the limited evidence that exists indicates that their health needs are considerable.

My own literature search (see Appendix A) revealed only eight studies with primary health data in the British Isles regarding the impact of lifestyle, beliefs, attitudes and perceptions on their access to health care. The focus of these studies is virtually limited to the area of maternal and child health, with a particular emphasis on immunisation, consanguinity and congenital anomalies. As Atkin and Chattoo²³² observe, this particular limited health focus can be problematic, particularly if prior causal assumptions are made, and if the ethnic minority health experience is misrepresented by use of stereotypical myths to explain beliefs and behaviour:

this results in research often blaming ethnic minority communities for the problems they experience, because of their deviant, unsatisfactory and pathological lifestyles (p102).

As we have seen, behavioural and cultural explanations for health inequalities can be used to avoid contextualised examination of structural explanations. I will consider these implications further as I describe the findings.

3.7.1 Cultural lifestyle impact on Gypsy and Traveller maternal and child health

The limited findings concerning maternal health were mainly related to pregnancy outcomes. Two authors^{233; 234} indicated a higher level of depression in Gypsies and Travellers. The only reported association with cultural lifestyle factors by both authors is that parents worry about being able to care for their children or to keep them safe. Hazardous and harsh environments with lack of basic facilities were reported in relation to these concerns but there was no exploration of the Travellers' perceptions of other possible causes. Doyal et al²²⁸ in their review also comment that although there has been mention of the impact of poor quality of sites on both physical and mental health in a few studies, "there has been no detailed examination of potential links" (p6).

A particular focus of studies is the prevalence of congenital anomalies, particularly metabolic conditions with autosomal recessive genes. Studies²³⁵⁻²³⁷ demonstrate an association with consanguineous marriages, specifically among Irish Travellers, and Flynn²³⁷ concludes that the association "should serve as a serious warning to parents not to encourage marriage between cousins" (p310). However, this is a complex area. Bittles²³⁸ refers to a phenomenon known as the founder effect as he advises against unquestioning acceptance of the link between the practice of cousin marriage and recessive genetic disorders. Barry and Kirke²³⁵ recognise the cultural benefits of cousin marriages and note that advice about consanguinity is usually given by members of the dominant culture who are critical of the practice and who do not recognise the relevance of "the positive social value" (p233). Atkins²³⁹ cites research on consanguinity as an example of pathologising culture, but whilst Barry and Kirke agree, they also warn of the need for balance between cultural sensitivity and the necessity of providing appropriate health information and of ensuring inclusion in neonatal metabolic screening programmes.

High accident rates and hospital admissions for infectious diseases were the few other areas of child health identified. These were descriptive findings and no evidence for causative factors was given. Only one study,¹⁸¹ included housed Travellers (29 % of

children in the study), and recommended vigorous pursuit of efforts to improve accommodation conditions. In the remainder there was no breakdown of morbidity according to accommodation status. Descriptions of the very poor environmental conditions on sites and lack of basic facilities, especially unauthorised sites, in studies, suggest that it is reasonable to assume a link.^{233; 234; 236} In contrast to the number of recommendations made in relation to poor immunisation uptake, relatively few focus on reducing the incidence of accidents and childhood infections nor are there any recommendations for further explanatory investigation.

Edward and Watts²⁴⁰ hypothesised that Traveller's hygiene and pollution concepts as described by Okely⁶¹ may explain low immunisation rates. They found that one of the reasons given by respondents for refusal of injections was the fear of AIDS from use of needles that they assumed were reused. Despite this reported fear based on mistrust; a misperception of needle re-use, they also found that the majority of Travellers were keen to have their children immunised. Some explained that the perceived risk of acquiring infection from 'dirty ground' (poor environmental site conditions) was a hygiene factor supporting immunisation. Conversely, Feder²⁴¹ found that one possible reason for low uptake of measles and pertussis immunisation was that these conditions were believed to be 'normal or 'strengthening.' Authors recommended culturally appropriate health promotion, preferably from a trusted worker, such as specialist health visitors. However, Feder showed that mobility was a factor related to incomplete immunisation courses when he demonstrated that uptake for the primary course continued long after the due completion date. Other studies reinforced this finding, leading authors to recommend outreach measures to improve uptake.

The focus on addressing immunisation uptake, at the expense of more serious health concerns which appear to receive less attention, is pertinent. As Atkin and Chattoo²³² observe, the apparent preoccupation with cultural explanations in ethnic minority population research, such as blaming consanguineous marriages for poor birth outcomes, means "that other important explanations - such as poverty, poor maternal health, inappropriate housing, or inadequate service support - are rarely mentioned" (p102). Ahmad reviews evidence of health and social care problems among ethnic minority communities that are identified as arising from cultural practices.²⁴² This pathologisation of culture is an example of the risk of poorly designed and poorly interpreted research that fails to contextualise the broader issues. However, there are

also notable exceptions. For example in other studies of Gypsy and Traveller health and health care^{233; 243}, where authors have demonstrated high perinatal and infant mortality rate as important areas of health inequality, they reported an association with poor environmental conditions and with the experience of oppression. The same authors also focus on inequity in access to health care, with Feder²⁴³ quoting Black et al on the social injustice of such inequity.

However it is over twenty years since these studies and there has been scarce attention paid to the findings either in respect of further research or policy measures. There may be various reasons for a dearth of subsequent reliable research evidence in the past couple of decades. The explanations may include the difficulties and costs of conducting reliable research with marginalised and mobile groups who are understandably suspicious of the motives. It may also reflect the lack of any baseline data due to their relative invisibility in health monitoring. Crucially, until recently, I would argue that the most likely lack relevant factors have been the lack of political awareness or will and the consequent low priority given to the health of Gypsies and Travellers by research funders.

3.7.2 Gypsies and Travellers: access to Health care

All reviewed studies exploring access to health care^{241;233;234;236;240;243} concluded that this was a major area of concern that needed addressing. Mobility was the most commonly reported barrier to care, either as a cultural lifestyle pattern or enforced - "being moved on." Several authors reported on the low percentage of permanent GP registrations, and made reference to GPs' discriminatory refusal to register Gypsies and Travellers. However, although studies also revealed a preference for returning to their original GP rather than re-registering locally after relocation, only one study²³³ suggests the importance of relationships with GPs: "Gypsies have strong loyalties and when registered with a sympathetic general practitioner are likely to be prepared to travel to see him or her"(p204). Studies^{233; 240; 243} also highlighted poor access to other health services, such as dental and maternity services, but improving access to health care cannot be effective without further understanding of the variety of factors that may be responsible. Only one of the reviewed studies^{240; 244} employed mixed methods; using in-depth interviews to explore a variety of possible factors that may affect dental health and access to dental health care. Most of the reviewed papers are of poor methodological quality. All the studies used surveys as either the main or the sole

method and for these to be reliable the sample surveyed needs to be representative of the study population, the sample needs to be an adequate size for results to be valid and reliable and there needs to be a sufficient response rate to limit bias. None of the studies reported detailed inclusion criteria and the estimated potential target size for each of the studies was not given. However, it was unlikely that any accurate baseline demographic data would have been available. Such omissions can result in a selection bias that lowers the validity of the results. For example, only two studies reported inclusion of housed Travellers^{236; 237} but results were reported without any differentiation between the accommodation types. Omission of a significant number of the population without specific exclusion criteria and generalising the results to all Gypsy Travellers lowers the validity of the results. Four studies used descriptive, cross sectional surveys^{233; 234; 236; 241}. Two of these^{234; 241} used selected comparison groups, but only Feder²⁴¹ used an age-sex matched comparison. Feder also used triangulation by collecting data from other sources i.e. routinely gathered health data on immunisation status, where available. Pahl and Vaile²³³ made comparisons with a similar study undertaken elsewhere a few years earlier and also compared with national collected data on infant and perinatal mortality. But the dearth of good scientific research necessitates inclusion and appraisal of all of these papers in order to highlight the evidence gaps and to identify the areas of concern that deserve more detailed examination.

I have included studies which explore the impact of cultural lifestyle on health outcomes. It may be assumed that lifestyle reflects or results from their beliefs, attitudes and perceptions. However, to take this assumption to its logical conclusion would indicate that Gypsies and Travellers choose to live in harsh environments with lack of facilities, whereas, in reality, although many may 'choose a nomadic lifestyle', they do not choose the conditions that are imposed. Some of these studies did relate health outcomes to the impact of lifestyle, or more accurately, to the environment, but few studies have sought to understand and explore the relevance of Gypsies and Travellers' beliefs, attitudes and perceptions and how these are shaped in the context of their sociocultural experience. Three further studies,^{112; 245; 246} all in Ireland, have differed in this respect by focussing on Travellers' views and perceptions of their health experience.

Ginnety,²⁴⁵ aimed to shape culturally congruent provision of health and social services by drawing on the health knowledge and experience of Travellers in Northern Ireland.

She concluded from this ethnographic study that it was illogical to discuss health improvement for Gypsies and Travellers without addressing the two major identified influences of poor environmental conditions and poor access to health and social services. Heron et al ¹¹² in their focus on the psychosocial health of Irish Traveller mothers concluded that while poor living conditions appear to be significantly associated with high levels of psychological distress, health and social care outreach was recommended. They suggested future research to examine health professional's views on their perceived problems in providing adequate health care. This two-way process is clearly important if barriers to provision of adequate health care are to be understood and addressed. Reid ²⁴⁶ goes further and acknowledges the limitations of focussing solely on provision of culturally sensitive care in order to improve Traveller's experiences of maternity care in the Republic of Ireland; she emphasises the need for midwives to be political advocates in tackling the broader political and structural factors that cause inequity of access, such as discriminatory barriers, poor housing and lack of public transport.

In summary there is a dearth of methodological robust research in the British Isles, into the impact of cultural beliefs, attitudes and perceptions of Gypsies and Travellers on their health and access to health care and into the extent and range of health inequalities. It is beyond the scope of this thesis to explore the literature on impact of cultural beliefs, attitudes and perceptions of Gypsies Travellers and Gypsies and Roma beyond these shores in depth, but some comparisons are worth noting. Authors in North America ²⁴⁷⁻²⁴⁹ and in Europe ^{250; 251} have identified similar health inequalities and many common attitudes, beliefs and cultural practices to Gypsies and Travellers in the British Isles; for example, similar versions of pollution beliefs, the need for groups of women to support each other by attending together for health care and having the support of many relatives visiting in hospital. What is particularly striking is the common contextual fear and mistrust of health care and communication conflict with staff. Sutherland notes that conflict often arises between Gypsies and medical personnel who find their behaviour: "confusing, demanding and chaotic" ²⁴⁷ (p276). Such potential for conflict was illustrated by Gropper and Miller: ²⁴⁹

Fear of mistreatment and a scapegoat mentality underlie the people's reluctance to admit they are a Gypsy...A visit to a doctor with a brusque no-nonsense manner can make them suspect that 'he wouldn't give me a pill; he doesn't want me to get well' (p104).

The same authors also acknowledge inevitable cultural adaptation by referring to changes in attitudes among some American Gypsies. They note that compared to a few decades previously it is now considered more acceptable to have one's own private space and a live-in nurse rather than be cared for and supported by relatives.

So, research to date suggests inequity of health and access to health care and highlights possible relevant sociocultural factors. The Confidential Enquiries into Maternal Deaths in England and Wales 1997-1999 ²⁵² adds to the limited evidence base in finding that a disproportionate number of Traveller women died in this period. A lack of certainty, attributed to their exclusion as a separate category in ONS ethnic group data, led authors to conclude that "it is therefore not possible to estimate the risk of maternal death in this group." In addition to social and economic factors, access to care was considered to be behind the risk of increased maternal death in disadvantaged women. However, it was clear that the group is "grossly overrepresented when compared to the 'white group' as a whole" and "quite possibly has the highest maternal death rate among all ethnic groups" (p41).

3.8 Conclusion

In this chapter I have explored the meaning and explained the socially determined nature of health inequalities, and shown how the unequal distribution of health determinants results in health inequity. I also explained the importance of appropriate measurement and monitoring of health inequalities, and particularly in respect of the need to identify health inequity. We saw how ethnic group data is particularly unreliable and how Gypsies and Travellers are relatively invisible in most current monitoring. I have emphasised the impact of cultural racism on social status and described the psychosocial effects that extend through the life course to contribute to a cycle of health inequality and social exclusion. I then showed how this can intensify poor social relations and highlight the need for social inclusion measures. We can see from Chapter Two chapters how social status arising from a racialised ethnic identity has a complex inter-relationship with social class. The focus in this thesis is on the impact of the ethnic identity of Gypsies and Travellers in accessing health care and in their relations with health care staff. The sociocultural context as a basis for beliefs and attitudes in relation to health and health care is relevant here and I have explained its importance. Finally I

have reviewed the limited evidence base about the health status of Gypsies and Travellers in the British Isles.

With reference to Gypsies and Travellers, the gaps in research evidence available so far suggest that priority areas to explore are mental health and the specific psychosocial factors, such as their relative low social status, that may be implicated in their high morbidity and poor access to health care. In Chapter Six I will show how the first phase of my work has helped to address some of these gaps. We have seen that various empirical studies of other disadvantaged populations have highlighted poor access to health care. The current limited evidence base also demonstrates poor access to health care for Gypsies and Travellers and this is specifically implicated as a factor in a high maternal death rate. Interpersonal communication and understanding is a crucial component of health care which I will now explore in the following chapter.

CHAPTER 4

Interpersonal Communication: Relationships between Health Care Staff and Patients

Introduction

In the previous chapters I have discussed the racialised ethnic identity of Gypsies and Travellers. I have referred to the ways in which they resist perceived assimilation and maintain their cultural identity, thus strengthening ethnic boundaries. Existing mutual mistrust is further intensified by the resulting lack of personal familiarisation with Gorgers and lack of opportunity to gain an understanding of other cultures. I have illustrated this with reference to policies concerning Gypsies and Travellers and to the ubiquitous negative stereotypes that are often repeated in the media. I have also discussed the impact of psychosocial factors in respect of health inequalities and explored the limited evidence base on Gypsies and Travellers' health status and access to health care. In this chapter I explore the evidence on interpersonal communication between primary health care staff and patients, to discover what is known and to identify gaps in knowledge relevant to the health and health care outcomes for Gypsies and Travellers. Historically doctors have been the first contact for primary health care patients and would dictate the role of other staff disciplines; much evidence refers specifically to medical staff, with relatively less that is specific to other staff disciplines. This is unsurprising given the dominant status of doctors in the health service and the research emphasis in medical profession career paths. However many aspects of interpersonal communication are relevant to all staff groups and I discuss concepts of power relations in broader terms to reflect this.

The status of Gypsies and Travellers in wider society raises specific issues for their relationships with health staff. Effective interpersonal communication is a necessary component of all human relationships and described by Finnegan²⁵³ as a dynamic and interactive process, which is fundamental, rather than a specialist, human activity. As a health service research study, this thesis does not have scope for a full, systematic review of the extensive literature on interpersonal communication. This chapter, therefore, includes a selective review, focusing on key points from research on communication between primary health care staff and patients. I discuss material

directly relevant to understanding interactions between Gypsies and Travellers and health staff, with particular reference to power differentials and to evidence on the impact of ethnicity on intercultural communication. I shall also refer to evidence on the impact of training in both communication skills and cultural awareness and diversity. However, this chapter will focus on the social psychology perspective as I share Thompson's²⁵⁴ view that within health care settings, communication is best understood from such a perspective where the focus is:

an attempt to understand and explain how the thought, feeling, and behavior of individuals is influenced by the actual, imagined, or implied presence of others.²⁵⁵

Sledge and Feinstein²⁵⁶ focus on the mutual contribution of the physician and the patient for effective communication. They emphasise the physician's need to recognise the multiple influences that may affect interaction. These include patient background factors, such as hopes, fears and plans, and physician factors, such as their communication style. They advocate an open style of communication, aiming to discover what the patient seeks by going beyond clinical enquiry to learning how their needs relate to background components in their encounter. I would argue that the need to be sensitive to influences that may inform and have an impact on the patient's perspective, and a desire to actively seek the patient's meaning through open dialogue, are moral requisites of all health staff - patient encounters. This is closely related to the need for empathy which is fundamental to the practice of effective interpersonal communication. Gianokos²⁵⁷ describes the understanding acquired through empathy as the "physician's moral compass" and an empathic physician as one who "imagines what it is like to think, feel and suffer like a patient" (p135).

This is the essence of dialogic communication as described by Buber. Spiro²⁵⁸ refers to empathy in Buber's terms, as being apparent when 'I and you' become 'I am you' or 'I might be you' (p843). Cohn²⁵⁹ also refers to Buber's description of a dialogical approach to communication, or an 'I - thou' relationship, as relevant to current medical practice. This approach, in contrast to an 'I - it' relationship, requires mutual respect and a desire to see each other's perspective. These features are also the essence of a person-centred approach to patient care, as distinct from the traditional biomedical model. I will now discuss these models with respect to their influence on communication with patients.

4.1 Communication processes

4.1.1 Models of medical care

Wilson²⁶⁰ argues that biomedicine has been the predominant medical model of the 20th century and cites McWhinney's definition that places the doctor in the paternalistic role of a "detached neutral observer" with the patient as a "passive and grateful" recipient of care (p204). He views this definition as consistent with an objectivist philosophy of medical science i.e. that there are universal truths about the nature of disease, with the implication that interaction between doctor and patient has no influence on disease outcome. This paternalistic model is best understood within the historical ethical context of non-maleficence in the doctor's Hippocratic Oath²⁶¹ in which one of the duties towards patients was to "keep them from harm and injustice." Wilson suggests the persistence of a medical model can be explained by the conflict for doctors between the positivist epistemological basis for the scientific search for knowledge in medicine and the subjectivist basis required for the practice or art of medicine. He suggests that doctors become "enculturated" in the particular objectivist approach in medical school, as they acquire knowledge that is independent of context; this renders it difficult for them to engage with patients who may expect greater involvement. This is particularly relevant today in the context of increasing use of the internet for self-diagnosis and use of patient support groups. I will discuss the relevance of this view later with respect to contemporary approaches to medical training.

However, this biomedical approach has not been as universal as Wilson indicates. Walker²⁶² described a patient-centred approach in the mid 20th century, with the doctor-patient relationship as "a very special one, based on mutual respect and understanding" (p207). He saw the creation of the NHS as threatening the unique doctor-patient relationship through a division of loyalties to the patient and to the ministry of health. His advocacy of a patient-centred model was evident in his warning;

Unless mutual respect and a feeling of partnership are preserved between the patient and the doctor, medical treatment will be severely handicapped (p97).

The term 'patient-centred' was first used by the Royal College of General Practitioners in 1972 as an approach to encompass 'the patient's total experience of illness.'²⁶³ Several doctors have published their views and perspectives on more recent patient

centred policy directives.²⁶⁴⁻²⁶⁶ Mead and Bower²⁶⁷ acknowledge the complexity of the concept and argue that the lack of agreed conceptual definition hinders empirical development of the model. They quote Balint's definition as simply "understanding the patient as a unique human being" (p1087). A central component of Balint et al's concept and a key difference between a biomedical model and a patient-centred model is that the latter is:

two-person medicine...where the doctor and patient are influencing each other all the time and cannot be considered separately (p1091).

This definition is the essence of a dialogic perspective that I feel is crucial to understanding the nature of communication and which I will develop further in this thesis. Mead and Bower²⁶⁷ argue that a broadly accepted concept of a patient-centred approach is to pay attention to the patient's psychosocial needs by conveying empathy and facilitating active patient involvement in decision making within a partnership approach. They identified five distinct dimensions of a patient-centred approach that differ from the biomedical model: biopsychosocial perspective, 'patient as a person', sharing power and responsibility, the therapeutic alliance and 'doctor as a person.' Howie et al argue that it now represents "the defining philosophy of general practice" (p459) with its emphasis on the patient's perspective. Despite an apparently increased acceptance of patient-centred principles, doctors vary in their understanding of the concept. Stewart²⁶⁸ describes it as:

becoming a widely-used but poorly understood concept in medical practice. It may be most commonly understood for what it is not- technology-centred, doctor-centred, hospital centred, disease centred (p 444).

Capron²⁶⁹ argues that Katz also recognised "the inherent mutuality of the physician-patient relationship" and showed this by prescribing "true communication (rather than silence or evasion) to build lasting trust and to enable decision making" (p xii). He refers to Katz as one of the significant challengers to the traditional medical model in the last quarter of the 20th century, but suggests that his ethical basis for replacing it with a "rights" model of informed consent, based on dialogue and mutual decision making, was not easily accepted by the medical profession. He refers to the threat to a

blind trust - and godlike status - many physicians enjoy, because true communication entails admitting personal ignorance and collective uncertainty (p xv).

There have been more recent and possibly irrevocable threats to such blind trust arising from recent high profile scandals, including the Harold Shipman case. I discuss the implications of some of these events later in section 4.1.3.

However, these challenges to the medical model have persisted and gained ground in the last two decades. Whilst arguing that the medical model remains dominant, Wilson¹⁹⁷ refers to evidence for doctor-patient relationships making a major contribution to patient outcomes. He proposes a social constructivist medical model, which relates closely to the interpretive and subjective theoretical perspectives of this thesis:

Patients suffer from illnesses arising from a matrix of cultural beliefs and biological systems. A complex interaction occurs between patient and clinician, and behavioural outcomes are constructed from their negotiations and the doctor's physical interventions. Patients are accorded 'sick' status according to social conventions unique to each sub-culture. Recovery from illness will depend on individual beliefs, cultural support systems for the patient, the influence and process of the doctor-patient relationship, and biological factors (p7).

This reference to the complex interaction between patient and clinician and need to challenge a traditional biomedical model of doctor patient interaction relates closely to Foucault's concept of power and medical discourse which I discuss in section 4.1.3

The apparent shift by doctors from a paternalistic medical model to greater acceptance of a patient-centred model is partly attributable to changes in society, which similarly influence other health staff relationships. However I argue that paternalism has not yet been completely replaced. Although the 2005 Primary Care Patient Survey showed greater emphasis on the patient's perspective, with a high percentage of patients reporting satisfaction with their doctor in taking time to discuss their problems, a high percentage also reported a lack of information and choice in decision-making.²⁷⁰ A related key outcome of the survey is that patients want to have a say in their care and be helped to help themselves. Coulter explains that more patients now expect to be given information about their condition and the treatment options, and that doctors will take their preferences into account; this is in contrast to the paternalistic model of patient

involvement that is confined to seeking a patient's consent to their doctor's informed decision about what is best for them. Authors of a study comparing doctors' and patients' perceptions of priorities of general practice care found that although GPs partly shared the patients' main priorities of aspects which increased their understanding of their condition and optimising their possibilities of getting the treatment that they desired, GPs had conflicting interests in respect of workload and time management and practice management²⁷¹

4.1.2 Models of nursing care

Nursing models, typically focusing on activities of daily living for patients, have been most closely applicable to nursing of sick patients in hospital and at home following hospital discharge. However, there is now increased patient contact with practice nurses and nurse practitioners in primary health care as a result of policy changes. Practice nurse numbers increased six-fold between 1982 and 1992 as GPs struggled to meet the contractual requirements of the 1990 GP Contract, with its focus on health promotion and disease prevention and associated target payments.²⁷² The increased role for practice nurses and nurse practitioners has continued with the introduction of the GMS contract for GPs in 2004²⁷³ and health policies that continue to focus on health promotion such as Choosing Health.¹³⁰

In the nineteenth century, with Nightingale's emphasis on responsibility for a patient's health, a nurse's role was to care for the patient under a doctor's direction.^{274; 275}

Although nurses historically followed the biomedical model, influences and theoretical perspectives and definitions of nursing have varied since the development of the nursing process in the 1950s.²⁷⁶ Common to all definitions, despite different emphases, is a patient-centred focus. In 1971 Pearce²⁷⁷ still refers to nurses as doctors' assistants in her classic nursing textbook, but also refers to an unchanged "compassionate approach to patients" in "a closely knit patient-centred team", within which "a patient must be listened to" (p3). Pearce does not cover the development of communication skills in this comprehensive textbook, despite highlighting their importance, but implies that they are intuitively developed in the professional role:

nurses soon learn to realize (sic) the value of a pleasing professional approach...by exercise of her skill [she] can convey sympathy and assurance to a patient...(p4)

The Royal College of Nursing recently reviewed the various theories and models to agree a core definition of nursing, supported by six defining characteristicsⁱ that include a commitment to partnership.²⁷⁶

Central to the process of any interaction, including the health staff-patient relationship, is the power dimension. I shall now explore the concepts of power relations within overall staff-patient relationships, before discussing key features of communication processes among distinct staff groups.

4.1.3 Power Relations

Concepts of powerlessness and empowerment

From a Marxist perspective, it can be argued that health care organisations and professionals play a key role as agents of social control in relation to subordinate communities and individuals, for example, through limiting access to ‘sick certificates’ and to other aspects of care or treatment resources. Recent debates have also emphasised the ways in which current state health policy and provision emphasise individual responsibility for health at the expense of addressing social or environmental factors.²⁷⁵ Critiques of some Marxist (and Marxist-inspired) analyses have identified ways in which a central focus on the capitalist mode of production and class relations fails to account clearly for other aspects of subordination, including inequalities related to gender, ethnicity and sexuality. In this connection, a range of perspectives (feminist, postmodernist and others) have focused on individuals as having agency, rather than being passive victims in relation to the state or to other powerful groups or institutions. In particular, many studies have been informed by Foucault’s argument that power is relational and operates in a more diffuse way than suggested by classical Marxist analyses.²⁷⁶

ⁱ The six defining characteristics are: 1. A particular purpose: the purpose of nursing is to promote health, healing, growth and development, and to prevent disease, illness, injury, and disability. 2. A particular mode of intervention, ie nursing interventions are concerned with empowering people, and helping them to achieve, maintain or recover independence. 3. A particular domain ie the specific domain of nursing is people’s unique responses to and experience of health, illness, frailty, disability and health-related life events in whatever environment or circumstances they find themselves. 4. A particular focus: the focus of nursing is the whole person and the human response. 5. A particular value base: nursing is based on ethical values which respect the dignity, autonomy and uniqueness of human beings. 6. A commitment to partnership: nurses work in partnership with patients, their relatives and other carers, and in collaboration with others as members of a multi-disciplinary team.

Foucault's view is that power is not a commodity, something that one person or group possesses exclusively; but can only exist when it is being exercised.²⁷⁷ This concept allows for the recognition of resistance, for example through defiance or non-compliance. Power relations can be present in all social relationships. Individuals can simultaneously undergo and exercise power.²⁷⁸ Thus the patient in a health care setting can resist control and in turn exercise power to some extent. This perspective does not obscure the wider issue problem of state control over marginalised groups such as Gypsies and Travellers. However, as Foucault argues, organisations funded and established through the state – including healthcare organisations – adopt a range of strategies and tactics through which power and control are exercised. In most cases, these rely on a degree of cooperation by all involved. In this sense health staff and the organisations they work for (a GP practice, Walk-In Centre or NHS Trust) can be seen as monitoring and regulating people's activities. For example they may judge a person's behaviour and be a means of controlling that behaviour by applying a psychiatric label that suggests that they pose a threat to society, thus deeming a patient as deviant; they may monitor a patient's parenting capacities or 'compliance' with medical care and contribute to deciding whether or not a patient is fit to parent a child. A range of medical experts are accorded the function, through their professional roles in society and their status, to define 'normality' and hence define the identities of those who depart from specific that norms as 'ill', deficient or deviant or 'abnormal' in some way. Foucault describes these patterns is in terms of power-knowledge where the 'regimes of truth', developed by health care professionals among others, are deemed as the right or 'normal' ones to which people should adhere. These mechanisms of normalisation and surveillance are examples of forms of the disciplinary power that Foucault describes in *Discipline and Punish*.²⁷⁹ He also describes how people come to modify their behaviour under this 'inspecting or therapeutic gaze' as they internalise this control and self-control their activities. Peckover provides an example, when she describes the social control function of health visiting in this context by means of the professional discourse of motherhood, which is normalised on the basis of dominant majority cultural assumptions.²⁸⁰

Power can be defined as the ability to do or act and to influence other people or the course of events.²⁸¹ We saw in chapter two that lack of control in any form over one's destiny or the course of events is one of the psychosocial factors associated with poor health status. Empowerment is not a straightforward concept and does not automatically

guarantee power and control in the hands of the 'empowered.' To empower is defined²⁸¹ as 'to give authority or power' and 'to give strength and confidence.' This implies a willingness to change the existing power relationship; the sociocultural context is relevant to this decision. Skinner and Cradock²⁸² describe five desirable minimum features of effective patient empowerment: acceptance by the healthcare provider, affect i.e. the reciprocal responses in the partnership relationship, autonomy of the patient in respect of their right in making health care decisions, alliance or partnership, and active participation. However Williams²⁸³ argues that the concept of patient empowerment can pose challenges for health care professionals working in a traditional paternalistic model, particularly for staff such as nurses who may themselves have not experienced empowerment and may feel threatened or uncomfortable with patient empowerment.

Why Empowerment? the drivers.

Some individual doctors,²⁸⁴ had pursued a consultation style that afforded greater patient autonomy, prior to recent major NHS reforms, from personal moral imperatives. Irvine²⁸⁴ describes this preferred approach as breaking free from a "cultural straight-jacket" "[sic] as it was against the current tide (p14). A patient-centred model of interaction, as advocated by Katz, Wilson and others, gained further prominence following recommendations by the 'Bristol Inquiry' in 2001.²⁸⁵ This public inquiry investigated events surrounding the high number of neonatal deaths following poor surgery outcomes, by one particular cardiac team during a seven year period in Bristol.²⁸⁴ Irvine argues that "the true significance of Bristol and other high profile failures is that it signalled the moment when change became inevitable"²⁸⁴ (p200). The public inquiry remit included recommendations for future high quality care in the NHS. One, under the heading of 'Respect and Honesty', was that patients should be treated as "equals with different expertise."²⁸⁵ This recommendation was taken directly from point 71 in the Position paper to the Inquiry from the Royal College of General Practitioners (RCGP) which elaborated on the respective expertise as: "The doctor has the medical knowledge and skill, but the patient has personal knowledge and skill (and sometimes family knowledge and skill)"²⁸⁶. It could be argued, somewhat cynically, that this still falls short of the concept of patient partnership, with the doctor still holding the power of knowledge and not necessarily sharing that knowledge in accessible ways to allow for shared decision-making. I would argue that many doctors do aspire to a more equal doctor-patient partnership but are often constrained not by ideology, but by practical consequences such as limited consultation time and other service

considerations. The UK government had already started a drive for greater accountability in the NHS in the wake of erosion of confidence from previous publicised cases of doctors' malpractice.²⁸⁷ A policy of increased public involvement in a 'new NHS'²⁸⁸ was followed by a process of increased regulation and greater public choice and autonomy with publication of the NHS Plan²⁸⁹ These and subsequent health policy documents²⁹⁰⁻²⁹² refer to empowerment or partnership in promoting choice for patients. Although these were specific drivers for acceleration of patient empowerment measures in the UK, similar health system reforms were taking place elsewhere.^{269; 293} These reforms are economically driven in the face increasing pressures and demands on health services.²⁹³

The 'Choice Agenda' is now central to the present Government's plans to reform public services and a cornerstone of current NHS policy.^{290; 292; 130} However, there is debate about the true extent of patient choice. Wanless²⁹⁴ advises:

capacity is a pre-requisite for choice; today's severe capacity constraints therefore limit choice in reality (p 18).

In addition, to offer choice without sufficient information, with an implied message that making the wrong choice could result in a poorer health outcome, can create greater anxiety and be more disempowering than relying on the respectful authoritative judgement of a professional who is mindful of the patient's perspective.

Although increased emphasis on more interpretive and empathic patient-doctor consultations is associated with a move from hierarchical to partnership styles of interaction, more negotiation within consultations with unchanged power asymmetries may fail to 'empower' the patient. I would argue that 'true' choice includes the option of being empowered not to choose as a consumer but to be enabled to share decision-making as an autonomous rather than a deferential patient. This would inevitably mean that patients were empowered to make what may be considered 'bad decisions' from a medical viewpoint. For example, a patient may decide to forego treatment that could extend their lifespan because they value the quality of the life remaining over potential greater longevity. If the patient has had the benefit of full and frank information and discussion they are ultimately the only ones who can decide what is best for them. This empowerment is possible within an egalitarian health staff-patient relationship where

the patient, confident of being valued, is encouraged and empowered to articulate concerns and needs.

4.1.4 Obstacles to empowerment

Patient empowerment should be viewed within the sociocultural context of the historically high status afforded to the medical profession. Newton²⁹⁵ explains this in reference to Perkin's description of a status-based society:

the professional society is based on human capital created by education and enhanced by strategies of closure – that is, the exclusion of the unqualified (p116).

He maintains that a status-based society consists of professions and other corporations that confer status on their members and those professionals expect clients or patients to trust them on the basis of their profession's reputation. Parson refers to the 'sick role'; when patients relinquish their power to health professionals with perceived specialised knowledge, and professionals willingly accept it.²⁹⁶ Foucault's concept of medical power in encounters where doctors take control and fulfil the expectations of the patient is one which sees power relations as productive.²⁹⁷ In other words, power relations are strategic and subtle rather than coercive, with social order being maintained through voluntary agreement.²⁹⁸ As Lupton argues, this perspective is one where there is collusion between doctors and patients to create and sustain medical dominance.²⁹⁹ Bilton et al argue that a profession is established when members of an occupation control the market for their expertise and are granted legitimacy by the State.³⁰⁰ There is no single fixed or agreed definition of a profession. However, frequently-ascribed characteristics include specialised knowledge and training, public service, an ethical code of conduct, self-regulation and restricted entry by qualification.³⁰⁰ Health professionals vary in their perspectives on professionalism from those who view it in ethical and altruistic terms to those who see it more as a style of communication.³⁰¹ Currently doctors and nurses, including health visitors, hold legally recognised professional status, although the roles of these professionals have altered with various changes to professional boundaries.³⁰²

There has been a period of deprofessionalisation since the latter quarter of the last century, with increasing erosion of the autonomy and privileged status of health care professionals.^{295;303} This has coincided with a move to a contract-based society which as

Newton²⁹⁵ argues, “emphasises individualism, public regulation and external accountability” (p116). Economic forces and the rise of consumerism are drivers for this change and are implicated in the reduced trust afforded to professionals by the State. Although Newton suggests that the State has “stopped trusting professional groups” (p119), he maintains that the public largely continue to respect their status and that this outcome is dependent on the professional’s body’s response in maintaining public confidence when its reputation is challenged by serious errors or scandals such as the high number of neonatal deaths in Bristol (see page 103).

So we see a recent phase of de-professionalisation associated with the assertion both of ‘patient-centred’ health care models and ‘consumer choice’ rhetoric. Hence, paradoxically, efforts to resist the threat of deprofessionalisation and to maintain professional status can be major barriers to empowerment and result in counterproductive distancing from partnership in professional relationships. This is not conducive for developing trust. A full discussion of professionalisation and deprofessionalisation is beyond the scope of this thesis (see for example, Nancarrow and Northwick).³⁰² I refer in more depth, later in the chapter, to the specific issue of trust, which is directly relevant to Gypsy and Traveller perspectives. However I shall first discuss the extent to which various health care professionals hold and exert power by virtue of their status in patient encounters.

In a traditional paternalistic model of medicine the doctor or other health professional holds the power in deciding what is best for the patient. Johnson and Webb³⁰⁴ describe the power that can be exerted by nurses to ensure that patients conform to their nursing care goals, with patients complying in order to avoid being labelled as ‘bad.’ Health professionals can exercise power and control insidiously and, to varying extents, unconsciously. However it cannot be assumed or inferred that such methods of interaction are necessarily disrespectful of patients. Tudor Hart,³⁰⁵ in describing his long years of practicing paternalism, whilst supportive of patient autonomy, explains that he “did what I thought was best for my patients” (p 623). Canter³⁰⁶ describes different dimensions of power by which health professionals can, for example, be subtly coercive in a charismatic way in controlling the patient agenda. He argues that the desired power shift from doctors towards patients, as advocated by the Secretary of State for Health,³⁰⁷ is not straightforward, and proposes that health staff should be trained to become more sensitive to different manifestations of power. For example, he

argues that doctors may feel that they only present facts to patients in an unbiased way so that the patient can make a choice. They would therefore argue that they do not act coercively as in first dimensional power or in a way that controls the agenda by steering the conversation towards favoured options or away from other options. However he refers to the more subtle, third dimensional power, such as shaping the patient's worldview by, for example, by setting the condition only in a conventional biomedical framework in which other possibilities such as complementary alternatives do not figure. Descombes³⁰⁸ similarly describes the reality of empowerment as "a tool of control" (p95), when the person holding the power maintains the status quo in deciding how much power to share. Advice can be given, either selectively, edited or in incomprehensible terminology, so that the patient, although ostensibly being offered choice, feels powerless and defers to the professionals 'greater knowledge.' This subtle form of power is also very much in line with Foucault's concept of medical discourse as power, where power is in the control of information and scientific knowledge gained through medical training.²⁷⁶ In such use of medical discourse the patient is placed in a position of having to trust in, or bow to, the doctor's 'superior knowledge'. Medical discourse represents one form of knowledge on a topic and the power is in portraying it as the 'truth', or the only reality. This power of discourse is closely linked to the disciplinary power of the 'medical gaze'.³⁰⁹ Patients are conditioned to accept various forms of medical surveillance that are considered by health professionals to be in their interests.

Flannery³¹⁰ argues that power is an inextricable characteristic of professionalism and suggests that there is an inevitable power imbalance within professional relationships. She emphasises its implicit and often subtle nature and advises reflection to avoid using power as a form of domination. However, she makes a helpful distinction between power and authority in the concept of professionalism arguing that the latter is conferred rather than imposed. To confer authority implies a shared acceptance and agreement about how power will be used, in contrast to power being imposed without consent. Flannery and others have proposed models of professionalism that address concerns about power and detachment and place greater emphasis on authority, service and empathy. For moral reasons and fitting with my own experience and perception of professional roles, I am drawn to Flannery's³¹⁰ description of the "midwifery-as-metaphor" model. In this she describes the professional as a nurturer/ healer:

whose role is to “be with” another person to assist or guide in the unfolding process and who stands outside while also being fully engaged and empathic (p25).

She argues that trust and mutual respect are implicit in the relationship. She quotes her role model, physician, Mary Howell, as she describes the partnership aspect of this model of professionalism:

I have found a different role model, that of the wise old woman of the village....who has been privileged to learn from her predecessors and to share with the many generations of village folk their experiences as family members and who can convey what she knows to others so that they too can use that wisdom (p28).

Patients who challenge professional authority by rejecting advice are traditionally viewed as non-compliant and by inference as ‘difficult patients’ rather than empowered patients.²³⁶ In either situation, the outcome can be jointly constructed. The health professional can control the agenda by influencing the patient’s choices, while the patient responds by deferentially choosing to accept advice. Alternatively, instead of viewing patients as non-compliant, the breakdown in the staff-patient relationship can equally be viewed as a failure of the health professional to engage the patient in a spirit of concordance. However, Hewitt-Taylor³¹¹ argues that individuals and groups resist relinquishing power and that, despite policy directives, any changes in the power relationship between health staff and patients will be hard to achieve. Potential loss of perceived status is not a sole reason for this resistance. Dingwall³¹² emphasises the imbalance of knowledge and expertise between medical staff and patients in arguing that it would be irresponsible for doctors to take a literal shift towards ‘patient power’ in acceding to requests for unnecessary treatment such as inappropriate antibiotics. This argument depends on perceptions of the nature of ‘patient power.’ He omits any indication of dialectic perspective in such decisions. For example, I would argue that patients may not be seeking the power to demand antibiotics or other treatments and the choice is not simply to accede to or refuse such requests. Patient power lies as much with having their concerns heard respectfully and in gaining an opportunity for true dialogue to understand alternative treatment options. I suggest that within a trusted doctor patient relationship, founded on respect, a reasoned refusal accompanied by full explanation is likely to be accepted. It is possible that where the relationship is one of

mistrust, the patient is more likely to be suspicious of the motives for refusal and may pursue the 'right' to choose antibiotics more vigorously.

There is inevitable tension between choice and cost constraints in a third party payment system. For example, NHS rationing of health care interventions, by recourse to evidence of effectiveness through the National Institute for Clinical Excellence (NICE), sometimes conflicts with the ability to offer patient choice. Dingwall³¹² refers to NICE and other evidence based medical decisions as necessary safeguards against a 'consumer driven society':

as a taxpayer I do not want to see my income sequestered to indulge the fancies of others when there is a clear medical view that an intervention has no clear and established benefit (p1368).

However doctors can be disempowered by NICE making decisions for them on a cost-benefit basis for wider society, with inevitable consequences for individual patients. In a response to recent guidance on withdrawing existing drug treatments for new patients with Alzheimer's disease, the Alzheimer's disease society are reported to proclaim the guidance as "...putting doctors in an impossible position."³¹³ The extent to which health staff are themselves empowered is implicated as a further obstacle to patient empowerment. This will be explored in more detail in differing relationships between patients and separate groups of health staff.

Dingwall's³¹² reticence about 'patient power' apparently stems from ethical concerns for the greater good in the consumerist nature of 'the choice agenda', in which individual choice may be achieved at a cost to others. This concern is realistic when there are limited resources and seemingly limitless demands for healthcare. The increasingly complex nature of service delivery led a multidisciplinary, international group of health care professionals to produce a set of shared ethical principles (the 'Tavistock Principles').³¹⁴ This group emphasised the role of health professionals in making ethical decisions in healthcare delivery but feared that lack of unity and co-operation between different professionals would result in mistrust amongst them, with poor outcomes for wider society. They agreed on seven overarching principles:³¹⁵ Rights (to health care), Balance (with care of individual patients central but health of populations considered), Comprehensiveness, Co-operation (with each other and those

served), Improvement, Safety (do no harm) and Openness (p616). However, implementation of the principles has proved difficult, in part because of their broad and abstract nature. The second principle, of balance, in particular has been subject to debate in editorials and letter pages of the BMJ, where the tension between care of the individual and the health of populations is recognised, especially in terms of allocation of resources and in a global context.³¹⁶ The group who devised the principles concluded that they were essentially an aspirational code and published them in the hope that they would be adopted as a code to live by. However, a search of the literature in 2007 reveals no recent reference to the principles.

There was no input from non-professionals in developing these principles, nor did they include explicit commitment to patient empowerment. In contrast, the Justice in Health Care foundation, an American group comprising health care ‘consumers’ and practitioners, included choice and accountability in a similar set of principles.³¹⁷ The inclusion of ‘choice’ and ‘accountability’ would appear to place a greater emphasis on partnership where accountability includes “consumer” and provider responsibilities. However, in this consumerist approach, there is a risk that health systems would change in response to educated and empowered consumers without addressing the needs of the less educated and empowered consumers. In many respects, those who are already structurally disadvantaged, either financially or because of health or social constraints, will be further disadvantaged in ability to choose; they may not have the means to ‘choose a better service’ that is not ‘on their doorstep’ or they may not have the necessary resources to make informed decisions about treatment choices. If local ‘poor services’ become reduced due to lack of uptake as a result of ‘the choice agenda’, it will be detrimental to those who are unable to choose to go elsewhere. Gypsies and Travellers would have little say in such a consumerist approach. The least empowered in society may also be least able to articulate their choices in ways that increase their chances of having those choices fulfilled.

Hoggett,³¹⁸ in discussing different models of agency, argues that choice is not always a result of reasoned deliberation and that ambivalence due to external or internal conflicts, such as conflicting obligations, can lead to urgent or impulsive decisions. He also suggests that the experience of domination or powerlessness can lead to the ‘dominant other’ seeming to invade our minds and ‘tell us how we think’; this can result in overt aggression (resisting perceived attack) or in passivity or depression. Either response

may potentially compromise dialogue with health staff and inhibit the ability to make informed and reasoned decisions. This is an important consideration in the context of incorporating patient's perspectives. Meryn³¹⁹ reminds us that communication is an interactive process in which patients also need skills and support to participate in decision-making. Directing patients to national patient organisations who can provide advice and support is a way of making this support available.

In summary, I have described various obstacles to empowerment in the context of a policy-driven consumerist approach, and perceived threats to the role and status of professionals. These obstacles include resource implications and other contextual workload factors. Lack of available time is one impediment for doctors in responding with an empowering and patient centred approach to health policy directives.³²⁰

However, in combination the evidence suggests that the greatest obstacle to shifts in power relations, required for a patient-centred relationship, appears to be attitudinal. I argue that a patient cannot be empowered in the absence of an empathic, respectful and reflexive patient-centred health staff relationship, but that health staff also need to feel empowered and enabled to use and develop these required qualities within the relationship. However, power relations are complex and subtle, as we have seen, and ultimately a sizeable shift in power relations can only take place if health professionals are able to develop the attitudes required to relinquish their control by disciplinary power, as described by Foucault, and afford real choices to patients. I shall now examine communication within staff-patient relationships for a better understanding of attitudes, expectations and outcomes for both groups.

4.2 Communication outcomes for staff and patients

4.2.1 Doctor-patient relationships

Studies of the effectiveness or quality of doctor-patient relationships focus largely on the correlation with patient satisfaction and outcomes. However there are various dimensions and interpretations of effective doctor-patient communication and of patient satisfaction and outcomes. Patient enablement, defined³²¹ as “the effect of a clinical encounter on a patient's ability to cope with and understand his or her illness” (p 865), is a commonly measured outcome. Fewer studies focus on the processes, influences and outcomes on doctor-patient relationships from the doctor's perspective. However, in a consultation to define ideal patient experience, participants make an explicit link

between staff and patient satisfaction.³²² Mead and Bower²⁶⁷ acknowledge the difficulty in demonstrating evidence of beneficial patient outcomes as a result of differing concepts of the meaning and also the use of differing outcome measures. The concept of patient satisfaction as an outcome measure is complex. Turris³²³ argues that the concept grew from a consumerist perspective and political need to demonstrate quality and accountability of health care service delivery, leading to an essentialist checklist approach. This is pursued at the expense of seeking a deeper contextual understanding of wider psychosocial factors, relating to individual experience, that influence patient satisfaction. The logic of the consumerist perspective is a narrow view of health care as an economic commodity rather than a therapeutic service. This perspective leads to the notion of patient satisfaction as a product rather than a perceptual, multi-dimensional, relativistic, dynamic, patient-centred, attitudinal and individual process, as described in a comprehensive model by Strasser and Aharony.³²⁴ Coyle and Williams³²⁵ argue for the concept of 'personal identity threat' as an effective tool for measuring person-centredness, focussing on the extent to which patients feel valued. They elicited threats to patients' identities from feelings such as dehumanisation and disempowerment in a qualitative study that focussed on patient dissatisfaction. The tool included questions covering holism, and empowerment in the sense of being involved in decisions about treatment and respectfulness. Although their study was secondary care-based the conclusions that improvements are required in valuing people as individuals may usefully be transferred to primary care. A critical difference in their approach was to elicit dissatisfaction on the grounds that many tools for gauging satisfaction tend to invite positive responses.

In the absence of empirical evidence of beneficial patient outcomes, the continued emphasis on use of a patient-centred model can be seen from an ethical perspective. Pursuit of quality in doctor-patient relationships led to the emergence of patient-centred care as an indicator.³²⁶ Howie et al describe the evolution of patient-centredness and holism, dual components of a biopsychosocial model, as core values for general practitioners, but they also refer to difficulties of definition and in measuring the benefits.²⁶³

Doctors can feel disempowered in trying to maintain good interpersonal relationships in the face of complicating factors.³²⁷ These include the extended doctor's role which is evolving to deal with more complex psychosocial problems and discussion of varied

options for management; they compound pressure on time in a climate of increased demand for appointments.³²⁸ Although average GP consultation times have increased to 11.7 minutes in 2006/7; an increase of three minutes since 1992/3, so too have the number of consultations (up from 88 per week to 122).³²⁹ Practice nurses see an average of 60 patients a week, spending 15.5 minutes per consultation. GPs inevitably see a heavier concentration of the more complex consultations, but there is no breakdown of consultations by social class and gender. Although they acknowledge that a fair comparison cannot be made with results from 1992/3 because of changes in the GP contracting system and the ways in which GP services have subsequently been delivered (for example a reduction in home visits with opting out of evening and weekend work), GPs commenting on the results feel that the intensity of their work has ‘rocketed’. A representative of the Patients Association commented that the trust and relationship with the GP service is “very quickly being eroded”.³³⁰

The concept of ‘the expert patient’ is one potential influence on patient expectations. The Department of Health enshrined this concept in policy in 2001 as part of the choice agenda.³³¹ The policy aim was to empower patients living with chronic health conditions, giving them greater control through self management, with the added potential cost benefit to the health service in reducing pressure on staff time and resources. From one perspective this policy maximises the opportunity for shared decision-making within doctor-patient relationships. Patient training programmes include components aimed at increasing patients’ confidence and skills to work in partnership with health professionals. Some doctors have expressed qualified enthusiasm;³³²

the minority of patients who have the resources to find out about their illness and want to take an active part in managing their own care are to be welcomed as allies and partners (p724).

However, the debate³³² within the medical profession reveals other interpretations of the concept that raise similar fears to those expressed earlier by Dingwall about ‘patient power’, where ‘the expert patient’ is conceived either as a “demanding patient, unreasonable patient, time-consuming patient or ‘the patient who knows it all’”(p723). Such fears about workload implications and potential increased rather than decreased costs can lead to defensive health professional attitudes rather than the partnership that the programme promotes. Goodyear³³³ astutely recognises that these fears and

reservations are not unexpected when a programme aimed at patient empowerment does not simultaneously attempt to address the power imbalance by focussing professionals' attitudes. He quotes Bennett as laying the foundations for the 'expert patient' concept and advises a different stance on the patient's position within doctor-patient relationships;

The greatest benefit could come in the future if patients could take more responsibility for their bodies and minds, in other words learn to activate the potential for help and healing that is latent within themselves. Doctors then may come to acknowledge, perhaps through a greater openness in their own lives, that they too are needy and vulnerable along with the patient, and that doctoring is something of a joint venture between patient and healer, in which the doctor serves as the guide (p723).

I quote this in full because it encapsulates the requirements for addressing the power imbalances that can inhibit enablement and emphasises instead the empathic and empowering nature of a patient-centred approach similar to the model advocated by Flannery. This emphasis on relationship indicates a need to review in closer detail the prerequisites of effective interpersonal relationships within doctor-patient consultations.

A review of studies to determine the influence of effective communication between physicians and patients on patient health outcomes showed associated emotional health benefits in addition to physical benefits such as symptom control.³³⁴ The dimensions of effective communications in this review were similar to some components in various definitions of patient-centredness, namely a holistic approach which takes account of the patient's expectations, feelings and ideas. Although Stewart concluded that no specific communication style could be recommended from the findings, a patient-centred style is implicit in their view that the key variable influencing a shared decision making outcome is "provision of a caring, respectful and empowering context" which allows for engagement (p1428). For example physicians who explicitly ask for the patient's opinions, and sought their understanding of the problem, promoted negotiated consensus, and this was related to patient satisfaction.³³⁵ This finding is confirmed by participants defining an ideal patient experience, who did not view choice as essential, provided that other values, specifically equality, were upheld.³²² Little et al³³⁶ measured various components of patients' perceptions of patient-centredness. Although perceptions of important features or desired levels of partnership were not specifically

identified, the importance of continuity was implicit in the emphasis on a personal relationship with the doctor.

Continuity

Stewart³³⁷ also refers to the importance of continuity for a strong ongoing patient-clinician relationship, citing dimensions of trust, caring, feeling, power and purpose as being more enduring within such a relationship. Saultz and Albedaiwi³³⁸ reinforce this opinion with a review of studies showing a strong correlation between continuity of care and patient satisfaction. Howie et al³³⁹ used ‘how well patients know their doctor’ as a proxy for continuity as an outcome measure to also show a positive correlation with patient enablement. Interpersonal continuity is equally a factor in doctor satisfaction as it enables the doctor to build from previous consultations without inevitable duplication of stories.³²⁸ These factors are particularly relevant to Gypsies and Travellers, who, as we have seen in section 3.7.2, prefer to return to familiar doctors than attempt to register elsewhere when they move.²³³

Roberts³²⁷ cites evidence on quality and continuity of care for her assertion that a patient-centred ideology underpins the “intrinsically therapeutic” (p232) doctor-patient relationship. Doctors’ listening skills and interpersonal skills are rated highly by satisfied patients but the other highly valued qualities: empathy, ease of communication and friendship, trust and commitment, are all associated with personal continuity. Although good communication skills are emphasised as essential for effective and satisfying doctor-patient relationships, they do not always result in patient satisfaction. The patients’ perception of the doctors’ relationship with them hinges less on their how well they communicate but more on trust in their expertise and whether they have a unique relationship with them built on respect for their autonomy.³⁴⁰ The use of the term ‘friendship’ as a sought-after dimension indicates the importance of a personal individual relationship with the doctor. The patient’s meaning of the concept in this context is not explicit but it suggests a desire for mutual warmth and ‘the personal touch’, that makes the patient feel special and valued as an individual, and is considered central to the patient experience.³²²

One aspect of a friendship element is shared humour. Contextually-appropriate humour can be intrinsically therapeutic within a doctor-patient relationship, but shared laughter can also reduce the relationship power imbalance by demonstrating the doctor’s

acceptance of the person as an individual.³⁴¹ Humour, and matched use of language, alongside non-verbal signs such as smiling and eye contact are important indications for patients of a satisfactory interpersonal relationship with their doctor.³⁴⁰ Patients have also identified personal sharing, humour, being friendly and being a friend by 'going the extra mile,' as important aspects of nurse-patient interaction.³⁴² This dimension appears to be particularly sought by Gypsy and Traveller patients who comment on these specific characteristics of trusted health professionals, as we see in Chapter Seven. I will now consider other limited evidence that is specific to nurse-patient interaction.

4.2.2 Nurse patient relationships

Most features of effective communication between doctors and patients are relevant to communication between nurses and patients. Turriss comments that studies on patient satisfaction do not always clearly separate the influences of doctor-patient interaction, nurse-patient interaction and the physical environment.³²³ Further, systemic constraints such as heavy workloads, that inhibit the ability to develop relationships, are likely to be similar for the different staff groups in various practices. I have found no studies of nurse-patient interaction in primary care settings from a patient's perspective. However, the few available studies in other settings indicate similar expectations of nurses to those of doctors when seeking care: to be respected and valued as a person.³⁴² Patients focus more on interpersonal interaction than on other aspects of care when asked about their experience of nursing care.

Shattell³⁴² emphasises the reciprocal nature of interpersonal communication in studies showing that patients had contrasting experiences of exclusion or confirmation in nurse-patient interaction. Patients are particularly vulnerable when they depend on nurses for their basic needs, more usually in a hospital or home nursing situation. However, they are also vulnerable in situations where nurses are required to ask intimate questions, for example in health screening interviews, where there is potential for loss of face. She refers to Goffman's theory of 'face work' to describe the purpose of these interactions as managing impressions of both self and other, by presenting a front, verbally and non-verbally. In various studies where patients were seen as demanding or uncooperative, nurses tended to distance themselves and were then seen by patients as emotionally 'cold', avoiding eye contact and giving less supportive care. Nursing students prefer to care for patients who are cheerful, accepting of their ill-health and who communicate well.³⁴³ These findings on the effects of patient communication characteristics have

particular implications for Gypsy and Traveller patients, as we see in chapters six to nine. Pettigrew and Turkat³⁴⁴ suggest that:

Patients may have a far greater impact on and responsibility to the health care relationship than previous provider-patient research has revealed (p391).

Nurses are included in NHS policy documents promoting patient empowerment and choice and are similarly directed to this goal by their professional bodies.^{308; 311}

However the context is altered by the role constraints of nurses; this influences their ability to empower patients. Whereas the traditional medical model is described as paternalistic, nurses have traditionally been associated with a maternal 'caring' role towards 'vulnerable' patients. The nurse gains respect and power whilst the patient remains dependent.³⁰⁸ In this context nurses can also resist relinquishing their status or sharing power. However a nurse's status is usually seen as lower than that of doctors.²⁹⁸ Consequently, nurses as well as patients can be disempowered by the paternalistic medical model, with less ability to offer patient choice. Williams²⁸³ asserts "an antecedent to patient empowerment is staff empowerment" (p100).

4.2.3 Health Visitors

There is greater emphasis on interpersonal communication in various models of health visiting, a branch of nursing concerned with promotion of health and prevention of ill-health and with a focus on home visiting to 'well families.' Prioritisation is given to the development of interpersonal relationships, one of the four groups of skills identified by the Council for the Education and Training of Health Visitors (1967).³⁴⁵ Health visitors work independently of doctors and have more autonomy than nurses in their work with patients in primary health care. They have an opportunity to develop relationships with patients who, in theory, are in less vulnerable situations in their own home environment than when they present with ill-health at the doctor's surgery. However, health visitors may also be seen as exerting disciplinary power in the Foucauldian sense. For example, Peckover describes how health visitors can be seen as 'policing the family'.²⁸⁰ She quotes Abbot and Sapsford:

Health visitors played a role in creating and identifying 'the inadequate mother.' They then became involved in programmes of reform to transform her behaviour so that she became an adequate, a 'good enough' mother (p144).

Individuals or groups who already feel stigmatised are the most likely to be sensitive to the perception that health visitors are policing agents.

The different emphasis and setting of a health visitor's work may be more conducive to an empowering partnership approach than other nurse roles. Raymond³⁴⁵ contrasts the position of the "uniformed nurse in a position of authority and responsibility" to a health visitor:

who comes alongside the individual and family to share her skills...to help them become as independent of her as possible...whilst recognising the moment when her intervention is necessary (p 221).

I will discuss this supportive role of health visitors in relation to Gypsy and Traveller patients in this study in later chapters.

Other studies³⁴⁶⁻³⁴⁸ have suggested that a reciprocal relationship between health visitors and clients, seen as a vital element of the health visitor's public health role, may help to empower the client. In literature reviewed for a study to identify clients' perceptions of home visits by health visitors, the supportive role of the health visitor was unclear, although some studies suggested that mothers feel emotionally supported and better able to cope following a visit. However, it was unclear which aspects of the interaction were responsible, with insufficient detail of how clients defined the support, or the relevance this concept had for them.³⁴⁹ The authors used Cobb's definition of support as:

Information leading the subject to feel that he [sic] is cared for and loved, is esteemed and valued, and belongs to a social network of communication and mutual obligation (p790).

In their own study, clients reported receiving reassurance, increased confidence, feeling better, alleviated anxiety and also ease in being able to discuss issues. Some mothers explained these responses as being a result of not feeling patronised, and instead experiencing a genuine interest and willingness by their health visitor to discuss anything. Although the authors point out that their study requires replication with ethnic minority populations, their findings suggest that health visitors conveyed empathy, trust and respect to induce these client perceptions of support. Empathy, trust and respect consistently feature in studies as desirable elements of good doctor-patient relationships. Although there is an apparent focus on doctors because of the disproportionate

availability of evidence, I argue that these are essential features of a patient-centred style required by all health staff for effective interpersonal communication, and I now consider these separately.

Empathy

Emotional experience is a key driver for overall patient satisfaction and this is evident from the patient experience definitionⁱⁱ, agreed after rigorous consultation, and used to inform policy.²⁹⁰ Empathy is described as³⁵⁰

the ability to understand accurately what another person's world looks and feels like from their point of view and to convey this understanding in a relationship (p67).

It is a key component of an effective interpersonal relationship and patient-centredness. Mercer found a strong correlation between patient enablement and perception of the doctors' empathy.³²¹

Trust

Burkitt Wright et al³⁴⁰ found that patients started interactions with doctors on a premise of trust but that it could be lost irretrievably if they felt misled. Not all patients start from such a premise. Gilson³⁵¹ argues that those with least power are less likely to invest in interpersonal trust. We have seen that Gypsies and Travellers are reluctant to invest trust; this can be explained by their experience of discrimination. Trust is relational and is dependent on dispositional, or the psychological propensity to trust. Cooperative doctor patient relationships also require a secure situational trust. The trust that results will be modified in each subsequent consultation.³⁵²

Sztompka describes four dimensions of trust.³⁵³ In addition to 'trust culture' and 'trust impulse' which determine a person's propensity to trust; he refers to primary and secondary trust. He cites reputation, performance and appearance, including body language, intonation, and readiness to smile, as key qualities by which to judge whether a person is trustworthy. However he argues that the context in secondary trust is also

ⁱⁱ "We want an NHS that meets not only our physical needs but our emotional ones too. This means:

- Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way;
- Having information to make choices, to feel confident and to feel in control;
- Being talked to and listened to as an equal;
- Being treated with honesty, respect and dignity"

important in terms of background accountability. Innes suggests that Sztompka's model is a useful framework whereby all four dimensions are addressed in rebuilding trust in health care.

Respect

Respect means 'to give due regard for the feelings or rights of others.'²⁸¹ A patient's desire for respect for their autonomy is just one aspect of respect; it is insufficient unless broader respect is shown by treating them with dignity, indicating that they are valued as a person.³⁵⁴ The need to be treated with dignity or to be valued and accepted unconditionally is consistent amongst all groups although it appears more important to ethnic minority groups.³⁵⁴ The fundamental need for respect is indicated by its inclusion in the ideal patient experience definition.³²² We saw in Chapter Three how perceived disrespect, with feelings of shame, humiliation and social inferiority that can result, is the most frequent trigger to violence among people:¹⁵⁶ I argue that no person, whether behaving violently or otherwise, is undeserving of respect, and that such behaviour has to be addressed without succumbing to disrespect for the person.

The struggle for respect is a struggle for human recognition for social existence itself and violence is the mother tongue of domination (p151).

Rogers's concept of 'unconditional positive regard' similarly implies respect for a person's unique and inherent value.³⁵⁰ This interpretation of respect is consistent with Kant's philosophical tenet; respect for other people is a key moral concept as described in his formula for humanity. For Kant all humans have distinctive worth or dignity which is unconditional and therefore does not depend on status or perceived merit. Hugman³⁵⁵ applies Habermas' theory, warning against power being exercised through distorted communication as a means to an end. He gives the example of dominant communication directed to the professional's goals rather than seeking agreement through the patient's goals having equal status. I will now consider this concept of empowerment with reference to primary health care receptionists, a key group of health staff who are mostly overlooked in the literature on patients' experience of health care.

4.2.4 Receptionist-patient relationships

Receptionists are usually the first point of contact for patients and therefore crucial intermediaries between patients and doctors. Despite this there have been few studies of

their role. In these limited studies they are generally perceived to be unpopular, mainly because of their 'gatekeeper' role.³⁵⁶ Receptionists are required to make judgements and to exercise discretion about urgency or necessity of requests for access to doctors' or their services. Although they are put in the position of making clinical judgements, few receive any formal training that will assist them in making decisions or in communicating with patients.^{356;357} The intermediary role appears to put the receptionist in a position of power, but by acting on the doctor's behalf they can become the target of resentment about doctor's implicit or explicit 'rules' concerning access. Arber and Sawyer³⁵⁶ introduce the concept of a doctor-patient-receptionist relationship as they refer to antagonism felt by patients towards receptionists. Receptionists experience two major sources of work-related stressors as 'appointment problems' and 'feeling caught between demands of doctors and patients.' 'Difficult patients' were a further, possibly related, stress.³⁵⁷ These stresses are illustrated in a study which showed that 68% of receptionists were verbally abused in a 12 month period.³⁵⁸

In exercising their role receptionists have been shown to vary their discretionary power and their interaction according to their perceptions of different groups of patients.³⁵⁶ Younger patients and parents with children experienced more communication difficulties with receptionists compared to older patients and were more likely to be 'persuaded' against a requested home visit in favour of attending the surgery. Social class of patients was not shown to influence the receptionists' behaviour or their quality of communication.³⁵⁶ Although this is a surprising finding there are so few published studies of receptionists' views and attitudes that I am unable to find any evidence to dispute it.³⁵⁶⁻³⁵⁸ Receptionists can feel excluded from membership of primary health care teams and the practice manager has a key role in facilitating communication to ensure that their work is recognised and that they are supported in their role.³⁵⁷

4.2.5 Primary health care teams

Health staff are required to work together in primary healthcare teams to provide for the healthcare needs of their practice population, but there is much confusion and ambiguity, even among team members, about team composition and functions.³⁵⁹

A forum, comprising a range of representatives from professional health organisations, with a remit to examine the practical aspects of primary healthcare teamwork, recommended that the patient, carer or their representative should be recognised at

“individual patient-centred team level” (recommendation 1 p9)³⁶⁰ as an essential primary healthcare team member.

One of the main listed benefits of effective primary healthcare teamwork was provision of a more responsive and patient-sensitive service. However poor communication was cited as an important barrier to teamwork. Professional divisions, closely associated with differing status of team members, were also important factors, with entrenched attitudes of team members sometimes leading to conflict. Their report concluded that high quality healthcare is best delivered by effective teamwork and that teams should establish a common agreed purpose and agree on the teamworking conditions for resolving conflict.

Effective teamwork requires good organisation to develop team cohesiveness, shared goals and clearly defined roles.^{359;361} The size of a practice team can influence effectiveness, with too few or too many team members being problematic.³⁶¹ The challenges of effective communication in larger teams are greater; communication with receptionists is reported to be poorer in larger practices.³⁵⁷

The reference to entrenched attitudes as a result of differing status of team members reinforces the influence of power relations within teams. It indicates the need for mutual respect among team members to create a climate for patient empowerment. Team climate, reflecting how well members work together, is an important variable associated with high quality care across range of aspects.³⁶² Staff who feel threatened or isolated within teams will be less able to empower themselves or others.

4.3. Errors and misunderstandings

Misunderstandings occur in a high percentage of doctor-patient interactions;³⁶³ many of these are based on inaccurate assumptions by each party as they failed to explore unvoiced expectations and meanings. Britten et al³⁶⁴ found four main categories of misunderstandings: lack of relevant information exchange from parties, apparent conflicting advice and information from the doctor and other sources, failure to understand the diagnosis or treatment decisions, and actions taken in order to preserve a doctor-patient relationship by either party in relation to prescribing treatment. They concluded that each of these forms of misunderstanding could be avoided or reduced by a process of shared decision-making and exchange of information. It is probable that

such misunderstandings are not exclusive to doctor-patient interactions, but I have found no evidence of similar studies with other staff groups such as nurse practitioners.

Although it is necessary for effective communication that both parties share relevant information, Britten et al ³⁶⁴ acknowledge the inherent power asymmetries in doctor-patient relationships by placing the responsibility on the doctor to take the lead in facilitating the process. Hoggett's suggestion that a sense of powerlessness can 'invade one's mind' is pertinent here; a study ³⁶³ which compared patients' presentation in medical consultations and in research interviews in exploring their unvoiced agendas found that in the former:

patients seem only partially present with only limited autonomy...[whereas] outside consultations patients are more fully present, socially and contextually situated, thinking, feeling people with their own ideas on their medical condition and opinions and possible criticism of medical treatments (p1249).

The authors concluded that improved outcomes could occur if doctors' views and behaviours changed in order to facilitate a change in patient consultation behaviour. This goal is expressed in the following definition of concordance,³⁶⁵ a philosophy which is implicit in a patient-centred style of interaction:

The clinical encounter is concerned with two sets of contrasted but equally cogent beliefs- that of the patient and that of the doctor. The task of the patient is to convey her or his beliefs to the doctor; and of the doctor, to enable this to happen. The task of the doctor or other prescriber is to convey his or her (professionally informed) health beliefs to the patient; and of the patient, to entertain these. The intention is to assist the patient to make as informed a choice as possible about the diagnosis and treatment, about benefit and risk and to take full part in a therapeutic alliance. Although reciprocal, this is an alliance in which the most important determinations are agreed to be those that are made by the patient (p12).

The way that information is conveyed and meaning derived is an important factor in avoiding misunderstandings. A universal method of communication is to tell a story;³⁶⁶ "We live our lives by telling stories about them" (p106). Storytelling is part of the cultural tradition for many Gypsies and Travellers, as Richard O'Neill, an English Gypsy, explains so clearly on his web site promoting the art.³⁶⁷ This has been evident in my work-related encounters when I have often been told stories of past events to

illustrate experiences. Buckler had a similar experience as she explains in her book on Gypsy-ness in North East England: ³⁶⁸

one thing people would do when they were telling me what it meant to them to be Gypsy was tell me stories about their experiences (p48).

I will now explore the increased use and function of narratives within health care settings as an accessible medium for creating mutual understanding.

4.4. Narratives in Health care

Bolton ³⁶⁶ and others emphasise the centrality of narratives to human understanding and communication. Kornfield and Feldman ³⁶⁹ describe the power of stories:

As we are touched by [these] stories, our imagination travels beyond the limits of our individual experience. Our hearts open to feel the sorrow and courage of another person, to experience the world through the eyes of another, and to empathise with their struggle. We begin to see more clearly our own story reflected in the stories of others (p6).

Stories are an effective means of making sense of our lives and our identity, and of transmitting that identity through our culture and values. Robb ³⁷⁰ describes how men draw on dominant public discourses, in their personal narratives of fatherhood, to produce their identities “in and through discourse and the complex interaction between personal narratives and public discourses” (p128). The meaning of illness is similarly co-constructed through joint narratives. A narrative-based approach to medicine is one that focuses on the ‘art’ of medicine and a relationship between doctor and patient that allows the patient’s story to be shared and heard. This interpretivist approach recognises that patients’ experience of illness is contextual and will be experienced in unique ways.³⁷¹ Narratives are viewed as contributing to medical ethics through co-authoring between health practitioner and patient to construct a joint narrative of illness and medical care. Although there are many potential interpretations of stories, the patient is the ultimate author of his or her story.³⁷² Dialogism is implicit in the practice of narrative-based medicine;

In an ideal form, narrative ethics recognises the primacy of the patient’s story but encourages multiple voices to be heard and multiple stories to be brought

forth by those whose lives will be involved...Patient, doctor, family, nurse, friend and social worker for example may all share their stories in a dialogical chorus that can offer the best chance of respecting all the persons involved in a case (p255)

This argument assumes that the opportunity to hear different perspectives of a situation through another's story, will increase understanding and inform ethical decision making. However, although this narrative practice does elevate the patient's position within the power relationship, a potential remains for professionals' perspectives to dominate and for them to exert their authority. For example they may decide to take a child into care against the patient's will. However, as Carson³⁷³ argues:

Seeing that there is more than one story to tell could help doctors and nurses to practise in a more ethically conscious and thoughtful way. While we do tend to practise, most of the time, without thinking too deeply about our initial impressions, I think that we can, as in everyday life, re-evaluate these initial assessments. What narrative methods do is to remind us that behind every practice, there is a person, waiting to be heard (p202).

The need to know and understand the other's story is a greater challenge when the context of the other's experience is culturally unfamiliar, such as with ethnic minority groups or people from other classes. This is particularly relevant to communication with Gypsies and Travellers.

4.5. Intercultural communication

In the extensive literature concerning intercultural communication there is appropriate focus on language barriers and associated needs such as multilingual resources. However, effective intercultural communication requires more than linguistic skill or understanding; communication also involves important non-verbal components. Nelson Jones³⁷⁴ refers to shared common characteristics that transcend different cultures, giving examples of seven main facial expressions for emotion: happiness, interest, surprise, fear, sadness, anger, disgust or contempt. He emphasises the mental components that determine how people communicate: "skilful communication and action follows from skilful thinking" (p213). In this sense any prejudicial thinking may be betrayed and communicated by non-verbal cues and behaviours.

Gerrish³⁷⁵ found that people from minority cultures identify negative attitudes, conveyed non-verbally for example by intonation or body posture, as having a major impact in intercultural communication. Perceptions of disrespect and perceived discrimination in patient-staff relationships are also associated with lower use of services.³⁷⁶ The lack of respect signified by these attitudes was often associated with cross cultural ignorance.³⁷⁵ Disrespectful attitudes, resulting in poor communication, can affect all patients but those from racialised ethnic minority groups are highly sensitive to any perceived interpersonal hostility that reinforces their marginal status.³⁷⁵

Primary health care workers recognise that their failure in cultural understanding is part of the problem when they have identified communication difficulties with ethnic minority patients.³⁷⁷ All admitted to feeling frustrated, angry or helpless on different occasions, with these feelings sometimes aimed towards the patients. Team members whose approach differed noticeably were health visitors who, by visiting patients in their home environment, had spent time in learning about their cultural needs and lifestyles.³⁷⁷ By taking time to gain understanding through “quality communication” they ‘respected’ cultural rules and priorities (p188). This reinforces the need for staff to invest their time in order to build a relationship with patients, although, as we have seen this is not an option that is readily available in the context of the pressures in general practice today.

Knowledge of patients’ historical and political experiences as well as their personal experiences is important for developing a fuller understanding in order to avoid oppressive relationships.³⁷⁸ Burke and Harrison argue for reflexivity among practitioners to minimise oppressive power relationships by considering how their own social identity and values affect their interaction with patients from different social divisions.³⁷⁸ This is important for avoiding ethnocentric practice.

Conflicting differences in core beliefs can be a major obstacle to effective intercultural communication. A person’s overt actions or behaviour rather than their statements are indications of their beliefs. Understanding our own and another’s beliefs is important for effective communication, as this will predetermine the behaviour born from our attitude towards those beliefs. Robinson³⁷⁹ refers to three components of attitudes:

- the cognitive component, or the belief about a person or situation,

- the affective component, or the emotional response to the belief,
- the behavioural intention component, or how one actually responds.

She describes racial prejudice as one of the most disruptive attitudes which can be directed to whole groups or towards individuals as members of a group. Ponterotto and Pedersen³⁷⁹ describe prejudice as “[including] internal beliefs and attitudes that are not necessarily expressed or acted on”(p112). Our values that determine behaviour can be both personally held as well as culturally bound values. Robinson describes many different dimensions of cultural values which she views as mechanisms for understanding inter-ethnic communication conflicts.³⁷⁹ One example is the dimension of emotional and behavioural expressiveness: this varies between cultures with the result that members of an emotionally expressive culture may be viewed as unreasonably hostile or hysterical by members of a culture that is typically more emotionally restrained. I perceive this to be particularly pertinent to Gypsies and Travellers who risk being inappropriately perceived as threateningly hostile when expressing their emotions. Each dimension will be predominant in different cultures and influence desirable methods of communication. If a dominant cultural value system is viewed as a desirable ‘norm’ and alternative value systems judged as inferior there will be a negative impact on intercultural communication. Robinson suggests that such negative impacts can be avoided by reflexivity among practitioners, with conscious examination of the underlying basis of their own value systems and attempts to gain understanding of others. Meanings attributed to health and illnesses also vary according to different cultural beliefs and these beliefs will influence patient interaction with health staff. In order to contextualise patients’ explanations of ill-health, Helman⁷⁰ emphasises the importance for practitioners to understand the patient’s cultural background in addition to their social background, hopes, fears and expectations. Like Robinson, he stresses the need to acknowledge and respect alternative medical models of ill-health and diversity of health beliefs. He cites the need for reflexivity to achieve successful intercultural communication.

Awareness of patients’ cultural differences and how they impinge on communication is only one aspect of a respectful attitude to patients’ views, beliefs and wishes in trying to reach concordance. A ‘culturally safe’ approach to practice goes beyond cultural awareness and competency. This approach was first developed and advocated in New Zealand by a group of Maori nurses, in the context of the poor health of Maoris.

Irihepati Ramsden, their leading spokesperson, recommended its teaching in nursing practice, on the basis that it is relevant in “any environment where power sharing and resources distribution between people of diverse background is unequal.”³⁸⁰ It requires a practitioner to examine his or her own cultural identity, values and beliefs, in relation to knowledge of the patient’s structural, historical and social context, together with their impact on his or her practice.³⁸¹

The terms cultural competence and cultural safety are sometimes used interchangeably, as both concepts have similar aims. The Royal Australian College of Physicians (RACP) provide helpful explanations that describe both the similarities and the difference:

cultural safety centres on the experiences of the patient , whilst cultural competence focuses on the capacity of the health worker to improve health status by integrating culture into the clinical context.³⁸²

Helman⁷⁰ advocates a similar focus on ‘internal contexts’ of culturally based experience and on ‘external contexts’ in the form of social and economic inequalities. He also refers to their influence on power relations between patients from certain cultural backgrounds and practitioners from dominant cultures.

In summary, I have outlined the importance of effective interpersonal communication between health staff and patients. I have identified various components and outcomes of effective communication and argued that these are mirrored in a patient-centred approach, although the interpretation of this approach varies among proponents. I accept the interpretation of a patient centred approach as one which involves an empathic focus on the patient’s perspective and meaning, with an aim of facilitating partnership. In advocating this approach I have emphasised the need for staff to be reflexive and self-aware in order to perceive how they are experiencing and interpreting a patient’s experience, and how they in turn are being perceived by the patient. This involves an awareness of power relations and an examination of the values that underpin their style of communication.

I have argued that empathy and respect for individual worth is fundamental and that these are essential conditions for building trust. I have also suggested that there are

attitudinal and structural obstacles to commitment to a patient-centred style. I find Coyle and William's³²⁵ concept of 'personal identity threat', used to describe the patients' experience, as appropriate for describing the disempowerment experienced by many health staff in the face of structural obstacles, particularly in regard to social change and policy directives that change their professional role perception. A personal identity threat which makes staff feel devalued is likely to make it more difficult to recognise value in others and create the conditions for mutual respect. This leads to the role of education in transmitting values and I now consider this within the evidence base of communication training for health staff.

4.6 Communication training for health staff

Certain skills are required for the effective communication between health staff and patients. Maguire and Pitceathly³⁸³ refer to these in the context of key tasks to be performed in communication between doctors and with patients (see box 1).

- Eliciting (a) the patient's main problems; (b) the patient's perceptions of these; and (c) the physical, emotional, and social impact of the patient's problems on the patient and family
- Tailoring information to what the patient wants to know; checking his or her understanding
- Eliciting the patient's reactions to the information given and his or her main concerns
- Determining how much the patient wants to participate in decision making (when treatment options are available)
- Discussing treatment options so that the patient understands the implications
- Maximising the chance that the patient will follow agreed decisions about treatment and advice about changes in lifestyle

Box 1: Key tasks in communication with patients (reproduced from Maguire and Pitceathly)³⁸³(p697).

Competent completion of these tasks requires a mix of technical, intellectual and interpersonal skills. A wide range of factors such as power imbalances, cultural differences, language, ability, personality, environmental factors, available time and

involvement of others can be potential barriers to effective communication. However, none are absolute impediments to successful engagement if recognised and dealt with appropriately.³⁸⁴

Teaching and practice in communication skills is now considered an important priority in professional training since 1993 when the UK General Medical Council recommended its inclusion in medical student training.³⁸⁵ The priority is reflected in the inclusion of practical assessments of communication as elements of clinical competence in postgraduate examinations.³⁸⁶ This should help to negate the current relevance of Wilson's argument, that the emphasis on objective science in medical training is responsible for the persistence of a paternalistic model. However despite the relatively long history of medical training in communication skills most complaints about doctors centre on communication problems rather than clinical competency.³¹⁹

Hulsman et al³⁸⁷ recently posed pertinent questions about evaluation of effective communication; its role in reducing health disparities, and effective means of teaching and learning. They posed a fundamental question about the basis for guidelines on effective communication. In highlighting the difficulty of discerning the difference between moral and evidence based guidelines, they warn of dangers of guidelines based on assumptions related to human understanding rather than evidence-based evaluation of patient experiences. The first recommendation of the 1991 Toronto Consensus Statement from an international workshop on 'Teaching Communication in Medicine' responds to this overlap between the ethical and empirical basis for teaching communication skills; emphasising the need for a broad view of communication in medicine while stating that both teaching and assessment should be evidence based.³⁸⁵

Education about doctor-patient communication should include not only the development of relevant skills, but also an understanding of the nature, context and ethics of the doctor-patient relationship (p192).

Hulsman et al³⁸⁷ also discovered supporting evidence for teaching communication throughout the curriculum and ensuring that it is promoted as a core element of being a good doctor rather than an additional skill. Kline,³⁸⁸ who refers to listening as the essential component of communication, in the context of 'a thinking environment,' quotes her GP, Fitzgerald;

The important change is for medical training to make the creation of a Thinking Environment and the removing of an appendix equal in the mind of the doctor - both essential to healing (p209).

This is reflected in Toronto Statement recommendations that emphasise integration of medical knowledge with patient-centred communication tasks.³⁸⁵ Recommendation 2.4; “Communication teaching should foster personal and professional growth” deserves particular examination. The rationale is that in responding to the student’s needs, the student in turn will be more likely to respond to the patient’s needs. It was recommended that students have the opportunity to discuss demanding and distressing issues that they encounter in their medical work in planned small group discussions where they can safely develop self awareness and learn appropriate coping strategies. Feedback methods were also envisaged to encourage reflection on their strengths and identify areas that need improved competency. I consider this to be a crucial recommendation, although I question whether enough emphasis is given to this in training curricula of medical or other health care practitioner students. The rationale for attending to students’ personal growth is wider than attending to their needs as a means to an end, but should be a model for valuing them as individuals. Coyle and Williams refer to the importance in concluding that improvements are required in valuing people as individuals.³²⁵ I suggest that it is easier for students to value others if they have first experienced respect from their tutors as role models.

Hulsman et al ³⁸⁷ suggest that the involvement of psychologists in skills teaching may be a key element of improved skill acquisition. For example, they would be well qualified in aspects of undergraduate medical training, such as dealing with ill or dying patients, which can lead to forms of emotional distancing or similar self-protective strategies.³⁸⁹ Stephenson et al ³⁸⁹ advocate the incorporation of professionalism i.e. professional growth, in the curriculum, with one of its three key aims to:

instill and nurture the development of personal qualities , values and attitudes , and behaviours that are fundamental to the practice of medicine and health care (p868).

They advocate experiential methods and activities that foster self-awareness as well as emphasising the need for pastoral care, in recognition of the emotional aspects of the doctor-patient relationship. Spiro ³⁹⁰ makes similar observations about the risks inherent in historical medical training methods:

students begin their medical education with a cargo of empathy, but we teach them to see themselves as experts. To fix what is damaged and to 'rule out' disease in their field... We first teach them science, and then we teach them detachment (p101).

This is perhaps a fair comment, but it may be more accurate to say that rather than teaching detachment, earlier training failed to teach strategies for dealing with death and distress and that emotional detachment was a natural coping strategy. This view is endorsed by Smith and Kennan who suggested that such tactics as transforming the patient into an analytic object and other detachment tactics developed by students could lead to serious emotional repercussions later in their personal lives.³⁹¹ Spiro also promotes the benefits of enhancing professionalism and teaching the component skills and attitudes through experiential learning with patient involvement.³⁹⁰

Reflexivity, an important tool for personal growth, as discussed earlier, is increasingly promoted in nurse training.³⁹⁰ Bolton³⁶⁶ promotes many benefits of reflective practice, including aspects of personal growth; for example, it can:

facilitate and enhance...reflective critical awareness of personal values, ethics, prejudices, assumptions of professional identity, decision making processes (p24).

Egan's³⁹³ advice demonstrates the need for reflective practice in training:

You need to be proactive in your search for the beliefs, values and norms that will govern your interactions (p48).

However tutors need to facilitate the development of reflective practice skills by fostering a safe learning environment for students.³⁹² Ruth- Sahd contrasts Dewey's perspective on reflective practice as a monologic process to Habermas who argues that reflective practice has both a social and psychological basis "that does not stop at the individual, but rather may be dialogic"³⁹² (p489). This illustrates the importance of reflexivity in developing a dialogic perspective of patient-centred care.

The focus of these various teaching recommendations has been generalised, without specific reference to intercultural communication. However Hulsman et al do explicitly recommend greater attention to patients' cultural and ethnic background in doctor-

patient communication education.³⁸⁷ Within this context they argue that acquisition of communication skills does not guarantee patient-centred communication and that many factors, such as time constraints, can impinge on doctors' practice so that they will avoid using the skills to engage fully.

Gerrish et al³⁷⁵ conducted a study of the relevance of nurse training curricula to the health care needs of minority ethnic communities. They found wide variation; with many training institutions making great efforts to prepare nurses, to others where efforts were, at best, tokenistic. For example, some training institutions merely brought in professionals or service users from minority ethnic communities and used their experience, instead of supporting staff development to deliver curriculum content on ethnic diversity and in devising competencies to prepare nurses for practice in a multi-ethnic society. The overall view of nurses undergoing the training programmes was that their training was inadequate. A disturbing finding was the extent of racism experienced in workplace settings. This indicates that training alone is insufficient in the absence of anti-oppressive workplace policies. They concluded that training to equip nurses to respond effectively to the needs of ethnic minority groups is not the sole responsibility of education institutions but requires recognition of the broader context in which training takes place. The onus is on health service providers and statutory bodies to address issues such as staff recruitment from ethnic minorities, and to tackle institutionalised racism in the workplace.

Chevannes³⁹⁴ identified the perceived training needs of a multiprofessional group for improving care of ethnic minority patients, and devised a ten-week skills-based training programme tailored to these needs. In the evaluation, which included a focus on reflection and learning, she found that in addition to increased awareness of ethnic minorities, students demonstrated self awareness and critical analytic skills and had gained confidence in evaluating their practice. She supports the role of reflective practice and also concluded:

sustainability of learning to care for ethnic minority patients and other service users is best undertaken in the environment where professionals and patients interact on an ongoing basis (p297).

However as Gerrish has shown, the ability to provide culturally safe practice requires more than use of communication skills and awareness of ethnic minority groups gained

through reflexive self-awareness. It is also important for health staff to recognise structural influences, such as institutionalised racism, that may not only affect health care access but may also influence the power relationship between themselves as representatives of those institutions and individual patients from ethnic minority groups. I purposely emphasise the word ‘individual’ when I refer to ‘individual patients from ethnic minority groups’ because a true culturally safe approach does not focus on cultural practices or differences viewed as common to a group; this risks ignoring the individual. As we have seen in earlier chapters we are all ethnically configured, and all patients belong to diverse groups with different cultures, with as many possible differences within cultures as across cultures. However, what is important is recognition that power relationships in the social context have an impact on the individual and on the way that health services are provided for individuals as members of groups who are marginalised or disempowered as a result of their social position. Health staff need to be aware of power differentials by responding to and meeting the needs of individuals within that context. This is the background to the development of the concept of cultural safety. Polaschek,³⁹⁵ another New Zealand nurse, like Ramsden, promotes the teaching of cultural safety over other approaches, such as Leininger’s transcultural nursing model, which he argues:

ignore the differences in power which affect their lives in a society, manifested ultimately in racism (p456).

The Royal Australian College of Physicians advocate that:

all health care service delivery and training organisations recognise the need for cultural competency in healthcare service delivery and include specific training at all levels of education and professional development.³⁹⁶

They also make explicit the importance of cultural competence training in attempting to reduce health disparities in its promotion as a means “to reduce institutionalised racism that maintains Indigenous health standards.”³⁸² Whereas this clearly relates to the context of the Australian Indigenous population, we have seen in these chapters how the same concept relates to marginalised communities who suffer discrimination or racism in the UK and elsewhere. This then indicates that cultural competence is a process; this is emphasised in the RACP statement that cultural competence is only achieved when health gains are maximised.

I have examined methods of teaching communication skills training and cultural competence, and recommendations with reference to different professional health staff groups. However it is noticeable that there is no reference to training for other health workers, even though many, such as receptionists, have direct patient contact and may often act as 'gatekeepers' of access to health care.

4.7 Conclusion

In summary I have examined the nature of communication between health workers and patients and outlined the empirical and ethical basis of a patient-centred approach. I have emphasised that the acquisition of communication skills does not guarantee a patient-centred approach and explored the obstacles in the context of staff-patient relationships, with a specific focus on the structural factors such as power differentials, which impinge on the use of communication skills.

In emphasising the need for an empathic understanding or dialogical approach to communication, I have focussed on attitudes and values and discussed their inclusion in the personal and professional growth element of health professional training. I have outlined the need for reflexivity and self-awareness in order to develop these values in an experiential context, but have also highlighted the apparent absence of available training provision for non-professional health staff groups.

Finally I have suggested that training in communication skills that incorporates the ethical component of empathy and respect for individual patients, is the fundamental basis of cultural competence. It is demonstrated by valuing patients and seeking to understand their perspective by hearing their 'story'. However I have explained how the need for cultural competence in reducing ethnic or other health disparities based on group difference also involves recognition of the structural factors that are implicated in these disparities and may be part of the 'untold' patient story.

Introduction and overview

In this chapter I explore my background as a practitioner and its influence on the design and conduct of the research. I then describe the methodological issues and the research methods. The research study falls into two phases. The first phase is my qualitative study of the relationship between Gypsies and Travellers' cultural beliefs, attitudes and health perceptions and their access to health care. This was part of a larger mixed methods study of the health status of Gypsies and Travellers in England.^{397; 398} Low expectations and poor experience of health service provision were key findings of this phase and were illustrated by many examples of communication barriers between Gypsies and Travellers and health staff. This led to the second research phase where I explored these barriers from both perspectives with Gypsies and Travellers and health staff. I begin by discussing my ontological and epistemological positions. I then discuss the methodology and the methods I used for the first phase of the research, before finally discussing the background to the proposal for the second phase, a participatory action research study.

5.1 Study Background

In May 2000, following the pilot work described in chapter one, I designed the qualitative arm of the mixed methods study. Mixed methods were required to address the full range of research questions (see Appendix B). When quantitative methods are used alone in health and social research, there is a possible danger concerning interpretation. For example, studies that demonstrate negative associations between cultural lifestyle and health outcomes may be interpreted as indicating a need to change the lifestyle rather than a need for health services to adapt or respond in a culturally appropriate manner. This danger may be avoided by including qualitative methods in an overall design, with the scope to explore the perspective of those studied and how they interpret their social reality.³⁹⁹ A qualitative approach is essential to discover and understand beliefs, values, decisions, attached meanings and actions in relation to health and access to health care. I undertook this qualitative arm of the study, as an integral

first stage of my doctoral research. Prior to detailed discussion of the study design and methods I will outline my perspective concerning qualitative research.

5.2 Ontological and epistemological position

Guba and Lincoln⁴⁰⁰ summarise an ‘Inquiry paradigm’ as posing three fundamental questions:

- The ontological question –the form and nature of reality: ‘what is there that can be known about?’
- The epistemological question –‘what is the nature of the relationship between the knower or would be knower and what can be known?’
- The methodological question – ‘How can the inquirer go about finding out whatever he or she believes can be known?’ (p37)

I adopted a constructivist position, seeing the social world as constructed through social interaction. There is not a single truth or reality but only interpretations of reality:⁴⁰¹

people construct the world , both through their interpretations of it, and through the actions based on those interpretations. (p67)

This is consistent with my view of a social model of health, focusing on the wider context of societal and environmental influences and a holistic approach to health care, as opposed to a medical model.⁴⁰²

However there are different perspectives on reality within a constructivist paradigm. A full constructivist position takes a relativist view in the realist-idealist debate: “there is no single shared social reality, only a series of alternative social constructions”⁴⁰³(p16). This view is at the idealist end of the debate spectrum with idealists believing that “no external reality exists independent of our beliefs and understanding.”(p16) An extreme relativist view holds that each of these perspectives is equally valid, but I am not persuaded as this negates the possibility of deriving any shared or collective meaning. There is also an extreme realist view, a positivist view known as ‘naïve realism’ which makes a clear distinction between beliefs and understanding about the world and an external reality. However I also find this view of a clear distinction untenable as I believe that knowledge of reality is contextual and socially constructed within a cultural, political and economic context. In as much as health is political (see Chapter

Three on tackling health inequalities), so too is health research.⁴⁰⁴ Health research cannot be divorced from the social realities that contribute to health states and beliefs and attitudes concerning health.

Between these extreme positions on the epistemological spectrum there are intermediate positions. I am influenced by Hammersley's 'subtle realism'.^{401; 405} there are multiple realities or perspectives, and individual interpretations of research data will yield different types of understandings that may be further interpreted by me as a researcher. Subtle realists, recognising that phenomena can be represented from different perspectives, do not seek to reproduce reality but to represent it.⁴⁰⁷ My intention is to explore, understand and to represent the perceived realities of Gypsies and Travellers and of health staff. Rice and Ezzy⁴⁰⁷ equate this form of realism with hermeneutic realism, and I find the approach persuasive because:

it provides information that is related to events that happen in the world and considers the political and socially constructed nature of the research findings.
(p34)

However a similar position of critical realism is described by Winter and Munn-Giddings.⁴⁰⁸ They assert that social inquiry is always part of the social world it describes, but emphasise that the purpose of inquiry is to understand situations in such a way that it is possible to effect change. There are differing nuances between these similar perspectives, but overall I have taken the view that the inquirer has a value-driven role as a facilitator for individuals to develop greater insight into their situation and potential for action.⁴⁰⁰ I will return to these features in relation to action research below.

This ontology is allied to an interpretivist epistemological position, and this is the driving force behind the choice of methodology and method. Interpretivism is basically concerned with understanding and with developing theory, or induction, in contrast to positivism which is concerned with objectivity and empiricism and the testing of theory, or deduction. The researcher's interpretation and representation of the participants' perspectives, whilst aiming to stay as true to their accounts as possible, is informed by her own observations and understanding of those perspectives and by deeper theoretical insights that help to place the interpretation in a broader context.⁴⁰³ In an interpretivist

stance the researcher and the social world are viewed as impacting on each other, in contrast to a positivist stance where the social world is seen as independent and the aim is for the researcher to be objective and value free.⁴⁰³ Reflexivity is necessary for explicitness about the process of interpretation and is therefore an important feature of an interpretivist approach. Guba and Lincoln⁴⁰⁰ describe constructivist-interpretive as one of four major interpretive paradigms in qualitative researchⁱ and assert that the nature of social constructions requires a hermeneutic or dialectical approach. Hermeneutics (i.e. interpreting human action) and phenomenology (i.e. how people make sense of the world) are important philosophical bases of an interpretivist methodology. These terms are closely related and often used interchangeably. However there are different traditions and philosophies underpinning both phenomenological and hermeneutic inquiry. Ezzy⁴⁰⁹ defines hermeneutic interpretation as both a science and an art. Understandings of reality are not only influenced by interpretations but by pre-existing interpretations based on prior assumptions and structural/ political processes.⁴⁰⁷ Sophisticated understanding is developed by interpretations and theories being developed and continuously redeveloped in a hermeneutic circle.⁴⁰⁹ Three basic tenets of the hermeneutic circle are described by Bassett⁴¹⁰ (p158):

- Our cultural background which presents us with a way of understanding.
- Pre- understanding as our structure of 'being in the world' i.e. our history and story which is always present
- Co-constitution i.e. we are constructed by our world and simultaneously we construct the world from our experience and background

These tenets resonate with my research approach. The influences and pre-understandings I bring to the research situation inevitably inform my understanding and interpretation, and it can be argued that by using this approach one's personal bias will inform the findings. However, as long as I am reflexive and revise my interpretation in the light of new information, the interpretation will be constantly developed and redeveloped as described. An important part of the research analysis process is that I made my emerging findings available for critical scrutiny with participants according to reflexivity principles. As Ezzy explains: "Interpretation involves an ongoing circular process of moving between one's own perspective and the perspective of the other person"⁴⁰⁹ (p27)

ⁱ Four major paradigms also include: positivist and post positivist, critical or Marxist emancipatory and feminist-post structural.

Phenomenology focuses on situations in the everyday world ('life world') of the experiencing person.⁴¹¹ It was first described in the eighteenth century by Immanuel Kant but has been developed and adapted by various philosophers and social scientists throughout the 20th century, including Husserl, Heidegger, Sartre, Merleau Ponty, Levinas, Gadamer and Ricoeur, in response to the realisation that phenomena need to be studied contextually to understand the perceived reality of human experience.⁴¹⁰

When I devised the qualitative research strategy for phase one I was unfamiliar with the details of interpretivist philosophy. However I am persuaded by my current understanding of hermeneutics and phenomenology that my research questions and approach towards understanding are guided by the principles of hermeneutic phenomenology. I was adopting these principles as I attempted to understand the health and health care experience of Gypsies and Travellers through insights I gained from the meaning and interpretations that they described in statements such as 'it's these houses which kill you, you know.' There are different opinions and emphases within interpretivist approaches, including different forms of phenomenology. However these do not disrupt my basic position regarding data collection and analysis. I concur with Van Manen⁴¹² who refers to a hermeneutic phenomenology as:

through the processes of reflection, writing and rewriting, and thematic analysis, the researcher may describe and interpret the essence and meaning of the lived experience (p47).

I will elaborate on methods and analysis as I describe the separate phases of my research.

5.3 Phase 1: Relationship between Gypsies and Travellers' cultural beliefs, attitudes and health perceptions and their access to health care

5.3.1 Method

The purpose of this phase of the research was applied policy research. There is not necessarily a contradiction between applied and theoretical research; in this instance, the qualitative study aimed to contribute to theory by providing greater understanding of the associations between health status and Gypsies' and Travellers' beliefs, attitudes and experiences, as well as providing empirical findings. I decided to use individual in-depth interviews in preference to focus groups, principally because the research topic areas are very sensitive and I was already aware, from my practitioner background, of

the need for confidentiality. There were also practical considerations such as arranging focus groups in a range of geographical locations and settings. In-depth interviews are also particularly appropriate for detailed and contextual understanding of people's perspectives and the meanings of their experiences and for detailed subject coverage.⁴¹³

5.3.2 Researcher/researched relationship

As a research team we worked closely throughout all stages of the study with Gypsy and Traveller members of our project advisory group and also with Gypsy Council members. This element of participation is an important ethical and moral dimension of research, particularly with marginalised or disempowered groups. Research that aims to inform the experience of a particular group of people should not mirror the imbalance in power relations by ignoring the contribution of 'insider expertise.' As Ezzy argues:⁴⁰⁹

If qualitative research is to assess and inform policy and practice, then it must also be informed by the practicalities and priorities of the organisations and people involved (p43).

Lincoln also takes an ethical stance in advising that research results should be written for, and shared with participants, for their benefit and not solely for the researchers' consumption.⁴¹⁰

5.3.3 Sampling

I used a form of purposive sampling; known as maximum variation.⁴¹⁴ The aim is to reflect diversity among the study population rather than to achieve representativeness as in quantitative research. My aim was to achieve as rich a sample of in-depth study as was possible to examine the range of experiences, meanings and interpretations within the limitations of the study. So, sampling was undertaken in four localities to include Gypsies and Travellers of both genders, across four age categories (16-25, 26-45, 46-65, over 65), four different types of accommodation (roadside/council site/private site/housed), and two ethnic origins, English/Welsh and Irish Travellers. The sample comprised Gypsies and Travellers from the main study who had identified that they had health problems. A sampling grid was used to ensure that a spread of interviewees was achieved across each category. Interviews were also conducted throughout the year in order to reduce the possibility of seasonal variations in mood and health states influencing the findings.

Achieved sample

The protocol allowed for purposive sampling of between twenty four and forty eight interviews. Fewer men, people from unauthorised encampments and people from the youngest (16yrs to 25 yrs) and oldest age ranges (over 65 yrs) agreed to be interviewed. However, the twenty-seven completed interviews, (including the final two pilot interviews) were sufficient to cover the diverse variation of characteristics sampled for and I felt that the quality was sufficient to offer depth and richness in a range of views, beliefs and experiences in this population. (See Appendix C for final sampling grid and characteristics of interviewees).

Access to participants

Given the mobile lifestyle of Gypsies and Travellers and the various priorities arising from the known demands of daily living that they faced, I anticipated some difficulty in being able to carry out the required range of interviews, even allowing for their agreement in principle. Participants in the survey element of the full study were invited by researchers to consider taking part in this qualitative phase. I was then given the contact details of those who agreed.

My prior health visiting experience of working with Gypsies and Travellers provided a useful insight into questions that needed to be asked; this experience also helped in engaging with participants. Although I did not hide my familiarity with Gypsy and Traveller culture, I chose to avoid possible reference to my health care experience to minimise possible influence on the direction of the interviews. I was acutely aware, however, of the danger of making false assumptions based on my experience, and I bore this in mind by recording my observations based on personal experience, for later comparison with findings. When I subsequently made the comparison I found that I'd made many of the same observations in my health visiting practice that occurred in my findings, but the depth of explanation and the wider context in the research interviews aided and informed my interpretation of these observations.

I attempted, whenever possible, to make advance appointments to interview willing participants, although arrangements often had to be finalised on arrival in the location, partly due to the mobile lifestyle of the participants and their uncertainty about when they would be free. Most preferred to be contacted by mobile phone, with little advance notice, on a basis of "if I'm free you can come", or alternatively via their local health

visitor, who had been the original intermediary for the survey stage of the study. Out of the twenty-six days spent in fieldwork locations to conduct the interviews I had thirty-eight specific failed contacts compared to twenty-five successfully conducted interviews. The process of making suitable arrangements to conduct the interviews was often protracted, involving several repeat attempts. The most common reasons for postponement or for failed contacts were family illness or crisis, funeral attendance or the family having moved on. This illustrates the inevitable need for flexibility in the health and social research process. With the exception of two opportunistic interviews when it was also necessary to first complete the questionnaire, the participants had purposely made time to be interviewed.

There was an apparent catharsis for some respondents in being able to talk freely to a stranger about some traumatic aspects of life and health histories. Men were generally more reticent than women about being interviewed. An attempt to carry out opportunistic interviews, with men who had not previously completed a questionnaire, proved to be problematic. I perceived that one man who did agree to be interviewed did so to please his health visitor. By the time he had completed the questionnaire he then had only a short time available for the interview. The predominance of women who agreed to be interviewed was not a surprise; men always shied away from health topics in my health visiting practice and referred to health as 'women's business'. This was also no surprise to the male Gypsy and Travellers on our advisory group. However, this attitude is not confined to Gypsy and Traveller men; Ian Banks, the president of Men's Health Forum, an organisation dedicated to men's health, states:

Men's health is plagued by myth, ignorance and inequality, but most of all by a lack of solid research based on evidence-based work with men themselves⁴¹⁵
(Foreword).

Despite the gender imbalance I did achieve some rich data from interviews with a small range of Gypsy and Traveller men, although clearly it would have been helpful to have interviewed a wider cross section and to have included more men who were still travelling for example. It was much more difficult to follow up those men or women staying on unauthorised encampment sites who had earlier agreed to participate, because their stay was time-limited before being compelled to move on. The other groups who were less well represented were younger participants (under 25 years) who

were more difficult to recruit and older Gypsies and Travellers (over 65years) , an age group which was comparatively fewer in number to recruit from. However, the achieved sample did afford depth and richness in a range of views, beliefs and experiences and there were no comments to suggest that any contrary views or beliefs were missing when I fed the results back to Gypsies and Travellers on the steering group and to a larger number of Gypsies and Travellers at the road shows (fifty-five in total) and at the dissemination conference.

5.3.4 Data collection

I chose to conduct individual in-depth interviews with Gypsies and Travellers in their own homes or trailers, or other venue of their choice, in order to ensure privacy and confidentiality. I checked with each participant that they understood the purpose of the whole study (from their initial contact for the main study) and gave further information, paraphrased from the information sheet, about the specific purpose of the qualitative interviews. Most had already made an informed decision to be interviewed and had no further concerns or questions. Several intimated or stated directly that if their health visitor trusted the research study then they could. I obtained signed consent and left a copy of the information sheet with the participants. All but one interview was audiotaped with the participants' permission. The person who refused permission was willing for contemporaneous notes to be taken during and after the interview. I also completed a post interview record of observations about my feelings, rapport, insights and other non-verbal features of the interview.

Topic Guide Phase 1 study

I devised a topic guide (see appendix D) from my existing knowledge, advisory group guidance and from three initial pilot interviews. I refined this during subsequent pilot interviews, and used it to ensure that relevant areas were covered to inform the research questions. I used non-directive interview questions, to allow for exploration of health behaviours, beliefs, and barriers to health service access. Additional issues that arose spontaneously, such as pertinent information about Gypsy Traveller identity and culture and suggestions for improved service provision, were explored and incorporated in subsequent interviews. I allowed participants to direct the order of topics covered and used the guide only as a prompt. All interviews, except the short one mentioned, lasted between one and two hours.

5.3.5 Thematic analysis of qualitative data

I used the 'Framework approach'⁴¹⁶ for data analysis as it is specifically designed to answer policy-related questions and allows for rigorous and transparent data management. It is a structured process of inductive thematic analysis with distinct but interconnected stages. It enables the identification of relationships and patterns in the data so that explanations and theories can be developed. It is also grounded in the data, in that it is driven by the original accounts of the participants and the observations made by the researcher.

I used a software package, Atlas Ti™, to enable more complex data organisation and retrieval. After familiarisation with the transcripts, I noted recurring themes from the early transcripts. I identified five broad themes following coding of the first eight interviews. I then developed a coding framework from these grouped themes and applied it to each transcript. I made further refinements during indexing of successive transcripts. When I had completed the indexing of all transcripts, I charted the coded data for each theme and identified sub themes. The final part of the analytic process, when I had charted all the data, was to conduct a systematic examination for patterns, exceptions and associations (see appendix E for a sample of coded data).

5.3.6 Validation

My analysis was subjected to peer review at all stages of the process. Each transcript was read by an experienced member of the research team (KT). The coding, the framework, descriptive accounts and interpretative analysis were also subject to continuous peer review. Following the initial analysis, I presented and discussed the broad key findings with groups of Gypsies and Travellers in a series of "road shows" held in each of the original study locations. This allowed for early interpretation of results to be tested or challenged by a wider group of Gypsies and Travellers and for additional comments to be made. At each presentation I asked the following questions of each group:

- How credible the findings seemed to them?
- How transferable they would be to other groups of Gypsies and Travellers?
- Were there any concerns re confidentiality from the quoted speech used?

There was a consensus that findings rang true: “yes that’s us”. Everyone agreed that the findings would be transferable and nobody raised any concerns about confidentiality. Admittedly it would be hard for people to know the full extent to which the findings would be transferable to other groups of Gypsies and Travellers, but I would expect that if the findings were particularly surprising or irrelevant to those who attended, and if they thought that they were limited in their relevance to Gypsies and Travellers as a whole, I would have been told or would certainly have surmised this from the reactions.

5.4 Phase 2: Communication barriers between Gypsies and Travellers and health Staff

5.4.1 Background and Rationale

The survey in The Health of Gypsies and Travellers in England study⁴¹⁷ showed evidence of an inverse relationship between Gypsies’ and Travellers’ health needs and their use of health and related services. In particular, the first phase of this research highlighted widespread communication difficulties, with defensive expectations of racism and prejudice between health workers and Gypsies and Travellers. Their general mistrust of Gorgers in wider society extended to health staff. However, there were also positive experiences of encounters with culturally well-informed health staff, who were reported as being more empathic. Several factors emerged in relation to a reluctance to use health services, including aversive experiences, stoical and fatalistic attitudes to ill-health, need for privacy, lack of awareness of the significance of symptoms and practical barriers to access.

Several Gypsy and Traveller women, who attended the presentation of Phase one findings in Medham, stressed their strong feelings about the importance of communication with health staff. They gave examples of health staff reluctance to accept Gypsies and Travellers as patients and elaborated with several examples of doctors failing to communicate with them adequately or respectfully. This particular group of women enjoyed the chance to meet and discuss these issues and felt that work was needed from Gypsies and Travellers and from health staff to address the issue. This, combined with my reading of relevant literature, confirmed to me the relevance of making the themes of communication barriers the focus of my second phase of research. I could have focused solely on Gypsies’ and Travellers’ cultural beliefs or alternatively on the structural access barriers and the politically-situated nature of Gypsies’ and

Travellers' health experience. There are also other areas that I would be interested in researching, such as a focus on men's perceived health needs, the impact of ageing and premature mortality and also the evaluation of the effectiveness of training initiatives on cultural awareness and competency. However, aside from the importance that the Medham Gypsies attached to the issue of communication barriers with health staff, I felt that the experiences, views and attitudes of health staff concerning health inequalities between Gypsies and Travellers were an important aspect of any study aimed at furthering understanding of how to address the inequalities.

5.4.2 Research Strategy

The overall purpose of this second phase of my research was to understand the communication barriers between Gypsies and Travellers and health staff from both perspectives. I wanted to work in collaboration with both groups to generate potential solutions for improved access to health care (see Appendix B for full research questions).

One outcome from the dissemination event in Medham was that the women who attended, from the different areas of the city, subsequently started to meet as a women's health interest group. This was facilitated by the specialist health visiting team in the area. I subsequently approached them to gauge their interest in working with me to carry out action research into the communication barriers issue. The women expressed interest in working together in this way, with the ultimate aim of improving communication between health staff and Gypsies and Travellers.

5.4.3 Methodology: a participatory approach

This shared interest in investigating communication barriers and in the allied possibility of effecting positive change inspired me to seek the group's involvement in a research study. In seeking to discover and to understand the inverse relationship between health needs and use of services, and the specific role of communication barriers, I continued to draw upon an interpretivist epistemological position. However by deciding to explore these questions in partnership with Gypsies and Travellers, I chose to adopt a participatory action research approach. I was drawn to this approach because Gypsies and Travellers are frequently the 'subjects of research' and many are jaded and disillusioned by the experience - not least because they have rarely seen any benefits from previous research. Their common experience as research subjects has been a

reinforcement of the unequal power relations that they experience within wider society, where their voice appears to be unheard or unheeded. I was particularly aware of these moral and ethical considerations and the potential damage that can be caused by lack of participation. One Gypsy, Len Smith, whom I have come to know and respect, gave permission for me to quote a concern which he had articulated in a general communication directed towards researchers on a mailing list:

Please remember that we are real people with real feelings and emotions, not pedigree cattle or specimens of any kind. For too long now we've been used as a means of furthering careers or massaging egos by the majority of those who studied us. As more and more Gypsy Travellers become aware of what has been done and said and written to us and about us, more of us are beginning to articulate the resentment and anger this can cause. I guess it could be called psychological damage, because I know I for one have a big chip on my shoulder and boiling bile in my guts when I read some of the nonsense that so called 'experts' have committed to paper.

The Gypsy and Traveller involvement in the wider Health Status Study was seen by those involved, and by others, as a departure from this more usual experience. I felt some satisfaction that the occasion of coming together to discuss the research findings was seen both as a rewarding experience in itself and also as a catalyst for further group meetings between Gypsy and Traveller women in Medham. It appeared to open a new opportunity for them, outside of the day to day routine, and I was particularly keen to harness this interest in an action research approach.

Another dimension to this approach was the aim of including health staff as research participants, with objectives of gaining shared understanding of the nature of communication barriers and shared views about possible responses. I was keen to go further than simply discovering further explanations and understandings, by exploring possibilities for change. As Hunter and Killoran⁴¹⁸ argue, "there is a case for shifting the focus to understanding and evaluating the process of change and how it occurs as well as its outcomes" and they advocate a "sharper focus on action research in bringing the two activities closer together in ways that enable research to influence practice"(p13). However they refer to the continuing evident inverse care law as they warn against focussing on interventions at the expense of critical analysis of the effects of current policies and ways of working:

A focus on identifying new and effective interventions for addressing health inequalities may divert attention away from a critical analysis of the ways in which current policies, priorities and ways of working contribute to disadvantage, or from developing ways of ensuring new policies are critically and prospectively assessed for their effects on health inequalities (p13).

Critical analysis of current policies and ways of working are only the first step I aspired to; I originally envisaged that a further phase of this study would be to produce a shared model of intervention to break down the identified barriers with the aim of improving communication. In reality the process of engagement in a participatory process with both Gypsies and Travellers and with health staff required a longer time period than envisaged within the available time scale and budget. However, I have agreed with all participants that the intervention stage will now be pursued as a separate postdoctoral study. Since completing the research described in this thesis, I have held an exploratory meeting with some of the Gypsies and Traveller participants from Norville and Medham, and also some other Gypsies and health staff who have expressed an interest in putting together a research proposal for a pilot intervention study.

My heightened awareness of the exclusion and sense of low worth in the eyes of others experienced by Gypsies and Travellers in society, as evocatively expressed by Nita in my Introduction, was a strong motivating factor in adopting a participatory approach. I was particularly inspired by an aim of participatory action research model (PAR) as described by Smith et al:⁴¹⁹

When people form a group with a common purpose, investigate their situation, and make decisions ...[they] are transformed, losing fear, gaining confidence, self-esteem, and direction (p774).

However Birch and Miller indicate the difficulties in attempting to create a truly democratic research process with equal power relations within a participatory action research methodology:⁴²⁰

When we examined our experiences of encouraging research participation we found that a dissonance had occurred between the ideal of 'participation' presented in ethical codes of behaviour, our hopes of encouraging the research respondent to feel part of the process and what actually occurred during the process itself (p91).

Cornwall and Jewkes⁴²¹ also highlighted the challenges of participatory research, as it “rarely follows the smooth pathway implied by theoretical writing” (p1672). They warn that not only is control rarely devolved completely to the community, but that the community do not always desire it. I will elaborate on the process after exploring the meanings and aims in the field of participatory action research.

5.4.4 Participatory Action Research (PAR)

Ezzy⁴¹⁰ comments that research always involves politics and that it also has political consequences for participants. A participatory approach to research is usually undertaken to give a voice to and to recognise the expertise of the people experiencing the research issue. PAR has its origins in social justice in international development and is characterised by continuous collaboration and sharing control of the research process. Craig⁴²² emphasises the participatory aspect of social justice:

social justice is not simply about achieving forms of human welfare – of whatever kind – but the means by which that welfare is obtained.

After considering the various debates on the meaning of the concept, Craig, the first professor of social justice, suggests this wide definition; one which fits well with the end motives for conducting participatory research:

a framework of political objectives, pursued through social, economic, environmental and political policies, based on an acceptance of difference and diversity, and informed by values concerned with:

- achieving fairness, equality of outcomes and treatment;
- recognising the dignity and equal worth and encouraging the self-esteem of all;
- the meeting of basic needs;
- reducing inequalities in wealth, income and life chances; and
- the participation of all, including the most disadvantaged.

Macauley⁴¹⁹ describes PAR as research which:

attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched and to improve research protocols by incorporating the knowledge and expertise of community members. (p774)

This is particularly important for marginalised community members who might otherwise feel powerless to question the aims, methods and supposed research benefits or the researchers' motives. PAR is often described as emancipatory or empowering because research participants are partners in the process. Reason ⁴²³describes “empowerment thorough consciousness-raising” as one of two primary objectives of this approach, alongside “the production of knowledge and action directly useful to a community” (p187). However empowerment is a contested concept, as discussed in chapter four, and not a guaranteed outcome of participatory research. Johnson and Mayoux warn against the idealisation of the empowering capacities of participatory methods.⁴²⁴

PAR in the UK has been influenced by ‘emancipatory research’ and ‘user involvement’ in health and social care’ and shares some common underlying aims. Emancipatory research goes beyond PAR as it is driven by and controlled by users themselves. This model was given considerable prominence by the disability movement, with empowerment identified as a major goal. Oliver ⁴²⁵describes emancipatory research as a new paradigm for undertaking research by changing the social relations of research production and placing control in the hands of the researched. He suggests that it is impossible to incorporate true emancipatory research into existing positivist or interpretive research paradigms. Humphries ⁴²⁶also warns that a self-reflexive approach with emancipatory intent does not guarantee that outcome as he suggests that those wishing to undertake an emancipatory research approach need to recognise the contradictory elements in discourses of empowerment. He argues that researchers are inevitably implicated in power relations:

Although scientific knowledge appeals to a metanarrative of the liberation of all, the thrust of the knowledge produced is ownership by a privileged research community in the interests of the dominant groups (para 4.6).

Many researchers, including myself, aim for our research to be emancipatory but question whether we either can, or do, achieve this ideal. Stuttaford ⁴²⁷promotes the possibilities of emancipatory research but states “I try to be emancipatory but I don’t think I am.”

5.4.5 User involvement in health and social care

In the 1980s, self-organisation among mental health service users and among disabled people seeking change in public policy preceded current 'top down' policies of user involvement. Self-organisation took the forms of self-help groups, advocacy groups and pressure groups. Barnes⁴²⁸ draws on theories of new social movements and new theories of citizenship to describe two emergent central issues that illuminate the significance of self-organisation amongst groups who aim to influence service provision, whilst experiencing exclusion, oppression or disadvantage. First, she discusses the significance of identity as a motivation for collective action to form groups that express their identity, and enable pursuit of collective group objectives. Secondly, she notes the policy shifts that have created opportunities for user groups to act, as 'consumers' rather than citizens. Barnes describes an underlying purpose of such groups, who she terms as 'communities of identity,' "to campaign for the inclusion of people previously excluded from mainstream society" (p87). A new policy direction in the 1990s, in favour of consumer interests, provided 'users' with increased opportunity to influence health and social care services through 'user involvement.' However, Barnes adds that although there are benefits of self-organisation in enhancing citizenship among excluded groups, there are also potential dilemmas, such as 'consultation overload', in becoming reactive to official agendas, and conflicts with potential funders, which may inhibit campaigning activities. Another dilemma occurs where a market model of consumer involvement encourages competition between specific interest groups at the expense of collective action in pursuit of social change. The term 'user group involvement' is sometimes used in place of 'user involvement' to differentiate between individual and collective rights. Barnes⁴²⁸ highlights the tension:

Collective action based in common experiences of oppression, disadvantage or social exclusion should be distinguished from an assertive consumerism which seeks to maximise individual self interest (p82).

She distinguishes citizenship from consumerism, noting that the former is characterised by an emphasis on the ability to actively and collectively participate in the community. Similarly, Lister describes the sense of agency involved in conscious collective action in pursuit of social rights as a defining quality of citizenship.⁴²⁸ (p82)

5.4.6 User Involvement in research

User involvement, also referred to as ‘lay’ involvement, in health and social care, is a major influence on participatory research approaches and has emerged as a fundamental requirement for funders to allow ‘users’ a say in design ,delivery and choice of services. Various policy directives from the Department of Health continue to support this principle.^{288; 429} This requirement transfers readily to an ethical principal of lay involvement in the research process. In a scoping project aimed at highlighting lessons for health research from lay involvement outside healthcare, Baxter et al ⁴³⁰ defined ‘lay’(involvement) as “becoming involved through ‘life experience’ rather than any specialist , professional, academic or practical training”(px). The terminology for ‘users’ varies considerably in health and social care: ‘patients’, ‘consumers’, and ‘the public’. Telford and Faulkner ⁴³¹ argue that terminology reflects “not only the way we see the world, but also the way in which others see us” (p550).

In a research context, terminology can also betray attitudes and principles concerning participation and the power balance in the research relationship. In traditional researcher-led approaches there is a tendency to reflect a dichotomy between researchers and the researched, often referred to as research ‘subjects’. There is a common misunderstanding of the concept and meaning of user involvement, with some researchers indicating that they have involved users because users are the ‘subjects’ of their research.⁴³² In practice, there is a broad range of user involvement in research; from possible tokenistic user membership on an advisory group to meaningful partnership⁴³³ (see Appendix F for an Action Research typology). However a Rowntree report ⁴³⁴ on participatory approaches to research on poverty in 2004, states “participatory practice is not yet fully embedded in the mainstream social research tradition in the UK” (p34).

Telford & Faulkner ⁴³¹ put this in context by discussing a range of barriers to involvement of service users in research. These include practical issues such as the need for and cost implications of training and support for service users, competing research agendas of the funders and attitudinal barriers around debates concerning objectivity and subjectivity. Some of these barriers were potential hurdles for conducting participatory research in this study and I will discuss this later. Nevertheless, I favour the view that it is the underlying principles that are crucial to the decision to undertake a participatory approach to research. My underlying ideology is described by

Marincowitz⁴³⁵ as the basic values of PAR; equality in sharing control and power, with empowerment and social change as important goals. My hopes in wishing to benefit Gypsies and Travellers by enabling their views to be heard are similarly described by Morse's book dedication to research participants "we are trying to find ways to communicate what you know so that others may understand."⁴³⁶ However, the extent to which my research may 'empower' Gypsies and Travellers depends partly on some factors over which I have very limited influence, such as family responsibilities and also the wider structural social divisions that result in social inequalities. Potential empowerment resulting from responses to research outcomes may also be affected by outside influences. For example, any changes that are envisaged within primary care may be impeded by the vagaries of primary care funding and organisation. As we saw in Chapter Three, structural influences of ethnic health inequalities such as institutional racism can also be powerful factors. Given these examples affecting participation and the difficulties in ensuring empowering policy outcomes, there are limits to the potential for empowerment in a PAR approach. However, the extent of potential empowerment also depends on the researcher's understanding and use of the concepts of empowerment and of power relations. While describing PAR as falling most clearly in the critical theory paradigm, Kidd and Kral⁴²³ suggest that it is:

dialogical and proactive, typically focussing on empowerment and with researchers' and participants values both being central to the planning process (p187).

However, they suggest that:

any concerted effort to remove some impediment that hampers the growth of a group of people, be it structural or ideological, could be defined as action within the framework of PAR (p189).

It is this catalytic aspect of PAR that I aspired to achieve, in the same way that the first study phase had been a catalyst for some participants to form or join groups and to realise their potential as activists for political change.

5.3.7 Negotiation over methods options

I arranged an initial meeting with the embryonic Gypsy and Traveller women's health interest group and ascertained their definite willingness to engage in the study prior to

discussion about methods. The specialist health visitor for travelling families in Medham (LH), who facilitates the group, had also agreed to be involved as a research partner. Her involvement was particularly crucial in helping to convene the initial meetings as initial apprehension or even suspicion about my motives and expectations was to be expected. I consulted carefully about various aspects of the proposed research study: aspirations, aims and process. I also proposed the idea of a reference group on similar lines to the one convened for previous research phase. Following this preliminary discussion I arranged a subsequent meeting to discuss a proposed protocol, detailed methods and timescales. The anticipated hurdle of being able to meet with all interested participants at each proposed research meeting was evident at this first attempt. Five women managed to come but three more who had expressed an initial interest were unable to attend. After the meeting I was able to speak separately by telephone to two of these women and one came to meet me later in the day. However I gained enough encouragement from these initial discussions to begin recruitment to a reference group and to produce a draft protocol for discussion at the next meeting.

5.4.8 Reference group

Initially, I envisaged that the Gypsy and Traveller women would appreciate the chance to discuss their involvement with other Gypsies and Travellers with previous research experience and with other researchers who had previously conducted research with Gypsies and Travellers. I viewed this as an aspect of power sharing in the research process. In the absence of any suggestions from the women, I suggested some names known to me through previous contacts. They agreed to all my suggestions except for one, a male Gypsy, who had been on the steering group of the Health Status study. In retrospect this objection was not so unusual in a group who were accustomed to strong gender role divisions. At the time though, I was slightly surprised at the strength of the objection, as he had been encouraging when they met him in his steering group role, assisting in facilitation at the first phase Health Study feedback session. They were more enthusiastic about the involvement of their health visitor (LH) and her health assistant and relatively less interested in the concept of the reference group. This was also unsurprising in light of the need for reassurance from those in whom trust was already invested. The women did not view their anticipated non-attendance at the reference group meeting as a barrier and agreed that it should go ahead regardless of their ability to attend. This mattered to me more than to the research participants as I was concerned that I was discussing matters pertaining to their involvement without their active

participation. However, this did not appear to present any concerns to the participants. The reference group meeting was only convened once, prior to the start of the project, although I made attempts to continue to engage and consult with group members at subsequent project stages (see Appendix G for reference group membership).

5.4.9 Proposed Multi-method approach

Group interviews- Focus group method

My proposal was to use group interviews in the form of separate focus groups, for Gypsies and Travellers and for front-line health staff in primary healthcare settings, that is GP practices, a Walk-in centre, and an accident and emergency department, as these are also sometimes used for primary care.

Proposed fieldwork stages:

1. Group interviews with Gypsies and Travellers
2. Narrative sessions with Gypsies and Travellers
3. Group interviews with health staff, in various settings
4. Preliminary Feedback- Gypsy and Traveller focus groups
5. Preliminary feedback- health staff focus groups
6. Interim feedback- Gypsy and Traveller focus groups
7. Interim feedback- health staff focus groups

Kitzinger⁴³⁷ states that “group processes can help people to explore and clarify their views in ways that would be less accessible in a one-to-one interview” (p68). She asserts that they are particularly useful not only for examining what people think but also how and why they think in that way. My decision to use this method was based on pragmatic factors as well as methodological ones. The progressive stages envisaged in the study whereby Gypsy and Traveller participants would have an opportunity to reflect on health staff participants’ views, and vice versa, rendered one-to-one interviews an impractical option. However a focus group method was also in keeping with a participatory action research methodology. I was intending to work with groups of Gypsy and Traveller women and health staff to elucidate the nature of communication barriers and so it was necessary for me to work together with them and enable them to share their ideas as partners in the research process. The intention to explore solutions to any identified communication barriers was also an incentive to use

this method. The advantages of focus groups over one- to-one interviews, identified by various authors and summarised by Sim ⁴³⁸, influenced my method choice. In addition to the pragmatic economic advantage, Sim cites the following (p346):

- They provide information on the ‘dynamics’ of attitudes and opinions in the context of interaction that occurs between participants.
- They may encourage a greater degree of spontaneity in the expression of views.
- They can provide a ‘safe’ forum for the expression of views. (Respondents are not obliged to respond to every question.)
- Participants may feel supported and empowered by a sense of group membership.

Initially I was concerned that in the health staff groups, receptionists might be inhibited by the potential power imbalance with clinical staff. In the event this appeared not to be the case, judging by their level of participation and their contributions to discussions. I also had to weigh this risk against the practical difficulties of arranging homogeneous staff groups with sufficient numbers per group and the loss of the opportunity to maximise the exploration of different perspectives and dynamics between disciplines in a team context.

Narratives: group sessions, using a Stories Template.

One of the notable features of the one-to-one interviews that I conducted in the first study phase was the extent to which interviewees responded to questions by ‘telling a story.’ As we saw in Chapter Four, personal stories are a universal medium for communicating meaning and are frequently used by Gypsies and Travellers within their oral tradition.³⁶⁸ Their frequent use of stories in the interviews gave additional insight into the wider context of the situations they described and the sense of ‘what it is like’ for the Gypsy or Traveller storyteller. The significance of story telling in this context is suggested in this foreword by Kabat-Zinn ⁴³⁹

Stories are how we organise our thoughts, preserve them in memory, share them with others and pass on the lineage of the community and its experiences. What happened down the road is a story ...and even one story, if it is a good one is different each time it is told. For stories reflect the mind itself, and the mind itself is always changing, like the surface of the ocean...(p xi)

I was aware too of research evidence of the potential therapeutic value in the sharing of stories,⁴⁴⁰ as we saw in Chapter Four:

The value for health professionals of listening to stories about illness and health has been presented...in terms of improving the quality of patient carer communication (p61).

There are many features of story-telling that contribute to the process of change. They are particularly an accessible communication tool and they can have a powerful impact for people who are less used to communicating formally. There are various ways that narratives or stories are currently used in the NHS: as vehicles for organisational change, as a therapeutic tool, to inform service improvement or development; as a basis for clinical supervision and also as a form of heuristic inquiry or autobiographical discovery. These combined factors led me to use narratives as a method of inquiry in the focus group discussions, as a starting point for further exploration and analysis.

I was inspired by Greenhalgh who used personal stories with a ‘storytelling template’ within an action research approach to develop a complex intervention for diabetes support and intervention in minority ethnic groups.⁴⁴¹ She described stories as ‘sense making devices’ and a flexible, fun and creative tool for engaging people in organisational change. She also discovered additional therapeutic value in their use. The ‘story telling template’, used to facilitate discussion, consisted of the following key stages:

- Who is the story about?
- Why did you choose this story?
- What happened in this story?
- How did the people in the story feel or react?
- What aspects of the story had most impact on you?
- How could the story have ended differently?
- What would the organisation be like in order for this different ending to occur?

I acknowledge Greenhalgh’s rider, that a story is a drama that unfolds and cannot be ossified, but I too saw this template as a potentially useful and acceptable tool that could

be appropriately adapted and transferred to the focus group setting with the Gypsy and Traveller participants to explore the nature of communication barriers.

I obtained my narratives by selecting stories from the original phase one study transcript data, and then reducing each story to a coherent narrative by removing 'my voice,' in the form of questions or affirmations. I recorded these stories so that I could play them to participants in the narrative sessions and then used the story template as a discussion tool. I adopted the same process for health staff participants and used some of the same stories. However, in addition, following discussion with the Gypsies and Travellers concerned, I also included stories from their group discussions. I elaborate on this process later in the chapter.

5.4.10 Ethics and Research Governance

These studies were granted scientific review and ethical approval through the formal, obligatory Research Governance Framework governance procedures, in place at the time for any proposed research involving either NHS patients or staff. However, although ethical approval was granted on the basis of satisfactory compliance with ethical considerations, these procedures did not adequately cover the full range of ethical considerations associated with a participatory approach to research with a marginalised group. Full informed consent needs to address the political and social consequences of the research; for example, the social consequences for the participants from involvement in the research process. I have addressed some of these issues earlier when discussing PAR; in particular the need to avoid replicating the subordination of Gypsies and Travellers through an abuse of power in the research relationship. I regularly checked with participants the extent to which the research methods reflected their preferences. This sometimes felt uncomfortable, for example when acceding to a request to include some Gorgers friends of the participants in one of the research sessions. However, to have refused this request, which I understood to be based on a need for reassurance, would have been an abuse of power in a participatory research relationship where compromise and negotiation are important components. I also continually checked my interpretation of their experiences and view points through the feedback stages of my analysis.

Obtaining informed consent

My moral obligation to be as informative as possible about the implications and potential research outcomes was compromised by the participants' relative lack of interest in discussing or questioning these finer details. In both study phases, once they had agreed to take part they explicitly said that they did not require further information. The decision to take part was usually made on a basis of trust or recommendation from the 'gatekeeper.' Although Gypsy and Traveller participants later informed me that I had subsequently gained their trust, I had to accept the initial discomfort of being in a position of control and responsibility of the research process that was not fully shared at the outset.

I was less concerned with my ability to ensure informed consent from the health staff participants. After initial expressions of interest were obtained by LH as an intermediary, I negotiated recruitment of GP practice team staff through one key staff member. Although I offered to discuss the research in detail with staff, this was not considered viable for them within time constraints. Instead, the key staff member was the conduit for team consent for potential participation in the research study. I sent an information poster and information sheet handouts containing my contact details and offered an opportunity to raise any questions with me prior to any final decision to participate. This opportunity was not taken up by any of the staff; most likely because of time pressures and other work priorities and the knowledge that they could ask me for any further information on the day. I was subsequently invited to arrange dates for the first focus groups over staff lunch periods and to use the first part of that allotted time to gain informed and signed consent from each individual. However, I could not feel completely confident that the receptionist staff, with less autonomy in their working practice, felt as free and informed as their managers in giving their consent to participate. At the Walk-In Centre, my offer to meet with the staff to explain the study and invite participation was accepted. Two weeks prior to the focus group sessions I provided lunch and spent two hours over the staggered lunch period to meet with each staff member and obtain an expression of interest in participation. I subsequently gained signed consent at the start of focus group sessions.

Feminist ethical model

My ethical perspective closely adheres to an ethical feminist model as described by Birch and Miller.⁴²⁰ They argue that in a feminist approach the quality of research is

dependent on aspects of the research relationship, with a focus on components of closeness, trust and reciprocity. The notion of participation is an important aspect of the relationship. As Gillies and Alldred⁴⁰⁴ argue, the main objective of feminist research is to challenge the marginalised status of women by acting as a conduit for their views and experiences. Birch and Miller⁴²⁰ refer to Walker's ethics of responsibility as they highlight the reflexive analysis of personal research experiences as being central to their feminist ethical model. This model requires an acknowledgement that different interpretations of participation are possible and that constant re-negotiation and re-mapping of ethical judgements is required for a co-production of research accounts. Participation may be partial, and, once agreed, levels of participation may shift during the course of the research process. They highlight the potential power of the researcher to impose ongoing participation that is not sought or wanted. This approach requires flexibility in research practice to work from an ethically sensitive position to honour the research commitments.

5.4.11 Fieldwork

Gypsy and Traveller Participants

Eleven Gypsy and Traveller women, nine of whom were from three different families living in the countyⁱⁱ participated in the two introductory meetings at the embryonic women's health group. They all expressed an interest in engaging as research partners in this study and it was expected that they would become the core group members. However they also expressed a wish to approach their peers for possible inclusion. There was joint agreement and understanding that any new arrivals would attend research group meetings having expressed an interest in the study, and that we would make adequate time to obtain informed consent (see appendix H for list of participants). After protracted difficulties in arranging joint meetings, with resulting time pressures, it was apparent that great flexibility was required to facilitate participation. Other complicating factors were: the specialist health visitor having a long period of sick leave, resulting in the PCT temporarily disbanding Travellers health service; and the imminent start of the summer 'travelling season' reducing Gypsy and Traveller participant availability until the autumn. Following discussion with LH, the health visitor, on whom I was partially dependent for facilitating bookings and attendance, it was agreed that continued group meetings at the health centre were unviable. In

ⁱⁱ LH, the health visitor for Travelling families covers the whole county and the participants lived in a mix of housed and site accommodation

consultation, I devised two complementary strategies to facilitate and increase participation. The director and a member of a Gypsy and Traveller voluntary support group in Norville, (100 miles from Medham), had expressed an interest in the study when consulted at the initial formulation stage of the research design. They agreed to join the study and arranged a focus group of other Gypsy and Travellers who regularly attend their centre. This group included a Gypsy man who attended with his wife. He had been particularly keen to take part and the rest of the group seemed to be quite comfortable with his presence, in contrast to the usual gender divide about discussing health matters. The Gypsy and Traveller participants in Medham agreed to the proposed joint meeting with the Norville group, after the 'travelling season.' I also arranged to hold separate domiciliary meetings for each family group to facilitate participation in Medham. In the case of one participant this entailed an individual meeting despite the offer of transport to accept an invitation to join one of the family groups.

Health staff participants

I sought advice from LH about potential recruitment of various local GP practices who either regularly saw Gypsy and Traveller patients or who were known from comments made by Gypsy and Traveller clients to the health visiting team, to be reluctant to see them. I also approached the Accident & Emergency consultant in the local city hospital and the nurse manager of a Walk-In Centre in a local county town. It proved extremely difficult to recruit health staff partners, but I finally recruited two GP practices:

Elm surgery located less than a mile from Medham city centre on a busy crossroads is one of five general practices within a one mile radius. Medham's population is 280,000 of which 34% are from ethnic minorities. Elm surgery has five GP partners. They have a stable, but small housed Gypsy and Traveller patient population, and intermittently see larger transient groups as temporary patients. The surgery has good public transport links with the rest of the practice area and there are two hospitals nearby.

Rowan surgery is a large health centre and the only GP practice serving patients in Littleton, a market town 15 miles from Medham, and the surrounding villages. Littleton's population is 18,600, of which 4.2% are from ethnic minorities. Rowan surgery has ten full time GP partners. They have a large Gypsy and Traveller patient population; many coming from the two Gypsy sites in Littleton. In contrast to Medham, Littleton has low levels of deprivation; most wards are ranked within the 20% least

deprived areas in Britain. It is 16 miles to the nearest hospital, but there is a local minor injuries unit close to the practice. I held meetings at the GP practices during the hour-long lunch breaks and was therefore time-limited to a much greater extent than with the Gypsy and Traveller participants.

I also recruited staff from the Walk-In centre located in Pedley, a small market town in the same county, and with similar demography to Littleton. This was one of the first Walk-In Centres to open in 2000, when they were introduced to improve access to health care.⁴⁴² It is a busy centre with average attendances of 2000 patients per month. Thirteen local GP practices serve Pedley and the surrounding area. Here I held two consecutive meetings to enable staff to attend and still maintain 24-hour staff cover. Each convened group consisted of a mix of clinical and non-clinical staff. The Walk-In centre staff were unable to make time for continued participation after the initial focus group meetings.

Despite initial enthusiasm from the Accident and Emergency department consultant, after several weeks of attempts by telephone, and in person, I was never able to arrange a focus group with the staff. One staff nurse from the department who had expressed a particular interest via LH later volunteered and participated in an individual interview in her own time (see Appendix H for full list of participants).

5.4.12 Research meetings: chronology and structure

In addition to the initial focus group discussions, which took place as planned, I also held narratives sessions with health staff. Staff from the GP practices agreed to these subsequent sessions after hearing how I had used this format with the Gypsy and Traveller participants. Fewer staff were present for these sessions but this was attributed to staff availability rather than any reluctance to participate. The chronology and format of the different stages of fieldwork can be viewed in Appendix I.

Following transcription and preliminary analysis of all the focus group sessions I produced a report of preliminary findings to share with participants. I met first with separate groups of Gypsy and Traveller participants for feedback on my interpretation from their perspectives and to obtain their initial reactions to the health staff perspectives (see Chapter Seven). Similarly it was my original aim to repeat this process with the health staff, but attempts to contact the key staff members to arrange

preliminary feedback were protracted and complicated by staff absences. Eventually, as agreed, I sent the written report electronically to the key staff member in each practice to read and then to distribute to other health staff participants (see Chapter Eight). I incorporated data from the preliminary feedback into my analysis for interim feedback and evaluation, prior to writing a final analysis.

Gypsies and Travellers from both cities were enthusiastic about a joint meeting. Both groups were keen to travel to the other city but for practical reasons we agreed to meet in Norville. I arranged transport for the Gypsies and Travellers from Medham with assistance from the health visiting team; two members of whom voluntarily accompanied the participants and attended the feedback session out of interest. Various family crises prevented full attendance, but 'Family A', including a new additional member, attended and joined the Norville group for a feedback session followed by evaluation over a buffet lunch.

My original aims of holding a joint meeting of health staff groups for interim feedback and evaluation were impractical due to the workload pressures within the practices. Staff from Rowan surgery attended an interim feedback and evaluation (see Chapter Eight). Elm surgery staff declined any further feedback sessions, and instead, I met with the key GP to share the interim feedback. Through her I offered to discuss any residual concerns that staff may have about their views of the reported findings. Following this meeting I sent a letter to the staff via the reception staff manager.

5.4.13 Data Analysis

Analysis did not begin when data collection had finished but has been a continuing process from inception and throughout the study. In deciding to explore the problem of communication with the aim of effecting change I already brought knowledge and assumptions to the research from my practitioner experience and from the original study findings. The prior information I had gained of the lived experience of the participants and how I understood them to perceive their experiences, helped to inform my choice of research questions and methodology. In adopting a participatory method I was using my skills as a researcher to combine with their expertise to generate knowledge that would be meaningful and relevant to health service providers, policy makers and health service users.

There is no one universal method or technique for conducting data analysis. As there are many perspectives on approaches to exploring social life, there are also many perspectives and a variety of techniques to the analytic process. However, there are core features that all qualitative analysis methods have in common. There are two broad stages involved: data management and generation of findings. Spencer et al ⁴⁴³ describe an analytic hierarchy that is applicable to many approaches and which reflects the process I adopted, although they emphasise that the process is not linear but iterative. Conforming to my epistemological position I was influenced by many features of Interpretative Phenomenological analysis (IPA) in my analytic approach. This approach is most widely used in health, clinical and social psychology and combines the features of phenomenology, hermeneutics and symbolic interactionism. In IPA the researcher is concerned with the participants' perceptions and meanings that they attribute to their experiences but also in using her own conceptions to gain an understanding of their thoughts and beliefs through interpretation.⁴⁴⁴ Symbolic interactionism is an influence in IPA, which holds that meanings are only obtained through interaction with others and a process of interpretation. Meanings are not necessarily transparent and require close interaction with text while drawing on personal interpretative resources. Smith ⁴⁴⁵ refers to IPA as a double hermeneutic, where:

the participant is trying to make sense of their personal and social world and the researcher is trying to make sense of the participant trying to make sense of their personal world (p40).

Thematic Analysis

Initially I listened carefully to the recorded interviews and read the transcripts thoroughly to familiarise myself with the data before identifying initial codes in the margins. I used the NVivoTM qualitative software package to manage my data. In addition to coding the data within the package, I also recorded memos about concepts or aspects of the transcripts that seemed significant, and thoughts and insights that arose from fieldwork experience or were informed by further reading. After developing an initial coding frame with the coded data sorted into broad themes I continued the iterative process of continuous revision and recoding of the transcripts as I interrogated the data. I also incorporated the feedback from the participants in to this continuous revision. I used the software to retrieve the coded text under the different themes. By viewing the coded text within the transcript I ensured that data reduction for coding

purposes did not alter the meaning (see Appendix J for a sample of initial coding). I continued this iterative process as I began to write up my findings.

Narrative Analysis

In addition to using the story templates as a focus for discussion and then analysing the data from the discussion thematically, I saw their potential for analysing the nature of interaction in my data. This is a dimension which is harder to capture through thematic analysis alone. As I argue in more depth in Chapter Four and Chapter Nine, taking a dialogic approach to understanding interpersonal communications processes can provide a complementary approach to analytic perspectives which focus on social relations at a broader level. Story-telling is an important meaning-making device, and one that can reflect aspects of both private and public accounts of health experiences ⁷⁴ (see Chapter Three). So, as well as using stories as narrative device, in order to test the utility of a dialogic approach I decided to apply a narrative analysis to stories in the data. The defining feature of narrative analysis is that it examines the narrative as a whole, paying attention to both structure and content. The different parts or events within the story are significant only within the broader context of the complete narrative. Used in combination it was a method that was useful for checking and adding depth to the inferences drawn from the data through thematic analysis.

In telling their stories, participants reconstruct their experience as they hear it anew through the listener.⁴⁴⁶ Barre et al suggest that:

the shape of narratives are governed by deeply embedded notions and expectations about the normal course of life as well as unconscious rules about what constitutes a good story (p792).

Reissman ⁴⁴⁷ underlines the importance of telling stories in a way that sheds light on the frequent eagerness by the Gypsy and Traveller participants in this study to retell the same stories: “telling narratives is a major way that individuals make sense of disruptive events in their lives” (p1199). Ezzy ⁴⁰⁹ refers to Ricoeur’s narrative theory of construction of a narrative identity with stories being open-ended, but neither fixed nor malleable, as they are reinterpreted in the light of new experiences. She equates this to how history and identity are also continually reinterpreted.

Many authors however, use the terms 'stories' and narratives interchangeably. Gibbs⁴⁴⁸ defines narratives as involving a personal dimension to recounted events and related from a personal perspective. He argues that a 'story' is a narrower term that implies a specific structure with a causal sequence. Rice and Ezzy⁴⁰⁷ describe the 'plot' of a story as the organising theme of the narrative which weaves the successive events into a single story and demonstrates their significance, whilst giving power to the story through understanding of the sequence. Most different approaches to narrative analysis involve analysis of a plot structure. Reissman⁴⁴⁹ emphasises the transcription component of the analysis and the listener's place within the narrative, particularly in the form of entry and exit to a narrative. She highlights the relational nature of stories with the listener playing a role in the beginning and ending of a story.

I began the first stage of narrative analysis by selecting stories to exemplify key experiences from the focus group transcripts and deciding where these began and ended. In the first phase of my research, I had identified a number of communications patterns (both positive and negative); for the purposes of narrative analysis I chose stories that crystallised these and then reduced each story to a coherent narrative (see p159). I acknowledge the collaborative nature of story-telling and agree with Reissman's view that the manner in which I question, listen and respond to an account can shape the way stories are told. However, I deliberately omitted 'my voice' not as an act of denying the social interaction but so as not to detract from the coherence of the story.

I used Labov's framework for interpretation of meaning.⁴⁴⁸ Labov assumes that all stories are about specific past events and have a common structure of six narrative elements, with each having a separate function. These elements answer specific questions of the narrative and each help to elicit the significance of events for the storyteller. I chose this method because it enabled me to look at the internal coherence of the narrative, rather than at the meta-narrative of the teller and the listener. Although this model does not focus on an examination of the relationship between the teller and the listener, the inclusion of evaluation among these elements assists in interpretation of the overall meaning and attitude of the narrator, with an implicit recognition of the role of the listener. Reflexivity allows me to examine the purpose in telling a particular story and its perceived function. Reissman⁴⁴⁹ advises a focus on the structure and organisation of the story, rather than relying on the content to question and interpret the meaning. For example, one narrator used her story implicitly to emphasise her opinion

that discrimination is an underlying reason for poor care. Similarly, a health staff narrator used a story in an apparent attempt to elicit sympathy and gain greater understanding on the part of the listener of the health staff's predicament in terms of the unpredictable nature of Gypsy and Traveller plans for antenatal care.

When I had reduced each story to a coherent narrative I used a grid to display it by using Labov's six elements (see box 1). I completed my initial analysis by reflecting on each element within the context of the story. When I subsequently situated the narrative analysis within the broad themes within my analysis as a whole I found that the meanings I interpreted from the narratives were closely correlated with the themed findings. This might be viewed as unsurprising, given that the narratives themselves were derived from interview data. However, as we will see in Chapter Nine, approaching the narratives from a dialogical perspective did facilitate a more detailed understanding of the co-creation of meaning than was apparent from thematic analysis alone.

Box 1 Labov's narrative elements

Abstract (a preface/summary- initial clause that reports entire sequence of narrative events.)
Orientation (location of action- information re time, place, identities of participants and initial behaviour.)
Complicating action (the next event e.g. what happened then?)
Resolution (an account of what finally happened.)
Coda (final clause i.e. moral or gist is made clear.)
Evaluation (the attitude of the narrator – occurs throughout narrative i.e. information on the consequences of the event)

Quality and Rigour

Rice and Ezzy⁴⁰⁷ argue that although there are procedures designed to ensure rigorous and ethical research practice it is insufficient to rely on these to ensure a rigorous and ethical study. They argue that rigorous research not only provides valid information about events, but considers the political and socially constructed nature of the knowledge derived from the findings. They consider various aspects of rigour: theoretical, methodological, interpretive, triangulation and evaluative rigour. I have

demonstrated theoretical rigour by clear explanation and reasoning of a research strategy that is consistent with the research goals. Methodological rigour has also been demonstrated by detailed accounts of the research process. There is a clear audit trail that can be followed to enhance credibility. I have also triangulated my methods by use of individual in-depth interviews and subsequent use of focus groups. However it is interpretative rigour that is specifically relevant to qualitative research. The analytic process allows the data to be viewed in various ways, with interpretation as the knowledge that is produced as the end-product.

Ethical considerations are inextricably linked to interpretative rigour. As a researcher who takes the view that research is a political activity, with the function of describing situations and giving those affected a voice to shift understanding and influence policy and practice, there is a particular imperative to ensure that my research interpretation is reliable and trustworthy. It would be possible to be constrained according to different interests in how I present, interpret and utilise the data. I have set out to demonstrate interpretative rigour as far as possible by demonstrating how I achieved my interpretation through the use of quotes and narrative structures but also by checking my interpretation against the perspectives of the participants. Evaluative rigour refers to the ethical and political aspects of the research and I have addressed this by reflexive accounts of my role in the research process.

5.5 Conclusion

In summary, I commenced this chapter by describing the background to the first phase of this study, within the context of the wider Health Status study, and then explained how this led me to make communication barriers the focus of the second phase. I have discussed my rationale for using a participatory approach and explored the practical difficulties associated with this approach. I have also explored the aspirations of empowerment that are associated with a participatory methodology, which mirror my belief in cultural safety, as discussed in Chapter Four. I then described the multi-method approach of group interviews and narrative sessions. I have described some practical difficulties that arose during fieldwork and shown how a reflexive approach has been important in enabling me to recognise when it has been necessary to modify my research goals and adapt my research strategy. Finally I described the analytic process.

In the following chapters I present the results and show how my choice of a participatory approach has been vindicated by the continued enthusiasm and engagement of the Gypsy and Traveller participants. In Chapter Ten I reflect briefly on the research process as a whole, including strengths and limitations.

CHAPTER 6

Phase 1 Results: Relationships between Gypsies' and Travellers' Cultural beliefs, Attitudes and Health Perceptions and their Access to Health Care

Introduction

In Chapter Three I established the need for methodologically sound quantitative research on the health status of Gypsies and Travellers in the British Isles. Qualitative research has also been lacking, concerning the relationship between cultural beliefs, attitudes and perceptions among Gypsies and Travellers and their health and healthcare access. In my view, it was necessary to carry out this research with active Gypsy and Traveller participation, to take account of the factors that they view as important.

The large multi-centre and multi-methods study addressed several research questions related to the health status of Gypsies and Travellers, access to, and provision of services. Gypsies and Travellers reported poorer health on standardised measures than comparable groups of socially disadvantaged inner-city residents, other ethnic minorities and rural residents; the study also found an inverse relationship between health needs and use of health and related services.^{397, 417} The full range of findings from the qualitative arm of the study are reported elsewhere.^{398, 450}

As the full report¹ shows, one finding was that the issue of communication barriers was a very prominent concern. In this chapter, I focus on three inter-related themes which are directly connected with communications processes in relation to health:

- culture and identity
- health beliefs
- barriers to accessing health care services.

I conclude by discussing the ways in which findings in these areas underlined the need for a further stage of research, focusing specifically on underlying communication processes between health staff and Gypsies and Travellers and on the barriers to communication from their respective points of view.

6.1 Culture & Identity

Gypsies and Travellers are not a homogenous group, and there is no suggestion here that their culture is the sole explanation for the way in which they experience health and use health care services. There are many other relevant factors beside individual experience, such as educational opportunities, socioeconomic status and environmental factors. As discussed in Chapter Two, both culture and identity can best be viewed as dynamic rather than static. However, interview responses clearly underlined the importance of Gypsy Travellers' sense of their own ethnic and cultural identity. Below, I illustrate the ways in which these responses reinforced an understanding of ethnicity as identity.⁴⁰ This was particularly striking, as I did not ask specific questions about culture; instead comments about aspects of cultural identity arose spontaneously in the context of descriptions and explanations of health experience. Many of these comments were made in the context of a sense of threat to identity from perceived attempts at assimilation; many also, arose in the course of participants' explanations of the health effects of having a racialised identity. However, Gypsies and Travellers also expressed a strong sense of cultural pride and the need to convey this to Gorgers, in order to increase not only our understanding but also our respect for them as a group. For example in discussing the importance of extended family care, implicit favourable comparisons were made between aspects of Gypsy and Traveller culture and some practices seen as common among Gorgers, such as allowing family members to receive social care from state or private institutions. Comments made in interviews conveyed a distinct sense of the need to inform Gorgers about the many aspects of cultural beliefs and practices that impact on Gypsy and Traveller health care experience.

6.1.1 Identity

Gypsies and Travellers expressed a strong sense of identity and of belonging to a Gypsy or Traveller culture. Although Irish and Scottish Travellers and English Gypsies were interviewed, their common self-identity was as a Gypsy or Traveller i.e. not a Gorger, first and foremost:

FKⁱ : we didn't ask to be born into Travellers. We didn't ask to be brought up this way. It's like my kids, they didn't ask for it, but it's who we are.

ⁱ Each quote is attributed to the interviewee by their unique anonymised identification code. F or M as the first initial denotes male or female. See Appendix K for age and accommodation of interviewees

The respondents who spoke of trying to maintain their identity emphasised the importance of ‘cultural codes of conduct’. The most frequently mentioned ‘rules’ concerning gender roles and sexual behaviour have particular relevance to health and use of health services. Several respondents spoke of more freedom for the younger generation of Travellers; however, certain absolute ‘rules’ were still spoken of, such as the importance of a woman remaining a virgin until married. One young Traveller explained:

FE: but if she was an English girl she is going to have more than one man, that’s her way and up to her...but like a Traveller girl... gets married to the boy.

Gay y Blasco identified a similar emphasis on Gypsy morality; in the case of Gitanos the emphasis on each Gitano person upholding their cultural morality is important for maintaining the difference between Gypsies and non-Gypsies.⁷⁹ This ideal of the Gitano person upholding Gitano morality is viewed as a more essential aspect of their shared ethnic identity than connections with shared territories or shared past history. We see further examples of such cultural codes of conduct and gender roles in sections 6.1.4 and 6.1.5.

Identifying features that define a ‘Traveller way of life’ are seen as important for maintaining the culture and passing it on to children. Some respondents expressed concern that Gypsy and Traveller culture is dying out; this was most commonly attributed to moving into houses with a consequent change in lifestyle:

MA: I started to mix more with Gorgers ... and I seemed to be getting more and more in their way of life than a Traveller’s life.

Several Travellers interviewed were of mixed parentage or had some relatives from the settled community who had ‘married in’. For them, the sense of a separate Traveller identity was as strong as for others: “I’ve had my feet in 2 camps all my life” (FK). There is the sense in which the difference that marks their cultural identity as a Gypsy or Traveller is important, but a simultaneous awareness of being connected to a wider society can also cause conflict for individuals: “she’s sort of pulled 2 ways.” (FI) Some, who felt forced to change their lifestyle as a result of external pressures, faced the added threat of identity loss and a feeling of ‘being outcast.’ There is an

acknowledgment that any culture is dynamic, but this appeared to some respondents to be a threat:

young girls are not allowed to go and mix...you're not allowed to make a mistake like that, ...they're sort of outcasted...They know the rules and regulations. But girls are changing; they're not like they used to be when I first got married. (F9)

It would seem that the perceived assimilation threat from young Gypsies and Travellers being increasingly influenced by the less desirable morals and cultural practices of wider society is also viewed as a threat to their continued acceptance as Gypsies and Travellers. There is therefore a double jeopardy: the threat of being ostracised by their own wider community of Gypsies and Travellers for rejecting the moral aspects of the culture, whilst also retaining a racialised identity and being rejected as Gypsies and Travellers by 'Gorger' society. As we saw in Chapter Two, Barth⁶⁷ and Jenkins^{45a} emphasise the interactional and indefinite nature of identity boundaries. We saw how people can have multiple and fluid identities and choose to emphasise different identities depending on the context of the situation. In the same respect we also saw how boundaries can be strengthened in the face of identity threat. We see examples in this study of the need or desire to strengthen boundaries, thus reinforcing a sense of cohesion as a group:

MD: at the end of the day Travellers are an ethnic minority and we do live in our own way, we do speak our own language...So we should be treated like that...

Yet we also see the risks inherent in the maintenance of a visible, distinct identity, through an increased risk of rejection and discrimination.

6.1.2 Racism and discrimination

The experience of racism and negative stereotyping is pervasive, and automatically anticipated, with many examples given from all areas of life:

FK: It is frightening being a Traveller love, because no-one wants you...if they could, they'd build a hole and they'd shove all the Travellers into it and they'd just bury them all there. If there was no law they would do that.

The depth of mistrust was demonstrated in reactions to unexpected positive treatment: "and then I thought perhaps they're only putting that as a show on" (F1). However,

reactions to the experience of discrimination vary. Some described defensive, hostile reactions, often in expectation of discriminatory treatment, while others showed resourcefulness in overcoming discrimination. There is also despair and impotence at the inability to overcome racism:

FB: oh that's alright then, 'I'm only a Gypsy, I'll come to you when I'm dead' and I put the phone down on 'em.

FK: that was all lies, I only said ... to make them do something.

FJ: makes you feel that no matter what happens, there's nothing you can do about it.

However, the extent of the racism experienced and anticipated in all areas of life results in wide mistrust, often leading to a felt need to hide identity in order to avoid discrimination:

FI: they try and avoid [giving] the address, they try to pretend they're not a Traveller in other words...but it don't make no difference, I think they just look at you and they know who you are.

The expectation of discrimination in encounters outside the community is an added reason for avoiding isolation in houses and instead, strengthening a shared sense of ethnic identity in the face of hostility. Similarly there is avoidance of encounters with unknown 'Gorgers':

MD: we had one neighbour complaining because my dog was barking and the dog was only 6 weeks old, and it wasn't to do with the dog, it was the sheer fact that we were Travellers...so I'd rather be with your own kind of people, you know, people that moves with your life.

This becomes a reinforcing need either for a nomadic existence that affords the opportunity to move on or away from such hostile experiences, or for a more settled existence, surrounded by close members of their own group, that voluntarily excludes them from wider society.

6.1.3 Nomadism

Most of the respondents were living either on sites or in houses at the time of interview, but many expressed a belief that travelling was an essential aspect of their lifestyle. One explained that travel is necessary for economic reasons "to earn the money" but he also expressed the feeling that travelling was a way of life:

MD: ...they can't stay in the same place, do you know what I mean? It's a way of life. It'll never be changed.

Others expressed acute loss at no longer being able to travel and therefore missing the opportunity to transmit that aspect of the culture to their descendents:

FJ: you miss it for the children ...They're kind of losing our culture, the children over it... because it was our proper culture.

The suggestion that travelling is inherent in Gypsy and Traveller life was illustrated by stories of children who had been reared in houses but later readily took to living in a trailer. However, identity is not defined by whether people physically travelled; as we saw in Chapter Two, nomadism is "a state of mind". Like McVeigh, Liegeois makes this point very clearly as he explains that "as a sedentary person remains sedentary even when travelling, the Traveller or Gypsy is a nomad even if he does not travel" ⁴⁵³ (p53). One respondent illustrated this point as she emphasised that her children were Travellers regardless of whether or not they travelled:

FK: these two Gypsy boys [her sons], because they'd never travelled, but they're still Gypsies, they're still travelling boys, you can see that...

Negative aspects of travelling, such as being continually moved on, lack of access to basic facilities and difficulties in accessing services, were also mentioned; these were often reasons given for abandoning the travelling lifestyle for all or much of the time. However, the strong sense of loss for many was evident:

FI: You're just as well stay in the one place and just learn to live every day because there literally is nowhere out there that you can stay and have a week or fortnight and move on again...

In the past when most Gypsies and Travellers still travelled there was regular connection with extended family, but there was also the choice of when to move away:

FE: used to be lovely... it used to be different because you'd get two or three weeks in one place and you'd be with all different families and just nice...

Since nomadism is associated with freedom, the sense of loss of freedom was described as having a profound effect on the Gypsy and Traveller psyche:

FO: because they're used to sort of getting up in the mornings, seeing people all the time. You get up in the morning and you don't do it, they call that lonely. And when you get lonely so you're getting depressed aren't you.

This sense of loss of freedom, combined with relative isolation from extended family support, and compounded by a loss of control over the situation, appears as a crucial factor affecting the emotional health of Gypsies and Travellers. As we saw in Chapter Three, such profound effects on the psyche can also influence physical health.

6.1.4 Kinship – family ties

The importance of close extended family in an otherwise hostile world is a major feature of Gypsy Traveller culture:

FJ: we come from a very big family community love, very big family...And we're all very close.

Respondents spoke in terms of their goal and purpose being to raise their family, and of children being a major, cherished feature of their lives. One respondent expressed the strong sense of purpose in life that having children afforded:

FP: kids are everything to Travellers, that's why they get married for it's to have kids and rear children up

This young mother described vividly the dominant purpose of her life as caring for her children:

FM: I've had my life, I've had what I wanted, five lovely children...it was the children that mattered.

Children are also seen as a motivation to resisting the urge to give in to hardship. Respondents spoke of the children being 'what kept them going' in circumstances that can otherwise leave them devoid of other personal aspirations or ambitions:

FP: when I was growing up I was looking after kids anyway, always looking after kids, if it wasn't my brothers and sisters it was my cousin's kids and friends kids...I don't know what I'd do without them to be honest.

The focus on children's emotional and physical needs, and the warmth and respect shown towards children, were observed both in women and in men during the interviews. Utmost patience and calm were observed with crying babies or toddlers. It was particularly striking that not a single respondent ever suggested any feelings of exasperation or talked about any need for a break from the children, even among those who were depressed or anxious. One respondent explained that having children around her helps her to stay healthy:

FI: being around the children. I think you feel more alert when the children are around you and you've got the courage to go on every day with them...I don't think I'd want to live without them.

Interviews demonstrated a cultural expectation and desire for the family to give support and care to each other - "we look after our own ourself" - although this conflicted with a desire to avoid burdening each other: "my family is there like, but you've got to help yourself."

Gender roles concerning division of labour within the family are clearly understood and are described similarly by Okely.⁶¹ Women saw their roles as being good mothers and it was important to be seen as fulfilling this role. An older respondent described the division of roles between herself and her husband:

FN: Your work's important...and keeps you going... [bringing up family] that was my work...look after them and keep them clean and feed them. He was the reins, to put them in their place and what they had to do and what they did and they listened.

Although not a major focus of this thesis, the above references to clear gendered roles are aspects of Gypsy and Traveller culture that are viewed as important to uphold. It is equally important for health staff to be aware of these values. Since these interviews took place, a Gypsy has written descriptions of gendered roles, included as positive aspects of Gypsy culture under the heading 'The Family', in a cultural resource book for health care staff.⁸⁷ There is a strong role expectation and sense of duty in being a good parent through rearing and protecting children from many anticipated hardships. This respondent, while describing how her children recognise when she is upset, stressed the indications of her success as a good mother:

FM: they [her children] do little things to make me feel ok and that makes me feel good, like I must have been doing a good job.

Respect and deference to older relatives does not appear to diminish as people age:

FN: they'll come to me ... 'what do you think of this Mum, and what do you think of that', and I tells them.

Relatively large average family size facilitates close ties among families through marriage, especially as there is an expressed preference by many for keeping relationships within the Traveller community.

FI: everybody, somewhere along the line has got someone who's married into one family or another. You're tied somewhere along the line.

For some this is a positive feature that means a strong family support network. One respondent spoke of having over one hundred cousins and over two hundred second cousins "and we're all very close." However for others it is more difficult to maintain contact with kin family:

FJ: I like to be with my side as well as his side but sometimes my husband don't do it that way, he wants to be all his side and not my side.

There is an apparent ambivalence about living among a close-knit family, in respect of the need for privacy. This was illustrated by several examples of 'conspiracy of silence' to 'protect' family members from distressing news or to avoid 'being a burden':

MB: I think the family's keeping it quiet, they won't tell me...I'm sure now that there's something wrong.

There is, then, a tension inherent in the lifestyle of many Gypsies and Travellers. A commitment to mutual support within the community of Travellers, versus 'outsiders', may sometimes conflict with the desire for privacy and the perceived risks of sharing personal problems. Together with a suspicion of 'outsiders' and the concerns about discrimination, the tendency to keep worries hidden from family members to 'protect' them can lead to late presentation for medical diagnosis of symptoms with the potential result that medical conditions could have progressed to become more serious.

Ambivalence about the need for privacy is sometimes apparent and difficult for individuals to resolve. For example, in one of my health visiting encounters, a young Traveller woman who was experiencing high stress levels, surrounded by her family in the trailer, announced to the rest of the family that she was going to go out for a walk to be on her own for a while. One of her female cousins immediately offered to go with her. Personal space is a concept that sometimes appears alien to a community in which individuals so rarely experience being alone. This amplifies the loneliness that can result when such isolation becomes forced, for example through having to move into housing. This tension between the need for privacy, in the form of personal space as well as confidentiality, and the closeness of tight knit family support obligations, has particular implications for health care. There can be a conflict between the need for the emotional support required for dealing with ill-health or disturbing symptoms and the confidentiality that may be warranted. Such conflict about attending health consultations with the support of a family member, where there is an extreme health anxiety, can lead to requests for neutral support, such as a trusted family health visitor. The need for privacy, with its implications for health care, requires further elaboration.

6.1.5 Privacy and shame

Privacy was a feature that most interviewees identified as pertaining to their upbringing as Gypsies or Travellers. For one young mother, understanding of the need for privacy was the second thing that came to mind (after religion) when asked what would really make a difference in terms of cultural understanding. In this sense she used the term privacy in the context of embarrassment and shame:

FP: about contraception, and about being pregnant, that's really embarrassing for us, that's like we keep that private for ourselves and find it embarrassing going to the doctors about things like that.

This was emphasised as a cultural feature rather than an individual or age-related trait:

FO: maybe it's just through the way we were brought up, it's our kind of shyness and embarrassment whatever.

References to 'upbringing' related directly to 'cultural codes of conduct' regarding gender roles and expectations, as discussed earlier in terms of moral codes. The secrecy and restrictions on relations with the opposite sex appear to increase the embarrassment.

Liegeois⁴⁵³ and Okely⁸⁷ describe the social rules pertaining to sexuality and sexual relations as being concepts related to pollution or purity. A loss of purity threatens the boundaries between Gypsies and Gorgers and is seen as the basis for this strong socialisation pertaining to codes of conduct. This has implications for levels of ignorance about sexual development and relations with the opposite sex among young Gypsies and Travellers. Many Gypsy and Traveller parents are uncomfortable about school sex education and refuse permission for their children to receive it,⁴⁵⁴ although the rules appear to be more relaxed for boys. One young father, who stayed on at school later than most boys, said he attended sex education lessons:

MD: if I was a girl I wouldn't have done...just that boys will be boys

The children themselves are also socialised to adhere to the social 'rules'. This can extend to girls excluding themselves from this source of embarrassment, despite the more usual adolescent need for group conformity. One mother described how her daughter had reacted to a male teacher giving sex education lesson to her class by just getting up and leaving the class. This example demonstrates the pull of the moral code of shared cultural identity, even when in a minority among Gorger peers. It also demonstrates the strength of the emotion of shame, described appropriately by Scheff⁴⁵⁵ as the 'master emotion'. Scheff and Retzinger⁴⁵⁵ distinguish between the narrow concept of shame in most Western societies - the shame of disgrace and severe emotional pain - and the wider concept, which includes a more positive concept of shame as modesty. This broader concept is more evident in other societies, specifically Aboriginal societies. This concept of cultural shame or shyness is similar to that described by Maori people, as 'whakamaa' and is also described by them as a potential barrier to attending for healthcare and informing doctors about worrying symptoms.⁴⁵⁶ Metge describes whakamaa as meaning shy, embarrassed, uncertain, inadequate, incapable, afraid, hurt, depressed or ashamed.⁴⁵⁵ Gypsies and Travellers also used the concept of shame to cover a similar range of emotions, a broader range than the one more usually associated with shame among Gorgers. Specific connotations of privacy were often referred to in the context of shame. Embarrassment at receiving physical personal care or needing intimate examinations was cited as something to be avoided as far as possible. One female Traveller highlighted the significance of this attitude by dropping her voice to a whisper when describing her need for such care:

FA: and personal things, like, I need washing and stuff.

Poulson ⁴⁵⁷ quotes Lewis in distinguishing between shame and embarrassment:

While shame appears to be an intense and disruptive emotion, embarrassment is clearly less intense and does not involve the disruption of thought and language that shame does (p7)

I suggest that shame is the dominant emotion for many Gypsies and Travellers in situations where embarrassment may be more usual for others, because the situations in which shame is so readily referred to, either explicitly or implicitly, concern the violation of their cultural codes of conduct; a key element of shame according to Lewis. ⁴⁵⁷ Gender roles in division of labour discussed earlier differ in this context; the cultural rules concerning shame and privacy take precedence over the usual 'caring' role of women and are strictly adhered to whenever possible. One woman explained why her father had carried out all the physical care at home for his terminally ill father:

FI: we don't believe in women seeing to men, because men sees to men and women sees to women.

However, she explained that these rules would be relaxed if no alternative family member was available:

me brother always says he's there for me dad and like we're there for me mum, but if anything happened to me brother and me dad did need to look after , then we would look after him ourselves.

No men mentioned privacy in relation to embarrassment. A young Traveller father refuted the idea of embarrassment preventing access to care in the context of a hypothetical sexual problem between married partners:

MD: I'd go straight to the Doctor and I'd tell him, because in my status I'm married you know, so the fact that I had some problem I'd go because of sex with my wife.

However, one Traveller woman spoke for her husband and described his embarrassment at the thought of having nurses wash him as "it's pride." We will see in Chapter Seven, however, that it is considered shameful by men and women for any discussion of

‘women’s matters’ - pregnancy for example - to take place in the presence of men. The strength of this ‘cultural rule’ was noted at one of the health status study feedback sessions, held in a health clinic room. When a ten-year old boy picked up a leaflet showing different stages of foetal growth during gestation and showed it to his mother, she quickly removed it from him saying it was ‘dirty’.

Another aspect of privacy is confidentiality. This aspect, in the context of avoiding gossip, is considered important in respect of impressions formed by others in the community:

FP: you don’t want people knowing your business; your own business is your own business.

This is an important factor in the design of caravan sites. The sites visited for this study, like those with which I’m familiar through my health visiting work, afford no privacy at all. Few site designs allow for families to be together on one site while affording some privacy in not being directly overlooked. However, a degree of close proximity is unavoidable and this helps to explain why some respondents yearned for family sites where unwelcome neighbours could not intrude. This is also a consideration for visits from health care staff, such as health visitors. Any exclusive visit to one particular family is likely to be noticed and the person visited may be concerned at being identified as being in need of a ‘special visit’:

FP: privacy’s the main thing- no one else would know about it.

This fear of gossip regarding confidentiality in accessing services is closely linked to lack of trust in health staff: there is the fear that they may disclose information to others. However, privacy as ‘shame’ was another reason that emerged for keeping certain health matters secret. One mother, describing the prevalence of drug use, explained:

FI: well the ones I know, it’s never talked about. Bury it under the carpet. It’s a shaming thing ‘oh my boy mustn’t do that.’

The wider aspects of privacy and shame will be discussed further in the following chapters in relation to health and communication, but it is important to note the positive way in which Gypsies and Travellers view these beliefs in relation to their moral position in society. At one of the feedback sessions, we were asked a very pertinent

question; why we did not look at the subject of teenage pregnancy. The questioner made the point that if we had done so we would have found that teenage pregnancy in single girls was far less prevalent among Gypsies and Travellers than Gorgers because “we are more strict”.

6.1.6 Cleanliness, appearances, and pollution concerns

The importance of cleanliness and hygiene was much in evidence among the women interviewed in this study. Interviews were often timed to make sure they did not interfere with this daily task. The importance of cleaning was not seen solely as a precaution against pollution or infection, but was also a matter of image and pride, and central to the importance of social relations. In this sense it is closely related to the concept of shame, where failure to fulfil standards or meet cultural expectations of cleanliness is an element of shame.⁴⁵⁴ It was an aspect of how people felt judged by others and an important feature of identity:

FE: you always keep the place always clean, because somebody might come and visit you and it'll all be dirty.

A clean and presentable home also is also a source of pride that counteracts the negative stereotypes of ‘dirty Gypsies’. However, as we will see in Chapter Seven there is indignation that the stereotypes persist in spite of this contradiction.

The centrality of cleaning was emphasised by respondents who mentioned it as an aspect of keeping healthy. One respondent described the consequences of her loss of mobility due to a chronic disabling illness. No longer being able to perform the role of keeping a clean and presentable home was a loss, additional to the loss of mobility per se:

FA: Good health is everything you know ... I was so unlucky, I loved life, I loved life, I love the cleaning, I love the cleaning.

The link between cleaning and health was emphasised in an immediate response by one woman to a question posed about how they or their families stayed healthy:

FL: normal things is it? Clean up. Make sure things is clean and place is clean.

Another explained the importance for her well-being:

FD: like if this place wasn't clean, I'd be depressed.

Such strong concerns about cleanliness relate also to hygiene and are particularly relevant in a health care context. This was evident in one of the findings feedback sessions, when the health visitor brought in a selection of clean coffee mugs. She was questioned closely by one of the Travellers about whether they had been in general circulation and whether they had been scoured clean with bleach. The importance of a clean and hygienic environment was also a factor for a respondent who once needed to go into a women's refuge: "I couldn't cope with it" because it was "scruffy". Such concerns are also relevant to any potential hospital stay. An older Traveller explained her caution about the food she bought and about 'eating out' in relation to hygiene as she criticised television cookery programme showing meat being prepared:

FN: took it straight from the cellophane and dropped it in the pan. And you think to yourself they that does the packing, how many hands do go through them? Eh and they put it straight in the pan!

These findings lend support to Okely's⁶¹ reference to symbolic boundaries when she discusses cleanliness concepts. Although links are made in my study between hygiene and cleanliness, the link between cleanliness and pride in appearances is also apparent, as with an older respondent, who had lost the ability to carry out all her cleaning tasks, but ensured that her home remained presentable:

FN: I'm still able to dust and do, but can't do anything like the windows...I've got good daughters see, she comes down every so often and does a good clean up for me.

The smart décor and cleanliness of all the homes visited for these interviews indicates great pride in presentation. The intimation that presentation is important because people may visit and judge by appearances also extended to physical appearance in the eyes of some respondents. One respondent, whose daughter has a facial deformity, emphasised how well she was accepted outside of the home and included in her list of attributes her acceptability to others:

FM: she takes a lot of care about her appearance, doesn't want to get fat, dresses nice, likes make-up...

Although her child had other disabling symptoms such as severe hearing impairment, this mother exhibited most distress about the implications of choosing to allow her daughter to undergo corrective surgery. Among the factors that most distressed her was "the mind part of it"; her fear that in choosing for her to have the operation, her daughter would think she was 'not accepted':

I just don't want her to think I don't like her the way she is.

The general emphasis on the importance of appearance and presentation appears to be linked to psychological well-being and to feeling acceptable to others:

FE: you'll always make sure to have make-up on and fix yourself because you don't know who you're going to see.

Another mother expressed pride in her daughter but illustrated the importance of appearance, when explaining that her daughter has a particular health problem, although this was not visibly obvious:

FJ: ah she's very pretty though, eh? [to the child] 'Are you a pretty girl? Show the woman your nice eyes.'

The link between dignity and pride and appearance and presentation is important in relation to health care interventions, as illustrated by this respondent who felt that her mother should not have undergone amputation:

RS: I mean she was dying anyway, they could have let her dignity and have a little bit, but to have no feet and no legs ...

This bears out Goffman's arguments about the importance of presentation of 'self' and stigma management in maintaining a social identity.²¹⁴ Physical signs of difference that are seen to stigmatise an individual in effect tarnish their social identity and make them feel less valued. This emotional impact of such responses to visible difference or stigma is compounded by being members of a group that is stigmatised as a whole by society.

Attempts to present an ‘unspoiled’ identity therefore are important for self esteem and feelings of acceptance.

6.1.7 Self-reliance and control

The pride in maintaining appearances, noted above, reinforces the value attached by interviewees to dignity, self-reliance and resilience. To fail to maintain these standards would be consistent with ‘giving in’ or losing control. These traits are seen as arising from experiences of adversity and exclusion, described in recollections of fighting for survival (literally and metaphorically). One woman who was widowed when young and left with eight children under the age of seven explained:

FH: I always had a hard life ...when you have to cope, you have to cope.

In Chapter Three we saw the adverse health effects of lack of autonomy described by Wilkinson.¹⁵⁰ Restricted life choices underlie the need to exercise some degree of control in any given situation. One frequently described hardship was the lack of control over personal destiny, in light of policies that restrict self-determination, and authorities that exclude Gypsies and Travellers in various ways. The sense of powerlessness was a frequent theme that arose in the context of being unable to freely choose a preferred lifestyle. One manifestation was in the belief that succumbing to an imposed or alien way of life and giving up the will to fight as a result, will lead to dire consequences for well-being. We have seen how the loss of freedom from no longer being able to maintain a nomadic lifestyle, in turn leading to isolation from wider family networks, for example, has profound consequences for mental health. The impotence felt about such unequal power relations resulted in despair for some respondents, while others resisted domination and fought hard to achieve some control. One respondent, who talked specifically about “having some control over your life”, explained how her father exercised some control by metaphorically drawing a line when the police failed to compromise and used their power to force him to move on:

FA: if they insisted that we had to move, he’d say ‘well I don’t mind what you do about it old son, but we’re staying here, we’re resting tonight, we’ll be here tomorrow’, because he used to take the cartwheel off....and chuck it in the pond. So we didn’t feel victimised or picked on because, like I say, we used to speak up for ourselves.

General mistrust in wider society reinforces the cultural belief that one should be 'tough' and not 'give in' to difficulties and worries. There were signs of this trait being fostered at an early age. One young Traveller father, who displayed overt affection for his toddler child, simultaneously said to him, with apparent pride, when he fell and banged his head:

MD: you're a tough man aren't you?

A belief in self-employment is another aspect of self-reliance. Families spoke with pride about their men's work ethic and saw it as an absolute priority for boys to learn how to earn their living:

MC: when young Traveller boys, fifteen, sixteen years, they're more interested in learning how to go out and earn a living, whereas at fifteen, sixteen most kids up and down estates are bunking off school ... fifteen, sixteen year old in a house'll get a factory job... whereas when you're a Traveller you've got to learn.

This same father recognised the importance of formal education in addition to practical skills for young Travellers to be able to continue in self-employment. He was aware of the increased need for formal qualifications to be able to compete, particularly in a hostile and discriminatory society where it is felt necessary to hide a Gypsy and Traveller identity to succeed. Men are strongly motivated to provide for their family and they take pride in their independent work ethic. They also try to ensure that their sons follow their example and they compare themselves favourably to settled families in this respect. Okely describes the importance of self employment and how it is part of a Gypsy identity, with a sense of shame attached to the restrictive nature of wage labour and contempt for Gorgers who resort to this form of dependence.⁶¹ A woman with dual heritage, discussing differences between Travellers and settled people, commented:

FE: Travellers are good workers.

There is a favourable attitude to work, whatever the conditions. It is viewed as a character-building opportunity for young men, who are enabled to develop initiative, resourcefulness and motivation as modelled by older Travellers:

FI: the boys more or less learned how to earn a living... because if they was doing a day's work, and the boys with them, they'd say 'come on' and... they'd teach each other what to do and how to do it, so they can always turn their hand to something. And then when they were old enough and got married, thank goodness, they were capable of thinking for themselves.

Self employment allows for greater flexibility to acquire these character building skills, where, as Okely describes, Gypsies and Travellers need to adapt themselves to a variety of circumstances.⁶¹ However, in terms of time, a desire for flexibility to meet obligations can sometimes appear to sit uneasily with an apparent sense of urgency, for example, concerning practical problems. We see in this and later chapters how important it is for families to meet their obligations to each other when a family member is ill or suffering some form of adversity. Time spent with family members is important and events which require family members to change their plans to meet those obligations cannot always be foreseen. The importance of time spent with people and listening is frequently emphasised, particularly with regard to desirable characteristics of health workers. Conversely the sense of urgency for practical matters to be dealt with and lack of time is emphasised in the context of the lives of Travellers. One male Traveller explained this in the context of life on the road:

MC: like, say, in the house, if you've got something wrong with the motor or whatever, you'll just leave it, 'I'll do it tomorrow', but when you're in the caravan it's 'oh I better do that' and you'll go out and do it, you know? What I mean like, you've more go in you.

Keeping busy and therefore not having time was also used as a coping mechanism by not dwelling on adversity: "I ain't got time to complain."

Another aspect of autonomy is the need to be able to demonstrate outward signs of success. Demonstration of success and accomplishment is the reverse of displaying weakness or revealing hardship and appeared to be a means of fighting against adversity and retaining a sense of self-worth. One respondent, after describing how her father became a "different man" [depressed] after he had moved into a house, explained how the need to "keep up with the Jones" with outward signs of success in the form of "tackle and cars and diamonds" could be a motivating and positive aspect of life:

FI: you've got to keep up with the Jones's and I think when you move in a house it takes some of the pressure off ...they've still got ambition and right

nice things but they chill out ...they haven't got anything to prove after a while and I think they just enjoy a laid back lifestyle, cos they're not getting up every day of their life and going out there...haven't got to fight so hard...The ambition was gone and they didn't want to try to keep up with the Jones's or get this and get that. And they just give in.

These comments relating to visible displays of success or 'flash and show' bear out the work by Wilkinson ¹⁵⁶ and by Gilbert ¹⁶⁰ on a desire for self-worth and the sense of inferiority and associated feelings of shame for those who lack such 'status symbols'.

6.1.8 Education

Respondents clearly expressed a sense of disadvantage resulting from non-literacy. 'Form aversion' was frequently mentioned in association with lack of formal education and poor literacy. There is evidence that although an inability to read and write is often regretted, it is also seen as an inevitable aspect of Gypsy or Traveller identity. Embarrassment about explaining poor literacy is accompanied by a fear of being identified as a Traveller and an explanation for avoidance of such situations. This sometimes leads to reluctance to attend new health care settings:

FO: you've got to do all this on forms and or whatever, and say you can't do that, straight away you've got to tell them who you are.

Older respondents explained their lack of opportunity for education as school children due to mobility and also family priorities:

FN: I did go to school but I didn't go much no, because I was the oldest of the family

Older respondents who had received some formal education explained how the family had needed to cease travelling to achieve this opportunity:

FA: then my mother and father got a house. Before that I was travelling and none of us that time knew how to read or write or anything. So I went to school for about 2 or 3 years.

However, one elder suggested that an older Traveller's identity might be questioned if she had been educated:

FB: Mum was educated; though she was real Gypsy she was educated.

This illustrates the perceived threat to the Gypsy and Traveller culture through formal school attendance, also described by Kendall ⁴⁵⁸: the fear that education in school will be a vehicle for the cultural values of the dominant majority to be imposed and therefore threaten their identity.

Younger parents explained some of the existing external barriers, including the frequency of moves, which for many respondents was forced rather than chosen:

MG: so like my kids, they lost a good bit of education...but like when you're doing that all the time and moving, your kids cannot learn to read and write.

For some the difficulty of getting their child into a chosen faith school was another barrier, sometimes seen by respondents as resulting from racial discrimination. The risk of being discriminated against or bullied in school is another major barrier to a school education:

MD: I wouldn't like him to go to school by himself. They'd call him Gypsy this and Gypsy that. If it was a case of him going to school by himself or having a group of Travelling children being taught on the ground, I'd rather have that.

Although school attendance is greater among younger Travellers today than in previous generations, a traditional expectation persists that formal education at secondary level should be abandoned early. ^{454, 459} Nevertheless, exceptions were still considered noteworthy by this respondent in his early twenties:

MD: I went to school till I was twelve ...I suppose I've got the upper hand a little bit because I went to school a bit longer than most of them.

This is slowly changing as parents' attitudes change towards the nature of educational qualifications required for employment in today's society ⁴⁵⁴; we saw this in the previous section on self reliance. This is another example of the dynamic nature of cultural identity and the need for flexibility to adapt to changing circumstances.

6.1.9 Religion

The comfort and strength derived from religious belief and practice was seen as fundamentally important by some interviewees:

FI: everybody prays to the Lord if they need him, don't they?

Religion is an integral part of the life experience of many Travellers, particularly Irish Traveller Catholics and evangelical Christians across all groups. Religious occasions such as baptism, weddings, communions and funerals are also important for maintaining family networks.⁴⁵⁸ Apart from family, religion is the other 'comfort and support' in the lives of many Travellers. Gypsies and Travellers spoke of their strong religious faith helping them to overcome or to cope with ill health:

FP: all of us Travellers are really, really, really big religion but that's what helps us a lot as well. Gets us through things. If someone dies it gets us through, the grief of it. So it helps a lot.

Most Irish Travellers spoke of their strong Catholic upbringing and faith. Some also placed great belief and hope in the 'curing people' and of going to great lengths to travel to see 'holy' people for their intercession.

FK: You know, my father-in-law, he was very ill and he found the curing people helped a lot...that's like that's a part of our religion. That's what we believe in.

The importance of going to pilgrimage shrines such as Lourdes or Knock for healing and a belief by some in faith healers was also emphasised:

FO: if you pray hard enough and like Padre Pio and all the other angels and saints and all the rest and they sometimes things do come true....we do have strong belief in that kind of thing.

Increasingly other Gypsies and Travellers are turning to Evangelism or Pentecostalism ('Light and Life') and find this a support:^{469, 79}

MA: I became a Christian and Jesus put that peace in me. You know, when I'm content I could live on top a mountain. As long as I can get to a meeting, you know what I mean, and fellowship- then I'm content.

Gay y Blasco makes a credible argument that Gypsy Pentecostalism represents a method of transforming the meaning of 'Gypsiness' and that it is important in maintaining their boundaries of difference from the non- Gypsy majority.⁷⁹ However, in

this study views were often polarised and for others, ‘born again Christians’ in particular were sometimes viewed with suspicion:

FI: I know there’s hundreds and hundreds of Travellers turning into these Christians and personally myself, I think they’re hypocrites ...I think they’re clutching at something to try and change their life.

Many interviewees of any religious persuasion felt that their destiny was determined according to ‘God’s will:

FC: if someone was sick you’d pray to God. But I think the way you look at it, if God wants to take them, he’ll take them. You know what I mean. If someone’s dying their number was up.

Religious convictions, in addition to other cultural features above that support a strong sense of identity, hold particular relevance for attitudes towards preventive health care and I now discuss these further in the specific context of beliefs and attitudes towards health care.

6.2 Health Beliefs and Attitudes

6.2.1 Attitudes to illness and health

The WHO definition ⁴⁶⁰ - “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” - appears a remote and unrealistic ideal to many Gypsies and Travellers. There appears to be an acceptance that some degree of ill-health could be expected; one would not be considered to be ‘in poor health’ as a result of one or two complaints. One young Traveller, who described a chronic back problem for which she was regularly seeking treatment, reported that her health was “perfect, really lovely” when asked at the beginning of the interview. Another, older male Traveller (MB) described several health problems but reported his health in terms of being good for his age: “I have a few complaints- not too bad- I’m seventy-one”

Stoical and self-reliant attitudes, described in section 6.1.7 as features of a Gypsy or Traveller’s cultural identity, are particularly evident in relation to managing ill-health,

such as dealing with depression alone in preference to accepting a need for medical help:

LC: you can't just sit and let yourself be depressed. You have to get on and do things. I think 'oh my children, they've lost their father and I have to carry on.

One older man appeared disapproving that Travellers today seemed to be attending more for health problems and commented:

MB: I've seen a lot of them at clinics there and all that, like headaches and pains and aches and all that. I often tells them I often got a bit of a tent in the ground, I'd be wet all over...feel nothing about it.

The fear of being seen as weak or 'lazy' by other members of the community and the consequent risk of 'not being accepted' appears to be a factor in self-reliance and stoicism. One respondent explained that her family were ostracised when they were 'down', but when she 'got on her feet' they got respect. However, for some this predisposition to a belief in stoicism can lead to inner conflict and be as much a pressure as a motivator, particularly, if someone is so depressed that they are simply unable to 'get over it' without help. This respondent expressed some guilt at her judgmental attitude towards a relative who she felt was 'giving in' to depression:

FI: to me she's got a good life. She hasn't got to get up every morning and go out there to work and worry about her living.

The stoical attitude of keeping hardship and suffering to oneself to protect family members can also have distressing psychological consequences. This respondent had kept her suffering to herself for a long time before eventually breaking down and telling her older sister:

FI: I didn't want to put the burden on her, and she's the oldest sister, but we look up to her, she's like a second mum to us.

Such guilt can conflict with acquiescence in the caring 'duties' of relatives. This elderly respondent eventually asked her daughters, who had taken turns to stay and care for her at night, to return home to their young families, explaining:

FN: 'I'm selfish, you go on back, and go to see to your children and that ... I'm all right, if I ain't all right, I got the phone near me' or I said 'I can ring you up or you can ring me up.' So from that love I put a stop to it.

Pride was expressed in concomitant ability to recover quickly and 'get on with life' following an episode of illness or surgery, as shown in the story below, told in order to demonstrate a favourable comparison to Gorgers:

FI: they come round and said, do you need any painkillers now? And I said no, I'm fine and then all the other women was ringing bells and asking for painkillers... I never noticed until one of the women said, 'well you're recovering quicker than what the other women are. And you've had more surgery'...and they seem to think it was because we was Travellers... 'You didn't need all the fuss and all that'...The consultant said ...'you've took the attitude there's something wrong, get it sorted, do what you've got to do and I'm going to get better.'

Although stoicism and self reliance are factors in delayed access to health services, there were also examples of a fatalistic attitude: "I don't think you can stop any ailment" and "there's not a lot I can do, just if it's going to happen, it just happens." However, the need to retain control is also evident in many health care situations, such as fear of drug treatments for depression, connected to a dread of capitulation and dependency.

FR: [if] you can't fight it yourself you're dead, you get worsen. If you just think you haven't got it, just let it go, try and control yourself, it's better.

This attitude is a marked contrast to fatalistic view of causation, described in Chapter Three as symptomatic of an external locus of control. However, we do see more examples of such a fatalistic view in terms of attitudes towards preventive care.

6.2.2 Attitudes to screening and diagnosis

In common with many other communities, there is a fear of the inevitability of a fatal outcome following diagnosis with certain conditions such as cancer; one study found that among some groups it was those with least education who were more likely to hold such beliefs, but locus of control, as discussed in Chapter Three, was also influential:⁴⁶¹

FH: I started screaming, I said no...for the fright, for the shock of hearing it ...because I knew [if I had it] I was going to die right quick.

The common assumption that a diagnosis of cancer is an inevitable death sentence seems to be born out of most respondents' experience. Where there is also a fatalistic belief that 'nothing can be achieved by attending for screening or potential early diagnosis' this can result in more serious outcomes; the view that terminal illness is an inevitable outcome is then reinforced:

FH: I think cancer is one of the biggest fears of Travelling people...I would talk to five thousand Travelling people and [if] the first word is that, anything at all about that they just dies, they just falls to pieces.

A partial explanation for avoiding the opportunity for a diagnosis of cancer appears to be a belief that death will be inevitable, but a view was also expressed that the diagnosis in itself was implicated in a fatal prognosis:

MB: a lot of Travellers blame [it on] if him or her didn't find out they had it, they'd live for another 30 years and all that ...a lot of people going for check ups have found out and when they've found out they've died straight away you know. But if they hadn't gone that's what they'd claim like ...He might live for another 10 or 20 years.

Another Traveller suggested a similar fear as she cited an aunt, a grandfather, a grandmother and two uncles who all had cancer; one of these relatives had died within five days of being diagnosed, thus reinforcing her view. Such fears about cancer often result in late presentation. For example, a woman who had recently attended her doctor and been referred with a possible cancer diagnosis commented:

FI: I've had it [lump] about 12 month now so it's only recently that I went to the Doctor about it.

Strong fears about screening, related to the perceived likelihood of a terminal prognosis, can be understood in the context of more general attitudes towards death and dying.ⁱⁱ Respondents in this study spoke powerfully about death and dying in the context of health care. The grief of bereavement was itself perceived as a cause of illness and often even as an indirect cause of death. One respondent, whose own ill-health commenced a year after her husband's death, attributed the onset of asthma to her bereavement:

ⁱⁱ See qualitative report and paper for fuller description of cultural attitudes to death and dying.^{398,450}

FN: a year from when he died... I was took with asthma, very, very bad...I was a strong and healthy person; I think the cause of his death caused my illness.

Beliefs about the relevance of screening are a major factor in whether preventative measures are seen as a priority:

FN: if God borned you to have a short life, you had a short life; if He borned you to have along life you'd have a long life- nothing you could do to alter it.

Her fatalism reinforced this respondent's perception that nothing could be done to prevent the likelihood of disease such as heart disease, strokes and so on. Even when it was mentioned that some people did exercise or watched what they ate, she felt that such behaviour "doesn't make any difference." A belief in God's will also produced varying views regarding the action of seeking medical intervention. Some respondents believed that certain conditions such as Aids and cancer were "God's will", or felt that:

FD: what I don't know can't hurt me.

For one respondent, whose religious faith was fundamental, trust in God is an alternative to medication:

FK: when I got them depression tablets I took them for a while...and I sat down, I said to Jesus ...and I'm not taking no more tablets because I'm going to trust in you.

However, another respondent, a 'born again Christian,' had a different interpretation of God's will. He explained his commitment to his diabetes self-management:

MA: I've got to do it health wise, otherwise I'm going to kill myself aren't I, and I know God wouldn't want that...God put doctors on this earth didn't he?

Other respondents, who did have a belief in prevention, were motivated by recognition or fear of the health consequences if they did not access advice. As one woman explained, with reference to health advice about blood pressure checks:

FJ: like cos of me having a stroke, it could happen again... I don't want that to happen with five kids.

Less fatalistic respondents expressed a range of attitudes to prevention:

FD: I think of the future very much...I must smoke about 10 fags a day now and I'm 21, what am I going to be like in 20 years, so that's why I'm going to give up [smoking]

Perceptions of the causes of ill-health, as well as of expected outcomes, play an important role in attitudes towards prevention. Although age is a possible factor, in contrast to the avoidance of screening due to fears of prognosis, reported by many respondents, a specific fear of cancer could prompt attendance for screening among people who might not seek screening on other matters:

FE: I'd like that they check you out from head to bottom and they'd know like everything through your system...for all the bad complaints...cancer and all that.

Respondents demonstrated their strength of feeling about screening, whichever view they took, by describing their views as typical of other Gypsies and Travellers. This respondent believed in the merits of cervical screening:

FI: I don't honestly know one woman, say on this ground, that don't go for them...[they] didn't maybe 15 or 20 years ago.

Conversely, and possibly implicitly invoking the cultural moral code of respectability in relation to such intimate procedures to explain her view, another stated:

FP: I don't think any Traveller woman does [go for smears]

6.2.3 Attitudes to health services

As Helman⁷⁰ emphasises, culture is not the only influence on health-related beliefs and behaviour; the context of being a marginalised group in society, in combination with other socioeconomic factors is also relevant. However, the specific beliefs outlined above also have implications for Gypsy and Traveller experience of health care. A society that has demonstrated entrenched and widespread hostility towards Gypsies and Travellers, has contributed to wariness about trust in outsiders. The reality, according to the accounts of most respondents, is that their pervasive experience of racism has a significant adverse effect psychologically, fuelling a general mistrust of settled people,

particularly those in authority. One respondent gave an illustration of an exchange with Gorgers:

FA: “lady, please may we please use your toilet?”-

“No, it’s out of order, you can’t use it”

“I’m pregnant”

“No you still can’t use it” -

Even when you’re pregnant you know? that’s when people put away half the trust that you’d have in people...It’s awful...they make up a hundred excuses, they won’t actually say because you’re a Gypsy...”

The general mistrust of Gorgers in wider society extends to health staff. Many comments about mistrust of health workers related to perceived discriminatory attitudes. One respondent illustrated this in her explanation of the real reason that a particular doctor who misdiagnosed her son’s meningitis is now shunned by other Gypsies and Travellers:

FI: they will not go near him. They don’t like him whatsoever. My husband won’t even go to him and he’ll go and see any doctor, but he will not see him. He said it’s like he’s scared he gets a case of leprosy if he touches yer. He looks at you like that and does not come near you, but he’s about the worst I’ve ever seen.

This has important implications for use of health services. Although several respondents in this study described positive experiences of health services, these were often depicted as exceptions to the norm. Overall expectations were low and often manifested as fears of illness, either in terms of investigations, procedures or treatments. Alternatives to use of primary care services were often mentioned in terms of actual or perceived failings of the services. In the absence of a trusted doctor, some Travellers prefer to confide in a religious healing person, as we saw in section 6.1.9, and some Irish Travellers also spoke of their preference for and experience of consulting specific religious healers or curing people. One explained how her son was cured by a ‘healing woman’ from a ‘scar on the brain’ and was then taken off all medication:

FH: because we believe that Travelling people is cured by healers... anyone seeking help used to ring her [religious healer]...don’t get me wrong , it’s not everybody who can cure you...you could go to one hundred but still make no difference, but you will get the one who can cure you.

Others dismissed this belief:

FD: some Travelling peoples believes in healing men and I don't believe in any of that ... I think if you're sick you should go to the doctors.

Some women deal with their reluctance to attend a doctor for their own health care by using their child's health as a pretext. One mother who needed regular and unpleasant treatment in the form of injections for anaemia admitted her reluctance to attend and explained how she used her child's health in this way:

FJ: when I make an appointment for the baby, I tell the doctor about myself.

There is no avoidance when it comes to fears about a child's health. In such situations, there are desperate attempts to consult a doctor promptly. Stories of other's experiences of misdiagnosis, particularly examples of misdiagnosed meningitis, fuel this urgency:

FR: and my little boy had meningococcus, the dangerous one in the bloodstream. If I had listened to him [doctor] and taken the boy home and lying him down, I wouldn't have him today.

Such stories of misdiagnosis were told to explain mistrust of doctors. Separate accounts of a family member having a child misdiagnosed and then subsequently being found to have meningitis seem disproportionate to the actual prevalence of a relatively rare serious childhood illness. However, when the size of the extended families is considered, the number of people who would be acquainted with or even related to one of the affected children can explain the extent of this fear. Whereas we have seen that fears about the possibility of fatal prognosis can sometimes be a deterrent to an adult Gypsy or Traveller seeking help, the paramount concern for the welfare of the children above their own wellbeing would seem to override that reluctance when it comes to parents seeking health care on their behalf. Nevertheless the underlying fear explains the sense of urgency when seeking an appointment for a child. Fears about a fatal prognosis expressed by respondents in this study were often based on experience and they compound a fear of hospitals:

FI: I think they've got this old fashioned stigma that you're not going to come out once you go in.

However, such fears also reflect a deep-rooted lack of trust in the staff concerned. Many respondents knew of a 'close other' or had themselves experienced an apparent medical mishap and these experiences underline pre-existing mistrust:

FB: there's more they could do with this hip, but my aunt, she had one hip done and was mental after she had the other one done...they gave her too much anaesthetic.

Hence, the mother who was worried about her daughter undergoing an anaesthetic explained: "because so many little kids is dying through anaesthetics" (F14). This mother explained that she had given her daughter breakfast on the morning of a planned dental extraction under anaesthetic, adding "and I shouldn't have." The doctor had to postpone the procedure as a result, but he recognised her fear and spent time reassuring her. She elaborated:

FK: he said 'what if I do it in a proper theatre; I promise you and I give you my word he said, that she will be in and out in 15 minutes'...When he was doing it then I knew [it would be alright] and I said to my husband, and my husband doesn't trust like I do and I said to him, and he was nearly crying, and I said, 'she's fine.'

Lack of accurate information available to assist in weighing the risks of such relatively rare mistakes is an important factor in decisions about accessing care. In some circumstances the collective beliefs and perceptions within the family or community appears to override a need to challenge or seek an independent view or understanding. This is sometimes reinforced by a fear of displaying ignorance to health staff. Reluctance to seek a medical opinion is also evident in fears relating to reported side-effects from medication. This woman described her anecdotal knowledge of the side-effects of a particular medication:

FH: but I heard that you can get a stroke from that, can't you, from the tablets, from the side effects, so I wouldn't go on them.

The reluctance to access services until urgent is seen as unavoidable, and the low expectations of health service providers is strongly associated with mistrust. One of the most frequently cited reasons for satisfaction with a health worker is that they 'understand Travellers' or know their personal or family history. This appears to be a

strong factor in the more overt trust invested in health visitors. In cases where someone has demonstrated trustworthiness and shown respect for Gypsies and Travellers the trust and respect is reciprocated: “when you find somebody good you appreciate it.” (FI)

As with news of ‘bad’ doctors, news of a good doctor or health worker spreads rapidly. As an example, I was told a story of one father who, grateful for a locum doctor’s prompt diagnosis and treatment of his child, recommended everyone to go to him. The doctor was compelled to ask him to stop, because his list was growing so large that he couldn’t cope with the demand. However, the trust invested in staff who have demonstrated their worth also comes with high expectations and demands of that person. Even for those who have chosen to stay with a practitioner the doubts are ever present:

MG: it’s just that you check, you check everything. That’s just the ways I am, check everything, all medication, even for myself.

It would seem that as long as society in general is experienced as hostile to Gypsies and Travellers and appears to support discriminatory policies towards them, it will be difficult for them to build trusting relationships with any non-Travellers, including health workers. Any apparently trusting relationship will nearly always be tested and cannot be assumed.

6.2.4. Lay referral, help seeking behaviour and family care

In addition to mistrust, beliefs in self-reliance and family or community support may be explanatory factors for a reluctance to seek professional medical advice. One woman, often approached by younger women for advice on various matters, including health, explained her father’s views on independence and self-reliance:

FK: if any of us pick up assistance [welfare] it will be worse for us, good Gypsies are good foragers.

Although she was keen to impart advice she also had reservations about the possible effects of creating dependency. She explained her concern in terms of being seen as an advisor on all matters:

[women would say] ‘ah I’ll take it to ‘Y’, ah yes, don’t understand it, don’t want to, [respondent to me] but what about when ‘Y’’s not there? ...you can spoon feed the people sometimes, you know.

She described a few situations where she advised both women and men on health matters. Her advice was mainly in favour of natural or ‘mind over matter’ treatment and she actively dissuaded people from using prescribed medicines. She was keen to point out that she advised them to check with their doctors:

if those pills aren’t absolutely necessary , talk to your doctor first, but get yourself off them if you can, because you’ve got far too many pills up there.

However, in advising her own son she was unconcerned with seeking a doctor’s approval and was very definite in dismissing medical advice to use a prescribed inhaler after he told her he had been diagnosed with asthma:

I said to my son ‘baloney, you’re full of toxins...cos you’ve laid rough...you’ve got to get to bed, get water down you, proper food down you , you’re going to be alright son’...So I wondered, she’s trying to keep herself in a frigging job. My boy hasn’t got asthma!

This response underlines her basic mistrust of health staff and such mistrust, is likely to be a strong factor in the preference for advice from trusted others and for family members to deter their relatives from seeking professional help unnecessarily. As we saw in Chapter Three, there are various factors that determine whether or when someone will seek medical advice and these triggers are closely linked to beliefs about what constitutes illhealth and the consequences of the symptoms- experienced or anticipated.⁴⁶³ Several Travellers spoke of consulting their mothers about whether to see a doctor. One woman described her action when asked who she would talk to if should she discover ‘a lump’:

FP: My mum...I’d show it to her, say ‘what do you think they are? And if she says,’ no harm, but go to the hospital’, we listen to that. But then by the time we’re there the sweat’s falling off us

Friedson⁴⁶⁴ described the process of help-seeking behaviour as the ‘lay referral system’, referring to the extensive network of family and other informal confidants that may be

approached before any decision is taken to seek professional help. This process is described as typical among Gypsies and Travellers:

FO: say someone was out somewhere and met somebody and if they had problem, the women will talk and they will tell you what's wrong with them and that. It's been hundreds of times, been said to me. 'I don't know where this is coming from' or 'I wouldn't know what to do about it and I'm ashamed to this' ...and so you would tell them and then probably the other person would say, 'you should do such a thing, you should go to the doctors.'

The lay referral system is the most common alternative to use of health services for treatment. One elderly Traveller man who had been describing some of the natural remedies that Travellers used to use, spoke of how this was common practice in the past:

MB: In Travelling groups, if one woman didn't know what to do with the child, like the next one would tell her try this, try that.

Although natural remedies were not reported to be in common use today, there is evidence of self reliance in conjunction with lay advice in the form of self-treatment. One young Traveller spoke of self-diagnosis and of using lay advice to obtain the treatment that she deemed appropriate from her own experience, without consulting a doctor, reporting this as common practice.

FD: I thought it were a kidney infection, but I just said to someone, have you got antibiotics?

The same respondent also used lay advice to confirm her own suspicion that her daughter had chicken pox, but then ignored subsequent advice, explaining her need for further reassurance:

there was a rash, but it had heads on them, so I thought straight away it was chicken pox. I brought her down to some of the women, I said 'look, I'm going to bring her to the hospital and they said, there's no need, it's only chicken pox, there's nothing they can give you. I said, no, I'll bring her, for me own peace of mind.

However, she also spoke of going against her own intuition by accepting and trusting her mother's advice about her daughter's dental care.

I'm not giving her them antibiotics any more because of her teeth. Mum said, they're only her first teeth; she'll have more, just carry on giving it to her. I said 'alright', I'm very easily led.

This readiness to go against her intuition shows a marked contrast in levels of trust to that invested in health professionals. However the need for privacy, discussed earlier in section 6.1.5, has a greater influence for some and militates against seeking lay advice, even from family, especially for matters pertaining to sexual or reproductive health. One young Traveller mother when asked replied:

FP: not really to be honest. If it's personal, it's like that's personal, you don't want everybody knowing your business.

As we saw in section 6.1.8, practical reasons, such as illiteracy, are another explanation for using lay advice.

FH: there's a good friend of mine, comes up here very often...and if I go the doctors, if I get a new tablet that I know I haven't been on for a while, I have never been on, well I'll get the leaflet out and I'll get her to read it to me, and to read the side-effects what's on it.

This is also related to lack of trust; we see further examples of lack of trust in prescribing behaviour of doctors in the following chapter.

There were fewer reports of men seeking health advice at all. One man who was asked what sort of advice he might give to a mate who was depressed said:

MD: there's not a lot I could do, I shouldn't imagine that like one of my mates would come to me about that sort of thing.

He explained that men were more likely to keep such matters to themselves, or at best turn to their family, but commented that if they were bad enough to need a doctor he would probably notice and tell their brothers, or would proactively advise them to seek help. One young woman explained this in terms of the cultural concept of shame as discussed earlier (see section 6.1.5).

FC: Men are just...they wouldn't go to the doctors or anything. They'd be ashamed.

The reticence among Gypsy and Traveller men to seek even lay health advice is a concern that one of our Gypsy advisory group members, Richard O'Neill, recognised and has sought to address by producing a leaflet aimed specifically at Gypsy and Traveller men.⁴⁶⁵

General mistrust in the wider society reinforces belief in the importance of mutual family support. Respondents spoke with pride of providing for and caring for their own family members and of putting their welfare, particularly the children's, before all other priorities. The cultural expectation that as far as possible the family should care for sick members means that care at home is the preferred alternative to any form of day care. Practical help in the form of aids and equipment is acceptable but not substitute carers:

FI: my grandfather needed help for a bath and that. They wouldn't have home help. They looked after him. We don't believe in home help...and me Dad used to carry him upstairs to the bathroom, bath him, dress him, and bring him back.

The idea of a relative going into residential social care is particularly deplored. One respondent explained why her husband immediately drove several miles to remove his mother instantly from a care home on discovering that his sister had placed her there for temporary respite:

FB: she was used to somebody every night sitting chatting to her, but she was in a room and had the door locked.

The benefits for family members, who can trust that loving and supportive family will care for them in ill health and adversity, are balanced by costs from the increased burden on carers, many of whom receive no outside support. This woman had cared for her mother at home despite her doctor's view and that of a specialist that she needed to be in hospital for psychiatric care:

FK: I had never been apart from my mother...my mother got worse when she thought I was going to leave [to get married] and when she thought I was going to stay she got better and when I was about to leave she got worse again...But I soon joined up with her again when I was married.

We see that mistrust in wider society further reinforces a belief in the importance of self-reliance and mutual family support. Twin beliefs in self-reliance and stoicism in the

face of ill-health, combined with mistrust and low expectations of health staff, contribute to delayed access to health services. Lack of awareness and understanding of these beliefs and attitudes on the part of health staff are factors that contribute to poor communication and create barriers to service access.

6.3 Communication and encounters with health staff

Many Travellers reported the experiences of close others and described the profound effects on their own expectations and decisions. However, the data presented here relate to first-hand accounts. Most Gypsies and Travellers were interviewed in locations where there was specialist health visitor provision and in this respect their experience is not universal. However, many also had experience of living in areas where this service was not available and so were able to relate alternative experiences. Health staff behaviours, and most importantly, communication difficulties, were the factors that most influenced Travellers' impressions of their health care experience.

Communication difficulties with health professionals results in many respondents being unclear about their actual diagnoses and sometimes about the potential significance of their conditions. One man described having been in hospital for:

MB: a big needle through my back into my kidneys and liver. I still don't know what's wrong...everything's working out right now so far.

This limited information and understanding may help to explain some of the variability attached to significance of a diagnosed condition and the greater weight attached to manifest symptoms. In some cases, extreme anxiety can lead to angry and hostile styles of communication which in turn can lead to staff resentment. Despite an emphasis on communication in professional staff training, as described in Chapter Four, a cycle of communication breakdown can ensue:

FB: my husband he went completely mad, that was his baby and he was going to kill the doctor. Honestly he lost his temper. This other doctor came in and calmed him down and that and she was in there 14 days. But this specialist came and said why don't you just go home. 'If we go home, we take the baby home'. He said 'why don't you Gypsies get your own doctor.'

There were no reports that such misunderstandings arising from communication difficulties are explored or even fully realised. Health workers may believe that their explanations are understood, but as one Traveller explained:

MB: they told me, but I wouldn't know; they did [explain] but I didn't understand.

Many Gypsies and Travellers, particularly older people, described the effects of a lack of formal education in relation to access to health care. Lack of familiarity with the vocabulary and fears about inability to communicate are major concerns:

FD: I don't open up to a lot of people...I'm not a very good communicator.

This is associated with a lack of confidence about communication and a fear of being ridiculed for their ignorance of health matters or for expressing particular concerns:

FD: I wouldn't go to the doctor now about anything like that [sexual or maternal health matters]...Because they think I'm a fool [that] I don't know about them things.

These are good examples of Foucault's notion of the power of medical discourse where the doctor is in control through the power of legitimate knowledge as discussed in Chapter Four.^{278; 375}

Some unspoken fears give rise to conflicting views between the patient and doctor about the perceived relevance or urgency for a consultation. One respondent, anxious about her amenorrhoea explained her anxiety:

FJ: cos I was a bit worried about not seeing them [periods] because I thought it go up to your head and that was probably causing the headaches ...I was getting worried about it when I didn't see them, but I've seen them now.

Poor communication in consultations can also give rise to misunderstanding about prescribed treatment and the purpose and appropriate use of medication. There is evident need for health professionals to be aware of the importance of eliciting the accuracy of the Gypsy or Traveller understanding about their diagnosis, the implications and advice, as there is with other patients from minority ethnic groups. As we saw in

Chapter Four, several authors have identified the need for cultural understanding and competence to avoid communication difficulties and an ethnocentric misuse of power with patients from minority ethnic groups.^{375; 377; 378; 394; 466}

6.3.1. Health visitor advocacy role

A family member is often brought to an appointment in order to assist communication, but this can also be inhibiting. One Traveller spoke of withholding information from her doctor because of her family's presence:

FJ: when I got to the hospitals and all that with my family around me I would never say I'm a [diagnosis] or anything like that.

For many, the specialist health visitors working specifically with Gypsies and Travellers are preferred advocates, and often viewed as a back up to the doctor. These trusted health visitors are relied upon to translate the medical discourse into everyday understanding.

FH: if I go to the doctor and he tells me there is anything wrong and I'll ring [health visitor] and I'll ask her.

Interviews indicated that it was cultural understanding, in particular, that helped to engender trust in, and reliance on specialist health visitors:

FP: it's so easy to talk to her [dedicated health visitor for Travellers] because she understands how Travellers go. She understands everything about them...you can talk to; you can sit down and you can have a conversation with her and really confide in her, which you can't with most people.

Health visitors also assist access by instilling self-confidence:

FA: we always embarrassed to go to the doctor...you know a conversation with someone, it's embarrassing. She's taught us...to have your say, you know? You're entitled to a doctor like everyone else.

The varied nature of the support expected and provided by a dedicated health visitor for Travellers in this study usually exceeded a traditional health visiting role; in addition to their advocacy role between the client and other health professionals, this included

making and reminding about appointments, and outreach clinical work more usually associated with a practice nurse. This can pose a dilemma in resource limited NHS service provision, but in the relative absence of culturally sensitive service provision and given the low level of confidence in accessing services, this extended role is often necessary in order to avoid delayed presentation with potential harmful consequences.

6.3.2 Staff awareness of cultural factors

As described in section 6.2.2 respondents often attribute their non-attendance for cervical screening appointments, and also for early antenatal appointments, to embarrassment.

FP: I've only ever had two smears and I would never get another...it's very personal ... you see Traveller women don't like strange people looking at their private parts whatever.

Indirect communication is often the preferred way to deal with private matters within their own families:

FO: I tell them in different ways, I don't come right out with it...well you're hinting and that sort of thing.

Direct questioning about embarrassing or sensitive issues from health staff can inhibit further communication. It was remarked that, rather than admit their embarrassment in a consultation, some respondents would stoically sit through it but would simply make a decision not to return:

FO: if it's a male doctor I wouldn't say nothing, put up with it and just fly out of the door...make sure I didn't go back again.

The felt need to keep private matters to oneself can prove detrimental. One respondent spoke of an occasion when she had attempted suicide and had been referred to a psychiatric nurse. She made the comment about the nurse, saying, "she couldn't understand why I was suffering with it [depression]." Yet on exploring this in the interview it transpired that she had not felt able to explain to the nurse that she had been experiencing domestic violence. Domestic violence remains a taboo subject within

communities, as would be expected with the emphasis on presenting appearances and avoiding negative judgment. One of the women explains:

FI: one particular woman, I know she's got a terrible husband and her life is not what she makes out for it to be, but she will not have it said that it's any other way and she'll say I'm fed up with this and I'll say, what is it, have you been arguing or something? 'Oh no, no, I haven't been arguing.

However the same respondent felt able to mention her own daughter's experience of domestic violence ("he used to beat her to death") and was ambivalent in whether she as a mother was 'doing her daughter any favours' by cushioning her and making life easier by allowing her to leave him and come home or whether this was giving her a false sense of security "that she knows there's always somebody there and that isn't always true." The sense of needing to foster self-reliance in a hostile and hard world is very much to the fore in this account as in others, where it is mentioned that parents won't always be there. Such attitudes further reduce the likelihood of bringing abuse to the attention of health staff, except where a trusting relationship has been developed.

Desirable characteristics of health staff were frequently mentioned, and the demonstration of cultural sensitivity, whilst granting the same respect to Gypsies and Travellers as to other patients, featured most emphatically. Many supported the idea of a separate dedicated service, based on their experience of culturally competent specialist health visitors, in order to achieve this desired outcome. There were numerous examples of health staff, and doctors in particular, who failed to 'listen' or to take them or a family member seriously. We saw in Chapter Four how easily people from minority cultures identified negative attitudes from non-verbal communication.

FK: they don't listen to you, they tell you what they feel....it's like you are there, but in their eyes you're not there.

Doctors who do listen are much appreciated:

FK: he was very good like that he listened ...he just wanted to listen. I explained all that to him and he examined me...

Many spoke of lack of confidence in the doctors for their failure to examine them (or their child) as they attached great importance to 'being checked over.' It is also

important for doctors to be convincing in their diagnosis. One Traveller was particularly unimpressed with her doctor who thought her child's rash was due to chicken pox:

FD: She didn't tell me, she said I think it is, which is different... she was a divvyⁱⁱⁱ I think

6.3.3 Continuity and GP registration

One reason cited for satisfaction with a health worker is their knowledge of a patient's personal or family history. This instils confidence. A need to reveal personal details and risk misunderstanding or discrimination from an unknown health professional is an obvious deterrent to seeing a new doctor:

FM: well like I've just told you and you understood, but they [others who don't understand Travellers] would think 'oh isn't she thick.' So I'd not be bothered with them. Let them think that and I'll not bother.

This desire to return to a trusted doctor is also connected with a fear that a new doctor would not have the information available to treat them appropriately. Great lengths are taken to ensure continuity of care:

FI: Her mum has been all over the country and no matter where she's been, if she had an appointment with that hospital she'd drive all the way back, even if she had to live with relatives or book in bed and breakfast... She won't take them to any doctor; they stick with the one that they know.

Although it is usual for Gypsy Travellers to carry and use their pre-school children's health records, only one respondent with chronic ill-health mentioned self-held records in the context of travelling:

FJ: got all me records; I've even got the papers where they've got me scanned.

This may not be of such importance for those who always return to a trusted doctor, but this is not always possible. Many expressed concerns that doctors would not have their records available if they needed to be seen elsewhere and were only temporarily registered. This importance attached to records and to continuity was given as an explanation for it being easier to be healthy if living in a house:

ⁱⁱⁱ 'Divvy' is a regional colloquialism meaning fool or idiot

FO: if you were travelling and you were going in all different places...how would a doctor know about you?...whereas at least if you are in house your doctor, like my doctor's got all my records.

There is also a lack of trust that information would be passed on safely between hospitals. One respondent explained why she continued to return to a London hospital for her child's appointments rather than accept an offer of transfer to a local hospital:

FD: I'm afraid, because I think, like all these tests that they've got all on paper at their hospital, I think they'll get lost and she won't get seen properly.

Apart from a conscious desire to travel to a known and trusted doctor, there are considerable practical difficulties encountered in trying to re-register in a new area. One respondent (FM), when asked about the greatest obstacle to Travellers being healthy, replied "to get signed on with a doctor." There was a consensus that it was more difficult to obtain health care when travelling.

FF: if you've no fixed abode, they'll no register you.

However, one respondent commented that this had not always been her experience and that in the past a Traveller could:

FF: just walk into any doctor's and tell them you're just moving around...but that was about 20 odd years ago...there's a lot of doctors now won't see you temporarily.

Some Travellers who are not continually travelling and have a local permanent address adapt by effectively having a local temporary GP, whilst permanently registered with a GP elsewhere, and choosing which to go to according to their needs. There were several accounts of 'getting around the system', knowing that a permanent address is required:

FI: it took em nearly 12 months to be registered because you used to go in and fill in a form and say temporary or if they filled in temporary they might not be accepted. So what they'd do was, I'd say I'm over with my cousins and I'm having a week here, just so the doctor would see em while they was here.

One housed respondent, who stated that she had no trouble in registering with a doctor, mentioned the importance of understanding the system, citing her aunt's difficulty in getting any doctor to register without intervention from the specialist health visitor. Several respondents described being seen as temporary residents, but more often, only for specific minor immediate needs. For chronic conditions or anything considered serious enough, there is a general preference to return to a GP with whom they are registered and with whom they have built a trusting rapport.

6.3.4 Discrimination and racism

Cultural insensitivity, whether arising from ignorance or from racist attitudes, was a strong feature in accounts of compromised communication:

FI: you can tell by their attitude, they don't look you in the eye, it's just sort of 'what's the problem'...they do palm you off the minute they find out you're Travellers.

Racism was also blamed for failure to obtain services, with several experiences reported of inability to get registered with GPs. Certain hospitals were named as being discriminatory towards Travellers, as illustrated by this respondent:

FF: the x hospital, they're not interested in Travellers.

Discrimination is not always overt, but excuses are readily recognised. One Traveller described a typical scenario where she would be asked for her address and be told 'oh well the doctor's busy he can't see you'. She explained:

FR: we've got it so many times through the years ...it's got to be [an excuse]

Receptionists acting as gatekeepers were often described as showing particularly hostile or unsympathetic attitudes:

FI: the receptionists are harder to get past. They're not nice I think they're doing the doctor a favour ...keeping you away from him- 'I did something good today, I kept the Gypsies away.'

The overriding need is to be treated equally. It was deemed sufficiently uncommon to be worth mentioning when respondents felt that they had not been subject to

discrimination. Positive comments about treatment were sometimes qualified by the explanation that they were treated the same as other people:

FI: they were very good, they never treated you no different from nobody else.

The pervasive experience of racist and hostile attitudes results in anticipation of such treatment. One expectant mother advised that her expected baby was going to be born with spina bifida, was offered a termination of pregnancy but reacted with suspicion (her baby was subsequently born in a healthy state without the condition):

FK: but I think myself it was they wanted to take my life in their hands and get rid of the baby...my husband was with me and he really did lose it... But the way I looked at it, it was because I was Traveller, just less Travellers born to, just abort it and sterilise her and that's it.

Defensive and hostile behaviour from respondents is a common reaction to the experience of actual or suspected discrimination. One woman, who suspected that her doctor was being dismissive and patronising towards when giving her tablets that he said 'would make her feel better', described her response:

FI: so I picked them up and threw them back at him and I said, I don't want your tablets ...you're a waste of time, I've been coming her for months, getting worse and you won't even examine me, you don't have the faintest idea what's the matter with me.

Such deep distrust, arising from negative experiences of being demonised by virtue of a Gypsy or Traveller identity, is difficult to surmount and is a crucial factor in communication with health staff. We see many examples of strong aggressive reactions to such experiences, and such reactions are recognised as common responses to the emotions of shame and humiliation which discrimination can engender.⁴⁶⁷ These important features of communication between Gypsies and Travellers and health staff are explored in the second phase of the study and discussed further in the following chapters.

Gypsies and Travellers also acknowledge that their behaviour is often based on the anticipation of problems, and is sometimes calculated to ensure that treatment is obtained:

FF: they just wouldn't accept us because we were not registered and we had to kick up a fuss at the desk to try and get her seen.

Many avoid the perceived risk of delayed or sub-optimum care, especially for a sick child, by going directly to Accident and Emergency departments. Here they can still encounter barriers:

FI: She had a virus through her body and I took her to the hospital and they wouldn't see her. They told me to fetch her back to her own GP and I told him that our own GP is in x town and it was like a 3-hour journey to get back ...I said straight, because I lost my temper, it's all because we're a Gypsy, that's why you won't see my child. ...They didn't see her so I had to take her to another hospital.

6.3.5 Lack of knowledge & understanding among Gypsies and Travellers

Lack of prior knowledge, about the body in general, medical conditions, prevention of ill-health and related health matters, influence the likelihood for attendance for health care. Illiteracy was frequently mentioned as a handicap in this respect:

FP: if you don't read and write it's difficult to get information.

Much information about health and health services is readily available to a literate population in the form of leaflets, notices and posters, articles in popular magazines and in newspapers and increasingly via the internet. None of these routes are available to large numbers of Gypsies and Travellers who were unable to avail of a formal education. Instead, there were two main sources of information: information handed down or deliberately sought from family or peers in the community, and the television:

FC: just learnt it for myself, picked it up from the old people, from me great grandparents and me own mother and father.

Stories in the media often create fear in the absence of alternative information. However, in some cases personal experience compensated for lack of formal knowledge:

FP: when you rear four kids you know when they're really, really unwell.

For others, however, lack of knowledge increased the fear factor and this had a considerable negative impact. One man described his initial fearful reaction to the diagnosis of diabetes:

MA: I thought it was a very serious illness...[I was afraid] that me leg would fall off, that I'd lose me eyesight, you know you hear all these kinds of things.

As we saw in section 6.2.1, fears and perceptions are influenced by stories of others' experiences. Decisions made on others' experiences are common in other situations, for example, reluctance to attend school because of the parent's or older siblings experiences of bullying when they were at school.⁴⁵⁴ Imagined fears, unless informed by clear explanation from health professionals, can influence the extent to which respondents continue to suffer symptoms rather than opt for possible investigations or treatments. One woman declined an investigation because of her mother's account of the procedure:

FJ: They take away a piece of your gut. My mum was often telling me it was a very severe test, so I didn't really want to have it done...

Unintended cultural insensitivity in explanations of procedures can make a situation worse through incorrect assumptions of Gypsy and Travellers' understanding. One respondent spoke of her distress and embarrassment at an antenatal hospital appointment:

FD: the woman said to me 'do you want an AIDS test, HIV whatever. I said 'no love'...I felt like, insulted ...So she said are you sure, what do you call it routine, 'no love I don't need one, I've only ever been with me husband'...I got really upset with the woman; I didn't have one anyway.

Lack of knowledge and reluctance to seek explanations resulted in some respondents enduring ill-health or, in the case of one woman who feared blood transfusions, receiving unpleasant alternative treatments.

FJ: he [doctor] wants me go up and get a blood transfusion ...I wouldn't go for one...I'm frightened of the AIDS and all that ...I have the iron injections every second day , eleven of them.

6.3.6 Appointment systems

Appointment systems are viewed as problematic in several respects. One respondent's explanation for a children's health clinic being held on her site instead of at the local GP surgery was:

FK: because Gypsies have had a problem about making appointments, keeping it and waiting in surgery.

By getting to know the doctor and developing confidence in him at the site clinic visits this particular respondent eventually trusted him enough to consult him about herself and then felt able to take up his suggestion of making an appointment to see him at his surgery – something that she had previously avoided.

Many respondents stated a preference for avoiding or delaying an approach to a clinic or practice, rather than making an appointment and then failing to keep it. The majority of respondents spoke of making conscientious efforts to keep appointments that they had sought for themselves. One elderly respondent explained:

FN: I don't let he down and he wouldn't let me down I don't think... I don't miss cos I think to myself, when he was waiting for me and I'd had an argument with myself saying he's neglecting somebody else, and I wouldn't do that.

Unsolicited appointments for cervical smears or other undesirable procedures are less likely to be kept. This would be a particular concern for GPs, conscious of needing to meet Government targets. One respondent avoided having to miss antenatal appointments and then explain her absence by consciously avoiding notification of her pregnancy:

FK: I just kept away until I was perhaps six months. They'd say where have you been?

Common with many other patients, the major concerns expressed about appointments were the unacceptable delay if there was serious concern about a child, and the practical obstacles, or lack of confidence for some, in feeling able to make an appointment. These concerns are relative to the perceptions of urgency which in turn have been shown to be heightened in areas of socioeconomic deprivation. There are multiple factors which

trigger a consultation, ⁴⁶⁸:⁴⁶⁹ but no conclusion has been reached to explain differences in perceptions of medical urgency. ⁴⁶⁹ As we saw in section 6.2.1 there is much greater concern and perception of medical urgency amongst Gypsies and Travellers in respect of children. Close knowledge and experience of serious ill-health in other children appears to be a crucial factor in seeking urgent appointments.

In contrast, the busy, hardworking lives of women were often mentioned as an explanation for their non-attendance at GP surgery or at hospital appointments. One mother explained why she never kept her referral appointment for a scan:

FK: time went so quick, when you have kids you haven't got enough hours in the day, the time goes so fast. I still do suffer with my side.

These pressures can reduce the likelihood of attendance in the context of priorities in busy lives. This respondent did keep her appointment but explained:

FL: they keep you, you're there for hours...it's hours and hours waiting around.

However, some respondents spoke of the importance that they attached to certain appointments. One spoke of her profound distress due to a housing officer's failure to keep an appointment with her and therefore delaying her and causing her to miss an antenatal appointment:

FF: I got up at about half past eight and I had an appointment at the hospital for twelve o'clock which I never miss, my antenatal appointments and I sat there a full day waiting and she never came and that put me in a bad depression, I went mental...I was shouting, I was angry, I didn't want anybody around me I just wanted to be on my own...

Women portray men as being most reluctant to wait for appointments:

FP: they don't like having to wait in a queue and sit and listen.

Time may be the factor here, but others factors, such as embarrassment, may be equally valid explanations. One respondent explained the difference it made when his psychiatrist gave him time:

MG: he was all in a rush at you , the doctor GP , but she talks slow and gives you time to think, there's no rushing you.

Fear is an added explanation for the urgency sometimes exhibited when an appointment is sought. This fear is intensified when it is a child that requires medical attention. One respondent explained her reason for going to a hospital emergency department rather than wait in a "walk in and walk out centre":

FI: you would have had to wait a long time and we would have had to wait about seven to ten hours...it was quite long enough and she was burning up and being sick.

When a child's health is at stake absolute priority is given in respect of time and urgency, in contrast to the lack of time priority for their own health needs. One mother explained how she was prepared to wait and insist on her child being treated even though the hospital staff felt that his case wasn't urgent and were going to send him home to return the next day:

FR: if you have to see to a sicker kid, go ahead I said, I won't stop you ...[could have waited if it was matter of life and death] , but I'm telling you [he] is not well , it's just when you're ready, I said, look at him ... We will sleep on the floor, we don't mind, get the business done.

Prior experience of time being crucial to the prompt diagnosis and treatment emphasises this urgency. One mother who had experienced a near fatal delay in diagnosis of meningitis in her sick child stated:

FA: I imagine every minute counts when a baby's not well because you don't know what it could be.

6.4 Conclusion

This chapter has shown that Gypsies and Travellers express a strong sense of ethnic identity. This supports the model of identity as including self-ascriptive aspects, as described by Barth⁶⁷, as well as the specific cultural dimensions discussed by Okely⁶¹ and Smith⁸⁸ in Chapter Two. The experience of a society that demonstrates widespread hostility towards them, and has done for many generations, strengthens the belief among

Gypsies and Travellers that they should be wary, and slow to invest their trust in outsiders, until convinced otherwise. General mistrust in wider society further reinforces a belief in the importance of self-reliance and mutual family support.

Poor access to education, with resulting low literacy levels, further compromises formal communication for many. These factors, combined with contact with some services in which there is poor cultural awareness, result in reluctance to engage with services and in difficulties on all sides when engagement becomes necessary. When encounters with wider society are necessary, many interviewees reported a pattern of defensive and hostile communication with Gorgers, in anticipation of experiencing racist or discriminatory behaviour.

There are specific cultural beliefs that have implications for health, for instance, in terms of concepts of hygiene, pollution and privacy. The combination of denial of symptoms, delayed presentation and reluctance to accept outside support has consequences for the lack of early intervention for both physical and psychological ill-health. We have seen in Chapter Three, how health inequalities can be compounded by such psychosocial effects related to social exclusion, as discussed by Wilkinson.¹⁵⁰ Many of the potential misunderstandings about the health-related behaviour of Gypsies and Travellers; for example, apparently inappropriate use of emergency services, refusal of investigations, missed appointments, and failure to accept referrals, might be avoided with increased awareness and proactive reassurance and explanations. For various reasons, often related to extended mistrust of Gorgers generally, Gypsies and Travellers in this chapter demonstrated low expectations and poor experience of standard health service provision.

Mutual misunderstandings resulting from poor communication were major factors in barriers to effective access to health care. Ginnety²⁴⁵ has also emphasised problems of communication and misunderstandings that arise between health care staff and patients from a different culture; poor literacy and embarrassment at admitting to this, the heightened importance of verbal information, listening, and a 'proper' examination. Although certain aspects of communication between patients and health care staff are universal aspirations of a health care system and desired by all patients, as discussed in Chapter Four, some specific communication problems and lack of sensitivity to culture are strongly endorsed in this study population and are mediated through cultural factors. It is suggested by Burkitt Wright et al,³⁴⁰ in their study of communication of trust, care

and respect in breast cancer, that research on communication should focus on what patients need rather than what professionals think they need.

Other studies have focused on patient satisfaction and patient-physician communication among different cultural groups,^{334,472} although these have mainly taken place in North America and have focused primarily on hospital staff relationships with patients. There has been no previous research that focuses on Gypsies' and Travellers' and health staff experience of culturally specific communication barriers to gain an understanding of the underlying communication process. The following chapters describe the findings from the next stage of the study that sought to remedy this deficit with the ultimate aim of moving towards improved patient experience and health outcomes for Gypsies and Travellers.

CHAPTER 7

Phase 2 Results: Communication with health staff.

Gypsy and Traveller perspective

Introduction

This chapter presents the findings from the focus group sessions with the different groups of Gypsies and Travellers in both Medham and Norville. In Chapter Six I demonstrated the ways in which issues of culture, identity and discrimination affect relationships between Gypsies and Travellers and health services. Here, I move on to address specific themes concerning communications processes and barriers.

Through an approach drawing on IPA analysis (discussed in Chapter Five), I aim to present below the experience of the participants from their perspective. Inevitably this is an interpretive exercise; the result is a co-construction between the observer and the observed. To avoid repetition I have omitted phrases such as 'I found that...', 'analysis revealed that...', 'further investigation demonstrates...', 'my interpretation of this is...'. However, I have taken care not to go beyond the evidence in my choice of themes and interpretation of them. The feedback sessions at preliminary and interim stages enabled me to check specific interpretations. The results presented here are several stages removed from the raw data, as described in Chapter Five, but quotations from the transcription are used to illustrate the findings.

Some common themes emerged in both phases of research: for example, references to trust, respect and self-reliance in health care contexts. Where findings from focus groups directly supported those from the phase one interviews, I have illustrated this briefly. Below, I start with confirmation and elaboration of these existing themes, with specific reference to communication. I then explore new insights and perspectives on existing themes, and these are discussed in more depth. Finally, I include new themes identified in phase two, such as cultural competence and responses to feedback about health staff perceptions.

7.1 Trust: confirmation of existing themes

Phase Two findings confirm the various meanings and manifestations of trust or distrust in the context of the lived experiences of Gypsies and Travellers.

7.1.1 Anxiety and Access to health care

Trust is seen as a fundamental feature of a good relationship with any health care staff member but Gypsies and Travellers concurred that they found it hard to trust. Every respondent indicated in some way a difficulty in being able to, trust Gorgers generally, and this was as much a feature of encounters in health care situations as elsewhere.

EL: Let me tell you something. I've been here 12 years and it's took a long time for me to gain trust.

Lack of confidence or trust in the doctor's ability, combined with fear of difficulty in communication are common reasons for reticence in seeking health care, in addition to fears about the potential diagnosis. By the time a Gypsy or Traveller has decided to attend a doctor the underlying fear that has finally triggered the delayed consultation and lack of trust that they will be taken seriously compound a sense of urgency:

EL: At one point I got very, very, very worried and because I was losing an awful lot of weight. Couldn't eat, couldn't sleep and my mind wouldn't shut down. My mind was ticking 24/7 and I went in really into nothing. And I'm not really fat now but I went into nothing altogether. So I went to doctor Q... I said look, I says, I need, I want, I says, blood test, I says and I want it, I says, as quick as possible.

Respondents recognised the effects of their anxiety on staff as they confirmed the need to seek out trusted doctors who could communicate in terms that they understood and who understood them.

SB: Because when you go into a doctor's surgery you get that panicky because you don't, you're not going to understand what they're saying to yerand that's...

MA: "And you talk at 90 miles an hour... You try and get everything in at once because you're frit in case you can't say it properly to let them understand.

We see in these two examples how anxiety about the possibility of a life-threatening diagnosis can be compounded by anxiety about the consultation process and can cause internal conflict about how soon the former anxiety outweighs the latter so that there is an imperative to attend.

Another reason, often given for avoiding health care from professionals was the wish not to waste the doctor's time. This was sometimes portrayed as an altruistic wish to make sure more needy patients weren't denied at their expense.

MA: Because I think people like who's in car crashes and fires or just little kids like who was really ill, are more important than my broken foot.

However there appears to be an internal dialogue here, where the respondent accuses herself of not being genuinely ill or deserving of a doctor's time. Often there was implied concern about appearing to waste a doctor's time and how this might be perceived in the eyes of peers: seemingly weak or indulgent behaviour. This self-judgement reflects a low degree of self-value. The concern with the views of others and with self-worth is discussed later in relation to shame and to self-reliance.

7.1.2 Diagnostic certainty

Generally, the degree of trust placed in a doctor or nurse was referred to in the context of clinical competence. Doubts about clinical competence were sometimes reinforced by specific uses of language by health staff. There was an agreement among several Gypsy and Traveller patients about the misunderstanding that can occur over phrases such as 'I think it is' when diagnosing a patient. This can reinforce mistrust in their competence and fuel anxiety. There is a very high expectation of what a good doctor should be able to do, leaving little room for doubt or 'differential diagnosis.'

MS: she said to me 'They think it's gastro enteritis' ...

TO: But when they said 'they think' you know in your mind it's not.

EL: If I took one of my grandchildren to the doctor and he says to me, "Do you think" . I'd say 'what are you getting paid for that you think, you either know or you don't know.'

In discussing this finding at a feedback session VT explained the anxiety and fear behind the need for certainty in diagnosis:

when you go to a professional who is paid to tell you what's wrong with you then you don't want 'I think,' ...I get 'I think' from me mam. When there's an illness, it is sort of instant, bang. You need to know what it is.

This does not necessarily suggest that Gypsies and Travellers have unrealistic expectations of an instant diagnosis in all situations. What it does suggest is that uncertainty is not tolerated as a final outcome of a consultation, that is, without resorting to further tests to obtain a certain diagnosis. This leads to a questioning of what it is about a doctor's expertise that makes their knowledge superior if they cannot show confidence in their own diagnosis. Lack of trust, combined with desire for certainty, features in other forms of misunderstanding with GPs. Two Travellers agreed that they found it a contradiction to be asked by a GP: 'What's the problem?'

KM: He's a doctor. Do you ever see a doctor and they say what's the problem?
'Yes well what's your problem?'

EL: He's the doctor. He's the professional isn't he? He should know if you tell him all the symptoms.

Their explanation indicates that they perceive this question literally, and as a sign of the doctor's doubt or lack of certainty; they possibly feel burdened by the apparent responsibility of having to make a judgement and therefore 'do the doctor's job.' There was an apparent lack of appreciation that the doctor may be seeking to understand underlying fears in order to give reassurance, or that the doctor may be seeking the patient's experience and history to inform a diagnosis. The reality of the interpretation of the question 'what's the problem?' is that it fuels the mistrust in the doctor's competence and erodes any hope of concordance. Doctors argue in Phase Two focus groups that Gypsies and Travellers often come in with fixed ideas of what's wrong and what they need and cannot be reasoned with.

So, although the doctor is expected to be an 'all knowing' expert, he or she is also doubted unless the patient's own suspicions are confirmed. This has implications for the overall NHS policy direction promoting patient choice and dialogue with patients in consultations. For Gypsies and Travellers, it would appear that there is some conflict between promotion of patient autonomy and the requirements of empathic cultural

sensitivity. Empowering Gypsy and Traveller patients to share decision-making may not always be taking their perspective into consideration in a culturally sensitive manner; this may require considerable time in the context of a continuous relationship.

The need for proof of competence and respect was far less evident where there was a longstanding trusted relationship, as with the culturally-competent health visitor referred to below, working exclusively with Gypsies and Travellers. There was apparently unquestioning faith in her suggested treatment for a child's problem:

MA: I told [Health Visitor] ages ago and she said, "Maybe he's having too much milk", so now he don't have milk. He hasn't had milk since, and I told them that and that must be a good six months ago. And he don't really have milk now, only like on cereal and stuff.

The lack of a precise diagnosis was not seen as a cause for doubt, and trust did not seem lessened by the apparent lack of improvement resulting from her suggested intervention.

And he don't even have that that much, but it's still the same.

Similarly, a trusted doctor who proved that he 'cared' through empathic behaviour was not required to demonstrate that he deserved trust by carrying out an examination:

TL: That doctor, he's a nice doctor. But he doesn't examine you. You just go and he'll just say well I feel this, and tell me how you're feeling he says.

The need for proof, in the absence of such trusting relationships, relates to past experience. There were many stories of past errors of diagnosis, prescribing, and treatment and these were by no means always first hand; the collective experience of other Gypsies and Travellers was readily taken into account. Reliance on second-hand experience is a problem as there is no guarantee that the experiences they are relating to have any close correspondence with their situation, either in terms of presenting symptoms or possible outcomes. However, this can be seen in the context of cultural folk memory and tales as guidelines for living in a Gorgger world, as they amplify the perceived dangers of trust in interaction with Gorggers.

EL: Ulcer busted. And they were treating him for different things completely... septicaemia set in and poisoned his whole system.

MA: person I know who lives on the site, a young woman, she had a little baby

and the baby was bad .She took the baby to the doctors and he give a prescription. When she got the prescription, the chemist...asked her how old the baby was and she told him and he said 'if you give that baby one spoonful of that medicine it will kill it', it could kill the baby.... It was the wrong medicine that he prescribed the child.

A diagnosis made on history or observation would be deemed as suspect, with much greater proof expected as confirmation.

EL: You should tell them you want an x-ray. Say you want an x-ray on your chest. You could have a bad heart.

One of the signs that Gypsies and Travellers look for in assessing a GP's competence in diagnosis is whether he examines them.

MS: You know if they examine you I think that reassures you. I mean I, like, some of them won't take your blood pressure or nothing. They'll just guess and then you come out and you say well how does he know? he never examined me.

This need for proof of diagnostic competency was very clear in the reactions of separate groups of participants to a Traveller's story of her doctor having told her that he thought her child's rash was chickenpox:

MS: Yes, but he should have looked more and instead of saying "I think" he should have made sure, shouldn't he? I mean 'I think', ain't no good is it?

TO: He should have just have tried a bit harder to give her a bit more peace of mind.

MA: He should have said 'Well, I'm not sure but we'll do some tests just to make sure...'

TO: '...I'm not sure but it looks like it but if you bring the child ...'

KM: Well a Doctor, in my opinion if he thinks there's a rash like that, he's not sure, he should say 'look, admit her to the hospital, maybe it's nothing but, to be sure I'll send her there.

EL: Yeah. Just for a check-up.

Past experience of serious illness within extended families, such as meningitis in children, can play a part in the urgent need for evidence of competency. Health staff may not necessarily be aware of these shared perceptions:

MS: I mean for all she knows she wasn't sure it was chicken pox, therefore it could have been meningitis; it could have been anything ...

Group discussion revealed a feeling that most health practitioners do not understand the very real fears of Gypsies and Travellers; concerning children, people are particularly anxious that they won't be taken seriously:

MS: You're constantly being told you're over protective.

Therefore, there is an added need for continuity, with the underlying expectation that only a trusted doctor, who knows or understands Gypsies and Travellers, will appreciate this background. This has particular implications for practice organisation and for the 'trusted' doctor concerned. We saw in Chapter Six how Gypsies and Traveller can overwhelm a 'trusted' doctor by all seeking to see him or her exclusively. Not only does this overwhelm that doctor and present organisation issues relating to workload, but it places him 'on a pedestal' that in reality can be very precarious; once he makes an error, that trust could disintegrate.

7.1.3 Respect

In addition to concerns about clinical competence, trust was found to be dependent on the level of confidence in the doctor, nurse or health staff member as people.

Confidence is typically inspired by a display of humanity and empathy.

EL: To me I could sit and I could tell her every problem that I had, and she sits and listens.

JL: I go to see the nurse. I have to have my blood check every three months ...

TL: Yeah. She's nice.

JL: She laughs and jokes and she is very, very friendly.

One of the essential features associated with health staff who were liked and appreciated was a sense of respect for the Gypsy or Traveller individual. This feeling is seen as a crucial prerequisite for investment of trust.

MA: Some doctors is nice and they talk to you civil, even if they don't give you the right answers that you want to hear, they still talk to you civil and treat you with respect but others don't and if they make you feel like that big then you won't ask them anything.

Gypsy and Traveller participants gave many examples of situations where they felt that they were disregarded, judged or unwanted, by some members of all staff groups.

MA: Judged and intimidated. You felt like that. You felt like they [unknown generic health visitors] was gonna take the child off you, and you weren't clean enough for 'em....

JP: Because I don't like the attitude of the receptionists, they like look down at you like you're dirt.

There is an acute sense that as Gypsies or Travellers they often feel they are viewed with contempt rather than respect. This is illustrated by the way one respondent infers her GP's view of her:

KM: I call him dog doctor.

These responses reinforce the points made in Chapter Four concerning the way in which the collective experience of discrimination can render marginalised groups hypersensitive to negative attitudes and signals of insult and disrespect. I suggest that this experience underlies Gypsy and Traveller defensive attitudes of mistrust.

7.1.4 Discrimination & prejudice

As we also saw in Chapter Six, Gypsies and Travellers attributed many of their bad experiences of apparent clinical incompetence to prejudice and discrimination.

TL: They don't properly look at you, do they, the doctors, when they find you're a Traveller?

Discussion of the narratives raised the issue as to whether some experiences of incompetence were possibly just examples of poor clinical practice. There was general agreement that not all cases of incompetence were down to discrimination:

MS: There is some bad doctors, aren't there.

PVC: That are bad with everybody, not just because you're Gypsies and Travellers?

MS: Yeah, yeah, And there is some that just don't like Travellers.

Equally however, there was consensus that discrimination was still a common explanation:

MA: It is the Travellers with him, because I've been in there before and he says to me 'you haven't got to come into the surgery, you haven't got to come, just ring up and tell the symptoms over the phone and I'll leave it outside in the box.'

This interpretation is understandable in the context of common experiences of discrimination, prejudice and hostility in everyday life.

VT: You should hear beauty salons impressions of Gypsy culture believe me, especially if you're sat there having something done.

There is also an awareness and sensitivity to being stereotyped, blamed or held responsible for the actions of others, by association due to their identity, regardless of individual behaviour:

MS: I've been here 6 year ... I get on with my neighbours really well. There was Travellers down here... and when they went like some of the people from down the street come and they was telling me! ... they [neighbours] were saying, 'have you seen the mess that your kind of people have left down there and I kept saying 'yes but it ain't me is it ?' I ain't put that mess down there, you know? Some people still class you the same as others..."

Group loyalty does not prevent participants from condemning any inappropriate behaviour among other Gypsies and Travellers: "the Travellers was ignorant." In the feedback sessions there was a tendency for participants to be highly critical of negative behaviour by other Gypsies, which led to further discussion about how the attitudes of Gypsies and Travellers themselves could influence outcome:

VT: Yeah but I mean, anytime that ... health care person, has any contact with Travellers, that's going to be going on in the back of their head. Which to be honest with you, there isn't much justification for it but you don't know what was going through the [Traveller] woman's head.

There was a sense of feeling torn between group loyalty and a wish to distance themselves from 'undesirable' Gypsies or Travellers who are 'giving us a bad name':

MA: Yes because we're ashamed of some Travellers ourself and think, God look at the state of them, they're giving us a bad name . Cos some of them are really a state but then, and you, especially if any of them's in the area what's a state , then you're ashamed to sit up and say 'oh I'm a Traveller' cos then they think that you're a state like them ones.

This perception of being discriminated against on the basis of the specific stereotyped behaviour of some Gypsies and Travellers risks a reinforcing of the stereotype at the expense of responding to or recognising the deeper causes of prejudice and racism towards Gypsies and Travellers as a group. The personal risks and costs of attempting to challenge such stereotypes, and instead concurring but alluding to 'a few bad apples,' also serves to increase divisions among Gypsies and Travellers in what Wilkinson described as the bicycling reaction ¹⁵⁶ (see Chapter Three).

The pervasive experience of negative prejudice and discrimination compounds the feeling of low worth in the eyes of the wider population, including health staff. This is a facet of shame which I explore later. The need for trust and the required demonstration of acceptance are particularly important for a group who perceive that they are the most marginalised in society as a whole.

JL: I'm going to say something now. I'm not racist, what I'm going to say, right. You take Sikhs, Pakis, Indians right, them Asians, all nationalities. A Gypsy is the lowest one of them all, and I don't know if we come under race relations...I was going to say if you happen to call a dark fellow a black so and so,

KM: You'd be done for discrimination again yeah

JL: You're straight up, right, but they can call you whatever they want and there's nowt else said about it.

This response to the experience of marginalisation appears to show a propensity for similar stereotypical attitudes towards other minority groups. In this example, JL is not expressing hostility towards these other groups, but he goes on to give an example of discrimination towards Gypsies and Travellers by other minority groups. That is, he describes how "Asian people...a lot of Sikh Indians, Sikhs, Pakis, the lot" petitioned successfully to get rid of the car park site where Gypsies and Travellers had been camping when there were no official sites. So we can see here another example of the bicycling reaction ¹⁵³, where dominance relations result in those who are marginalised seeking to assert some superiority to increase their status over those perceived as more

vulnerable. Rather than identifying with others who are also marginalised, there is increased likelihood of inter-minority racism.

7.2 Self-reliance and avoidance of health staff encounters

Past experiences of fatal outcomes of health care experiences are circulated and well known by Gypsies and Travellers and so the consequences of having misplaced trust can feel life-threatening and enormous. This is a context for self-reliance, in which Gypsies and Travellers take pride and portray as a cultural trait arising from adversity. However whereas self-reliance can be a response to marginalisation it can also contribute to, or further that experience. The characteristics of self-reliance and of resourcefulness are apparent in some of the strategies employed for meeting health needs. As we saw in Chapter Six, if symptoms are minor and therefore not causing great distress or disruption there is a tendency among adult Gypsies and Travellers to avoid trying to see a doctor about their own health, as opposed to their children's, for as long as necessary. However, a self-reliant attitude to health problems, combined with mistrust, can also result in late presentation and inappropriate self-treatment:

KM: I said I had to be very bad even though ...I must take three weeks before I went did I? But then I had to go for it was getting worse.

Discussing the concern expressed by some health staff about following up a diagnosis with appropriate advice on management, VT offers an explanation:

They've got what they've come for- 'You've a busy man, thank you very much, I'm off now and I can look after myself once I know what's wrong with me. I can go and ask me Uncle' ...

Although many Gypsies and Travellers have poor literacy, there is still reliance on the written word in medication leaflets, particularly when mistrust leads them to assume that the doctor may have little time or even inclination to discuss possible side-effects. They will often ask for someone to read the medication leaflets before taking the prescribed medication. Health staff may construe failure to take medication as 'non-compliance' rather than as the result of fear, mistrust or failure to discuss discrepancies between instructions from the doctor and the written warnings in the leaflets:

AP: he [doctor] said, "Did you take the full course?" I said, "No, that's because they made me bad." I said, "It says in the leaflet if it's making you bad don't take 'em." I was following the leaflet, and he was telling me the opposite.

When possible, other routes to health care, such as a chemist, will be used for minor symptoms, particularly if advice or specific 'over the counter' remedies are sought:

AP: If you're really in pain and you can't see what's wrong with you, then you would go to the doctor, but if you've got a rash and you can see it and you can show someone it, then, well I'd go to the chemist then and I'd say, 'look I've got this rash. What do you think it is?' he'd probably give me some cream straight away for it...

Chemists are often preferred; partly because there is no long wait for an appointment, and partly because the chemist is seen as someone who will give time and read the medication information leaflets. Narrative examples showed that chemists were seen as accepting: there was not the experience of discrimination or of ridicule for lack of knowledge that collective experience often led Gypsies and Travellers to expect from doctors:

EL: I went to the chemist in x town and they're very, very, very nice people in there. Very, very, understanding, civil. So I asked them ...I says 'can you tell me' I says 'what I can take and I can't take with this' and he read it to me. He just explained to me.

NHS Direct is also increasingly being used for similar reasons: carefully explained practical advice. However, an added reason for using alternative services such as NHS Direct is that Gypsies and Travellers, in common with other patients, are sometimes directed there when they try to obtain a home visit from a GP:

TO: I mean I have tried to get the doctor out before and they told me to phone up that 'direct thing.'

Although other groups of patients may react with annoyance or may not mind this suggested alternative, we can see how Gypsies and Travellers, in light of their previous experiences, are more likely to perceive this suggestion as another example of exclusion.

7.2.1 Strategies to obtain required health care

Interviews and group discussions provided examples of subtle ways of ensuring access to trusted health staff. NHS structures and rules about registration are not allowed to get in the way of GP continuity if a family needs to move out of the practice area and there is knowledge of the need to give a local address. LG's Gorgers friend, invited to her house during the focus group, explains "JP keeps her doctor and uses her mum's address."

Often, the alternative chosen strategy for getting seen urgently by a doctor is to go directly to the Accident and Emergency department "Normally if it's really bad you go to the hospital" (VT). For those living on sites who have no other option because they cannot obtain a home visit this becomes a necessity:

KM: I never, never see the emergency doctor coming on our site. They won't come.

EL: A doctor should treat everybody equal... Why will they not come on the caravan site? You mention that you're on a caravan site and he says 'no we don't do that.'

Gypsies and Travellers are aware of their lack of appropriate language skills to convey their needs; they recognise that middle-class, educated 'Gorgers' know how to say the right things to get seen:

VT: ...as a Travelling woman ringing up and you're saying 'I want me child seen, I want me child seen.' ... You don't have the words to say 'I know that's it's policy that if it's a baby then she's gets priority' A receptionist is going to react better to a nice polite woman on the end of the phone...

EL: Yes, but Travelling people don't understand the words.

There is evidence for the perception that it easier for middle-class patients to access health care because of their superior health literacy and greater confidence and ability to articulate their needs. Le Grand et al identify the interaction of health beliefs and health literacy skills as important factors in differential service use between middle-class and poor people.⁴⁷³

Some Gypsies and Travellers therefore work out their own tactics to get seen, although these are sometimes recognised and then resented by health staff. One common way to

gain confidence in the face of anticipated refusal or discrimination is to go accompanied. There is an added advantage that by speaking to each other in their own language they can help each other without being understood:

TO: like I say we're still go in pairs or whatever, and we... can still talk under us breath and we can be in that surgery right next to them and can still be talking under your breath and they ain't got no idea ...

MA: We can have a full conversation in that surgery for her to tell what I wanted to say to the doctor and they won't [know]...

Whereas this is a useful tactic to gain peer support, it demonstrates an existing mistrust on the part of Gypsies and Travellers, while simultaneously decreasing the opportunity for creating conditions conducive to building trust. Although the practice of solidarity and mutual support has been explained as a cultural characteristic, it was suggested in focus groups that this can also be used tactically at times as a last resort by some Gypsies and Travellers to intimidate or force health staff to meet their needs:

TO: Like when me Dad was in hospital there was about 30 or 40 of us down there, down in the hospital. But we was trying to be right, we was in the waiting room. And one had walked down and asked the questions and come back like that but then when we wasn't getting no [answers] ...we let our uncle and he started, you know what I mean., wanting to know.

Although there is some attempt to do things the 'right way' rather than use tactics to get information about a relative in hospital, there is evident sympathy here with a need to resort to "starting" [becoming challenging] because it is not until then that they get results:

MS: But he did keep starting didn't he? ...

MA: Yeah but sometimes when you do be right, you don't get no answers sometimes you think well...

MS: Yes I was just going to say but I will admit, although he started, we was getting, you know they were coming back with feedback to us, letting us know different things, you know. Before we were just like waiting.

In comments like these, such tactics are presented as a necessity to get services that others would possibly get without effort. Such experience often led to a tactical approach in anticipation rather than as a last resort:

TO: Yeah. There will be one in the background with the one what's trying to get, say an appointment and if they're saying no, other one'll kick off ... and get a bit louder and that one will just intimidate that one so you'll get it [an appointment].

This can result in the very opposite of what Gypsies and Travellers are really seeking i.e. respect and understanding from staff. Paradoxically, the tactics resorted to in anticipation of, or reaction to, perceived discrimination often intensify existing mistrust and apprehension on the part of health staff. Staff also anticipate trouble and then everyone's negative expectations and stereotypes are realised and reinforced. LG also shows the importance of initial impressions and how they set the scene for interaction in such encounters:

LG: When you go, you've got your guard up. Cos you don't know how they're gonna, you know, speak to you... If they speak to you nice well you speak nice back. But if they're nasty to you, well straightaway your back's up and you're defending yourself. Because you've always had that... you've always defended yourself. And nobody listens to you, and we're always in the wrong. Even when we're in the right we're in the wrong. And I, you know, even my parents, they...it's like you haven't got a voice.

Anticipated discrimination, combined with fear of the consequences of delay in receiving attention for a sick child, is portrayed as grounds for going to any lengths in demands to be seen. In response to a narrative vignette about a mother who experienced delayed access to health care for her sick child, another mother commented:

AP: I wouldn't have waited that length of time. I would have waited like a practical time, right. If they never bother I would go to the desk... I would have went in straight to where the doctors is. You know the little table. I like would have sit on that and put my child on it and insist on them to see her and whatever...And that would have been the top and bottom of the story and I would have told them... if it had come to the push I'd bring the police to them. And if they asked me what's you ringing the police for I'd say for discrimination, honestly I would, and I take it up then to the highest board as possible.

This type of language and other examples such as "I would have screamed the place down" were often used to emphasise strength of feeling and a sense of injustice that should be recognised, rather than necessarily a literal account of planned behaviour. However, there were many reports of angry outbursts, when the costs were disregarded:

MA: I'm a very shamed person but when it comes to me child and I know there's something wrong with them well then I won't, I'll just fight and fight till I get.

I explore the significance of such angry outbursts in the context of shame in Chapter Nine, but I will elaborate now on the study findings concerning identity and shame.

7.3 Elaboration on the importance of identity and shame

The importance of the views of others towards Gypsies and Travellers was emphasised during discussions. Shame is a term frequently used to describe emotions ranging from embarrassment to humiliation. Gypsies and Travellers often used the Romany translation 'ladged' to describe exactly what they mean by shame. There are many different facets of shame and different cultural and gendered contexts in which it is featured. As shown in Chapter Six, a sense of shame in the context of privacy is viewed as a cultural attribute. Pride is identified as another cultural attribute and loss of face or humiliation in this context is an important aspect of shame. I describe the findings concerned with shame briefly below but develop the arguments for their relevance and implications in Chapter Nine.

7.3.1 Shame: devalued identity

I have explored how a failure to diagnose accurately or perceive real concerns is often seen by Gypsies and Travellers as a sign of disregard or disrespect. Low expectations of respect and lack of trust were often apparent in the suggested explanations for Gypsy and Traveller actions in the narratives that were discussed. There is a strong feeling, seen also in Chapter Six, that delays in getting appointments are inevitable and largely, if not always, due to discrimination. Although some shared examples could have been misconstrued as discrimination by the participants, they also gave unambiguous examples, such as indirect refusal to register them:

EL: And I went up to see could I get registered there...they filled in all the forms and all, everything. The very minute that we give them our address they said, 'we're full up.'

Being disbelieved by health staff is seen as further evidence of disrespect, supporting the belief that a Gypsy or Traveller identity, along with its associated stereotypes, is at the root of the problem.

MA: He [doctor] starts to think you're telling lies because you want to put him in hospital, cos you don't want to look after him.

This felt lack of respect leads to Gypsies and Travellers feeling that they are worthless in the eyes of health staff, reinforcing a heightened sensitivity and low expectations:

KM: You can feel the vibe. You can feel that ...their attitude, towards you.

EL: It's like you going into a place and you know. You can feel straight away if you're wanted in that place or if you're not.... Look at you, like you've a hundred heads.

The feeling of being unvalued appears to be internalised as part of the experience of having a Gypsy or Traveller identity:

VT: If you get receptionists that's not willing to give you an appointment, it sort of opens the door for you feeling not wanted.

Such feelings can compromise meaningful engagement with health staff. There is a fundamental feeling of being 'different' by virtue of their Gypsy or Traveller identity. MS shows this underlying feeling of alienation as a Traveller as she describes neighbours who she gets on with:

MS: You can't connect properly because there's always 'you're a Traveller' and they're a Gorger. No matter how you try, your language is different to theirs, all the time.

The strength of the common divide between Gypsies and Travellers and 'others' is illustrated by this account from a Gypsy participant who has developed a trusting friendship with a 'Gorger'

JP:.... if you said to me ten year ago, "Well I've a friend, a Gorger person as a friend," [...], have somebody in your house, a Gorger as a friend, I'd have said, "No." I've told X this before, she won't be insulted at what I'm gonna say- "all that Gorgers are good for are earning some money out of!" Today, and I told all

the Travellers, “No, you’re wrong, you can have Gorger people as friends, and they can become close friends.” [...] But Travellers has also got to learn that...

JP’s comment that ‘Travellers have to learn’ is relevant to the creation of mutual trust. The fact that this research took place at all in this format was also recognition on the part of Gypsy and Traveller participants that effective communication is a two-way process and cannot be tackled from only one perspective. A willingness to see beyond stereotypes and long-held patterns of interaction, and to recognise people as individuals, is helpful in this challenge.

7.3.2 Shame as humiliation

A particular cause of distress for Gypsies and Travellers is in being ‘shown up’ or ‘disrespected’ in front of other people. This is sometimes inevitable when encounters take place in public waiting rooms:

SB: I think that when you’re talking to them one-to-one...everybody’s not there so you’re not too embarrassed, so you don’t fly off the handle. You’ve got time to talk, to explain...Because when you’re in the doctor’s room, you’re not too bad. It’s when you’re outside with all the people looking and listening at yer...

This again suggests that such examples of shame or embarrassment are not perceived as simply personal responses to them as individuals, but also arise from an expected negative judgement towards them because of their apparently obvious Gypsy or Traveller identity.

As we saw in Chapter Six, the strong sense of ‘otherness’, characterised by mistrust and low expectations of acceptance, has the apparent consequence of reluctance to reveal any perceived weaknesses that may open individuals up to ridicule. Shame in this respect is associated with feelings of inferiority. Family support is given to alleviate the stress of pushing oneself forward to question the actions or opinions of a professional:

JP: the one was having the blood test wouldn’t ask, the one what has been sat there would say ‘well why is she having the blood test then?’ Like when he [her son] was bad, you [her sister] helped me, because if I’d have just been there by myself I’d have been too ashamed to keep going up and pushing it...

The intensity of emotion and distress that can be experienced was illustrated by the family's shared account of the respondent's embarrassment and shame at having to reveal her lack of literacy in view of the perceived reactions of others to this. Low levels of literacy have already been identified as being viewed as facets of a Gypsy or Traveller identity, and although there is no shame attached to this among other Gypsies and Travellers, when it is exposed to the (actual or perceived) unempathic or contemptuous gaze of the Gorgier, shame is experienced.

SB: When I go to the desk to book an appointment... I'm just looking at em, I don't understand at all what they're saying.

MA: Then they're huffing and puffing as you're asking them to help her fill it in so that....You're dying of shame because everybody's looking at yer. 'Well why can't she fill it in herself?' You must really feel like...

Avoidance is one reaction to such a situation:

SB: That's when I start sweating. My face goes blood red and then I start then and get all ...Half the time I'd walk out.

In other cases such apparent rejection can give rise to anger and resentment towards health staff who are, or are perceived to be, showing disregard in response to the identity and perceived characteristics of Gypsies and Travellers:

MA: I've been to the doctors, I've been the quietest person around, but if I'm not getting seen and I'm not getting listened to, I will shout and I will start.

MS: Yeah but you do, don't yer? That's if you think you're being neglected or ignored.

The released emotion can be so intense that an angry outburst can quickly escalate beyond control if a hostile audience is seen to be adding to the humiliation of the situation, as the last line of the following example illustrates:

TO: [I'd say] 'What are you looking at', but then if somebody started looking at me...

MA: It would take a lot to get you worked up in the first place but once you was, it takes a lot to calm you down.

TO: Yeah because you think you've explode, so you might as well explode, [Exaggerated defensive aggression mimicked as an example of what they would say] 'Get the Police then, get them!' (said in a sort of 'see if we care' tone of

voice). It is, and then you think, you just explode. You don't know what you're going on about, you're setting on people for nothing.

Despite the apparent freedom of expression of such anger, there are feelings of shame and embarrassment at the way they feel that they have reacted under pressure that reinforces their sense of low worth. MA later describes the sorrow and shame felt at the sense that other people might be scared and nervously anticipate their behaviour, simply because of their identity.

MA: Yeah, its one of the things, it is one of the things that I think because I can feel it sometimes when I go somewhere”

PVC: You can feel that they're scared?

MA: Yeah

PVC: How does that make you feel?

MA: Horrible, cos I'm not owt to be scared of, I'm not like that kind of person. As long as someone be civil to me I'll be civil to them but if someone be's ignorant to me I will be ignorant back. I can be ignorant, not going to say I ain't but I'm not usually ignorant.

An angry outburst in such situations is viewed by Gypsies and Travellers concerned as unavoidable, but also an undesired means of 'getting their voice heard' in the face of apparent disregard or hostility:

TO: We start off nice, but if they'd be horrible and we've tried and tried and tried and we just, that's it, then we be horrible and then they sort of change,

MA: They listen to you then ...

TO: but it takes that to do it ...and then it makes you feel horrible.

MA: And after you done all that you think well you're feeling horrible and you feel ignorant.

There is both awareness and a degree of resignation at the likely reinforcement of stereotypes of Gypsies and Travellers that such angry outbursts, unreasoned to an observer, may induce.

MA: they think you're violent and aggressive and like that all the time, don't they?

TO: So that's when they say, oh did you see that Gypsy in the such and such, and then it gets around and that how they see us, bad...

7.3.3 Concealing identity

The feeling of shame that results from being identified as a Gypsy or Traveller is avoided where possible by not drawing attention to oneself. However some aspects of cultural conformity, such as the need for large numbers of family members to show solidarity and respect for a hospitalised relative, can paradoxically cause more shame and embarrassment for that family member by inadvertently drawing attention to them. This can lead to a wish to conceal a Gypsy identity:

MA: You do get, sometimes it's embarrassing for the person... I mean you've got to be sick to be in a hospital but if you're not on the dying list or anything, it's so embarrassing. You think, "Oh, God", you know. You don't want them there.

There are also practical reasons for hiding identity, linked to the fear of being seen as inferior and therefore vulnerable to discriminatory treatment. There is a feeling that acting like a Gorgon may increase the chances of having needs met:

MA: I was trying to use these big posh words and everything but then...I still wasn't getting anywhere. Then my voice started trembling and then I started crying and I was getting all aggravated and I put the phone down on them. But I was really, really trying... but I wasn't getting anywhere.

There are perceived practical reasons for attempting to conceal identity; there are also indications of an internalised sense of shame:

TO: I think that we're got an ignorant voice, ignorant do you know what I mean?

MS: Loud

TO: I think we're so common and loud and horrible

MA: Yes, very common

At the same time a sense of injustice at the need to pretend to be someone different increases the sense of negative self worth:

TO: She should be herself. Even though I'm ashamed how I talk, but I still don't like putting it on

SB: But what she's after trying to do is to listen to her properly

TO: But I'm thinking to myself but why should she have to do that?

MA: But you have to don't you

TO: She's saying all the right things, she's not talking Traveller's ways, so why can't they just understand her?

7.3.4 Shame and cultural values

The experience of shame and concern about the views of others is not confined to experiences among 'Gorgers' or outsiders. There are strong cultural expectations with regard to privacy, and a different form of shame, can be engendered when these norms are violated. This form of shame is most frequently referred to in the context of privacy about intimate or sexual matters. In Medham I was unable to share results about privacy and shame in relation to female health issues during feedback because one man was participating. This reinforces the need for cultural sensitivity in communication in health care settings:

TL: Yes skip that, we don't talk about things like that [in front of men], like that ...do we K?

An example of the importance of the views or perceived judgements of other Gypsies and Travellers is apparent in the following discussion about the shame an adult would feel about appearing among others with visible signs of chicken pox:

HJ: He made me go out and tell people that he had an allergy to birds. Because he was shamed. He wouldn't admit that he had chickenpox.

EL: Yeah because nobody's going to walk out with big scabs on them are they?

VT: Yeah it's in case anybody else catches it. ... And it's your fault.

KM: "And you gets shamed. People keep looking at you with all these scabs.

In this example it appears that being seen with chicken pox is not solely a matter of self-image, but is also seen as shameful because of the possibility of being seen by other Gypsies and Travellers as a source of contagion. This is a similar reaction to those recounted in the phase 1 study: for example, keeping a diagnosis of depression hidden or hiding the knowledge of drug use in the family. Fear of being ostracised by other Gypsies and Travellers is very real. Okely describes the concept of public shame when cultural codes are broken.⁶¹ Spencer also describes the 'obligation to avoid'; a form of ostracisation in response to a personal offence or injury from another Gypsy or Traveller.⁸⁷ It is therefore important to uphold the strong values and beliefs consistent with a Gypsy or Traveller identity. The need for Gypsies and Travellers to be sure that a

treatment or diagnostic option is culturally acceptable can explain why they sometimes need each other's support in a consultation. VT explains this in the context of a midwife's account of three young Traveller women all wanting to be seen together for an antenatal appointment:

I think that's down to getting peer approval for something you don't know about. Because if you say yes and the other person's been told that you don't do that and that's disgusting and that, ... You're checking to make sure it's acceptable or not.

This apparent lack of concern for each other's confidentiality could be misleading to health staff; one aspect of the strong cultural belief in privacy is a great fear of other Gypsies and Travellers outside of their own close family 'knowing their business'. Paradoxically, there was sometimes evidence of a marked lack of trust of other Gypsies and Travellers, due to the belief that they would not maintain confidentiality.

LG: People talk, Travellers talk about, amongst their selves.

The lack of readiness to trust each other in this way was particularly highlighted in the feedback focus group when a discussion started about whether hypothetically they would prefer a Gypsy doctor or a Gorger doctor. There was unanimity that they wouldn't trust a Gypsy doctor to maintain confidentiality and that others would soon 'know their business.'

The embarrassment of having to explain deeply held cultural values of privacy, and the need to uphold them to Gorger strangers, compounds the shameful experience. This is a particular reason for the desire to see health staff who are culturally aware so that the need to explain is removed:

LG: if you can get through from them what's wrong with you, without coming out straight with it, because like you're embarrassed, so you won't tell them.

During an extra individual feedback session VT expanded on the relative importance of cervical smear tests and the acute embarrassment of undergoing the procedure. She suggested that because there is a cultural expectation and imperative for Gypsy and

Traveller women to remain virgins until they are married that the risk of cervical cancer would be negligible for unmarried women:

Yeah cos he [doctor] sort of went, 'oh you haven't had one, and you're 25' type thing and so I said 'well you know I never got married till I was 22.

However, compounding this reason for refusal was the acute embarrassment at having to undergo the procedure. Whereas many Gorgers women also feel embarrassed at this procedure, the following example illustrates how for unmarried Gypsy and Traveller women in particular it is perceived as shameful:

I know it's important, because I'm educated (laughs) ...And the other thing's the embarrassment of it. When I was in hospital before there were some tests that had to be done and I broke my heart for two hours afterwards, cried me eyes out. My dad thought they'd told me there was something desperately wrong with me.

Despite many examples of shame and low self-value, there were also indications of resilience and resourcefulness, and pride in these cultural attributes. Although Gypsies and Travellers often feel intimidated, or can easily be made to feel stupid by health staff, there is an underlying feeling of superiority over Gorgers generally, who are often judged to lack commonsense:

LG: I mean when I first went in the house that was one of things that made me laugh. Because if the electric went off, people was up in arms. "Oh, what am I going to do." So if you've got some milk or summat, put in a bottle of water, it'll keep cool. You know .. or if the water goes off, "Oh, what am I gonna do?" Well if you know the water's going off you fill your cans up. Like you probably fill your kettle up and stuff like. It's, like you say, it's down to common sense, innit, really? But why are they up in arms about it, I don't know.

Gypsies and Travellers appeared to rate common sense above the type of education provided in schools, which doesn't teach people how to fend for themselves in the natural world. Gypsies and Travellers viewed themselves as having superior knowledge in this respect.

7.3.5 'Being a good mother'

A fundamental and highly-valued role expectation among Gypsies and Travellers is to be a good parent. All participants, except JL, were women, hence, with childcare being predominantly viewed as the women's role the emphasis was on 'mothers.' To be thought of as a bad parent appears not only to be a personal indictment that could undermine self-image, but also to diminish Gypsy and Traveller identity itself. This is not to say that fears and concerns for children are not genuine; the evidence from the data is that this is not just about keeping up appearances but is a manifestation of an important cultural value. However in the following example the sense of feeling stupid and the perception that they would be thought badly of seems to be based on a projection of their own judgemental attitude, and hence highlights an internalised low self worth:

TO: I really wanted to know if they had whooping cough or not because if you go somewhere and they ask you all these questions, 'Have they ever had such-and-such?' I can't say that they did have whooping cough because I ain't sure.

MS: You don't know, that's right.

MA: And they ask you and then you say, "Oh I think they might have had whooping cough" (talking together)

TO: yeah and you make yourself look like nahh

MA: they say like, "Why don't you know then?"

MS: "you're the mother and you don't know whether he's had whooping cough or not?"

A sense of responsibility towards the family is closely related to the need to be strong and self-reliant, in the face of so many threats. Parental responsibility can seem particularly heavy when there is fear and mistrust about whether a child's health will be dealt with promptly and appropriately.

MA: Yeah If I went to the Doctors and he said 'oh you had this, you're all right, go away', then I'd go away and that's it , I'd accept that even if I wasn't sure, yeah because I'd think well I'm old enough , but with a child they aren't old enough to tell you . Their lives left in your hands.

This sense of responsibility coupled with mistrust in health staff appears to explain the consequent need to rely on their own judgement and to persist in seeking treatment when they feel that it is warranted. This anxious persistence on behalf of children is in marked contrast to attitudes about attending for one's own health care, as we have seen.

EL: I never left her that long. But if I had have been a neglected mother right, and say, never bothered, just ...

VT: Not even neglected, just a normal mother and believed him.

EL: Just took his word for it. Now we were on a camp. Now I could have, maybe, gone to a shop, right. But this was what he said. He said 'if you had to leave her...another half hour, he says your baby have been dead.'

This is a further example of the perceived experience of living in a dangerous world where death or disaster is always a possibility and leads to a need for constant vigilance and 'good parenting' to provide a safe environment for the children.

7.4 New Insights: Cultural competence in health staff

Empathy per se is not the only ingredient necessary for a good trusting relationship with health staff. It is apparent that the health staff are required to demonstrate acceptance by an easy, informal but genuine rapport. TL and her husband appreciate the informality and friendliness of the health staff towards them at the hospital that JL attends:

TL: I mean when he was in hospital the nurses they just call him [his first name] and it was always, 'is T coming.' If I packed sandwiches, it was 'oh give us a bite of that' don't they?

However, informality and trust have to be part of a two-way process; an important component is whether Gypsy or Traveller identity is an impediment to such a relationship. JP highlighted the usual low expectations associated with a Traveller identity by commenting as if noteworthy, the fact that her doctor communicated well with her:

It was good cos he knew I was a Traveller and wasn't a stranger to him.

Time spent with a person is another sign that health staff can be trusted. Time in its literal sense is equated with the metaphorical usage 'having time for you', i.e. tolerating or valuing you:

EL: Now I've only met her twice. I was in with her this morning...she'll sit down and she'll try and help you and explain to you and tell you. Whereas the rest of them don't have time...They have a prescription. Blah, blah, blah, and that's it, put out. They won't ask you your problem and how you feel.

Although most patients would feel this way, a failure to 'take time' by rushing a consultation seems to have a greater impact on Gypsies and Travellers due to its culturally-specific meaning. A doctor who takes time and even looks things up is seen as showing respect and offering a professional service; this is much valued.

EL: He won't just rush you out. And he'll look through all that book to make sure that everything's right with that. I think he's a doctor like that. He's a fair doctor he makes sure he looking through everything do you know what I mean.

There were some Gypsy and Traveller participants whose current experiences with reception staff are also good:

TL: Because every time I've rung them, I've always got in.

This same participant attributes this not just to lack of discrimination on the part of the health staff but also to their own attitudes and an ability to stay calm:

Every one's got to see a receptionist. You don't see a doctor now you've got to see a receptionist first. You're not going to run into her, there's a load of people there and you know they're waiting. You're not going to say 'well I want to go in now.' You can't because that's out of the question. Them people's been waiting. You just say 'excuse me could you see my baby. He's not well or she's not well and I've never been to this doctor before, would it be possible, could I see him. I'm very, very worried.'

However there is also a view that no matter how well they might behave towards health staff, discrimination cannot be overcome so easily:

MS: I think its how you go...

MA: No it ain't Mam ... it ain't how you go, you can go in there and be as civil as anything and then people just be ignorant to you.

Cultural competence is viewed as an important sign of acceptance and a necessary factor in a relationship where trust in the person's attitude towards them is so fundamental. Failure in cultural awareness can inhibit communication and effectively be a barrier to any potential relationship with health staff. JP gives an example of how staff can be perceived as too direct and unaware of cultural taboos:

There is private things. Sometimes you walk in, sometimes the doctor can be a bit too open to a travelling woman.

This is, however, almost a contrast to the friendly familiarity described by TL on p 248 that is appreciated. It shows that health staff have to tread a fine line in perceiving or recognising when it is acceptable to be more open and familiar. It also suggests that in the absence of continuity which is conducive to building a relationship with the patient, it is necessary to be more discreet. When lack of cultural awareness is demonstrated by inappropriate questions about Gypsy and Traveller culture, there is an assumption (quite possibly well-founded) that negative judgements are implied in the questions and this is resented:

JP: I've had three born in [this town] ... I've had different doctors for every one. They've sent their health visitors, they just seem to come in and look around. And then they start asking you silly questions. "How do you do this?" "How are you sterilising the bottles?" "And how are you getting a bath?" How are you doing everything. Our health visitors don't ask us that cos they know.

When 'Gorgers', health staff or otherwise, demonstrate empathy by their acceptance of the person, rather than just curiosity, the difference is readily recognised:

VT: I mean if you think somebody doesn't know what's going on. I'll be honest. If you think somebody doesn't know, you are more likely to tell them. If you think somebody doesn't care then you're not likely to bother to explain because you think you're not going to get anywhere anyway so what's the point of wasting your breath.

However, even where there is a good rapport with an empathic GP, mistakes and misunderstandings are still possible. AP reported experiences of 'blacking' [out] which she attributed to unexpected side-effects from her medication. Her doctor disagreed and reassured her, but after she had a subsequent blackout experience and nearly crashed her car while carrying her young daughter as a passenger, she demanded that the nurse read the medication leaflet to prove her theory. Her anger was intense because she had trusted her doctor and believed his earlier assurances. At the same time this prior trust enabled her to confront him:

AP: when I was 100% knowed for sure I gave him a piece of my mind. Because he is a good doctor ...I said 'at the end of the day you told me them tablets

didn't do none of that.' I said, 'how the nurse out there explained it to me, I said I'll explain it to you.' He said 'I do know about them. but there's only one out of a million it happens to.' 'Well then I must be the one out a million then cos I said it happened to me.' I said 'what would you have done, I said, if my baby had been killed. Or if the two of us had ended up in a wheel chair...I said why not tell me the truth? Sorryness and denyingness wouldn't do no good,'....He said to me, look he said 'A. I'm very, very sorry' he said, 'I just didn't think,' and really he said 'I didn't want to tell you to save you a worry.' But I said 'you should have tell. You've got to tell the truth'. ...I felt like betrayed by him, you know...I tell you how I felt...he is helping me but yet he don't care if I get killed. Do you know what I mean? I thought to meself, he can help you and kill you. That's the truth.

PVC: Do you still feel betrayed by him?

AP: No because partly he was guarding me and partly he, like he didn't want to worry me...I never like shouted, like screamed down to his face, I explained to him ...He said 'thank you for putting me in the picture' he said, 'how your mind thinks' he said.

This story poses questions about AP's theory that side-effects were the cause of her symptoms. But whether correct or not, it shows that trust is a fragile concept in the face of prevailing fears. It also shows that the mutual trust and respect that existed before this event allowed AP to feel safe in confronting her GP and seeking an explanation, rather than 'voting with her feet'. The GP in turn was able to listen and to convey his respect for her feelings. This evident respect was the ultimate reassurance for her that she mattered, regardless of her Gypsy and Traveller identity: "And the best about my doctor. He's not prejudiced, do you know what I mean." The revealing comment, that the Doctor thanked AP for letting him know how she perceived the situation ('how your mind thinks'), is a clear sign of mutual respect and willingness to achieve mutual understanding. Whereas this is an ideal that many practitioners may desire to aim for, we can see that this level of discussion and explanation would be hard to achieve in standard consultation times of less than ten minutes. However we can also see that failure to allocate sufficient time to achieve this mutual understanding can have serious ramifications.

7.5. Responses to Preliminary feedback

Both groups of Gypsies and Travellers who came to the feedback sessions were attentive and eager to hear about the health staff groups' views. However, some findings from their own sessions also generated particular elaboration; for example, the

conspiracy of silence that occurs to protect other family members when there is a diagnosis of cancer. The following response to this finding shows the extent of fear from a diagnosis of cancer and reveals the possible consequences of a fatalistic attitude that can result in unnecessary distress for all concerned:

TL: But you see, that's right .They're all on their own with it, aren't they? Then they can commit suicide because me mam's cousin, he thought he had cancer. He thought he had a tumour and he went and drowned himself. And he had to have [Post Mortem] Yes, Nothing wrong with him. But he had very bad migraines. But like you just said there, you keep it quiet.

The discussion generated many more stories of relatives who had died from cancer but it also revealed how trust in possible curative treatment may be gained. One participant, whose husband is in remission from cancer, explained how she now realised that cancer was not necessarily a fatal diagnosis.

TL: ...with cancer, the name just frightens. You screech it out isn't it? When say you've cancer, you say 'oh my God that's the end of me.'

PVC: When did you recognise that there was some hope if you get cancer?

TL: Well you hear a little, when you, like I used to go out, I used to go like gathering scrap and you'd get to some like women and they'd tell you their story and they'd say 'well our so and so's got it. But she goes through that..., what do you call it...yeah, chemotherapy which is all right.

This participant had explained her optimism by recounting a personal story rather than reference to any information that she may have received from the hospital staff treating her husband. This reinforces the power of personal stories as a form of communication and information but also highlights the danger of reliance on personal anecdotes if the stories heard are more usually ones with fatal endings. This reliance on personal experience, whether or not it is a second-hand account, is a useful signal to staff that giving anonymised accounts of personal experiences may be a more useful method of conveying information about a condition. There is additional scope for giving information in this format in the surgery setting through access to the 'patient experience website', DIPEX.org.ⁱ However, care would need to be taken to ensure that information given in this way was supplementary to a full consultation and that there was someone available who could answer any further questions that it may raise.

ⁱ DIPEX web site: <http://dipex.org/DesktopDefault.aspx>.⁴⁷⁴ enables patients, carers or health staff to read or to listen to the experiences of patients with a variety of illnesses of medical conditions.

7.5.1 Relationships with health staff and health staff views

There were some defensive and indignant responses to some health staff complaints about Gypsies and Travellers, for example about failure to return for appointments:

KM: yeah, but ...I often went to the doctor and missed an appointment, even a dentist appointment one time I had to give £10 to get me teeth seen again because I missed me appointment. I said look I'm a Traveller, I'm a roadside Traveller, and she said that's not our problem love. I said well it's not my problem either love, there's nothing I can do about it. They made us move the same day and I couldn't get back to my appointment ...

This story emphasises the negative repercussions of lack of control over environmental circumstances but also emphasises how the respondent felt more upset by a demonstration of lack of empathy and understanding. There was also some quiet scepticism expressed at health staff assertions that any negative views about Gypsies and Travellers don't stop them from 'treating everyone the same.'

VT: Hmmph!

Some feedback about health staff pressures however was met with understanding:

MA: some people do, they just leave it to the last minute and then go demanding and you can't do it . You should go in the first place....

MS: I think its true innit, most of what they're saying, it is true. If they were coming at us we'd be frit wouldn't we. "Travellers will come in groups.

TO: Some Travellers is like that.

VT: I mean I can understand how pressurised the health care professionals get because they have got structures to work to and you know Travellers don't live by them very often ... that they don't see the point of your ones type of thing. I feel so sorry for them because, yeah, they have a really hard job with so many constraints. Yeah I can understand it [staff feeling intimidated].

There was appreciation of empathic health staff comments, for example, with reference to understanding that Gypsies and Travellers don't expect to be treated well:

its good that they actually see those things.

yeah, some of them seem to understand don't they.

However VT , while expressing surprise and some apparent grudging acknowledgment that some health staff seemed to understand, also expressed indignation and disapproval at the apparent lack of ability of other health staff to see both sides:

Yeah, Travellers do have fixed ideas, but it's because nobody's bothered to explain why those ideas are wrong or why they may be misguided!

There was particular indignation from the inferred lack of respect indicated by use of health staff language. For example, VT felt offended by the inference that Gypsies and Travellers were a 'problem to be dealt with' rather than individual patients requiring a service when she heard health staff had used the expression "dealing with them". Despite recognition that 'bad attitudes' could be attributed to 'prior bad experiences' on all sides there was a view that health staff should have a more 'professional approach' and take more responsibility in interactions.

LG: But it's their job, but they should be more open minded than what we are reallytheir job tells them they can't be nasty to people.

The use of reflexivity in communication skills training and cultural competency, as discussed in Chapter Four, would increase the likelihood of health staff developing this 'more professional approach' that is seen by LG to be lacking. The apparent lack of reciprocal understanding by health staff reinforced perceptions of discriminatory treatment.

VT: yeah, you've got people who think oh yes it's your rules because it's us, not because it's your rules for everybody.

Some Gypsies and Travellers expected that health staff would be surprised that that they would agree with any of health staff feedback:

MA: I think that some of them would be surprised that we agree with them for some things. They don't think like that we'd agree because you know we don't never agree with them on nothing.

They made suggestions for making it easier to find ways forward - mainly for them to be given time to be listened to and for sensitivity to communication difficulties and the

need for privacy. There was agreement that having a key person for Gypsies and Travellers in the practice would be helpful:

MA: yeah. So if you went into the surgery and you know there's this certain person by name and you said 'could I speak to so and so'

SB: You wouldn't have to explain nothing.

Cultural awareness training for staff was also seen as a way forward:

MA: yes, that little bit of extra training would be a lot better and they'd know a bit more about Travellers and they'd understand why Travellers get so panicky so quick- it's because they're afraid and they don't know things, that's what it is ...cos you're like willing to explain, but then they appreciate then why you're like you are. But it's just getting them to listen in the first place. So if they have the idea, with the training and that.

There was also a view that Gypsies and Travellers would benefit from some cultural awareness about the NHS and that some misunderstandings were mutual:

VT: I think it's just complete and utter misunderstanding isn't it ...Travellers don't understand that....when you walk into a doctors ... they're live by their rules, you don't see that there's somebody down in London dictating to them what should and shouldn't be done and I think there does need to be a better understanding of that.

She summarised: it's all basically about understanding and misunderstanding isn't it?

7.6 Interim Feedback

The interim feedback findings were met with similar intensity of attention as the preliminary findings but with much less discussion as they were presented. Although there was opportunity for comment, only one was made during the process; HJ expressed surprise at receptionists' lack of power'. She had perceived them as being the ones with all the power. There was little ensuing discussion, but the Gypsy and Traveller participants seemed to be mulling this over. The only other noticeable reaction, other than acceptance and understanding of what was being relayed, was to the quote "we don't have any prejudices against anybody." At this point a young participant went "Humph" in a very sceptical tone. At the end of the feedback, which ended with

the summary that trust and respect appeared central to the outcome for Gypsies and Travellers, there was unanimous agreement. During the evaluation there were some further empathic comments in response to a question about first thoughts from the feedback:

Receptionist has a lot to put up with
Some Travellers do have a bad attitude

There were conflicting views about what had been learnt

Don't know anything (new) about health staff that we didn't know already
Have learned about health staff; can now understand reception staff more

It was at this point that the discussion, referred to earlier, about hypothetical Gypsy or Traveller health professionals arose, with views that they would be less trusted than a Gorgon because:

Gypsies would be laddered [ashamed] to talk to other Gypsy staff

This lack of trust amongst each other in respect of confidentiality appears linked to the fears of not being accepted, as the Romany word corresponding to 'ashamed' was used in this context. However there was a consensus that it would be helpful to share the findings with other Gypsies and Travellers and all expressed a wish to be involved in plans for dissemination to both Gypsies and Travellers and health staff.

7.7 Conclusion

These findings illustrate the high levels of anxiety that many Gypsies and Travellers experience in terms of their presenting needs for primary health care and their anticipation of difficult relations with health care staff. We have seen the ways in which the expectations of Gypsies and Travellers and health staff diverge or conflict, giving rise to many examples of tension and misunderstanding. In this context, the importance of a sense of shame and devalued identity is manifest, among Gypsies and Travellers.

The Gypsy and Traveller perspectives revealed in these findings underline the need for empathy from health staff, combined with cultural awareness. The positive experiences described, when practitioners do respond with empathy, suggest that there is considerable potential for improved communications. Before discussing these themes in greater depth in Chapter Nine, I now describe the health staff perspective.

Introduction

This chapter presents the findings from the focus group discussions with health staff from the two GP practices and Walk-In centre and the interview with an Accident and Emergency (A&E) nurse. As with Chapter Seven, I have drawn on initial group discussions and on subsequent discussions of narratives. The main themes discussed are:

- Staff expectations of Gypsy and Traveller patients
- Staff attitudes to cultural awareness, equality and diversity
- Organisational and role pressures
- Service delivery

I conclude the chapter by presenting the staff responses to feedback of preliminary and interim findings.

8.1 Staff Expectations of Gypsy and Traveller patients

Many of the problems identified by health staff mirrored those identified by Gypsies and Travellers, particularly in regard to mismatched expectations and resulting conflicts. Gypsies and Travellers and health staff all want a positive outcome in respect of health care from their encounters; differing expectations can have a significant impact on the potential for this. The meaning of good relations with Gypsies and Travellers for health staff differs according to individual expectations. In turn, these are influenced by past experience and by previous contact with Gypsies and Travellers. Views and perceptions among health staff also differ according to status (professional, administrative or clerical) and to some extent according to their practice team and setting. These differences will be noted here and discussed again in Chapter Ten.

8.2.1 Past experience

Previous experience of direct contact with Gypsies and Travellers varied; many respondents had never knowingly met any outside work. For many, this lack of

familiarity was associated with their perception of Gypsies and Travellers as avoiding integration:

They are a very closed society Travellers..., well they certainly don't mix in... the kind of circles that I'm mixing, I don't meet Travellers down at the gym where I go to, I don't meet them in the sort of place, you know the bars that I go to or the restaurants I go to. Nurse Walk-In Centre.

Many stereotypes familiar from the media were also expressed during focus group discussions:

my perception of them is that generally speaking they are...people who are untidy, who tend to apply the laws that they think are appropriate and not ones they don't, you know tax discs, things like that, insurance for cars... Nurse Walk-In Centre.

they see them driving round in mercs...and not paying tax and things which I think does rub up, certain, you know. Nurse Rowan surgery

Some staff stated that their negative perceptions came from the media: "You see the news." One receptionist illustrated in detail the power of the media in influencing and reinforcing stereotypical views:

some Travellers came on to the playing field and within hours of them turning up, we all had flyers through the letterbox saying we have an invasion of Gypsies... You see something very negative, you see the mess on you know, the evening news, that they've left behind where they've gone to a playing field... and you instantly think Oh, that's going to happen in my village and you know, children can't go down into the playing fields... you've got to be extra vigilant and so it's all the negative things that you see, mainly I think, all my views have come from the media. Receptionist Walk-In Centre.

After the first focus group, when staff were chatting together, I overheard comments indicating that their negative impressions of Gypsies and Travellers did affect their responses towards them. I could not follow this up with them at the time, but asked a direct question of the staff in the subsequent focus group. The Walk-In centre staff stated that negative views and attitudes towards Gypsies and Travellers would not affect the way they would treat them as patients:

Well it doesn't influence attitudes professionally. It would not alter the way in which I would deal with somebody professionally. I wouldn't withhold treatment, I wouldn't do a bad job, I wouldn't pay less attention to the history. Indeed this gentleman who came and saw us, despite the fact that he physically threatened me on at least two occasions, I still treated his foot.

Nurse Walk-In Centre

However, comments made during focus groups suggest that negative stereotypical perceptions persist. When staff recounted their actual prior experience of work-based encounters, it usually served to reinforce negative expectations:

I think they're rude, very impatient. Want to be seen now... when they come here, you can't just ask them ... you know if the doctor isn't available straight away, they don't want to know.

Receptionist Elm surgery

they are intimidating because as we said, they don't come in ones... they bring a pack and they're all over the counter.

Receptionist Rowan surgery

Some nursing staff, notably those who had worked either in A&E or Walk-In Centres as opposed to general practice, had not experienced any negative encounters. Others had observed attributes in their encounters that were contrary to their expectations and which left a positive impression:

...she was very sweet, very charming, very polite and she lived in a trailer and that trailer was absolutely immaculate and so was she and yet she was paraplegic. And I was quite surprised because I knew she was going to be paraplegic and I expected her not to be able to do a lot but she did everything... I was quite impressed and encouraged by what she did.

Nurse Walk-In Centre

A patient with attributes such as charm, politeness and an ability and will to help herself in the face of a serious health condition could be expected to be judged as a 'popular patient' by staff⁴⁷⁵ and in this case the patient's positive points outweighed any negative preconceptions the nurse may have held. However, it is a matter of conjecture whether it was her positive experience or a more reflective open-minded attitude that enabled this same nurse to challenge negative stereotypes mentioned by other staff.

you can't just say that you've got to be more vigilant, because that's assuming that they are going to be thieves. And where does that suspicion come from. That's the thing... If you see a mess that's left behind you can tangibly say that

you saw it yourself..., it was there for you to see but you can't, if it's somebody else telling you it's there. That's what's spread about and that's what causes a lot of bad communication.

Nurse Walk-In Centre

This challenge to other staff members shows some awareness of the danger of pre-judging individuals or groups on the basis of second-hand accounts and shows how such negative stereotypes are hard to overcome. Another nurse who had met Gypsy and Traveller patients in their home environment also spoke of the importance of suspending judgement. This A&E nurse, out of specific interest, had chosen, to spend a day with a specialist health visitor for Travellers as she recognised the benefits of seeing families in their own cultural environment. For her it helped to put their behaviour in the health care system into context and she spoke of her attitudes being influenced positively by this experience:

Just having more experience with it and around Travelling families and just having insight into their lives a bit more, because before it, you don't know really, do you... I mean generally as nurses ...we're people that tend to be, try very much to be non judgmental, to treat everybody the same, especially if you work on A & E., ... everyone tries to be very open minded but until you actually appreciate different people's culture and actual see their standards... you're going on what you've seen at work and in the media really aren't you?

This experience and increased understanding also reduced her apprehension about dealing with the unknown. However, the overwhelming impression from staff was that regardless of these exceptions, Gypsies and Travellers were seen generally as a challenging group of patients in terms of health needs and demands and behaviour associated with trying to get their needs and demands met, and this is seen as causing a considerable impact on relationships and on service provision.

In summary, staff attitudes towards Gypsies and Travellers are coloured by their variable range of prior experience. The receptionists were the most vocal, and mainly expressed negative attitudes, perhaps because of their difficult experience at the 'coal face.' However other staff expressed no surprise, and appeared sympathetic to these attitudes, with the only outright challenge in these discussions being the nurse to nurse example above in the Walk-In centre.

8.2 Cultural awareness, equality and diversity

8.2.1 Attitudes to cultural awareness

Most staff had not received any cultural awareness training, either when qualifying or later through staff development:

A. There are courses

B. I've never heard of it.

A. Yeah ...I was meant to go on one once but it was cancelled. It something you apply for rather than are asked to go to. Nurses Walk-In Centre

Rowan surgery was an exception, with staff receiving some direct input during this study (see page 268). However, some staff here also indicated a level of cultural understanding gained through their experience of working in partnership with Travellers. This had enabled staff to become more aware, and their initial perceptions were altered:

Because we were saying how we[were] quite nervous about some of the male Travellers[who] seem quite sort of aggressive and, she said, no they're pussy cats... well they're quite scared underneath and you know the women sort them out and there's no problems and it was quite a different perception of what was going on. Doctor Rowan surgery

However, most staff referred to a lack of specific information and understanding and felt that this made their encounters more difficult:

“It would have been useful to have that sort of cultural knowledge prior to just finding out ...on the job. So that's how they believe! And ...as I say, some of their health beliefs are quite strange.” Midwife Rowan Surgery

This comment about 'strange' health beliefs was discussed further and reference was made to the strong gender divide and to related moral codes concerning sexual behaviour in particular; for example “she's got to be a virgin”. It would seem therefore that the word 'strange' is being used in terms of atypical or different to the majority norm, rather than strange as bizarre or inexplicable. Many staff seemed to view Gypsies

and Travellers as separate, 'different' or 'exotic' others and expressed a sense of inevitability about mutual understanding not being reached:

Well, to them they're just plodding along doing what they believe in, their way of life and I suppose tunnel vision, if there's an illness or rash that needs to be seen. Because everything else is so out of character to the majority of the nation.
Receptionist Elm surgery

Only a minority of staff felt that more cultural awareness would be helpful and appreciated:

I think if you were new to working in health care in an area like this where you're going to come across Travellers on a fairly regular basis then actually understanding their cultural background would be useful.
Nurse Manager Rowan Surgery

However, most felt that training, if useful at all, would only be partially helpful: it would offer increased understanding, but this would be insufficient to deal with day-to-day problems:

Yeah it would have helped me understand. But it wouldn't have helped with the situation, because they were all there and they weren't going anywhere.
Nurse Walk-In Centre

Although some staff did express a wish to feel better informed, most did not spontaneously see awareness training as potentially helpful:

When they come here, they've come for health care. We're not talking about politics and what they're doing, you know, in their own life.

In this... environment where we interact so briefly with the patients, I think it's not as much of an issue as it would be perhaps if you were on a ward and you needed to be more aware of cultural issues like undressing and hygiene and you know how they eat and how they go the toilet, and you know sort of things like what religious beliefs they have. Whereas it doesn't really impact on a quick 20 minute consultation, you know. It really doesn't matter that much at this stage does it?

Nurses Walk-In Centre

This suggests that some existing models of awareness training haven't been very helpful; they may have become associated with a limited stereotypical focus on specific cultural needs of ethnic minority patients, rather than instilling reflection and mutual respect for diversity in general. The reference to politics also suggests a belief that it isn't necessary to understand the social context of a patient's behaviour and was mentioned to contradict any idea that the attitude of wider society towards Gypsies and Travellers would have any influence on their relations with health staff.

Mismatched expectations result in additional pressures on staff. For example, there was no awareness of the reasons (discussed in Chapters Six and Seven) which led some Gypsies and Travellers to self-diagnose and to have fixed expectations about consultations. Some staff also felt that it was Gypsies and Travellers who lacked awareness; that lack of understanding among staff was due to the relative lack of integration by Gypsies and Travellers and their limited knowledge of 'how society is organised':

There might be some point in encouraging them to come out into the community more instead of being locked in their little pocket ...they might get to know how the rest of the world works in a way.
Nurse Walk-In Centre

This outlook was reflected in similar views that patients need to learn the 'system.' Some believed that diversity or cultural awareness training is unnecessary because the required skills or attributes can more readily be gained from life experience:

Most of the cultural awareness is because people live here.... mature people who often have had children who have had schooling and life experience, not because of training.
Doctor Elm Surgery

Professional staff in particular felt that training would be ineffective in changing attitudes and therefore would not influence discrimination or prejudice:

you can give staff as much diversity training as you like, if they've got inbuilt prejudices, that's not going to change it.
Nurse Walk-In Centre

This view is closely associated with an opinion that nurses would routinely be used to people from different cultures and that such experience is sufficient to enable them to

give adequate care without additional training. However, others indicated that cultural awareness was necessary for anyone with difficulties in comprehension, not just 'ethnic minorities'. The following comment appears to support a view that an empathic understanding and approach to communication is a prerequisite for working with all patients, precluding a specific need for cultural awareness training:

If you realise anyone doesn't understand what you're saying, you go about it in a different way. I had a chap in yesterday and he'd got a poorly tummy and... he'd been in about 4 times within a week so I was trying to determine whether he was suffering from anxiety which was putting him off his food and all that... we went on for a half hour. This can happen with anybody. It's about what they're perceiving you're trying to get at... But eventually you can work out how to do it. How to say the right words to get them to understand. And that's with anyone.

Nurse Walk-In Centre

Cultural awareness appears to be a sensitive subject for staff, with defensive feelings engendered. This may possibly be because they are aware of their lack of information or experience and may feel out of their depth on the subject, but also because they perhaps feel criticised in this respect and feel the need to justify themselves. There was a sense that their attitudes towards cultural awareness reflected a similar unease about multiculturalism in general. For example, there was general discussion about the problems encountered with patients from other ethnic groups who didn't conform with the 'system'; "some cultures are a demanding society".

8.2.2 Attitudes to equality and diversity

There is a strong belief among health staff that there is and should be no discrimination: "We don't have any prejudices against anybody." Many equate this with saying that everyone is and should be 'treated the same.' Nurses particularly expressed the belief or hope that a professional philosophy of treating everyone equally would be enough to guarantee a fair approach without additional training or understanding:

that's something that should be sorted out in training really isn't it. You shouldn't really get through three and a quarter years through your nursing career and suddenly start on the wards and be told the first thing you've got to do is go and have a training course for three hours to look after different type of people. In theory that's what the three and a quarter years was about... from day one you met different people, some of them were English, some of them weren't, some of them were European, Polish, German, whatever else and some of them were Asian, some of them were Black Caribbean and some of them

were white Caribbean and some of them were African. And it was like, well this is it, welcome to nursing.

You treat everybody, whether they're, it's their ethnicity, their religion, their colour and their creed, their sex, their gender, that sort of thing. So that would be covered by our rules and regulations as nurses.

Nurses Walk-In Centre

Reception staff also believe in equality and feel affronted and misjudged when Gypsies and Travellers suspect them of prejudice:

...You know, you can't have an appointment right now ... No different to what we'd say to anyone else... but that is their standards you know and like 'oh it's because I'm a Gypsy' you know or a Traveller.

Receptionist Rowan surgery

This resentful type of reaction reflects a belief that treating everyone equally is synonymous with being non-discriminatory and shows a failure to understand the reasons for such challenges to practice. For some clinicians, a belief in equality co-exists with an acknowledgement that some staff hold prejudiced views; however, they emphasise the role of professional values in safeguarding against any expression of prejudice in working practice:

Well a lot of the caravans that I went in had got top of the range equipment in there you know, and they've all got new cars and things like that so it is, I think in a way it's understandable that people do feel like that. And you've just to hope that in their professionalism they will be able to put those feelings to one side.

Nurse Manager Rowan Surgery

This is seen as a positive, ethical and non-judgmental attitude; a required professional attribute and evidence of good practice:

We don't see them as a group that needs any more or any less support than anybody else. It's just that all the patients get treated exactly the same. It really is. It sounds very idealistic and you must think ooh they're a bit odd here, but it really is like that, every patient is treated exactly the same.

Nurse Walk-In Centre

The policy emphasis in the NHS of affording equity on the basis of differing needs, and on valuing diversity, is relatively recent; the distinction between these policies and a

more familiar 'equal opportunities' emphasis does not seem to have been adequately communicated to staff. Therefore most feel strongly that to treat people equally, is morally desirable. As an example, the following quote indicates no appreciation of the concept of equity, although it could also be interpreted as 'treating people with equal respect':

You know I treat everybody the same and I don't think just because they're black and don't speak English or just because they're a Traveller and aren't registered with a GP why should I treat them any different to you who comes in, who's registered with the local GP.

Nurse Walk-In Centre

Such views have implications for training which I discuss further in Chapter Nine. Alongside these beliefs however, there is also an acknowledgment from some that relying on professional values alone can be insufficient to avoid discrimination, let alone to meet the challenges of communication:

It's instilled in you all through whatever you do really as a nurse, isn't it, that you treat people the same...but ...I still notice racism amongst people...

We treat them the same as everyone else initially but there is a problem with communication. And I think they do, as a group of people tend to use language and mannerisms that aren't the same as the ones that other people use, therefore they're taken in the wrong way and change people's attitudes towards them.

Nurses Walk-In Centre

This remark also demonstrates a need for greater cultural awareness and a need for increased skills in understanding the subtleties of verbal and non-verbal communication and the meanings that are being conveyed and construed. These difficulties can add to workload pressures. Staff felt that they weren't able to spend long enough on the communications needed for effective health care:

I think you have to work quite hard at explaining, you know, that it's not going to benefit them, that they're actually going to get side effects from it and you know there's no point in putting side effects if it's not going to help.

Doctor Rowan Surgery

Clinicians often feel that Gypsies and Travellers are quick to perceive discrimination, if a desired treatment is not forthcoming, but that this is often a misperception. One doctor conveys the need for flexibility by both parties:

But with Travellers you feel that they have a very fixed idea and nobody's going to budge them and if you try and budge them at all, you're prejudiced against them ... and you're being mean, or you're saving money, or they're too much trouble and actually saying, 'No look that's not the treatment you need, you need something else'. It's very hard to move such a rigid agenda.

Doctor Rowan Surgery

Difficult consultations, with misunderstandings arising from differing expectations, are seen as compromising good practice. Apart from the personal dissatisfaction there is the added worry about patient safety outcomes and professional accountability. This is a particular issue for staff who are aware of poor literacy among Gypsies and Travellers:

you had a little kid in with a head injury and you're trying to explain to the mum and the grandmother and god knows who else is in the room with you what you need to be looking out for and this is really important and most of them don't read or write so they won't have any information to take away so you've really got to try and get it across and make sure they've understood, and... They've had the treatment and they just want to be out.

Nurse Rowan Surgery

Rowan Surgery staff did show a general awareness of specific Gypsy and Traveller needs. For example, they recognised cultural practices, such as family groups with children attending with the patient for support. However, such practices can cause additional pressure, both practically and in maintaining confidentiality and cultural sensitivity:

you may have one person in the consultation but you're actually dealing with all the people that come with them as well, which can be difficult.

Nurse Rowan Surgery

This reflects the same tensions, between confidentiality and the need for family support in consultations, expressed by Gypsies and Travellers in Chapter Seven:

They have a lot of their contraception sorted out without the family knowing which is difficult sometimes because they come in groups and then you ask them a question and then suddenly you realise there's a question that they don't

want to answer in front of lots of other people and that can cause conflict as well.

Nurse Rowan Surgery

Although Rowan Surgery staff had little explicit knowledge of Gypsy and Traveller relative health status, they were aware of apparent health inequalities and of the need for enhanced service provision:

we were concerned that our Travellers did have poor health. We'd sort of noticed without really seeing the figures.

Doctor Rowan Surgery

We're more anxious when we get a febrile Traveller child because it seemed, all the disasters seem to happen to Traveller kids, so we thought we would just try and improve the status, a lot of the Travellers don't get the routine monitoring of health care that they should do.

Doctor Rowan Surgery

A significant number of the Travellers are relatively illiterate and staff don't often appreciate that, so when a Traveller comes to utilise the services they get approached in a way by a staff member that is quite off-putting.

Nurse Manager Rowan Surgery

This practice planned to introduce in-house cultural awareness sessions for their staff.

8.3 Organisational Pressures

All staff commented on workload pressures. In Elm surgery however, there appeared to be additional organisational issues; signs of strain were clear from public notices and displays highlighting the shortage of appointments for patients and asking them to consider alternatives such as seeking advice from a chemist for minor health problems. It was also difficult here to contact staff to arrange the research fieldwork. The demands of working in a busy general practice can make it hard to accommodate a group of patients with extra needs. The frustration was apparent in the sympathy from other staff towards the rhetorical question from an Elm surgery doctor in response to a question about cultural awareness training: "What would you like us to stop doing whilst we have this?" However, despite this particular doctor's dry and sardonic communication style, his apparent defensiveness in response to the question also indicates a perception that such training was being advocated. He may therefore not have perceived my role as a researcher to be neutral.

When Gypsies and Travellers attend as temporary residents, a lack of information and continuity can compound organisational pressures and communication problems for clinicians:

Travellers come with no information and they want everything, “Oh, just give me something, Dr” and that is very difficult, because you need some sort of back up... But because of their temporary presence you’ve got no longer term information
Doctor Elm Surgery

This problem is often compounded by Gypsies and Travellers avoiding attendance until they feel it to be absolutely necessary and then presenting with multiple symptoms or conditions in one consultation, as we saw explained in Chapters Six and Seven. This then has the potential to disrupt the appointment times for subsequent patients and create additional pressure for all concerned.

And then when they’ve had 20 minutes and want to discuss...I said “Look, you’ve had 20 minutes. That’s why ...’I really can’t discuss this 3rd thing” and as they were leaving the door it’s well,’ blah, blah, blah.’ That’s the other problem isn’t it, we’re on 10 minutes and if you’ve got three problems...
Doctor Rowan Surgery

This problem again reflects the outlook that patients need to learn the ‘system’, as discussed on p237, and that there is little scope for flexibility, and consequent frustration, on the part of health staff in trying to accommodate patients who do not conform to required consultation behaviour. Several clinicians in both practices spoke of other pressures on consultation time; they appreciated that time, effort and empathy were required to overcome mistrust.

They think that if you’re not going to give an antibiotic it’s because you don’t think they’re worth it... You don’t always win the first time but I think you just have to spend a bit of time educating and showing that’s it’s not that we don’t care.
Doctor Rowan surgery

This is less of a problem with a stable Gypsy and Traveller population:

a lot of people seem to have got addresses now. Like I said with those people you’ve sort of built up a relationship and it’s not quite so overwhelming any more.

Doctor Elm surgery

However, staff also spoke about the difference it can make to have a trusted intermediary, a specialist health visitor, as an advocate to ease potential conflict and also to facilitate attendance for appointments.

it works really well, because she rings up and she says, 'I've got this lady who needs this, can you fit her in?' and she fits her in and she turns up and it's great. You can't honestly do it on a huge scale but that is a way forward isn't it, having an advocate... liaising and communication and so on.

Doctor Elm Surgery

There was a sense that by using a specialist advocate in this way it eased the inevitable barrier of mistrust or at least, by proxy, eased the process by reducing the necessary time investment. The A&E nurse who had observed the trusting relationship between the specialist health visitor and Travellers made the link between respect and trust:

I could see that they really respected her and obviously that was just through trust and ... they wanted her because they trusted her.

Any attempts to build trust are inhibited by negative stereotypical expectations of Gypsies and Travellers which invoke fearful reactions and responses. The extreme consequences of such stereotypical and anticipatory fears are illustrated in the example given by one GP of a visiting paediatrician's reaction to having to see a Gypsy family:

the paediatrician was very nervous indeed and his colleagues had said that if he wasn't back at the hospital within 40 minutes they'd send the police out.

Such underlying fears can only serve to reinforce a climate of mutual distrust. The impact of a Gypsy and Traveller patient population in organisational terms affects all staff but the nature of the impact varies for different staff groups.

8.4 Staff roles

In primary care, staff roles vary according to some basic factors:

- Public role status/ acknowledgement of expertise
- Degree of role autonomy
- Exposure to public gaze.

These factors are closely interrelated but I will present the specific role-related work pressures under these broad headings.

8.4.1 Public role status

Clinicians most commonly spoke of trust and respect in relation to establishing good relationships with Gypsies and Travellers; more prejudiced attitudes were apparent among clerical staff. However, the ability to develop empathy and trust is determined in part by the specific nature of encounters between different staff groups and Gypsies and Travellers. Reception staff are most likely to receive complaints from stressed or anxious patients:

It's like this morning you were running an hour late, weren't you, the people complaining 'how much longer?' Well we say 'The doctor's running late'... I say, "Well, just mention it to doctor when you go in" and they don't say a word, do they?

Receptionist Elm surgery

They are aware of their reputation as gatekeepers and can feel powerless in resulting conflicts.

I think some patients think that we are there to stop them seeing a doctor... 'What's it got to do with you? If the doctor knows I'm here, they'll see us!' Which we appreciate that, but we're the evil ones.

Receptionist Elm surgery

In some cases, reception staff can feel frightened and intimidated by the extent of confrontation and demanding behaviour when Gypsies and Travellers attend.

...they always bring somebody else with them and if they start, they all start. So, it just gets to be quite heated sometimes... I think it's just one or two tend to, but when they do kick off it's very intimidating. I'm glad that counter's between me and them to be honest with you.

Receptionist Elm surgery

Many clinical staff recognise the difficulties experienced by Gypsies and Travellers and the impact on their ability to trust outsiders, and appreciate the impact on receptionists:

If Travellers go to a surgery I think often, because people are so fed up with the things that have been said, they get a very negative answer immediately. I think that affects the way ... that they approach surgeries; they are already ready for a fight aren't they, when they're going in, because of the experience they've had before.

Doctor Elm surgery

Doctors and nurses rarely face such acute manifestations of anxiety:

...no-one has ever been aggressive to me. Once they're past the counter all the surliness, the bad language, it doesn't happen in the consulting room at all.

Doctor Rowan Surgery

Differences in the extent of role autonomy and in exposure to public gaze are two complementary explanations for such differences, as I will now explore.

8.4.2 Role autonomy

One clear role difference is the variable degree of staff autonomy. Clinical staff have more power to make changes than receptionists. So whereas doctors and practice managers can decide to be flexible and make an exception to see a patient without an appointment or to change how they work, receptionists have far fewer options and can feel out of control when faced with difficult situations. This was apparent in some of their reactions:

to an extent, you can handle it so far but when they just keep going and going and going, what do you do?

Sometimes whichever doctor's on call or whatever, we might have a word with them ...usually [manager] takes over to be honest with you ...

Receptionists Elm surgery

Some autonomous clinical staff described an ability to control situations through a flexible approach to their normal way of working:

I've even booked three girls to get, you know, to get an antenatal booking history, you know it's quite confidential and, you know, on a one to one. And yet you get three come ... 'I've brought my sister and I've brought my friend.' I said 'well I'll see you one at a time' ... I'm thinking but if this is the only way I can do it and get three of the girls booked and you know, on the books at the same time they might as well.

Midwife Rowan surgery

However, although a flexible approach is not always appropriate, clinical staff are still able to assert control of a situation with more authority because of their relative autonomy and their status as professionals. One Walk-In centre nurse, indicating a marked contrast to the previous example in terms of empathy, described her

immoveable approach in the face of demands for treatment that she deemed unnecessary or inappropriate:

They expected to be treated for something that they thought they'd got, which they hadn't got. But however much I tried to persuade them that they didn't need treatment they insisted that they did because it was what they thought it was. ... I just kept asserting that I would do what I felt was right and I wouldn't budge and just kept repeating myself until they left.

Clinical staff more frequently used ways of managing their own feelings and reactions rather than trying to assert control over the Gypsies' behaviour. An attitude of acceptance was one method described to help to achieve some feeling of control despite the pressures, and at the same time demonstrating a form of positive discrimination:

We're just going to accept that it's going to happen, and when we do we're going to just do the business and not say 'Oh God they're going to ask for the next one' ... I mean it's going to make us run late, but they make your run late anyway so it just means that at least we're doing it out of our own planning rather than feeling we're being [] which might make us feel different about it.

Doctor Rowan surgery

However, receptionists, who have less power to make such decisions and have to follow directions, are less able to be accepting and can feel resentful that Gypsies and Travellers appear to them to be taking advantage of them, as this Elm surgery receptionist complains: "They know how to work the system." This is yet another reference to the failure of Gypsies and Travellers to conform to 'the system', whether through lack of knowledge or as deliberate strategy.

8.4.3 Exposure to public gaze

This pressure from conflict is greater for reception staff because they play out their roles in the public arena of the waiting room, whereas clinicians mostly engage with patients within the privacy of consulting rooms or treatment areas. In addition to facing embarrassment, reception staff are concerned that other patients would see them as apparently caving in to pressure by giving preferential treatment to Gypsies and Travellers, and to be rewarding unreasonable behaviour (as suggested by the use of language 'waltz in and shout'), rather than recognising and responding to anxiety or urgent need:

...[Travellers] waltz in, shout at the receptionist and get an appointment with the doctor they wanted to see now, that creates tension for the staff at the counter to be seen to be being fair.

Doctor Rowan Surgery

Clinicians' ability to adopt an accepting attitude depends partly on their interpretation of the situation. It is easier to have an accepting attitude when there is better understanding of the behaviour:

when it first happened it was terrible because you know, it felt like they were doing it on purpose. But as they were there a bit longer and in fact they only came when the children were really ill and it was because they were worried; it was their emergency. I think once we decided, "Well, when they come, we'll see them" it all calmed down and you know, the tension went away.

Doctor Elm surgery

In summary, all health staff experience various role related pressures. Receptionists are the first people to encounter Gypsies and Travellers when they arrive at the health care setting and are the most likely staff to experience overt manifestations of anxiety related to reasons for attendance or to fears of being denied access. They also experience pressures in managing requests that involved them in a 'gatekeeper role'. The combination of lower status and fear of exposure in public obstructs trust and good communication for receptionists. Clinicians experience pressures in respect of professional responsibility and accountability in their role of providing safe and appropriate health care. However, the greater autonomy and status of doctors, and also of nurses in a range of roles, facilitates greater understanding and opportunity to resolve misunderstandings arising from cultural expectations.

8.5 Service Delivery.

In the organisations discussed here, distinct approaches to service delivery appeared to be dependent on several interrelated factors:

- Local setting
- Internal structure
- Internal culture and ethos
- External policy context.

8.5.1 Organisation settings

There are clear differences between the different settings in relation to the demography and the level of local need in the Gypsy and Traveller and the wider patient population, as we saw in Chapter Five. Elm surgery has a relatively small stable population of Gypsy and Traveller families who were housed in the area. Through familiarity, these are viewed as posing less difficulty:

our static patients, learn how the system works and they then recognise it, you recognise it and you all play the same game. Doctor

However, the relatively small and fluctuating population provides less opportunity or incentive for staff to gain a better cultural understanding of problematic behaviour:

It was more an issue of when they had that illegal Travellers' site just up the road. We use to get a period, a year or so, we had a lot of young families there and then they would just come with a baby with fever. Doctor

In contrast, at Rowan surgery there is a considerable and constant impact on workload from a large regular and transient Gypsy and Traveller patient population:

you very often get an appointment for one, if you're lucky you get that one but they usually come in as an urgent and then they will ask for the rest of the family to be looked at, at the same time, one after the other ... Doctor

Use of the narratives was helpful in eliciting in-depth responses from different staff. There were marked differences in responses in the two different practice settings. There were mainly empathic reactions from all grades of Rowan surgery staff, including receptionists; for example in response to a narrative about a young Gypsy's failure to obtain diagnosis and treatment for worrying symptoms from her GP, as they commented on the patient's feelings:

feeling as if she's being fobbed off. Receptionist

I guess she'd be on the defensive from word go. She'd always go in with the idea that nobody is going to tell her what's wrong with her and that nobody believes her.

Nurse manager

On the other hand, defensive reactions were more in evidence in Elm surgery. Alongside a level of empathy expressed by the doctor and nurse who participated, there were more 'victim-blaming' responses to certain narratives from the receptionists;

Doctors are getting a bit of a slating in that one weren't they?

They need to perhaps be more aware of diet and things and everything.

I think they do need to be a little bit more educated.

She's trying to say that that's all down to misdiagnosis as well, it's a bit ... overstated isn't it?

Receptionists

There is less evidence from receptionists here of a perceived need to understand the underlying feelings of mistrust illustrated in the scenarios and to work on building that trust. However, most of the narratives used with staff pertained to clinical encounters rather than waiting room situations, so because the examples were less directly relevant to their situation reception staff may have been less self-reflective in discussion. It is also possible that differences in attitudes between receptionists in the two practices were influenced by other factors such as the practice ethos, which I explore later.

In the Walk-In Centre, the staff team composition and their roles are quite different from those in general practice. However, at this centre relatively few Gypsies and Travellers were known to attend; "it's very rare that we see Gypsies and Travellers at all" - and therefore there was a relative lack of familiarity with Gypsies and Travellers as patients, and awareness of their specific needs.

8.5.2 Organisation structure

A fundamental difference in structure between any General Practice and a Walk-In Centre is determined by its function. A General Practice has a registered list of patients and provides continuity of care from a primary care team. Historically the service has developed from the concept of the local 'family doctor'. It is GP-led; patients from a defined catchment area are registered with a GP, not a primary care team. Walk-In centres provide a complementary service to GPs, providing treatment for minor injuries and illnesses; they have only been in existence since 1999. A Walk-In Centre is a nurse-led service, and is in a position to offer a 'wait and you will be seen service.' Crucially

however, there is less continuity in a Walk-In centre and so less necessity to spend time developing relationships and building trust:

You're generally so quick, like every patient. They come in, you assess them and hopefully treat them and then really, you know, you don't have that relationship that you would on a ward, you know you're not nursing them daily. They come in for a service and hopefully they get that service. And they're gone. So it's a really quick journey so you're not exploring social issues necessarily unless it's highlighted.

However, Walk-In Centre staff feel that their service is more attractive to most patients than a general practice. The benefits they mentioned were particularly relevant to Gypsies and Travellers, who mostly express a wish to be seen without the hurdle of registration and waiting for appointments:

it's a different set up here, people come with more minor things and there are things that we can deal with swiftly that they don't generally have a very long wait for but you know if we, I mean, most of our patients are seen within a couple of hours and treated and discharged and people tend to get what they want when it's here.

The flexibility of a 24-hour service is an added benefit:

people think the service is wonderful because they can access it at any time that suits them and they can just pop in and they can get whatever ...problem they perceive they have at the time dealt with at their convenience.

These benefits had the effect of making it easier for staff to have relaxed and positive interactions with patients who are likely to be less anxious about whether they will be seen:

They always say oh we love coming here. 'You're always normal, you're always so nice', you know. Some of them come in for a chat sometimes I swear.

Factors that deter Gypsies and Travellers from attending a GP, such as reluctance to attempt an explanation of their medical history, fear of being misunderstood and crucially, fear of being refused (with ensuing conflict in the waiting room) would all seem to point to a high level of attendance at this Walk-In Centre. It is unclear why this

is not the case; it may be that the service is relatively unknown to Gypsies and Travellers, combined with the fact that fewer of them live in or pass through this specific area.

There are further differences in structure between the two participating GP practices. The workload impact of a large Gypsy and Traveller population on Rowan surgery affords an opportunity to recognise apparent health inequalities. This also reinforced the message that effective and equitable service provision to Gypsies and Travellers is time-consuming and costly, and triggered a decision to apply for funding from the enhanced services initiative. Helped by this funding, they were able to take a more proactive, flexible approach:

We're actually trying to build that into the system, the enhanced service ... So actually we said right, well when we see one, we will actually deliberately ... take the medical histories of all the others as well and we fill in as many of our little templates on rest of the family...

Doctor

In contrast, the workload pressures from Gypsy and Traveller patients in Elm surgery, in the absence of eligibility for extra funding, militates against giving the extra time required for proactive health improvement:

you feel, you know, I've just had four of these and then you think, well what, you're sort of formulating how much time have I got, so how quick, quickly can we do this. You know you've got to give them a certain amount of time, you cannot do this in five minutes, you know they've got to have 10 to 20 minutes... if I hadn't got the time then to really talk about it, we'd have done the bare necessities but got her back again.

Doctor

Some structural differences in the practices are facilitated by the enhanced services provision as they enabled a dedicated worker to provide outreach work with LH, the area specialist health visitor. Rowan surgery staff acknowledged that their ability to set up an enhanced service for Gypsies and Travellers was also facilitated by the role of the specialist health visitor, particularly in developing outreach services:

we didn't announce that we were coming and I'd got [health visitor] with me and that was OK because a lot of them recognised her.

Nurse Manager

There was a partnership approach to developing the service, with the practice nurse manager acknowledging the need for the health visitor's contribution:

I'm not sure it would have happened in the same way...I suppose that I was a key player for [health visitor] and she and I wanted to develop different...so that they could understand what services we'd got here.

However the Elm surgery doctors wanted the specialist health visitor to take on a greater advocacy role to improve communication in the absence of a trusting doctor-patient relationship. This emerged in suggestions for improving communication in one of the narrative scenarios:

Well she could've spoken to the health visitor, the health visitor could arrange, (laughs) act, acted on her behalf, come with her to the consultation, sit with her and try and help move things along. (pause) Sometimes you just don't if, you know, you, you're rushed, you don't want to delve, you may be, you know, maybe you could have got her to come back at another time and spent some time with her as a longer appointment time just to sort of sort this out, you know, a double appointment like sometimes we do.

8.5.3 Organisation culture and ethos

Despite acknowledgement of differences in type of service provision, the Walk-In centre staff tended to feel that it was their team philosophy and non-hierarchical ethos that has a major impact on their approach and resulting patient satisfaction:

We are a team ...we all talk to one another. There is, nobody's 'oh I can't talk to her because she's senior to me' or 'I should really sort this out.'

Nurse

They feel that this team ethos is influenced by and encouraged by their manager:

Yeah I think that attitude is throughout the ward ... And that's something that, you know, [manager] promotes. He has this big open door policy and he's happy for us all to sort things out ourselves and it does work, you know. Nurse

They also suggest that their non-hierarchical team ethos can explain the difference between attitudes of their receptionists to those of receptionists in GP practices:

From a service approach I think what happens is in other areas is that to get like sort of receptionist protecting the doctors, they all get caught up in their little ivory towers and I think they actually forget what they're there for. Without the patients we wouldn't have a job. They're there to provide a service and they should just get on and do their jobs really and I think people should just get down off their high horses a little bit and certainly, you know, breaking down the barriers within units. It does work if people start to talk to each other a little bit more.

Nurse

Although the suggested explanations may need some scrutiny, there was a similar view from one Elm surgery doctors about their receptionists needing a reminder about attitudes to patients:

our reception staff are a good hardworking bunch but patients tend to be seen as nuisance.

She pointed out that this attitude was apparent with patients generally, not just Gypsies and Travellers, and that senior staff were endeavouring to change the policy, and to explain via the practice manager that 'actually, patients are not a nuisance and they are who we are here for.' This remark was made to me quietly to avoid being overheard, as we discussed the reception staff's defensive reaction to the feedback of preliminary findings. The discussion reinforced my perception that there is minimal communication to the reception staff of a practice philosophy and less of a team ethos. There appears to be dissociation in the way problems are conceived and it demonstrates how relatively unsupported the receptionists are in the way that this practice functions:

I don't think we see an awful lot of Travellers. I don't think it's a very big problem. I think the thing is we're on the most part flexible enough to cope with people and whether we see Travellers or not is really is a receptionists' problem rather than a doctoring problem.

Doctor

The main motivational ethos in this practice appears to be 'fire fighting' and 'damage limitation' in order to manage the immediate situation, with a flexible approach being a case of accommodating and reacting to needs or demands in order to avoid conflict and tension.

Yeah I think you know you tend to know the demanding ones, don't you, the ones who are going to want something like yesterday and we know the ones that are really nice and you can manoeuvre them and they'll accept what you say to

them but obviously the ones who go the other way, you've got to give whatever they want to really get rid of them ...Because otherwise they cause a scene or you know.

Receptionist

This appears to have the desired effect of avoiding a feeling of hopeless struggle to resist in the face of persistent demands. However, this pragmatic approach to flexibility appears to give only short-term benefit and is an ineffective measure for building trust and improving service provision.

if we could deflate , sort a quarter of the hassle, or a small percentage that would be worth it. If we can form a bridge, that would make it easier, and that would be a whole lot easier for the staff. For peaceful living...for them and for us.

Doctor

Despite a reactive approach, this practice does adhere to their philosophy of accommodating needs of any patients who wish to be seen, despite the inevitable pressures and demands:

I must admit, working here we do try our best with anybody in that's needs to see us...So I think here we are a lot more relaxed than some of the others.

Doctor

In contrast, a team ethos is more apparent in Rowan surgery. An example was the felt imperative to include and inform the reception staff in respect of the enhanced service developments:

One of the next things I think we need to do - staff. Doctors by and large know what's going on, but we need a staff training session about the Travellers because I think there's a lot of a misconceptions ... Did a fair bit about that at the last staff meeting, went through what I was doing why they were coming, why they were being registered and that you know, there was an assumption that had, they were, there was a cultural need for us to understand their needs.

Nurse Manager

This team ethos, in which reception staff are respected and included, is associated with facilitating respect in a patient-focussed approach. Although Rowan surgery staff also show a resigned attitude to accepting the behaviours and attitudes of Gypsy & Traveller patients, as we have seen, they redesigned service provision accordingly.

We did try...to take on board the fact that they just have a 'here and now culture'...The idea of planning ahead and coming back in six months to have your blood pressure checked or making an appointment in two day's time or three week's time is not something they do. They want a problem; they deal with it today, so in a way there's no good arguing with that.

Doctor

A practice ethos would seem to be influenced most strongly by the principal GP, who determines the basis for decision-making and the shape of service provision within the practice. We have seen how the local setting and context can influence these decisions, which in turn, will indirectly influence the team ethos. There are distinct differences in the two GP practices between a proactive and a reactive approach to work-related pressures concerning Gypsy and Traveller patients. These approaches also differ in respect of demonstrated levels of empathy and understanding. An Elm surgery doctor demonstrated a certain lack of empathy in the way he described his preferred self-protection approach to minimising the impact on his workload:

from the practice point of view, if you have a Travelling population [inaudible], there's really no reason to pick up this particular problem, because they're travelling [inaudible] sometimes. So the argument is that if you're not as approachable as you might be, then perhaps they'll choose somebody else.

Doctor

The same doctor described showed some empathic understanding of the thoughts and fears behind some of the tactics employed by Gypsies and Travellers, but used psychological tactics to defuse conflict by reducing anxiety so that he could explain and be heard.

someone comes in and says 'Yah, yah, yah' and I just say, 'Sit down; the answer's 'yes.' Right, that then deflates the whole argument and ... you can then have an open channel of communication and you can say to them, 'In reality I'm not going to do what you want me to do, and this is why. But now you're listening, whereas before you were just (clicks his fingers) 'give.'

This reactive approach does not necessarily convey the respect and acceptance that is sought by Gypsies and Travellers as a prerequisite for trust. Rather it conveys a disparaging attitude:

Once you've got [them] to the idea that ...we will see them, we will then defuse that. We then have to build a contract of how they use us, and with the static patients whether they are returners, once they are happy with what we are doing with them, it works. And it's the difficulty of the people who stream through who you can't educate because it's like running a motorway café, you know, you don't see returners all the time and they are all going through.

It also does little to communicate a culture of understanding and empathy; this was apparent in the considerable misunderstanding, and poor communication, with resulting frustration, among the practice staff:

they give you a mobile 'phone number but they never answer; they never respond to messages; they're never at the address they've registered at. And then one family is living in Birmingham! and just happened to be registered here so they could have a baby, and then you end up wasting time. And then the next time you see them, they're shouting at you at the counter when you've been ...trying to get hold of them because they're anaemic and they need treatment. And then the next thing they're waving their fist at you in anger.

Doctor

The generalisations about the supposed reasons why Gypsies and Travellers are not able to be contacted are given here as justification for the sense of injustice that health staff feel at being criticised by Gypsies and Travellers for failure to communicate. There was a sense of defeat in the inability to improve communication and reduce conflict other than by yielding to demands:

we've...decided that they can't cope with the normal system and in a way you just have to try and fit, offer them what they need there and then. And it doesn't seem to us in the years that we've been practising here any other way of dealing with the situation.

Doctor

A Rowan surgery doctor describes a respectful patient-centred approach, using empathic communication skills to reduce anxiety.

there's a lot can be done with things like body language and just to give somebody the impression that their relationship is respectful and that they're with somebody who's not going to bite their head off or get impatient with them and you know. So I think there are signals that you've got to make to tell somebody that it's OK to tell me crazy fantasies that you might have had...

However he also concedes that much time investment is required to build a trusting relationship where there would eventually be less need to defuse situations. He also acknowledges that it is much more difficult when Travellers ask to be seen on an emergency or urgent basis.

if somebody's learnt to distrust doctors and had a lot of bad experience with doctors in the past it's quite tough to get past that I should think. I mean Travellers, because they often come in at the last minute wanting an urgent appointment, it's always been done, you know, on the hoof as it were. They probably don't get the time and get listened to... often they are seen at the last minute and fitted in because they've insisted. So you've got a grumpy doctor saying, 'alright then if they insist, I'll see them now, ok but I'm late already' and so they actually then don't get listened to properly.

We have seen that this insight is reflected in a practice culture of aiming to understand Gypsies and Travellers as patients and to consult with them on how best to meet their needs. This method of working in partnership with Gypsy and Travellers in a proactive approach provides the basis for a more respectful and patient-centred service.

8.5.4 External policy context

Clinicians experience a reduction in power and control, with reduced autonomy, in the face of new NHS policy directives, as we saw in Chapter Four. The impact of policy directives on communications with Gypsies and Travellers varies according to practice settings and contexts, including the size and stability of the local Gypsy and Traveller patient population. For example, whereas Elm surgery recognised that a drop-in surgery suited Gypsy and Traveller patients better than an appointment system, they were prevented from continuing to offer this:

previously we used to be open surgery so, provided you were through the door at 10.o'clock, you could be seen that day, that morning...Not any more; it's all appointments now...That was a government directive we had to offer an appointment within 24 hours and they wouldn't accept our open surgery as fitting that... They [PCT] made us change.

Doctor Elm surgery

This directive also reduces the likelihood of continuity with a preferred GP, which is particularly important to Gypsy and Traveller patients. This forced change in working patterns, is also seen as contributing to unnecessary conflict:

Whereas now someone might have been on the 'phone for half an hour and [then] have got an appointment with the doctor they didn't really want to see.

Doctor Elm surgery

NHS changes reduce the autonomy of doctors in other ways. The NHS payment systems in primary care have a major influence on how services for Gypsies and Travellers are structured; instead of incentives there are disincentives to respond to their needs.

Although Elm surgery staff recognised the clinical benefits of continuity in registering Gypsies and Travellers as permanent patients, they also felt constrained from a business management point of view: many families were either passing through or it was not considered viable to register them permanently due to new conditions for receiving payment:

with the static patients and now more and more when we're sort of picking up on asthma, diabetes, hypertension, and things like that this is very much termed care. That is to say you see people regularly, you check they haven't got blood pressure, you check they haven't got asthma, you check their diabetes etc, etc. Now with a peripatetic population that just doesn't happen...If you're going to take some of those population into our list, then we'd like to open channels so that these will come to diabetic clinics and the asthma clinics and whatever clinics, because we are now being paid on the completeness of our care.

Doctor

They recognise that it would be difficult and time-consuming to encourage Gypsies and Travellers to attend for regular preventive care and that even by doing so the resulting extra workload may be an additional burden:

I know this is absolutely anathema to say this but the reality is that it's much easier not to... pick up problems if you can get away with it. So, if you take that argument, are you going to open your doors and say, 'Yes, all the Travellers must come here, no problems'? The answer is, "No you're not". So, so you know, we've actually got enough work to do without looking for work ... or being completely altruistic and make work for ourselves, with an occasionally difficult population. The answer's 'not really', we would like to do our share and we appreciate that it would be nice to do that share in sharing with everybody else, but we're not looking to put ourselves forward as ...first class ..., simply because we have got enough work to do already.

Doctor

In summary, although all health staff described challenges in developing trusting relationships and effective communication with Gypsies and Travellers, there were

some marked differences in outcomes. Negative assumptions and expectations in the context of varied level of impact from Gypsy and Traveller patients appear to be influenced by the underlying philosophies shaping service delivery. Staff in the different practice teams had developed either reactive or proactive strategies for service provision to Gypsies and Travellers. In either approach the view appears to be that acceptance and flexibility are required to deal with particular issues. However there appear to be subtle differences in the underlying philosophy of the approach. There is a more resigned reaction to the difficulties within Elm surgery, with some distancing from patients reported by doctors, aimed at reducing the likelihood of picking up extra problems. This approach seems to pervade the practice ethos; it is mirrored in the patient waiting room. Here the reception desk is unattended; patients are required to ring a bell if they want to speak to a receptionist. The doctor calls them in by means of a buzzer and a LED display. Such distancing and avoidance of casual interaction in this way further reduces the opportunities for developing trusting relationship, although from a practice management perspective it is likely to be seen as an effective tool for efficient use of receptionists' time.

The degree of staff empathy and understanding appears to reflect the overall practice philosophy that is filtered down either by example or by means of training and policies. However, various interrelated organisational factors and practice structures, related to local settings and context, interact to influence attitudes towards Gypsy and Traveller patients. An Elm surgery doctor remarked that other practices (none included in this study) deal with anticipated problems by trying to avoid seeing patients where possible: "there are places where the main aim is not to see anybody if you can." Although this exaggerated remark was made partly in jest to emphasise a point, it is an observation born out by participating Gypsies and Travellers in both phases of this study, who reported difficulties in getting registered or seen by various GP practices. This suggests that the reactive strategy reflecting the practice culture in Elm surgery is not unusual. However, the team ethos and respectful and inclusive practice culture at Rowan surgery is reflected in a proactive patient-centred approach, where service delivery is developed in partnership with all stakeholders, including importantly, Gypsy and Traveller patients. The differences in organisational structure and function appear to facilitate a similar cohesive team ethos and respectful patient-centred approach at the Walk-In centre. However both examples indicate that these factors are important for good communication with all patients. Rowan surgery staff have also shown how they

recognise the need for cultural awareness and understanding in combination with these factors in order to achieve optimum communication with Gypsy and Traveller patients.

8.6 Responses to Feedback

There are clear parallel themes in the separate health staff and Gypsies and Traveller findings. There are often mutual low expectations and misunderstandings, sometimes arising from past experience and sometimes from stereotypical impressions. Hidden background pressures for each group exacerbate the tensions and intensify a climate of fear and mistrust. Trust and respect appear central to any outcome for Gypsies and Travellers. If their first experience at reception gives a sense of being unvalued this is likely to influence their expectations of the practice as a whole. It reinforces any experience of being discriminated against and often leads them to resort to various tactics to obtain the treatment they feel that they require. This in turn increases the pressure and sometimes the fear for the health staff. Conversely, when Gypsies and Travellers feel valued they are more likely to trust the health staff and the explanations, advice or treatment that they offer.

8.6.1 Responses to Preliminary feedback

Rowan surgery

Rowan practice staff felt that their perceptions and knowledge had changed as a result of awareness sessions they had attended since the focus groups were held. They suggested that this improved understanding may also have influenced their present attitudes and behaviour. Despite this there was an understandable consensus that their attitudes can still be adversely affected when faced with aggression from Gypsies and Travellers and that the fear, aggravated by the unpredictability of such behaviour, creates a barrier. These staff, like those in Elm surgery, felt that Gypsies and Travellers did not understand the role of receptionists. The key health staff participant commented that

it is interesting that during the discussions with healthcare workers there is a general stereotypical attitude towards Travellers, but equally there is the same stereotypical attitude from Travellers towards doctors and nurses.

She commented: "In the end we really are ALL the same"

Elm surgery

Elm surgery reception staff were more defensive in their comments and interpreted the report as a one-sided account that was critical of them as receptionists. They agreed with each other that:

it is wrong that aggressive /rude/threatening behaviour that I have experienced personally from Gypsies and Travellers has been overlooked.

no matter how hard we try we are always the one's who end up looking mean and uncooperative.

They also repeated other comments that were in the original report and confirmed their view that Gypsies and Travellers were unreasonably demanding and did not merit any "special treatment." As I received this information indirectly via the GP I was not able to discover from the receptionists why they felt that the report had ignored their experiences, when in reality they had been clearly reported. This was one major disadvantage of being constrained to send a report instead of having the opportunity to share the findings at a meeting with the participants. At a meeting I could have given them the opportunity to vent their frustration again and invite them to consider and explain the basis for their frustration. However, the strong sense imparted by their comments, that their difficulties had been under-reported, possibly militated against any change in perception or gains in understanding of the Gypsy and Traveller perspective. The GP key participant felt that the report "emphasised the huge divide in understanding and lack of acceptance on both sides." Neither of the two clinicians who had commented felt that there was an easy way to resolve the issues within general practice, and the doctor repeated the view that a specialist health visitor was helpful as an advocate.

Due to the aggrieved responses from the receptionists in this practice I arranged a meeting with the GP to discuss my offer to meet with them (see Chapter Five). At this meeting the doctor could not understand why the receptionists felt criticised or blamed but agreed with my suggestion that they perhaps felt more helpless in the face of the difficulties as a result of their lack of autonomy in a receptionist role. She said that she had spoken to them at some length and they did not want an opportunity to air their views with me, not because they felt angry, but that they were just not that interested.

She clarified this by saying that Gypsies and Travellers were 'not a big issue' for them at that time as the current Gypsy and Traveller patients tended to be static and housed.

However she also said that they are now looking at how to best deal with situations rather than just digging heels in and saying "you can't have an appointment." She mentioned that there was one particular Gypsy, who had always been seen as 'a problem' and with whom there were frequent confrontations, and said that they were now tackling this in different ways and seeing how they could work things out. When I asked what may have influenced their changed approach she postulated that "it might be that they've looked at this [feedback]"

8.6.2 Interim feedback to Rowan surgery

Following discussion with the key participants it was agreed that I should come to present the interim feedback at a specially arranged staff meeting. Due to the limited available staff time and the need to include evaluation I condensed the interim findings to an overview of the main themes that emerged from each group of participants and an illustration of the overlapping linked factors. I explained that each theme fed into and resulted in either empathy or misinterpretation and these outcomes were closely associated with levels of trust. I continued by illustrating the different strategies used by both Gypsies and Travellers and health staff for dealing with issues. I finished with two examples of analysed narratives to illustrate these findings.

The staff did not express great surprise and were in general agreement with the findings. However they suggested that the combination of the cultural awareness sessions and the earlier preliminary findings had helped to change their perceptions. The GP, who had already demonstrated an empathic attitude and a high degree insight into the Gypsy and Traveller perspective in the focus groups, commented that he had gained much new understanding and was surprised at his previous level of misunderstanding.

8.7 Conclusion

In summary, the health staff have revealed explicitly that there is considerable, negatively perceived impact from Gypsy and Traveller patients on service delivery and that communication often takes place in a climate of misunderstanding and conflict. The contrast between the different organisations in this study, reinforced by the variable

responses to feedback, has revealed the relevance of many interrelated factors; the practice organisation, the local setting and demographics of the patient population in the context of external health policies. These factors either hinder or facilitate a respectful and inclusive team ethos and a patient-centred approach, developed in partnership, to improved relationships and communication with Gypsy and Traveller patients.

Introduction

Chapters Six, Seven and Eight have provided many examples of poor relations and conflict between Gypsies and Travellers and NHS staff in healthcare contexts. In this chapter, I begin with a brief overview of some key themes in my findings, and identify some parallels in the ways in which health staff on the one hand, and Gypsies and Travellers on the other hand, approach their mutual encounters. Some points appear specific to health care contexts: for example, the impact of government health policies, health service settings, structures and personal anxieties about health. However, each of these themes raises broader issues too. Following the initial overview, I draw on some of the theoretical perspectives that have become prominent in health-related research as I first discuss a number of points concerning power relations and inequalities at the societal level. I then move on to complement this by examining the ways in which a dialogic perspective can enhance an understanding of communications processes at the interpersonal level. In conclusion I discuss some implications of these findings for service delivery and staff training.

9.1 Gypsy and Traveller perspectives: racialised identities, mistrust and low expectations

Gypsies and Travellers spoke of a strong sense of identity and perceived themselves as 'different'; often referring to shared group understandings of cultural rules to explain their experiences. Their strong sense of 'otherness' and perception of having a racialised and devalued identity leads to an underlying distrust of Gorgers. This distrust is extended therefore to Gorgers health care staff, but it is also informed by past experiences and by stories within family and social networks, often concerning past medical errors and misdiagnoses. We have seen how Gypsies and Travellers often attribute such errors to discriminatory lack of care based on their identity. In turn, this leads to low expectations, and to the adoption of various strategies to manage health for as long as possible without recourse to health services. The consequent delay in attending for conventional primary health care can lead to more serious morbidity at presentation, thus fuelling fears and anxieties about the possible prognosis. The urgent

need to be seen and treated at this stage intensifies pre-existing fears of being refused an appointment or being taken seriously. Any refusal of a request for an immediate appointment or failure to receive a thorough examination can easily be perceived as a sign of discrimination, further reinforcing the underlying sense of a devalued identity and fuelling distrust.

As discussed in Chapter Seven, a sense of shame plays a part in this sense of devalued identity. As these experiences are interpreted in this way, stories about particular doctors, nurses, or even health institutions are circulated and become stereotypes. Reputations, whether good or bad, founded on rumours, influence subsequent contacts and communication with health staff. So for example, we see how a particular doctor is shunned by Gypsies and Travellers on the basis of a story which is circulated of his misdiagnosis of a Gypsy child's illness (p199). Similarly, but in contrast, we see another doctor being labelled as 'good' on the basis of a satisfactory consultation; he is therefore subsequently inundated with Gypsy and Traveller patients who have learnt of his reputation (p202). Receptionists in particular can be seen stereotypically as being there to 'keep the Travellers away' (p214) and we see how Gypsies and Travellers devise defensive strategies to resist possible dismissal, literally or attitudinally, and to obtain the care that they require. Such strategies can exacerbate tensions between them and health staff.

9.2 Health staff: some parallel preconceptions

Health staff also bring their preconceptions to encounters with Gypsies and Travellers. These, too, are based on prior experiences and / or on the stereotypes that they hold about Gypsy and Traveller behaviour. We see examples of references to these stereotypes among all disciplines of health staff and in all settings. There is a clear perception of Gypsies and Travellers as "so out of character to the majority of the nation" (p263). This sense of them as 'other' is attributed to their 'closed society' or perceived lack of integration into wider society, with the result that most health staff have very little personal experience of Gypsies and Travellers outside the workplace. Any knowledge of Gypsies and Travellers is therefore based on prior experience in health care settings or by report and reputation, often informed by negative media portrayal. Staff comments reveal anticipation, based on such stereotypes, that Gypsies and Travellers will be difficult and challenging; often, any behaviour based on social

discomfort or medical anxiety is interpreted as fulfilling these expectations, thus reinforcing any prejudices.

However, we also see evidence of various work-related pressures that contribute to the difficulties that staff experience in their encounters with Gypsies and Travellers. Some of these pressures relate to the individual staff members' identities in various roles and their associated responsibilities. For each staff member, in whichever role, there are expectations of how 'good' patients should behave. For example, we see references to 'playing the game' and 'knowing the system.' When Gypsies and Travellers do not conform to these expectations there is increased pressure on the staff members' abilities to perform their roles. Such role pressures vary in intensity according to the degree of exposure to the public gaze. For example, receptionists face potential humiliation in a public setting, when there is conflict with Gypsies and Travellers; on the other hand, nurses and doctors usually have the privacy of a private consultation room or clinic room for their face-to-face encounters.

In addition health staff experience work pressures related to current health policy directives, such as the need to meet government targets in areas such as immunisation, for which failure means financial penalties. We also see health staff endeavouring to fulfil wider policy directives, such as the duty to deliver equality of service provision. We observe their concern about how they may be perceived, in the eyes of other patients, to be favouring Gypsies and Travellers if they make exceptions to accommodate their specific needs. There are other difficulties associated with staff-patient relationships in the context of wider government policies, such as the 'choice agenda' (see Chapter Four), and the consequent pressure to treat patients as consumers. For example, in contrast with earlier paternalistic approaches in the NHS, doctors are now expected to involve the patient in dialogue during the consultation. We have seen how some Gypsies and Travellers interpret this as the doctor's lack of conviction in his/her own abilities and view it as a sign of incompetence.

9.3 Common patterns

From these two summaries it is apparent that there are a number of parallels. Both parties have internalised stereotypes which inform their attitudes to each other. This was indeed observed by a nurse in this study as she digested the feedback from the study

findings and commented “in the end we really are the same” (p288). Each party also brings to their encounters their own different expectations based on their personal experience and particular social or cultural context. Gypsies and Travellers themselves recognised that their defensive strategies served to exacerbate tensions (see p242). However, despite the expected outcome in terms of hostile reactions, inducing in them strong feelings of shame and humiliation, they also felt that their defensive behaviour was unavoidable if they were to obtain the services they required.

In Section 9.10, I will return to the question of interpersonal communications between health staff and Gypsies and Travellers, arguing that a dialogic perspective can help to uncover the meaning of the lived experiences of both parties. However, as Giddens argues with reference to processes of ‘structuration’⁴⁸, these lived experiences cannot be viewed separately or disentangled from broader social processes. Giddens is critical of theoretical approaches which treat actors as free agents in the creation of meaning at the expense of acknowledging the influence of social settings. Although social structures are intrinsic to, and reproduced within, social interactions, it is important to understand how specific patterns of marginalisation or stigmatisation of Gypsies and Travellers endure and influence the behaviour of health staff. It is necessary to acknowledge wider or macro level forms of control that influence power relations at micro-level. For example, we need to see the wider context in which an Irish Traveller, when her unborn child is diagnosed as having spina bifida, may perceive the offer of termination of pregnancy as a tool of social control or an excuse to ‘get rid of one more Traveller’ and reacts accordingly (p215). It is equally necessary to understand the wider context in which health staff see Travellers as so ‘other’; “locked in their little pocket”⁴⁹ compared to “the rest of the world” (p264), and find their ‘otherness’ a source of frustration.

9.4 Marxist perspectives on power and social control

Marxist ideas have informed a very diverse range of debates and perspectives, and my intention here is only to highlight some main points with reference to my own findings. From a Marxist perspective, it can be argued that health care organisations and professionals play a key role as agents of social control in relation to subordinate communities and individuals, for example through limiting access to ‘sick certificates’ and to other aspects of care or treatment resources. For example, we see (on p216) how

Gypsies and Travellers feel marginalised and controlled on the basis of their social status and their failure to 'observe the rules' of attendance at an Accident and Emergency Department. Similarly (p283) we see an example of doctors using their power to limit and control the level of health problems that Gypsies and Travellers may potentially bring to their attention. Recent debates have also emphasised the ways in which current state health policy and provision focus on individual responsibility for health at the expense of addressing social or environmental factors.²⁷⁵ As one of the nurses points out in this study, "it's a really quick journey so you're not exploring social issues necessarily unless it's highlighted" (p278).

At a broader level, Marxist perspectives on state control have also contributed to analyses of the specific ways in which power is exercised over Gypsy and Traveller populations, for example through laws restricting mobility and limiting access to stopping-places. Gypsies and Travellers are still subject to a level of physical coercion that is rarely experienced by other community groups, when they are 'moved on'. We see this hostility towards Gypsies as nomads reflected in the stereotypical attitudes of some health staff in Chapter Eight. The distinctive worldview of Gypsies and Travellers, with markedly different perspectives on land and economy and on the notion of wage labour, has been unacceptable to the dominant sedentary majority; it has been seen by the state as a threat to the social order since their presence was first documented in the 16th century.⁴⁷⁷ From the beginning, the legislative response focused on their nomadism through forced settlement and assimilation. Mayall describes the motivation behind such policies in the 19th century, and I argue that this has not significantly changed today:

Travellers offended every sense of good order and morality. They existed on the fringes of society and of the economic and political spheres, and this marginality to, or rejection of, a conventional, settled mode of life made them suspect or unwelcome. They were to be feared for the implicit threat their existence posed to a method of thinking that was increasingly to stress immobility and regularity, and to be resented for remaining apart from the pressures towards conformity, whether legal, institutional, cultural, or the many subtle pressures towards socialisation.⁹⁰ (p92)

I suggest that it is this underlying attitude towards nomads that is reflected in stereotypes that depict Gypsies and Travellers as 'free agents' rather than wage labourers, and therefore outside of the controls exerted on other 'working class'

members of the dominant majority; hence common stereotypical references to not complying with laws about tax discs and car insurance. We see the implications of such continued hostility in the form of health practices: “if you’ve no fixed abode, they’ll no register you” (p213) and we have seen references in Chapter Seven to the need to attend Accident and Emergency departments as a means to obtain urgent health care when a doctor refuses to visit a Gypsy or Traveller on a caravan site.

9.5 Agency, identity and social control

In Chapters Six and Seven, we saw examples of the ways in which Gypsies and Travellers themselves showed awareness of the power that can be exercised through clinical surveillance, whether or not the exercise of power is intentional: “you felt like they [health visitors] were going to take the child off you, and you weren’t clean enough for them”(p230). However, this is not to suggest that patients are passive in the process, as this form of disciplinary power requires tacit consent. Lupton explains the relational nature of this form of power in medical encounters from a Foucauldian perspective, as providing guidelines about how patients should understand, regulate and experience their bodies and persuading rather than coercing them that certain ways of behaving or thinking are appropriate for them.²⁹⁹ We see for example on p227 how a health visitor’s advice is readily sought and adhered to, even in the face of its apparent failure to achieve the desired outcome. Foucault⁴⁷⁸ emphasises the relational nature of disciplinary power exercised by health staff; he argues that doctors are not, as some Marxist analysts would describe them, crude ‘figures of domination’, but “people through whom power passes or who are important in the field of power relations” (p247).

The exercise of disciplinary power or social control through surveillance does not apply exclusively to Gypsies and Travellers, and it is not the sole explanation for the communication barriers between Gypsies and Travellers and health staff. Other patients in health care settings are, in Foucault’s terms, ‘objects’ of disciplinary power. We saw examples in Chapter Four of how mothers can be subject to surveillance by health visitors to ensure that they are adequate parents. Patients are also subject to routine surveillance in the form of universal screening tests which they feel obliged to undergo, as Lupton²⁹⁸ describes, “through the rhetoric of public health discourse” (p35). Women in particular endure invasive screening procedures in the form of cervical screening and

experience variable degrees of pressure from their GP practice to attend regularly so that cervical screening targets are met.⁴⁷⁹

However, as Foucault argues, where there is power there is also resistance and patients have various means at their disposal of exercising their own power through resistance.⁴⁷⁹ We see many examples of resistance by Gypsy and Traveller patients in Chapters Six and Seven. For example, one woman explained that rather than face having to explain her non-attendance for antenatal appointments, she simply delayed the notification of her pregnancy (p218). Other more overt examples are indicated by the language used: “I’ll just fight and fight till I get it” [access to health care for her child] (p238). In such situations health staff can feel powerless, as can be imagined in the face of the behaviour described: “we had to kick up a fuss at the desk to try and get her seen” (p216). Social status is a key factor in power relations. Although all patients, depending on the context, may either undergo or resist power, this will be to a greater or lesser degree according to their relative social status, which is influenced by factors such as social class, age, ethnicity or gender. As Lupton argues, all of these factors may influence the motivation to challenge and resist medical dominance.²⁹⁸ This helps to explain why Gypsies and Travellers, with their racialised and stigmatised identity, encounter particularly difficult inequalities of power in health care settings. Foucault’s position on the link between power and knowledge is relevant here, as he argues that knowledge is the power to define others through discourse.²⁷⁸ In other words, disciplinary power is productive and operates through the construction of new identities, knowledge and practices, in terms of strategies, tactics, struggle and conflict.²⁷⁶ I am in sympathy here with Richardson’s (Foucauldian) thesis; she argues that control of Gypsies and Travellers is exercised through discourse, as they are defined as deviant and ‘othered’ by such discourse.⁴⁸⁰

9.6 Health staff experience of power and control

Importantly, health staff are also objects of social control and surveillance processes. Foucault explains how they have become agents of control of the population and are required to deal with the problems of “demography, public health, hygiene, housing conditions, longevity and fertility”²⁹⁷ (p67). Hence we see doctors or nurses focusing on activities that the Department of Health has set targets for them to reach, such as immunisations and health promotion. There is a risk that these activities become a

priority, taking precedence over the presenting complaint that has brought the patient to see them: “If you’re going to take some of those population into our list, then we’d like to open channels so that these will come to diabetic clinics and the asthma clinics and whatever clinics, because we are now being paid on the completeness of our care.” (p286) Staff and managers are penalised if they fail to reach targets, with the ultimate risk that their services may become less able to provide the level of care that they would like to offer. We saw for instance (p285), how staff were required to re-organise their practice in accordance with policy directives, against their choosing, in ways that did not necessarily appear to benefit them or their patients.

Power differentials also occur within health care teams, and the degrees of agency with which power is exercised among team members are influenced by the relative status of those team members. Hence, those who are afforded professional status, such as doctors and to an arguable extent some nurses, have greater autonomy and are able to exert greater disciplinary power through power-knowledge than receptionists. Hence we see receptionists needing to get a doctor or a manager to intervene when they are faced with challenges to the appointment system that, theoretically, they manage.

9.7.1 Managing social identities - Gypsies and Travellers

As discussed in Chapter Two, Nazroo has shown there is a relationship between ethnic identity and health⁵⁷ and we saw in Chapter Six that Gypsies and Travellers express a strong sense of an ethnic identity. Okely⁶¹ describes how early socialisation imbues a sense of identity by reporting how Gypsy and Gorgor are the first words learnt after ‘dad’ and ‘mum.’ I have seen similar evidence of this strong sense of identity in a very young Gypsy child who, on mishearing a play worker complimenting her on her ‘gorgeous puppy’, indignantly replied that ‘he isn’t a Gorgor, he’s a Gypsy’ [puppy]! As Barth has emphasised, boundary maintenance is seen as important for a sense of belonging and acceptance, and shared values are important aspects of ethnic identity.⁶⁷ The need for Gypsies and Travellers to confirm with each other that they are adhering to those shared standards, aspects of their ethnic identity with which their behaviour can be judged by other group members, can be seen in this context. This mutual reinforcing of group behaviour was evident in the jointly constructed accounts; participants often finished each other’s sentences as they explained a point. This informal exercise of control in the form of peer judgment or emphasis on group approval, and its role in

strengthening cultural norms, was described by a Traveller woman in Chapter Six who explained how her family were ostracised when she was 'down', presumably interpreting this as not displaying the required cultural attribute of stoicism, and how she met with respect when she 'got on her feet.'

When presenting aspects of their own culture to Gorgers, Gypsies and Travellers experience a similar need to ensure that there is a united front and that one is not standing out from the group. So when one participant points out how certain 'private' women's matters cannot be discussed in front of the male participant, she seeks reinforcement from one of the other women. This is the context for the explanation given for three young pregnant Traveller women wanting to be seen together at the one consultation; to ensure that none of them inadvertently creates a 'faux pas' that would be at odds with the cultural 'rules.' This illustrates the double dilemma for Gypsies and Travellers in managing their identities; they must ensure they are adhering to cultural norms to ensure acceptance within their group, and at the same time manage the presentation of their 'difference' and devalued identity as Gypsies or Travellers within wider society. The shame that results from a devalued identity, and how this shame influences communication with health staff, warrants further exploration, but first I will discuss how health staff manage their identities.

9.7.2 Managing social identities - Health staff

Health staff too, manage their identities in interactions with patients as they attempt to exercise control through the professional status afforded to them. Professional status confers autonomy to a greater or lesser degree. An identity as a doctor, nurse or midwife is one that implies authority through recognised formal expertise. Professional status is internalised, with tacit consent and recognition of scientific knowledge by patients. However, as we have seen in Chapter Four, with a government emphasis on patients as consumers, there is pressure on, and redrawing of, professional boundaries. This has led to some reconfiguration, with nurses taking on aspects of doctors' roles and some nursing tasks being devolved to unqualified staff. There are challenges to the authority of professionals from other sources. These include an increased Government emphasis on lay or experiential knowledge and on consumerism, through policies related to the Choice agenda and initiatives such as the expert patient programme.⁴⁸² We also saw in Chapter Five (p152) how collective action and campaigning, in the form of advocacy and self-help or from patient pressure groups, has led to a greater prominence of the

'patient voice.' Such challenges to a professional's identity and status can also meet with resistance and strengthening of professional boundaries by the health worker. There are still clear disadvantages for patients who openly challenge this status, as professional status remains a means of control of access to services. Example can be seen on pages 274 and 283 as a nurse and a doctor assert control in different ways in the face of demands for treatment that they deem inappropriate. Yet we also see examples of tensions where doctors, nurses and midwives are attempting to reconcile their authority with a moral or ethical obligation of empathy, and to involve the patient or accommodate their wishes, despite the difficulties and constraints on their time (p273). Receptionists face stronger challenges to their authority: their gatekeeper roles are not associated with high-status skills or knowledge, and they are dependent on approval or permission from doctors or practice managers for their actions. Their identity as gatekeepers is one that is perceived as powerful in some respects, as they control access to the medical and nursing staff: "the receptionists are harder to get past" (p214). However their role is also less valued than those of clinical staff and they are stereotyped as the 'dragon behind the desk.'³⁵⁶ As with Gypsies and Travellers and their devalued identities, such labels often become internalised and act as self-fulfilling prophecies.

However, as we saw in Chapter Eight, the ways in which health staff manage their identities and respond to the various pressures on their professional boundaries are dependent on a number of factors related to external policies and to key features of health care settings: the nature of the demography of the Gypsy and Traveller patient and total patient population, the organisational culture and ethos and the organisational structure. I have summarised these key features in a table (see Table 1) to facilitate comparison. This table also demonstrates an argument that these key features combine either to facilitate or to hinder good communication and can impact on the social identity of various members of staff. As we deduce from the table, an empathic approach, a requirement of good communication, is not necessarily solely the result of personal or professional values. We can also see the many constraints that militate against an empathic approach in the face of external policy pressures and the varying level of patient need in particular organisational settings. Such constraints appear to be compounded by a directive style of management, as we see when we compare the approach in Elm Surgery with a more inclusive partnership style in Rowan Surgery. Although counter-productive in terms of staff relationships and associated attitudes

towards patients, it is probable that the time and investment required for successful team-building has been sacrificed at Elm Surgery in the face of work-related pressures. As one doctor remarked in relation to a question about cultural awareness training: “what would you like us to stop doing whilst we have this?” Such extra demands on time can cause ambivalence in management of an identity as an empathic member of staff who is concerned with giving good patient care. In Chapter Eight we see this inner conflict in a doctor when she knows a patient needs more time and is simultaneously working out how quickly the consultation can be managed (p279). It is likely that individual personality traits and attitudes may also be relevant and that a senior doctor or team leader can model these attitudes and behaviours, thus influencing the behaviours of other staff members, but I suggest that the wider contextual factors are highly relevant and should not be ignored. However, as we have seen, the scope for displaying the values and attitudes required for good communication are also dependent on factors associated with different staff roles. Hence we see that it is easier for a doctor with a high degree of autonomy, high social status and low exposure to the public gaze to communicate effectively than for a receptionist who has low autonomy and freedom to be flexible, low social status, and who works in the public gaze in a waiting room. I have shown how identity maintenance is partially dependent on categorisation by others: that is, how others perceive and react to a particular identity. I have also shown the complexity of the ways in which wider social factors influence that identity. I will explore in greater detail the level of self-identity in face-to-face interaction, but before moving on to this I will now discuss the ways in which the inequalities experienced by Gypsies and Travellers can be seen as part of a wider pattern of social exclusion.

9.8 Cultural identity: Inequality, inclusion and exclusion

The contextual nature of a Gypsy or Traveller identity provides the link between ‘ethnicity as structure’, as described by Nazroo^{40; 53}, and the interrelationship with the contested concept of social exclusion. As discussed in Chapter Three, I use the term social exclusion as defined by CASE¹⁷⁵ (p67), broadly to mean involuntary lack of participation due to social pathologisation. For Gypsies and Travellers, for example, their identity is reinforced by their experiences of stigmatisation and hostility as a result of Government policies resulting in their exclusion, particularly in regard to accommodation. I will begin with the wider aspects of lack of participation in describing how government policies favour a sedentary existence and place limitations

on access to services, opportunities for employment and appropriate accommodation. All these important features of social exclusion are important in the wider social context and are relevant to health inequalities experienced by Gypsies and Travellers in this study. They also form the context to hostile public attitudes and the ‘othering’ of Gypsies and Travellers which I then move on to discuss in further detail with reference to this study.

It is not the identity per se that defines a Gypsy or Traveller as socially excluded, but rather the extent to which he or she is able to participate, according to how that identity is perceived, which in turn depends on power relations and degrees of agency. Public opinion can affect changes in social policy, and tacit consent is therefore given by the public to policies which serve to exclude Gypsies and Travellers from participation on the basis of their failure to conform to settled norms and the perceived threat or fear of their ‘otherness’. Gypsy sites policies which determine where and how Gypsies and Travellers may live are overt means of control.ⁱ In the preceding chapters the consequences of Gypsy sites policies are not only apparent in the psychosocial health impact on individuals but are also implicated in social relations between Gypsies and Travellers and the rest of society. MS, a housed Gypsy gave an example of this on p231 when she described how her neighbours reacted to the “mess your kind of people have left” when other Travellers had camped on land nearby. I will return to the implications of the wider context of social exclusion when I discuss the implications in terms of training and policy measures aimed at reducing health inequalities faced by Gypsies and Travellers. First it is necessary to understand the context for the ‘othering’ of Gypsies and Travellers and how this influences interaction.

Karlsen and Nazroo argue, with reference to the virtual and nominal components of identity⁴⁵² that the experience of racism can structure a Gypsy or Traveller identity and affect interaction with others as a result.⁵⁹ The long history of persecution and hostility towards Gypsies and Travellers defines the social context, resulting in the wariness and avoidance of close relationships with Gorgers. We see such suspicion and avoidance in a remark made by JP (p239) about how she would never have believed that she could develop a close friendship with a Gorger, referring to her socialisation in the belief that “all that Gorgers are good for are earning some money out of.” Many stereotypical, reciprocal fears between Gypsies and Gorgers persist as result of early socialisation and

ⁱ These include the CJPO Act 1994

these fears are continually reinforced. The discourse of deviance plays a role in the formation and management of identity. As Becker argues in his labelling theory, no particular behaviour is deviant in itself until others, who are more socially powerful, observe this behaviour and react by labelling it as such. Those who are labelled as deviant are cast as outsiders and thus excluded from wider society.⁴⁸³ As society reacts in order to control and repress the cultural nomadic lifestyle of Gypsies and Travellers, their identity and ethnic boundaries are strengthened as they resist control and assimilation. The discourse of deviancy permits discriminatory behaviour towards them based on the 'othering' of their identity, as McVeigh¹⁰⁷ argues "not because of what they do but because of who they are"(p22).

We see health staff attitudes towards Gypsies and Travellers as a deviant group expressed in stereotypical views of them as 'law breakers' and people to be feared and avoided. The outsider status of Gypsies and Travellers is seen by some as voluntary and they are then blamed for their failure to integrate. This is indicated by a nurse who views delayed presentation for health care as the patient's 'fault': "they are a fairly close community who tend to sort their own problems out." This view of voluntary exclusion ignores the context; so, for example, the nurse does not consider the possibility that the patient may delay seeking health care because of practical barriers to access or because of adverse or discriminatory experiences in the past. As Barry⁴⁸⁴ argues:

we should always look at voluntary self-exclusion with some scepticism... an individual or members of a group may withdraw from participation in the wider society in response to experience of hostility and discrimination (p14)

However where there is voluntary exclusion from participation, such as in the desire to live a nomadic lifestyle rather than to participate in sedentary ways of being, groups can be positioned as socially excluded in order to justify attempts at their social inclusion or integration. We can see from this study that ethnocentric attempts to integrate Gypsies and Travellers, by forcing them either overtly or covertly into a sedentary lifestyle, can have the opposite effect as they are denied their cultural rights and become more isolated from their extended families. We see examples in Chapter Six of families who experience open hostility from neighbours, without recourse to family support, and seek to avoid this with a return to a nomadic lifestyle.

It is the nature of contact with the majority population that is a key factor in prejudicial attitudes towards minorities.¹⁰⁹ The Cattle review of intercultural conflict in the Oldham, Bradford and Burnley ‘race riots’ in 2001¹¹³, commissioned by the government and charged with the task of seeking ways to improve community cohesion, identifies the lack of interaction between different racial and cultural groups involved and refers to their ‘parallel lives’ as a key factor in the breakdown. However, the Stonewall study¹⁰⁹ on attitudes towards minorities showed that increased contact and familiarity with minority group members alone does not necessarily reduce prejudice or provide conditions for respect.

There is incontestable evidence of the felt sense of exclusion from a dominant Gorgers society experienced by Gypsies and Travellers in this study: “It’s frightening being a Traveller because no-one wants you” (p174). More specifically, they describe situations where they perceive that they have been denied health care on the basis of their racialised identities: “It sort of opens the door for you feeling not wanted” (p239). Here the tension between ethnicity as structure and ethnicity as identity, as described by Karlsen and Nazroo, can be understood.⁴⁰ Whereas we have seen how the boundaries of an ethnic identity are strengthened in resistance to attempts at domination or assimilation, on occasions Gypsies and Travellers in this study expressed the need to conceal their ethnicity in the knowledge that it is a racialised identity. Managing necessary interaction with Gorgers - as is the case when there is a need to obtain health care, in the knowledge that a Gypsy or Travellers identity is one that is devalued - is a considerable hurdle for individuals to overcome. In Chapters Six and Seven we saw examples of practical tactics to conceal a Gypsy or Traveller identity to avoid discrimination, for example in order to ensure registration with a preferred doctor. However we also saw examples of individuals wishing to conceal their identity in the context of their awareness and perception of an inferior social status as Gypsies or Travellers: “they don’t look at you, the doctors, when they find you’re a Traveller.”

9.9 Impact of the shame of social inequality and exclusion on communication

Wilkinson’s argues forcefully that the psychosocial effects of social position have the greatest influence on health inequalities.¹⁵⁶ He has shown that at periods and /or in places where social inequality is greater there is a corresponding tendency for greater discrimination against other vulnerable groups in that setting, whether they are defined

by gender, ethnicity or class. He refers to the 'bicycling reaction' to show how this concept of dominance relations accounts for gender, class and ethnic inequalities and that they are inextricably related. This helps to explain why those who are regarded as inferior by virtue of their perceived social status may try to regain their sense of self-worth by asserting their superiority over those deemed 'below' them in perceived status. It can also cast light on the oppression that can exist within Gypsy and Traveller communities. Although I have explained the limited reference to gender violence in this study, its existence has been revealed (see p210). Wilkinson explains the relationship between violence and inequality as a consequence of the psychosocial effects of low status: it is not primarily a matter of increased violence between rich and poor, arising from a sense of material poverty; instead, violence is expressed more frequently among those with lower social status.¹⁵⁶

We can see such power relations played out in health care settings between Gypsies and Travellers and health staff. Forms of attempted dominance by health staff are not merely played out overtly by exerting power through coercion or aggression, they are also apparent in more subtle means of devaluing people through attitudinal behaviour that conveys lack of respect. This form of discrimination, that conveys a sense of their inferior status, is readily perceived by Gypsies and Travellers: "they make you feel like that big [ie small] then you won't ask them anything"; "they look down at you like you're dirt" (p230). As Goffman argues, those who are stigmatised can come to see themselves through the eyes of those who stigmatise them, and accept their devalued or inferior social identity.²¹⁴ It is this sense of internalised shame that results from disrespectful attitudes and /or discriminatory behaviour that is a key finding in this study. Gilbert⁴⁸⁵ concludes that:

shame is about being in the world as an undesirable self, a self that one does not wish to be. Shame is an involuntary response to an awareness that one has lost status and is devalued (p22).

I argue that this gives rise to some of the many references to angry outbursts by Gypsies and Travellers, such as "I lost my temper, it's all because we're a Gypsy" (p216) and that not all such angry outbursts are due solely to the sense of impotence at being unable to get their voice heard, and the resultant attempt to do so. One Gypsy participant describes the intensity and involuntary nature of the emotion in a situation where she

felt humiliated in the waiting room of a doctor's surgery: "you just explode, you don't know what you're going on about, you're setting on people for nothing" (p242). Gilbert describes the involuntary acute anxiety and rapid arousal that occurs in response to a shame experience as being evolved as a defensive reaction in a hostile or dangerous situation. This corresponds closely to the experiences described by Gypsies and Travellers in these examples: the situation is not only hostile from the sense of negative judgement from the health worker, but is exacerbated by the perceived consequences of an inability to obtain health care for a family member, often a child. This consequence further serves to violate the moral code of their Gypsy or Traveller identity as a 'good parent' and induces further shame in that respect as discussed on p247. We see further examples of internalised shame that result in other manifestations of acute anxiety. For example, another Gypsy participant describes how she starts sweating and blushing before she just has to 'walk out'(p241). These two types of shame response are classical physiological 'fight and flight' manifestations of acute anxiety.

There are some important consequences of these conflict situations, as they are anticipated by Gypsies and Travellers and by health staff, and frequently replayed in new situations. In Chapter Six I discussed one of the consequences for Gypsies and Travellers: a preference for a lay referral system. Use of a lay referral system is one means of avoidance which, as we have seen, can result in late and urgent presentation for health care when such other avenues have failed to meet continuing medical needs. We have seen that late presentation, along with the urgency that is expressed, is a source of irritation or frustration for health staff: "they often come in at the last minute wanting an urgent appointment... so you've got a grumpy doctor saying alright then if they insist..." (p285).

Many of these patient attitudes and behaviours, such as stubbornness, anger, demanding immediate satisfaction, have been described as features of patients who are labelled as 'unpopular' or 'bad.'⁴⁸⁵ However, the extensive research literature on the links between patient behaviours and staff responses, and various factors associated with the labelling of patients as 'good' or 'bad patients', has been criticised on empirical, methodological, epistemological and theoretical grounds.⁴⁸⁶ In particular Kelly and May reasonably argue that complex social reality cannot be reduced to statements about supposed characteristics of either patients or health staff without taking account of the social structure, and the immediate social context. They argue that the literature largely

ignores the interactive nature of communication at the expense of a deterministic role model, with particular reference to Parson's concept of the 'sick role' which confers certain rights and obligations on patients to cooperate with physicians in turn for legitimisation of their illness. As they point out, patients do not passively accept such roles; both parties have power to jointly influence each other's roles by accepting or rejecting attempts to impose role definitions on each other. Johnson and Webb⁴⁷⁵ consider the influence of power in relation to the Foucauldian concept of the clinical gaze, where value judgements are imposed by professional groups who are socialised to define patients so that they remain vulnerable and compliant. They make a convincing argument in opposition to this view when pointing to the self-awareness and guilt at lowering their own professional standards that many nurses experience when making such value judgements. We see similar examples of nurses referring to desirable professional standards in this study in Chapter Eight. There is then, strong evidence for a focus on the interactional nature of communication that considers the sense and meaning of the situations and how people modify their attitudes and behaviour accordingly.

In this section I have shown how social exclusion is closely linked to social inequality and how a lowered social status has a profound impact on social relations. On the one hand this is an aspect of wider patterns of social relations, but it is also lived out in individual interpersonal encounters. With this in mind, and with consideration of the context of the discourse of deviance and wider social control exercised on Gypsies and Travellers, I will now examine in more depth the interactional nature of communication between Gypsies and Travellers and health staff at micro level.

9.10 Understanding interpersonal communications: the value of a dialogical approach

Each party brings to an encounter their own expectations, based on their personal experience and particular social or cultural context. Thus we can see both parties in dramaturgical interaction as they respond and present themselves according to the context of the encounter. Below, I analyse two stories taken from interview data, in order to illustrate how this perspective can complement and extend the analysis already developed in this chapter. This general perspective can be understood in terms of what Goffman describes as impression management.^{487, 488} He refers to the significance of

face-to-face social interaction or 'the interaction order', where the way we see ourselves (self-image) and the way others see us (public image) come together in the continual process of informing social identity. In this symbolic interactionist approach to human relations he highlights the underlying cultural assumptions that a person brings to an encounter, based on prior dealings with others "of their kind":⁴⁸⁸

At the very centre of interaction life is the cognitive relation we have with those present before us, without which relationship our activity, behavioural and verbal, could not be meaningfully organized. And although this cognitive relationship can be modified during a social contact, and typically is, the relationship itself is extrasituational, consisting of the information a pair of persons have about the information each other has of the world, and the information they have (or haven't) concerning the possession of this information (p4).

This combination of the relevance of broader social context, the individual's unique experience and face-to-face interaction for creating meaning bears close similarity to Bakhtin's theory of dialogism.⁴⁵¹ He describes a combination of assumptions about human action, communication and cognition and refers to two fundamental concepts of a dialogic process for "meaning-making": interaction and context. This fits closely with the relational concept of social identity described by Jenkins⁴⁵¹ (see Chapter Two). Gwyn⁴⁸⁸ describes the dialogic principle as follows:

the individual self is socially constituted through its relationship to the other, ... it is through a process of co-voicing with another person that we establish individual identity (p244).

To focus on interpersonal communication at micro level it is necessary to recognise that although wider social contexts are important, the influence of each individual's psychobiography, which results from their unique experiences in childhood and beyond, is also relevant. As Layder emphasises, individuals do have a degree of autonomy and are not totally constrained through discourse, socialisation and cultural rules.²⁷⁶ We have seen how different worldviews frame understandings and influence social relations; when one group's worldview is privileged above another's by broader societal structures that support it, this can be considered a form of dominance which Bourdieu describes as symbolic violence.⁴⁹⁹

However, although we have seen the relevance of broader social control in creating the marginalisation of Gypsies and Travellers, deterministic models and postmodernist or Foucauldian models of power and control have their limitations when it comes to understanding why some individuals or organisations react differently from others within the same broad social context. These models are very helpful in the broader analysis of power relations, but, as discussed in Chapter Five, a dialogical level of analysis is more helpful in understanding interaction in the doctor's surgery at a micro level. In addition to being a theoretical approach to understanding the nature of communication, a dialogical lens can be used to explore narratives of patient-staff interactions and to uncover the meaning of their lived experience. These two narratives below, from my findings, demonstrate the potential utility of this approach and have also been chosen to reflect key themes in the broader analysis. One demonstrates an empathic and positive interaction and the second is an example of a conflict situation. In each narrative, using Labov's plot structure, I interpret the interlocutors' perspectives through a dialogical lens. Through this method we can see the extent of dialogic consciousness of each party in the co-creation of meaning in interpersonal encounters.

Story one

This story was told as a response to my interview question to a Gypsy Traveller woman: 'So do you ever go to a doctor?' It is illustrative of the empathic approach found among staff in Rowan surgery.

If I'm ill No. Just if I'm poorly, physically not mentally. No. I think I did once when I was at x town and the children were all small ... and I don't know what was going on. I think there was some people on the site where we were and I think they were all fighting and arguing and [winding] each other up and all things like that and I think it was getting no sleep and being run down and worrying of kids and he couldn't handle money and things was hard. And it was winter and I used to sit and cry and cry and cry. I thought what was wrong with me. There was something wrong with me. But I did go to the doctor on that occasion and I said I think I'm being paranoid or something because I am continuously miserable and I sat there and talked to him for a few minutes and he was a nice man and he said well what's your problem. I said I don't know and then he said half a dozen words and in that half a dozen words that he summed up exactly what was wrong...He said, he said, are you sick of your way of life? He was asking questions, he wasn't really telling me anything. And he said, are you sick of your way of life? Are you sick of where you are? And he asked me half a dozen questions and I thought (laugh) yeah. That is it. Spot on. What he was asking me was exactly what the problem was. And he gave me anti-depressant tablets and I said I'm not going to take em and I never took em. I went home. I said to me husband. If it's hard here, it's going to be hard

everywhere but the atmosphere was too bad. I said, 'let's go'. And he said, 'no we can't go'. I said, 'we have to go'. And that was the first time I think in a long time I put me foot down. I said we have to go. And we did, we packed up and went and that was about it...And that made it better. And I thought, he's right. Whatever that doctor had said, he was 100%.

So the answer to your depression was to move on?

Yeah. It was to move on. Yeah. It was the place we were, the people we were with, where we were, and I thought it was just me being all misery and grumbling and groaning and kids, but it wasn't. But it took me to sit and talk to a stranger and then in like I say in half a dozen words, he'd hit the nail on the head and he said, 'it's your way of life.' And I know, and how he was talking about it, yeah he was right. That is the total root of the problem".

This story illustrates cross-cultural empathy in a dialogical interaction. (see Appendix L for story in Labov grid). It highlights the culturally competent and empathic attitude of the doctor; at the same time, it illustrates the storyteller's need for legitimisation and an acceptable explanation of her symptoms. The doctor listens to the patient's story, and interprets and responds to the satisfaction of the patient. Here, the doctor did not use the monological single voice of an authoritative professional, by diagnosing depression and advising treatment (antidepressants) as the sole option. Instead, he listened empathically and this enabled him to uncover the lived experience of the patient and to understand her perspective, as he questioned her and interpreted her responses. He was able to convey that he understood her perspective by asking a tentative question about her current situation. In order to achieve this, the doctor relied on his empathic sensitivity and engaged in an exchange of information that made her feel valued and vindicated. His tentative question validated her feelings and helped her to interpret them with new meaning. Being understood in this way empowered her to act. Not having information about where the doctor was based, we are unaware of whether he had some degree of cultural knowledge or whether some of the organisational factors illustrated earlier in this chapter may have allowed him to act more empathically.

The story-teller patient brings with her a sociohistorical context of self-reliance and 'keeping up a cultural tradition of stoicism'; in this context, she was feeling overwhelmed and defeated in relation to harsh and devaluing 'others.' The doctor engages in dialogical interaction to allow his questions to inform the patient's understanding. She is enabled to be confiding and open in relation to an empathic and caring 'other' and is able to find meaning in her situation, in a way that she had previously been unable to identify and articulate; she can respond to the doctor's empathy with the statement of her cultural need to 'physically move on' in the face of difficulties. She then feels validated, encouraged and empowered in relation to a

validating, encouraging and empowered 'other'. She has ultimately been enabled to make an informed decision about the best solution to her distress, through confirming and compassionate articulation by the doctor in a process of culturally empathic interaction.

Story two

This story was recounted by a receptionist describing a difficult encounter with a Gypsy patient. It illustrates the conflicts that can arise and which were more prevalent in the Elm surgery setting.

Receptionist A. I mean we had a lady, I think it was last week, I don't know whether she was taken into hospital and sectioned or something she wanted a prescription for an antihistamine and she tried every desk and there was nothing on the screen. She wasn't on a repeat and we kept saying you know, I'm sorry we can't just give you them. You've got to see a doctor. And she tried every one and then she'd storm out. 'Oh I can't breathe so if I drop dead will you call an ambulance. What do I do? You know. And she was shouting and every body, you know.

Receptionist B. Shrieking and ...

Receptionist A. You know and she didn't get it at one desk. Anyway in the end I think she, Dr X actually saw her as an urgent and she got her antihistamines what she wanted.

In this story about conflict and disruption from Gypsy and Traveller patients, staff express a judgmental and resentful attitude to their behaviour (see Appendix M for story in Labov grid). Use of Labov's plot structure helps to identify an apparent initial resentment on the part of the storyteller, i.e. the receptionist, to being asked for an unauthorised prescription. This fuelled the resulting cycle of demands and refusals. In a dialogical engagement with this story and examination of the different perspectives and sociohistorical contexts of the interlocutors, this analysis can be taken further.

The receptionist is situated in a role in which she has rules to follow about responding to requests for prescriptions. From the findings in the previous chapters, we can see that she is likely to have certain expectations of 'acceptable patient behaviour' in response to her explanations of her inability to meet a request for an unauthorised prescription. By telling this story in order to illustrate the difficulties posed by Gypsy or Traveller patients, she is interpreting their failure to conform to expected patient behavioural norms as a characteristic of a Gypsy or Traveller identity. Her previous experience provides a context for the meaning she attributes to this identity, which in turn influences her expectations. However, her voice as an individual, in a society in which

negative stereotypes of Gypsies and Travellers abound, is also likely to be engaged in an internal dialogue with her voice as a dispassionate receptionist who should not be influenced by prejudices. The Gypsy Traveller patient also brings to the current situation a sociohistorical context of discrimination and alienation. This influences her expectations of the response she may receive. She expects to meet resistance and is defensively prepared for it. What then ensues is that each person finds their assumptions and expectations reinforced, as they fail to see the other's perspective. The receptionist experiences the patient's demanding and aggressive behaviour as proof of her views of Gypsies and Travellers as demanding, rude or unreasonable; she perceives them to be deliberately manipulative in getting what they want. Her experience as a female in a non-autonomous role is relevant to the powerless feelings engendered by this perceived bullying. The Gypsy patient, on the other hand, experiences the receptionist's refusal to give her a prescription, which she thinks she needs and is entitled to, as unreasonable and rejecting. Her experience as a marginalised member of society, with specific cultural norms regarding need and communication, as we saw in Chapter Seven, is relevant to her feelings that she is being unjustly treated.

Paradoxically the various tactics adopted in anticipation of, or reaction to, perceived discrimination often intensify any existing mistrust and apprehension on the part of health staff. The staff also anticipate trouble and then their negative expectations are fulfilled. Mutual suspicion and intransigence can quickly ensue. Each person in the story asserts their position in response to the perceived hostility from each other and cycle of conflict develops without either being aware of the other's perspective. The staff perception of Gypsies and Travellers' belief, that their failure to receive the desired treatment is due to prejudice, compounds the difficulties for clinicians.

The second of these two stories illustrates the more frequent type of encounter reported by Gypsies and Travellers in this study, but both stories shed light on the spectrum of experiences and we see that there are various, marked differences between the behaviours and attitudes of staff in the two different narratives. It is at micro-level, through a dialogical lens, and using Goffman's framework, that we can endeavour to understand the full range of reasons for these differences. We can reflect on the situational context to determine how it influences individual attitudes. We see from Goffman that individuals define meaning and their sense of self through interaction and through their particular experience of an organisation and position within it. Goffman

has described how impressions are revised and changed as each interlocutor assesses and is assessed by the other.⁴⁸⁷ We saw earlier that approaches to service delivery appeared to be dependent on interrelated factors which included internal practice structures and organisational culture and ethos. Some of these differences were influenced by local demography and the resulting impact on workloads.

So for example in Elm surgery, where there was a fluctuating population, there was less opportunity or incentive for staff to gain in-depth cultural understanding and equally there was more likelihood that Gypsy and Traveller patients would be wary and mistrustful of staff, based on prior experiences. The reception staff in Elm surgery did not appear to have gained any increased understanding of the Gypsies' or Travellers' perspectives as a result of their participation in this research or from reading the preliminary findings report. In the absence of any familiar acquaintance with Gypsies and Travellers outside the work environment of the reception area, their expectations of Gypsy and Traveller behaviour had been based predominately on stereotypes. Negative encounters fulfilled their expectations and reinforced their prejudice. Their defensive reaction, in response to feeling overwhelmed by the demands of their Gypsy and Traveller patients, contributed to the patient's behaviour, resulting in escalated challenging behaviour in what Ryle terms a problematic reciprocal role procedure.⁴⁹⁰ Ryle draws on psychoanalytic object relations theory and Vygotsky's activity theory to assert the pervasively dialogic nature of the human world, where internalised self-other relationship patterns become the basis of 'reciprocal role procedures' governing intrapersonal as well as interpersonal relationships. These are problematic to the extent that aims are not achieved, yet the maladaptive sequence is not revised. In Ryle's terms, dysfunctional interactions between staff and patients are seen as enactments of interpersonal patterns in which the health practitioner is as active as the patient – that is, the difficulty is not located within the patient but is seen as fully relational, or dialogical. In this way, staff reported fear and a perceived threat from Gypsies and Travellers which obstructed any empathic understanding. The strength of their reaction to the findings indicates that the cycle of misperception and mutual antagonism has developed to such an extent that exposure to alternative perspectives through the research process had served to strengthen their defences. However, staff in this practice were also reported to have negative attitudes towards other patients. Their attitudes may be symptomatic of their lack of autonomy and sense of powerlessness. The ethos of this practice, as we saw, tended towards a reactive approach of damage limitation, with no indications of a team ethos or shared practice philosophy. The GPs, whilst sympathetic,

appeared to dissociate themselves from responsibility as employers for the receptionists' difficulties and this would appear to increase their sense of vulnerability and powerlessness.

In Rowan surgery there was a greater sense of staff engagement with the study, and, crucially, there was a team ethos and a commitment to ensuring that staff understood and shared the proactive practice philosophy of improving service provision for this group of patients. Their feedback, in contrast to Elm surgery, reflected this engagement as they reported new knowledge and understanding. Some of this new understanding of the Gypsy and Traveller perspective was probably gained through the cultural awareness sessions delivered by the health visitor. The narrative sessions and the feedback from the Gypsies and Travellers also had an impact; one of the GPs, who had demonstrated empathy, commented that he was surprised at how much he hadn't known. Some staff in this team reported greater understanding through inviting feedback from Gypsy and Traveller representatives, and from outreach work enabling them to meet Gypsies and Travellers in their homes. These initiatives illustrate the benefits of more balanced power relations; in both of these situations the Gypsy and Traveller patients are in more powerful positions and are being afforded recognition; this is conducive to building trust and mutual respect.

These differences in patterns of service delivery and staff attitudes within the different practice teams reflect differences in team ethos, with more hierarchical power relationships in Elm surgery in contrast to a more democratic relationship in Rowan surgery. The roles of team leaders and the relevance of their individual psychobiographies also appear crucial in this respect. Chapter Four showed that effective teamwork, with shared goals and clearly defined roles, is required to deliver high quality healthcare. However findings in Chapter Eight suggest that a commitment to equity, combined with respectful attitudes, may be insufficient to achieve desired levels of improvement unless factors influencing health service delivery are considered and appropriate resources made available. This reinforces Gilson's³⁵¹ view in her review on the role of trust in health care:

The effective delivery of health care requires not only the supply of care but also the acceptance and use of services by the patient....The patient/provider relationship is ...shaped by the institutions embedded within the health system.

Where these are seen to support provider behaviour that takes the patient's interests into account they are likely to underpin trust in the provider (p1459).

Trust and respect are key elements in interpersonal relationships. We saw some indicators of attitudes of GPs towards Gypsy and Traveller patients and vice versa that reflected differing levels of mutual trust and respect. For example in AP's story on p251 we saw how the mutual trust that had developed between her and her GP had allowed her to feel safe in confronting him and he in turn listened to her and conveyed his respect for her feelings. In contrast we saw a less empathic and less respectful approach to dealing with another patient's anxiety from the GP on p283 which is much less conducive to building trust. However, trust needs to be considered in wider terms than the micro level of interpersonal trust. According to Giddens, reflecting his efforts to synthesise micro and macro-perspectives, the propensity to trust is dependent on one's level of ontological security.⁶⁵ In the light of his definition of ontological security⁴⁹² we can see how Gypsies and Travellers collectively would have a low propensity to trust:

The ontological security refers to the confidence that most humans beings have in the continuity of their self-identity and in the constancy of the surrounding social and material environments of action. A sense of the reliability of persons and things, so central to the notion of trust, is basic to feelings of ontological security; hence the two are psychologically closely related. (p92).

We have seen in the preceding chapters how the ontological security of Gypsies and Travellers is threatened by their low social status and their lack of control over their environment. Giddens suggests that 'shame' resulting from this threatened status or position in society is an aspect of lack of ontological security.⁴⁹² I have argued for the need to understand interaction at an interpersonal level whilst recognising the influence of wider social contexts of each individual's psychobiography. I have taken two 'narratives' as examples to illustrate how insights can be developed and linked to other parts of the analysis. Having analysed my findings and their links with theoretical debates in this chapter, it is now important to examine the implications of these findings in the context of the Race Relations Act and associated policies. I now move on to consider these implications for culturally safe delivery of primary health care and appropriate training of health staff.

9.11 Implications of findings for primary health care service delivery

In this chapter I have shown how the study findings illustrate the importance of both the wider, and the immediate, social context of interpersonal communication between Gypsies and Travellers. This has implications for policies designed for effective service delivery for this excluded group of patients, and for the training of health care staff in relation to their needs. The contrast in service provision between the two practices and the Walk-In centre illustrates some of the barriers to effective patient-centred staff relations.

A significant finding is the confusion for many health staff between the concepts of treating people according to need and 'treating everyone equally'. There was a demonstrable lack of understanding here of the concept of health equity. We saw how this confusion caused problems for staff who were concerned at being seen as unfair if they gave 'preferential treatment' to Gypsy and Traveller patients. This is an example of the need for communication and in-house training within teams to ensure understanding and sharing of goals.

Similarly, there was little appreciation of the need for, and benefits of, ethnic monitoring and this partly explains the inconsistent approach to the routine collection of ethnic identity data reported by the Walk-In centre staff. However it was also apparent that staff felt uncomfortable in asking about a patient's ethnicity for fear of causing offence:

We've had to do it, on reception. We do White, Irish, British, Asian, I mean most of our Indians we put down as Asian...collectively the girls in reception have decided we only ask when we feel we need to ask.

Ethnic monitoring is not yet a routine undertaking in general practice or primary care, despite the mandatory obligation under Race Relations legislation³³ to produce race equality impact assessments of an organisation's policies. This research, although very limited in its coverage and therefore not generalisable, indicates that without appropriate staff training, any collection of such data is likely to be incomplete and inaccurate. As I discussed in Chapter Three, even where ethnic monitoring is routine, Gypsies and Travellers are not routinely included as ethnic group categories. Rowan surgery staff alone recognised the importance of collecting such data to evaluate their health care for

this targeted group of patients in order to achieve health equity. The study findings also highlight the need for training to accompany the introduction of ethnic monitoring.

In combination, these implications for Gypsies and Travellers and health staff can have wider application by informing local policy in terms of improving access to health care and reducing health inequality, for example through the Pacesetter programme.⁴⁹⁴

Gypsy and Traveller health is a core element of the Department of Health Pacesetters Programme aimed at improving the quality of care for patients by improving the health status of individuals from communities who experience inequalities. The programme aims to tackle inequalities arising from discrimination on account of age, disability, ethnicity, gender, religion, sexual orientation and gender identity. However each participating health trust will take on three of these issues as local elements, determined on the basis of a baseline audit and local consultation. The inclusion of Gypsies and Travellers as part of the core element of the programme is in acknowledgement of evidence that their health status is worse than any other disadvantaged group in England.⁴⁹³ This programme is being gradually introduced as a three year pilot scheme in six English strategic health authorities from 2007.⁴⁹⁴ Delivery of culturally safe health care and improving the quality of care for patients requires appropriately trained health care staff. Many of the study findings discussed in this and previous chapters have implied the need for relevant training and I will now consider the training implications in more detail.

9.12 Implications for Training

Gypsy and Traveller participants have emphasised the need for health staff to receive cultural awareness training in order to improve communication. They felt that training should be delivered by Gypsies and Travellers; this corresponds with the evidence that prejudice is associated with lack of personal contact. However, they were concerned to avoid “pigeonholing” of Gypsies and Travellers and agreed that training should not be simply about giving information on Gypsy and Traveller culture. Diversity training should be delivered from a Gypsy or Traveller perspective but aim to assist health staff to be able ‘to put themselves in another person’s shoes’ whatever their culture. These views mirror the debate about specialist provision for Gypsies and Travellers; that is, although there is currently a recognised need for designated culturally competent staff as trusted intermediaries, this specialist provision could be eliminated if all health staff

were “trained to respect people.” This highlights the varied broad components required of cultural competence training.

I have argued that communication skills, focussing on personal qualities, values, beliefs and attitudes, are essential to enable health staff to deliver culturally competent care, in addition to experiential training in cultural awareness. However, as we saw in Chapter Eight, many health staff participants in this study felt that training in cultural awareness and cultural diversity was unnecessary and that either their clinical training or professionalism, acquired through adherence to their ethical code, was sufficient to ensure culturally competent communication with all patients. Views were also expressed that life experience and maturity equipped non-clinical staff to communicate effectively with all patients. Most staff in this study had received either limited or no training in cultural awareness or diversity. In addition they were unaware of any available training. Yet since the publication of the Macpherson Report in 1999¹⁹⁸ there has been an increased focus on cultural diversity training in the NHS. As a result of the report’s recommendation that agencies review their training provision in “racism awareness” and “valuing cultural diversity” (recommendation 54), a duty was imposed on public authorities by the Race Relations (Amendment) Act 2000³³ to:

have due regard to the need to eliminate unlawful racial discrimination, and to promote equality of opportunity and good relations between persons of different racial groups.

Nonetheless, we have seen in this study that raising awareness is insufficient to achieve attitudinal and behavioural change and can sometimes strengthen a defensive polarisation of positions. The Stonewall study on attitudes towards minorities¹⁰⁹ found that:

informing people about minority groups and their culture can help reduce prejudice but can also risk fostering resentment (p22).

The interpretations of the Race Relations Act recommendations are varied in terms of training provision. In 2000, The Home Office commissioned a review⁴⁹⁵ of the impact and effectiveness of training across all agencies in the public sector. The report showed that only 62% of all organisations were providing any form of training although 94% had diversity policy statements. Of those who were providing training only two fifths

considered it to be a high priority. The report illustrates the lack of clarity among public sector staff of the meanings of racism awareness and cultural diversity and a corresponding lack of consensus and consistency in the literature. The review adds that consequently there are a wide range of models and current approaches to training. The underpinning philosophy is crucial to determining the approach used; whether the intention is to tackle racism, to promote equal opportunities by avoiding discrimination or to appreciate diversity. The key policy drivers are also relevant to the philosophy, for example the need to adhere to legislative duties such as providing equal opportunities for staff, or the imperative to avoid complaints and provide a quality service to users. The subsequent Home Office best practice guide to training⁴⁹⁶ states that training aims and objectives need to be specific; staff and trainers should be clear whether to focus on giving information, raising awareness, or to go further in changing attitudes, behaviour, or the organisational culture. Approaches also depend on whether training is targeted at individuals, groups, organisations or sectors. The authors noted a gradual shift in the history of training from a negative confrontational approach to a positive action-orientated approach designed to effect behavioural change. However a focus on behaviour change, such as tackling racial harassment, has also been noted to take priority over awareness-raising designed to change underlying attitudes. Only a minority of experts were reported to advocate a focus on attitudinal change as the vital instigator of behavioural change.

There has been a corresponding policy shift as regards behaviour change aimed at health service users, with a renewed emphasis on “health-related social marketing.” The social marketing approach to behavioural change explicitly incorporates examination of underlying attitudinal factors. An independent review of social marketing was commissioned by the Department of Health, in conjunction with the Choosing Health white paper and undertaken by the National Consumer Council. The report, “It’s our health”,⁴⁹⁷ published in June 2006, recommends this approach as an effective means to improve people’s health, reduce health inequalities and improve NHS efficiency. One of the core principles of health-related social marketing is to focus on the individual within their social context and to develop insight into the influences on their existing behaviour, and specifically to understand their underlying attitudes and beliefs that motivate them. The aim is then to adopt appropriate targeted interventions designed to achieve specific goals for different groups of users. This customised approach, in contrast to ‘one size fits all’, is readily transferable to cultural competence training and would allow for the provision of training tailored to identified need.

The Home Office report reviews several training models in use, but although it included consideration of the merits and limitations of external or internal trainers there was less focus on whether those cultural groups who are the focus of the training should be involved in the design and delivery of the training. There are few examples of training designed to focus specifically on improving cultural awareness for health staff in their encounters with Gypsies and Travellers. However one has been devised and delivered by a Gypsy.⁴⁹⁸ In common with many models of training in the NHS it focuses on giving information and dispelling myths. The objectives are clearly set out by Richard O' Neill in his 'Gypsy Traveller Diversity Training Seminar':

By the end of the course it is hoped that all participants will have a greater understanding of Gypsy Traveller culture and how to deal and work with them more effectively.

There is a clear need for this information and for raising awareness of an invisible and marginalised group, with the added potential benefits of authenticity and increased positive contact through personal encounters with a Gypsy as an external trainer. However, it is not possible to give an informed view of the effectiveness of these models in increasing cultural competence. In common with many other training initiatives in the NHS, pertinent questions arise; will those who hold deep-rooted prejudices attend? if they attend are their negative attitudes or prejudicial behaviour likely to be changed as a result? Unless there is also a parallel focus on communication skills and an individual approach, I would argue that this form of training is unlikely to change the attitudes of those for whom it is most required. Similarly, as Papadopoulos recommends, there needs to be an emphasis on the impact of social divisions in the wider context that covers and challenges forms of discriminatory thinking such as essentialism, ethnocentrism, and racism.⁶⁶

There were no descriptions in the Home Office review of training initiatives that indicated an intention to change attitudes through personal growth by fostering values of respect and empathy. However, there was a reference to Luthra and Oakley's 'education approach'⁴⁹⁹, a long-term approach which assumes that change will only materialise through "self- driven personal development of individuals" (p13). There is also an assumption that unless individuals identify a need for change, it will not occur. There is on the other hand potential for an increased focus on these wider components necessary for effective, respectful and culturally competent staff-patient relationships with the

advent of a new national policy, the NHS Knowledge and Skills Framework. (NHS KSF).⁴⁹⁴ This policy was introduced in 2004 to map occupational competencies across the NHS workforce, (although medical staff are excluded). Competencies in this context are described as “the knowledge, understanding and skill required to perform a specific task.” Communication, person and people development, and equality and diversity are three of six core dimensions from a possible thirty dimensions for each competency. This policy is in the early stages of implementation. The aim is to improve quality of service provision by identifying individuals’ learning needs and defining their learning outcomes, but whether training will be more focussed towards identified individual needs with this in mind remains to be seen.

The NHS is a large workforce and the need for inclusion of training initiatives that specifically target the prejudice and discrimination experienced by Gypsy and Traveller patients is far from realisation. In this thesis I have argued the need for this focus with the aim of improving relationships with health staff and of achieving equity in access to health care. There is a Police Service initiative with this targeted focus which arose from a project called ‘Moving Forward.’⁵⁰⁰ Two key objectives of the project were to increase trust between the Police Service and Gypsies and Travellers and to improve the service for these groups through a model of community focus workshops. The project involved partnership and active consultation with Derbyshire Gypsy Liaison group, a Gypsy and Traveller-led organisation. It was the first project workshop that was attended by the two Gypsy women participants in this study (see footnote iii) and it was clear from their response that they perceived benefits from their attendance. In addition to the close partnership with Gypsies and Travellers, another important aspect of this project is the inclusion of a clear evaluation strategy to accompany the desired learning outcomes, based on the first two levels of Kirkpatrick’s model.⁵⁰⁰ However, as with other awareness raising initiatives, the extent to which it can be a sole means of changing attitudes and accompanying behaviour among those who hold deep-rooted prejudices remains questionable.

I have argued the case for a sustained approach to identification of cultural competency in communication, in addition to cultural awareness, to achieve cultural safety for Gypsy and Traveller patients. Current competency levels can be assessed and identified through regular individual staff performance reviews, where targeted approaches can be identified to address individual need. Gypsies and Travellers should be involved in the

design and provision of cultural awareness components of training and all training should have clear aims, objectives and desired learning outcomes with evaluation measures incorporated. Training schemes are currently being envisaged whereby Gypsies and Travellers would be taught to train other Gypsies and Travellers as trainers in cultural awareness. I believe that such schemes would have great potential for inclusion of Gypsies and Travellers so that they can gain relevant accredited skills and compete as equals in the employment market. There is a precedent in Australia for the involvement of indigenous cultural mentors to deliver cultural safety training for health professionals. A cultural safety training programme was recommended by the Royal College of Australian Physicians, in recognition of the increased health inequalities of Aboriginal Australians and their poor access to and communication with health professionals. A subsequent training workshop^{50a} delivered by trained indigenous cultural mentors and a medical educator was attended by a multiprofessional group and included receptionists. It was evaluated well by participants. The group learnt with and from each other, modelling collaboration. The communication skills exercises were particularly valuable as was the invited story/narrative from a member of the local indigenous community. However, I believe that any current or envisaged schemes that focus predominantly on cultural safety training should be complementary and not an alternative, to long-term health staff training in communication skills.

In brief summary, these study findings reflect the literature on the broader social processes that create a racialised and stigmatised Gypsy and Traveller identity and contribute to tensions and unequal power relations between Gypsies and Travellers and health staff. Within this context the findings demonstrate the prominence of shame in a devalued identity and how this is a contributory factor in the reinforcing the communication divide. This social context is relevant to the individual psychobiographies that each person brings to an encounter in a health care setting and I have shown how a dialogical approach is helpful in understanding the dynamic and co-constructed nature of communication at micro level. I have explored the implications of these findings for culturally safe delivery of health care within the context of current policy initiatives and training models. In the final chapter I will now draw together the full conclusions of this thesis with reflections and critique of the process and consider the wider implications of the study findings.

Table 1

Key Features of Health care settings

	Rowan Surgery	Elm Surgery	Walk In Centre
Patient Catchment area	Market town population 18,600 and surrounding villages	City centre ; population 280,000	Market town. population 57,600
Demographic information	Low deprivation Low % minority ethnic groups	High deprivation High % minority ethnic groups	
Patient List Size	24,106	8,405	Walk In Centres provide a complementary service to GP practices; treating minor illnesses and injuries (average 2000 attendances per month
Number of Doctors	Ten full time GP partners	Five GP partners	Nurse led service
Gypsy & Traveller patient population	Small stable housed population; larger transient groups seen intermittently as temporary residents	Two Gypsy and Traveller sites in the area; a large stable population affording continuity	Rarely see any Gypsy and Traveller patients
Ethos as stated on practice leaflet	<p><i>"We endeavour to treat all our patients equally and strive to provide a first class clinical and administrative service. We aim to achieve the highest possible quality of care ..."</i></p> <p>No reference to the concept of patients' responsibilities.</p>	<p>On web site it is stated: <i>"We aim to provide the highest standard of personal care to families and individuals registered with us."</i></p> <p>No stated ethos on practice leaflet. but patients' responsibilities are stated: <i>" patients are asked to attend on time for appointments and treat our staff properly and with courtesy"</i></p>	No leaflet – list of services available only on NHS web site

Table 1 continued

Key Features of Health care settings

	Rowan Surgery	Elm Surgery	Walk In Centre
Organisational structure	Enhanced service provision for Gypsies and Travellers; dedicated nurse committed to outreach work. Flexible and proactive approach to service provision	Hierarchical doctor-led GP practice. Little opportunity for flexibility to meet unpredictable and varying levels of Gypsy and Traveller patient need. Reactive approach to service provision.	Nurse led 24 hours service; 'wait and be seen'. No registration or appointment required to access services, but no continuity of care. GP available on call.
Resources and funding	Enhanced service payments = additional funding	No extra funding and unpredictable influxes of patients increases demand on staff time and can adversely affect financial incentive targets.	Walk In Centres are part of the NHS- funded by local PCTs. No targets of financial incentives
Organisation culture and ethos:	Collaborative team ethos "at the last staff meeting went thoro what I was doing, why they were coming... There was a cultural need for us to understand their needs"	Directive and detached ethos "whether we see Travellers or not is really a receptionists problem rather than a doctoring problem"	Non- hierarchical team philosophy "we are a team.. we all talk to another"
Observed attitudes to patients	Generally empathic "there's a lot can be done... to give somebody the impression they're with somebody the who's not going to bite their head off or get impatient with them"	Patients can be seen as a problem or a nuisance "if you're not as approachable as you might be, perhaps they'll choose someone else"	Efficient- there to provide a service, but no need to develop relationships and build trust "they get that service and they're gone"

Introduction

This thesis has addressed Gypsy and Traveller experience of primary health care; I have discussed barriers to health care access, and also the cultural appropriateness of service delivery, from Gypsy and Traveller perspectives. Crucially however, the main focus of the thesis, communication between Gypsies and Travellers and health staff, is explored from the perspectives of both parties. Communication between health staff and all patients is a key factor that influences satisfaction with and effectiveness of delivery of primary health care. This thesis has provided an understanding of the broad social processes that underlie the communication difficulties that are such a key barrier for Gypsies and Travellers in their ability to access health care. However the main aim of this thesis is to inform primary health care provision at both policy and practice level, rather than to develop new sociological theory; in addition to demonstrating the part that health staff play in reinforcing racialised identities, the study findings have provided new insights into ways in which practice organisation can be improved.

In this chapter I begin with a personal reflection on the journey I have taken in engaging with and completing this doctoral research. I then discuss the methodological limitations of the work and how one could address them. I finish by drawing substantive conclusions to the thesis, in terms of my key findings: first, the ways in which racialised identities and an allied sense of shame contribute to the social exclusion of Gypsies and Travellers; secondly, the ways in which specific social and organisational factors influence health staff responses to Gypsies and Traveller patients; thirdly, the ways in which insights into the interaction between Gypsies and Travellers and health staff can be gained through the synthesis of theoretical perspectives at a macro level and micro level. In drawing these conclusions together I consider the wider implications of my findings and the implications for future research.

10.1 A PhD 'journey'

When I was awarded my research fellowship and registered for a PhD, I expected to learn from the range of training, seminars, discussions, and reading. Those expectations have been realised, as I have gained new knowledge and awareness and developed broader thinking in many areas. However, in doing this I became aware that this has only opened doors to further exploration; I have realised the research process is not one of closing down all uncertainty but raises new questions and that there is far more that I don't know.

Through my health visiting practice I had already gained understanding of the marginalised status of Gypsies and Travellers and their experiences of health and care; I understood their struggle to manage family roles in providing accommodation and ensuring the health, education, employment and welfare of family members in the face of many pressures and barriers. I have been full of admiration for their resilience, determination and good humour and for their generosity of spirit towards trusted Gorgers as they faced these life struggles.

During the course of my research I have become increasingly aware of the extent of Gypsy and Traveller health and social disadvantage, the vast repertoire of discriminatory experiences inside and outside the health service and the true depth of the sense of alienation they experience. This increased understanding has given me greater insight into the conflicting needs to defend cultural identity and at other times to hide it in the face of discrimination. I have gained a deeper insight into the psychological effects and the manifestations of these experiences. This greater awareness has deepened my admiration. I was less prepared for the far-reaching lessons of personal development on my journey. Whereas I had learnt experientially about interpersonal communication and cultural competence prior to commencing my PhD journey, I had learnt far less about internal reflection and uncovering the layers of my own story. This journey has been a catalyst, increasing my reflexivity during and after encounters, and as a consequence I am increasingly mindful of my own emotions and the thoughts and feelings behind them. By gaining greater insight into how I react in response to my own beliefs and feelings, and by questioning my assumptions, I have begun to see other perspectives more clearly and modify my reactions accordingly. Although it is painful to realise how past assumptions have influenced my interpersonal

interactions, the insight is also liberating. I feel that this improved understanding has increased my compassion for and empathy with others. This is not a linear process; as with any journey there have been obstacles, tunnels, wrong turns and sometimes cul-de-sacs. However I have learnt how to draw the map and have developed navigation skills. This could not have come about without the navigators who have guided me in the process with their belief and support. Their encouragement has enabled me to explore my thoughts with more confidence, and taught me to trust myself and my own thinking. This has not only been important for my own intellectual and emotional development but also a sobering role model for my practice – learning that I do not have to come up with all the ideas or the answers to people's difficulties. I have not failed if I cannot supply the 'right solutions', but can trust others to think things through for themselves and come up with their own ideas and solutions if they are listened to respectfully and given space and encouragement. I may be able to share relevant information, make suggestions or ask useful questions to aid that process, but shared discussion of thoughts and ideas is more likely to result in creative outcomes, with all suggestions valid for consideration. In other words, through good role modelling I have learnt a practical lesson in empowerment. Equally I have also learnt that people are not always ready or willing to put their ideas forward and that being free to be a silent participant until they feel ready is fine; to force active participation would be disempowering.

I will give one example of how my perceptions have changed on this metaphorical journey; I was enthused by the idea of partnership working with Gypsies and Travellers and health staff and felt that if each shared the other's experiences it would be a logical next step for each to change accordingly and for conflict to be reduced. In retrospect this was naïve and I was unprepared for the extent of prejudice and the intransigence of those who felt victimised and misunderstood on both sides. My increased knowledge and understanding of prejudice, and of the psychological and physiological implications of powerlessness and low status, has been helpful. However, I have also become more aware of my own angry and judgemental feelings towards health staff who display negative prejudices, and of my previous failure to empathise sufficiently with their feelings of fear and powerlessness. It is quite possible that, unintentionally, I may have communicated my judgemental feelings. I do not now condone their discriminatory or hostile behaviour, any more than I condone hostile behaviour born from fear and anxiety by Gypsies and Travellers. Instead, I feel I have greater understanding, compassion and empathy, and that I am more likely to communicate respect for all

parties (rather than earlier, possibly 'ill-disguised' criticism), and to facilitate a joint desire to work towards a solution and to instil greater confidence that each contributor to the process will be equally valued. My journey continues, but a valuable impact of starting it is my enjoyment of the scenery and sharing the journey with others, jointly realising fresh discoveries and possibilities, and recognising that destinations are only staging posts.

10.2 Methodological implications and limitations

In Chapter Five I discussed the intrinsic limitations of a PAR methodology. I encountered similar difficulties to those described by Birch and Miller:⁴²⁰ my original aims of creating a truly democratic research process with equal power relations within a participatory action research methodology were ambitiously naïve. I found that Gypsy and Traveller participants were content for me to initiate and lead as long as I afforded them respect and an opportunity to decide on their level of involvement. Family responsibilities and other cultural factors, such as illness among participants or their close family members, family crisis or the need to attend a funeral, were reasons for last-minute failure to attend meetings. This influenced the extent of participation and in turn limited their potential empowerment. One Gypsy needed to hide her participation from her husband and make excuses for being away from her domestic responsibilities. Others were unable to participate at all for similar reasons.

The hurdle of being able to meet with all interested participants at each proposed research meeting was evident from the start. Overall, the Gypsy and Traveller women expressed a continued interest in participating in the research but there was a lack of engagement with the planning detail. I found this understandable given their relative unfamiliarity with research processes and the more pressing issues that might take priority over a discussion about proposed research methods. The life events that prevented them from being able to meet collectively on the same day proved potentially problematic for relations between them as a group. The three women from 'Family A' who did manage to attend on the first arranged date were disappointed that they were alone and implied that the other women were making excuses for their non-attendance. I learnt through LH that some inter-family conflicts possibly played a part in engendering these suspicious feelings and I had to be sensitive to this complicating aspect of participatory research when arranging later meetings.

Yet despite these limitations there was positive feedback from Gypsy and Traveller participants concerning their degree of involvement. This indicates that, despite my unrealistic expectations of a PAR approach, and the original aims not being fully realised, it was nevertheless an approach that was rewarding for the Gypsy and Traveller participants. However, for intentions to be fully realised it is important that they are also as involved as they wish to be in dissemination. This has resource implications, with one of the limitations of much research funding being a lack of provision for this essential aspect. It would be an ethical concern if I raised expectations and was then constrained in my ability to facilitate further involvement in dissemination.

A greater limitation in my participatory approach was the lack of similar engagement with health staff participants. It proved extremely difficult to recruit health staff partners. The reasons for lack of participation were not always explicit; when reasons were given they were predominantly connected with workload pressures. Research participation was low on the priority list. These pressures were apparent throughout the fieldwork stages of the study, as it was very difficult to maintain communication and to arrange the research meetings within the proposed timescale.

I encountered similar engagement difficulties with reference group members. Despite enthusiasm for the project and interest shown at the initial meeting, two separate factors combined to explain the failure to convene for further meetings; reference group members were constrained by work commitments to travel for meetings, and the Gypsy and Traveller participants showed little interest in meeting with relative strangers when it was already difficult to arrange mutually convenient dates for research fieldwork meetings.

These difficulties have shown that it requires a great deal of early preparation to recruit and engage health staff. Failure to do so can compromise the partnership aspect of PAR, with health staff feeling that they are the 'lesser partners.' This has implications for project timescales, with a long lead-in time required before fieldwork can commence. Unfortunately current constraints in the health service compound the recruitment problems and ensure that it is health staff who are the 'hard to reach' group, rather than the marginalised populations typically described in this way.

A separate aspect of the recruitment difficulties was the potential for an unrepresentative and narrow range of experience among participants. The Gypsy and Traveller participants in the second research phase were selected opportunistically on the basis of their motivation to address the research question; it could be argued that the findings may not be transferable to other groups of Gypsies and Travellers. However, the participants ranged in age and in their exposures to health care in different settings, reflecting a broad variety of experience which is likely to be similar to that of Gypsies and Travellers in other parts of the UK. One further limitation in this respect was that in the second phase of the study, the Gypsy and Traveller participants were predominately female and so interpersonal communication has been explored almost exclusively from female Gypsy and Traveller viewpoints. However, this was not as a result of a failure to consider the inclusion of men but out of respect for the cultural preferences for women to meet together without them. The one man who did participate did so for his wife's sake as she never leaves him unaccompanied for his own health reasons. As we saw in Chapter Five, the other participants accepted JL's inclusion on this basis. However a separate piece of work would be required to fully explore Gypsy men's experience of and attitudes to access to health care from their perspective. A further limitation of this research is that I did not examine the impact of gender relations as I was prioritising ethnicity; this is an area that also requires future work.

So that a range of views could be explored, I intended to select health staff from varied settings that may be used by Gypsies and Travellers for primary health care, in order to include settings chosen by Gypsies and Travellers because of positive experiences and settings with a reputation for avoiding them as patients. Although I succeeded in recruiting a narrower range than intended, the contrast between the two GP practices, whose staff had different motivations for participation, did result in a broad range of attitudes and experience to inform the primary research question. The research achieved the primary intention of discovering and understanding the barriers to communication between Gypsies and Travellers and health staff as perceived by the relevant parties. Further research, with more resources and preparation time for staff recruitment, would be required to discover how transferable these findings would be to under-represented health care settings. Despite the limitations that I have identified, I do not believe that they invalidate the overall findings. I have taken care not to over-generalise the findings but I consider that they provide useful ground for further research in other settings.

My intention to facilitate a mutual exchange of views in a collaborative process to generate potential solutions was compromised in two ways. It became clear at the preliminary feedback stage that the level of conflict and mutual mistrust was such that a productive exchange of views between parties would require extensive preparation and facilitation from an experienced, neutral mediator. A research intervention of this scale was beyond the scope of the current project. The constraints for all parties in attending meetings were considerable and it became clear that this was over-ambitious for a doctoral research project. However, as discussed in Chapter Five. I intend to pursue this as a postdoctoral project with the aim of developing a feasibility proposal, and I have since held a preliminary exploratory meeting with some of the potential participants.

10.3 Conclusions and ways forward

As indicated at the start of this chapter, having examined communication barriers from the separate perspectives of Gypsies and Travellers and of health staff and then exploring processes of interaction between them, I have reached three main conclusions. Firstly, both phases of the research have shown how Gypsies and Travellers experience racialised and devalued identities, characterised by feelings of shame and humiliation, which contribute to the specific ways in which they experience social exclusion. Secondly, health staff reactions to Gypsy and Traveller patients are contextual; shaped not only by the broad social climate, but also by their role and status, organisational structures and policies and team ethos. Thirdly, in order to understand these themes and how they influence interaction between Gypsies and Travellers and health staff, it is important to draw both on theoretical perspectives which address power and agency at a broad level and those which inform understanding of interaction at an interpersonal level. I will now discuss each of these themes in turn.

The role of a racialised and devalued identity in communication barriers.

Gypsies and Travellers in this study express a strong sense of ethnic identity and we have seen how, due to the way that this ethnic identity is perceived by others and becomes racialised, structural dimensions of identity both strengthen ethnic boundaries and contribute to a sense of social isolation. This clearly reinforces Nazroo's^{40; 53} concept of the inter-relationship between structural dimensions of ethnicity and health inequalities, and confirms the relevance of his conceptual framework for considering

ethnicity in relation to health inequalities. The findings suggest that the hostile political climate is influential as it contributes to the marginalisation of Gypsies and Travellers. There are specific processes of 'othering' and stereotyping Gypsies and Travellers that are associated with the reactions of a sedentary majority to groups of people with nomadic identities and lifestyles. We have seen how government policies, resulting in poor housing environments, constrain Gypsies and Travellers through either forced movement or forced settlement; this process shapes their beliefs about their perceived lack of worth and status in society. This lack of control over their own life circumstances reinforces their sense of a stigmatised and devalued identity and is a further implication of the perceived risks involved in trusting in Gorgers. This threat to their ontological security is a health-damaging effect of low social status. I argue in this thesis that shame (feeling unworthy of respect), and attempts to ward off shame, are central features of relationships and encounters with health staff, as with relationships with Gorgers in wider society. The prominence of shame experienced by Gypsies and Travellers in this study, and its association with a sense of extreme marginalisation underlying any social interaction with Gorgers, supports Kaufman's⁵⁰² assertion:

...with shame as with disgust, societies ubiquitously select certain groups and individuals for shaming (p ix).

This thesis brings new insights into the importance of shame in a devalued Gypsy or Traveller identity, in the context of conflicts and misunderstandings with health staff. It reinforces Wilkinson's¹⁵⁶ work, showing the effects of shame on social status and the emotions engendered by perceived indications of rejection. The strength of such emotions, and the reactions they arouse as Gypsies and Travellers try to ward off the threat to their sense of self, create a climate where alienation is increased and the divide between Gypsies and Travellers and health staff is further strengthened. The broader social processes and structures that provide the social context of this marginalised ethnic identity are intrinsic to the interaction that takes place in the health care setting.

The shaping of health staff reactions to Gypsies and Travellers

Health staff responses to Gypsies and Travellers need to be understood at two levels; in the context of the wider social and political climate and in the context of specific influences on local health care settings in terms of policy, ethos and local demography.

By exploring the health staff perceptions and doing so in a range of different settings, we have seen how health staff reflect broad patterns of prejudice towards Gypsies and Travellers as nomads, and how these prejudices contribute to their negative expectations of Gypsies and Travellers as patients. My findings have illustrated the ways in which health staff responses contribute to the 'othering' of Gypsies and Travellers and reinforce their racialised identities.

However this thesis has also indicated new insights into the part that health services play in reproducing structural patterns of health inequalities, in a politically hostile context, by their failure to accommodate Gypsies and Travellers and their cultural lifestyle. External policies are created within the broader political context and we have seen how there are financial implications for redressing the balance to reduce the health inequalities experienced by Gypsies and Travellers. Political will is required to tackle wider health determinants responsible for such inequalities and we have seen the failures in this respect. Importantly though I have also been able to show that there are crucial differences at organisational level that influence the extent to which Gypsies and Travellers are accepted and receive equitable provision of health care. There are also financial implications for provision of equitable service provision at practice level; for example, we have seen how Rowan surgery required extra targeted funding to support their attempts to provide an equitable service and reduce health inequalities.

However, despite the influence of the broader political climate and social structures, this study has shown other differences at the organisational level that influence communication at a micro level. For example, where a practice has been in a position to develop a proactive teamwork approach, in a context in which Gypsy and Traveller patients attend regularly, they have ensured that frontline reception staff are included and supported in such goals. We can see the effects of this practice ethos in more empathic attitudes towards Gypsy and Traveller patients. In contrast we have seen how extra workload pressures, in practices that also have an unpredictable, fluctuating Gypsy and Traveller patient population, were associated with less empathic attitudes. This then created conditions for mutual distrust to be reinforced.

The theoretical synthesis of broad social control and managing identities at interpersonal level

Culturally competent interpersonal relations and health care for Gypsies and Travellers depend on an awareness and understanding of how broader political and social circumstances create a context for health-related, anxieties, attitudes and behaviours and relations with health staff. In addition to the shame of a devalued identity, experiences of marginalisation and hostility, revealed in this study, are important sources of psychosocial stress; these combine to give Gypsies and Travellers a collective sense of living in a dangerous Gorgor world. This study has shown how these experiences and fears create a context for relationships with health staff. For example, the collective sense of living in a dangerous Gorgor world would indicate the extreme fear of fatal mishaps to children and this in turn underlies the sense of urgency and expectations of resistance when seeking access to health care.

In this thesis I have argued that interpersonal relations between Gypsies and Travellers and health staff in primary health care settings are influenced by the negative expectations that each party brings to the encounter from their personal experience and their respective social and cultural context. These expectations become fulfilled prophecies and are then fuelled by hostile encounters. By using Foucauldian ideas of power and knowledge we can see how Gypsies and Travellers are kept in a subordinate position via their encounters with the health care system. I have shown how an analysis of the interaction between Gypsies and Travellers and health staff conveys the relational nature of unequal power relations. I have also shown, with reference to Goffman's theories of 'face work' and impression management,⁴⁸⁷ how each person brings their individual psychobiography to an encounter and meaning is created and recreated in a dynamic, dialogical process. At the level of interaction each person's social identity is forged and reinforced through the relationship with others. By considering the combination of the broader social context and individual experience, and their relevance for the creation of meaning in face-to-face interaction, I have demonstrated the importance of fostering a dialogical approach to reflective practice among health staff. In this way, it is possible to reveal and interpret the thoughts, feelings and understandings of the other and therefore to understand their perspective. I consider this to be an important training requirement for health staff to enable effective communication with all patients, but where the perceived differences between staff and patients are so substantial, it assumes even greater importance. However, we have seen

that a reflective and collaborative staff approach in primary care requires effective leadership and a shared team ethos, to provide the empathic focus needed as a starting-point for trust and effective communication. I argue that acquisition of good communication skills and development of experiential cultural awareness, whilst essential, are insufficient to guarantee cultural competence. A reflexive approach, focussing on personal qualities, values, beliefs and attitudes, is also essential for cultural safety.

In summary, I argue that this thesis shows that it is possible for interpersonal communication between Gypsies and Travellers and health staff to be improved and for a climate of mutual trust to develop, if certain conditions are in place. Whereas the political context is partly hostile, resulting, as we have seen, in the marginalisation of Gypsies and Travellers, there are opportunities for the balance to be redressed through human rights and equalities legislation. However, we have seen the financial implications of providing equity in health care at practice level. We have seen that the obstacles to good practice are not solely dependent on the political context and individual attitudes but also arise from specific policies and a lack of resources. Policies and resources to support development and good practice in health care are ambiguous. We have seen the negative effects of the neoliberalist commitment to consumerism: for example a misleading emphasis on individual choice; the skewing effects of targets and some very watered-down ideas about empowerment. On the other hand, we can also see some positive effects; for example, in the form of different service models such as Walk-In centres, and a health policy focus that is consistent with a commitment to reducing health inequalities in the Pacesetters Programme.

In addition to adequate resources, a reflective and collaborative approach with effective leadership and a shared team ethos is an important requisite. We have seen how staff who were unsupported in a more hierarchical structure tended towards a greater sense of powerlessness and vulnerability and were in turn more defensive about the study findings. Where staff have been supported and given opportunities to attend in-house seminars and a research findings feedback forum, and they have felt encouraged and safe to raise and explore their prejudices, they have acknowledged the benefits of increased cultural sensitivity and understanding. However, even in the practice where staff were less supported, despite their negative and defensive response to the research, we saw that since the study the reception staff had started to look at a longstanding

problem of regular confrontations with a particular Gypsy patient and were approaching the situation differently. The GP surmised that this may be a result of new understanding from the research.

As Gypsies and Travellers in this study have identified, there is also a need for Gypsies and Travellers to gain a greater understanding of how health services are organised so that they are less disadvantaged by 'not understanding the system.' We have seen in this thesis how the specialist health visitor can play an important role in this respect. However, other health staff can play a part in this education, but a climate of trust and a degree of continuity is required if this is to take place effectively. These study findings give new insight into how practice organisation can be improved to provide an environment where this is possible. For example, we have seen how a proactive team approach with regular team meetings with all staff grades, and open consultation with patients on how the service can meet their needs, can create an environment that is conducive to respecting and valuing all patients.

The study participants are ideally placed to assist in dissemination of these findings. As they have indicated, they feel increasingly confident in participating in other meetings and events and this provides an opportunity for capacity-building in presentation skills. This has been an important outcome of a participatory research approach.

10.4 Implications for further research

Although this thesis has argued that long-term staff training is required for improving access and providing effective health care for Gypsies and Travellers, it has also indicated a clear, immediate need to overcome the conflict that so frequently arises in health care settings. The findings imply that a simple educative process (cf 'diversity training') will not be adequate to change entrenched patterns of interaction. The Gypsy and Traveller study participants indicated their commitment to the potential of working in partnership with health staff towards an action research model aimed at improving relationships.

Although this thesis has made an original contribution to analysing the access to primary health care provision for Gypsies and Travellers by exploring the relationship between shame and racialised identities and the wider issues of power and inequality, there are other areas that I have not focussed on in depth. For example, the relationship

between social class, ethnicity and identity, and the relationship between gender, ethnicity and identity were beyond the scope of the current research. These are areas for future research that would require a different set of research questions and methods.

10.5 Wider Implications

In some respects, the lessons learned from this study about communication between Gypsies and Travellers and health staff can be applied to other groups of marginalised or disempowered people in relation to the health service. Gypsies and Travellers are stigmatised and 'othered' in an extreme way outside and within the health service; however, there are other groups who are marginalised on the basis of their ethnic identity or other forms of perceived difference, such as asylum seekers, Muslims, and people who are gay, lesbian or bisexual. The findings from this study also have similar training implications for other public and third sector service providers. Many of the conflicts and stereotyped attitudes and prejudices that we have seen in the health sector are mirrored, for example, in schools and between Gypsies and Travellers and site managers.

This thesis has shown that current communication barriers reinforce (and sometimes exacerbate) the social exclusion experienced by Gypsies and Travellers. This emphasises the need for wider policies aimed at social justice for all Gypsies and Travellers. If the current political emphasis on social cohesion is to be realised, there must be more realistic efforts to create policies that enable Gypsies and Travellers to feel that they belong and are accepted as citizens, without the need to hide or relinquish their cultural identity. In the absence of such policies, or if policies are restricted to those who are most visibly excluded as a result of forced mobility, mistrust and suspicion are likely to prevail and communication barriers to persist. Increased respect gained from a dialogical approach, as a result of values-based communication skills training, has the potential to provide a climate of trust in specific health care settings and therefore to reduce inequality of access to health care. Similar improvements could be achieved through similar methods within other organisations. In spite of this, if there is to be a sustained impact on reduction of health inequalities by tackling the wider health determinants, a multi-agency approach is needed, from the level of government policy downwards, to address the sociocultural factors that provide the basis for mistrust.