

The Health Status of Gypsies & Travellers in England

Report of Department of Health Inequalities in Health Research Initiative
Project 121/7500

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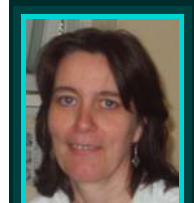
Mr Tommy Doherty RIP



Ms Jackie Mosley



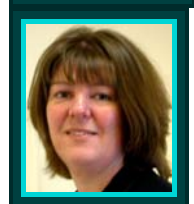
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The Health Status of Gypsies and Travellers in England

Executive Summary

1. Small scale, localised studies suggest that Gypsy Travellers (variously described as Gypsies, Travellers, Romanies or the Roma people) have poorer health status than non-Travellers, but reliable evidence on the health of adults is sparse. A team of health services researchers from the University of Sheffield, aided by Gypsy Travellers and health service staff, conducted a large-scale epidemiological study using standard health measures, supplemented by in-depth interviews to explore health experiences, beliefs and attitudes. A survey of Primary Care Trusts and Strategic Health Authorities in England addressed health planning and provision for this ethnic minority.
2. We quota sampled 293 Gypsy Travellers across five locations: London, Bristol, Sheffield, Leicester and Norfolk. Of these, 260 were matched for age and sex with a comparator living in one of the five locations, including British people in White, Pakistani, Black Caribbean ethnic groups, urban and rural environments, and those who were socio-economically deprived. All participated in a structured health interview including standardised measures of health status and specific illnesses, medication use, and health service contacts. A further 27 Gypsy Travellers with health problems were interviewed in depth about their health beliefs and attitudes and their experience of accessing health care.
3. Results of the quantitative survey show that Gypsy Travellers have significantly poorer health status and significantly more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents. Using standardised measures (EQ5D, HADS anxiety and depression) as indicators of health, Gypsy Travellers have poorer health than that of their age sex matched comparators. Self reported chest pain, respiratory problems, and arthritis were

also more prevalent in the Traveller group. For Gypsy Travellers, living in a house is associated with long term illness, poorer health state and anxiety. Those who rarely travel have the poorest health.

4. There was some evidence of an inverse relationship between health needs and use of health and related services in Gypsy Travellers, with fewer services and therapies used by a community with demonstrated greater health needs.
5. From these results, and from comparison with UK normative data, it is clear that the scale of health inequality between the study population and the UK general population is large, with reported health problems between twice and five times more prevalent.
6. Health status in the Gypsy Traveller group is correlated with those factors that are recognised as influential on health: age, education and smoking. However the poorer health status of Travellers can not be accounted for by these factors alone. Gender differences were found; women were twice as likely as men to be anxious, even when education, smoking and carer status was taken into account.
7. The aspects of Gypsy Traveller health that show the most marked inequality are self-reported anxiety, respiratory problems including asthma and bronchitis, and chest pain. The excess prevalence of miscarriages, stillbirths, neonatal deaths and premature death of older offspring was also conspicuous. There was less inequality observed in diabetes, stroke and cancer.
8. Travellers' health beliefs and attitudes to health services demonstrate a cultural pride in self-reliance. There is stoicism and tolerance of chronic ill health, with a deep-rooted fear of cancer or other diagnoses perceived as terminal and hence avoidance of screening. Some fatalistic and nihilistic attitudes to illness were expressed; that is, illness was often seen as

inevitable and medical treatment seen as unlikely to make a difference. There is more trust in family carers rather than in professional care.

9. In relation to Gypsy Travellers' experiences in accessing health care and the cultural appropriateness of services provided, we found widespread communication difficulties between health workers and Gypsy Travellers, with defensive expectation of racism and prejudice. Barriers to health care access were experienced, with several contributory causes, including reluctance of GPs to register Travellers or visit sites, practical problems of access whilst travelling, mismatch of expectations between Travellers and health staff, and attitudinal barriers. However, there were also positive experiences of those GPs and health visitors who were perceived to be culturally well-informed and sympathetic, and such professionals were highly valued.
10. Fewer than half of the PCTs, SHAs and PHOs responding to our survey had knowledge of the numbers or location of Gypsy Travellers locally. Information on Gypsy Travellers' use of services was more rarely available and only a fifth had any specific service provision. Only one in ten had any policy statement or planning intentions that specifically referred to Gypsy Travellers.
11. Our findings confirm and extend the practice-based evidence on poorer health in Gypsy Traveller populations. There is now little doubt that health inequality between the observed Gypsy Traveller population in England and their non-Gypsy counterparts is striking, even when compared with other socially deprived or excluded groups and with other ethnic minorities.
12. The impact of smoking, education and access to GP service is important. The educational disadvantage of the Travellers was extremely striking, and the single most marked difference between Gypsy Travellers and other socially deprived and ethnic minority populations. However, these factors do not account for all the observed health inequalities. The roles played by

environmental hardship, social exclusion and cultural attitudes emerge from the qualitative study, and are consistent with the finding there is a health impact of being a Gypsy Traveller over and above other socio-demographic variables.

13. Some implications of our research findings for health policy and provision are drawn out. These include:

- Methods are needed to improve access to and cultural safety of health services for Gypsy Travellers.
- Working in partnership with Gypsy Traveller communities in the delivery of health care would be both possible and effective. Examples are given.
- Commissioning dedicated or specialist health workers, including their community development and liaison role, would be welcomed by Gypsy Travellers.
- Improving the cultural competence of health service staff is a priority, to combat racist and discriminatory attitudes based on ignorance or fear, which feed into defensive hostility and promotes communication difficulties. Any developments in cultural safety training should be evaluated.
- Better coverage of Gypsy Travellers in NHS ethnic monitoring would address their 'invisibility' in public health terms.
- Primary Care Trusts may value advice on overcoming the difficulty faced by Gypsy Travellers in obtaining GP registration.
- Primary Care Trusts and Strategic Health Authorities have an opportunity to address this issue in their Health Equity Audits by 2006.
- As many of the determinants of health status are outside the remit of the Department of Health, inter-Departmental co-ordination with regard to Gypsy Traveller health seems advisable. A Task Force on a co-ordinated strategy to Gypsy Traveller health would command wide support.

1 Introduction

1.1 Background

This research was designed to address health policy objectives by identifying the inequalities in health status between Gypsy Traveller and non-Gypsy Traveller populations using a valid and reliable measure of health status. Among other health problems, we address mental health, stroke, and heart disease, as these are health service priorities and health improvement targets. A second strand of the research explores the health experiences, beliefs, and attitudes of Gypsy Travellers, and perceived barriers to service access or use. Finally, we survey Primary Care Trusts and Strategic Health Authorities in England to understand better the current pattern of health planning and provision for this ethnic minority.

Current health policy places particular emphasis on reducing inequalities in health and targeting socially excluded groups^{1,2} although ironically a 1999 policy document, *Reducing Health Inequalities: an Action Report*³, did not mention the health needs of Gypsy Travellers, perhaps demonstrating the extent of their social exclusion. The current research was undertaken to redress this omission within health policy.

Gypsies and Travellers (variously described as Gypsies, Travellers, Romanies or the Roma people) are socially excluded ethnic groups, which, on the basis of existing small scale and anecdotal evidence, have specific health needs that have not been systematically assessed.

Whilst it is important not to overemphasise group differences or to reify ‘ethnicity’, it is important to define the population sampled in this research. The people who are referred to as Gypsy Travellers in this report are comprised of four separate groups. These groups are commonly known as English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers and Irish Travellers. Each of these groups has a separate ethnic identity that is particularly evident from their different languages but they share many aspects of a common cultural identity as traditional Travellers or Romani people. Our study excludes New Travellers, who have opted for an alternative lifestyle but are not of the same culture.

World-wide there are more than 100 groups who collectively form part of a wider Romani population, estimated at 12 million people⁴. The common characteristics that identify this heterogeneous scattered group of Romani people are that they have a shared Indian origin, aspects of a shared culture and dialects of the same original language. Outwardly they may differ in many respects but they share a cultural identity that differentiates them essentially from non-Romani people (whom they term gadze, or in English, Gaujo, variously spelt as Gorgio or Gorjer). Conventional wisdom is that Irish Travellers descend from peasants who took to the roads as a result of the hardships of Cromwell's campaign in Ireland or the Famine. However, this view is not accepted by scholars, who note that Irish Traveller culture has more in common with that of the broad Gypsy continuum than it does with that of Irish farmers^{5:6}. We emphasise this in using the generic term Gypsy Traveller to encompass all four groups, whilst not disregarding group differences – we make specific empirical comparisons between Gypsies and Irish Travellers where appropriate.

Studies of Gypsy Traveller health

The lack of reliable research evidence on the health status of Gypsy Travellers is widely acknowledged. Feder⁷ noted this when discussing the health of Gypsy Travellers from a primary health care perspective and outlined some of the methodological difficulties that account for it, for example, difficulties in accessing a marginalised mobile population, people who mistrust authorities, where demographic information is unavailable. Hajioff & McKee⁸ note the almost complete absence of research on non-communicable disease in the Roma people, although they concluded that the limited evidence that exists indicates that their health needs are considerable.

There has been no well-designed epidemiological research with Travellers. In a review of the literature on access and use of health and social care services for minority ethnic communities in Britain undertaken by the MRC⁹, only one study¹⁰ was identified that focussed on Gypsy Travellers. Although Arai & Harding in the MRC review note that there is a large body of research on disease patterns, if not

causes of disease, among ‘migrant ethnic groups’, in the case of Gypsy Travellers a literature search revealed little evidence of either.

Although there is a considerable number of unpublished dissertations, theses, newsletter articles and book chapters, we found only eleven published primary research studies into the health of adult Gypsy Travellers in the British Isles; seven in research journals¹⁰⁻¹⁸, one in a practitioner journal¹⁹, two published as reports^{20;21}. Eight of these studies were conducted in the UK, including the authors’ 1999 pilot study for this research¹⁷. Most studies are small, localised, descriptive, and focus on maternal and child health, including immunisation, consanguinity and congenital anomalies. Few studies involved Gypsy Travellers’ active participation in the research process. The evidence from these studies suggests high infant mortality and perinatal death rates, low birthweight, low immunisation uptake and high child accident rate.

There is much less evidence on comparative health status of adult Travellers.

Travellers are invisible in national datasets. For example, they have no status in the national census, and limited ethnic monitoring based on self-classification does not allow them to be accurately identified. Comparative health data are available from Ireland, Sheffield and on maternal deaths in the UK, although the authors of the Confidential Enquiry noted the difficulty in obtaining accurate identification of ethnic group²³. A national study of Travellers’ health status in Ireland published in 1987 showed a higher mortality rate for all causes in the Gypsy Traveller population. Life expectancy of Gypsy Traveller women was 11.9 years less and of Gypsy Traveller men 9.9 years less, than women and men in the non-Traveller population²². In planning this research, we conducted a pilot study of 87 Gypsy Travellers matched for age and sex with indigenous working class residents in a socially deprived area of Sheffield¹⁷. Results showed statistically and clinically significant differences between Gypsy Travellers and their non-Gypsy Traveller comparators in some aspects of health status, and significant associations with smoking and with frequency of travelling. The report of the Confidential Enquiries into Maternal Deaths in the UK 1997-1999²³ found that Travellers have “possibly the highest maternal death rate among all ethnic groups.”

Determinants of ill health

Studies concerning determinants of the health of adult Gypsy Travellers are noticeably absent. Research evidence on environmental determinants is sparse, although poor environmental conditions and lack of basic facilities on sites, especially unauthorised sites, is well documented^{10;14;19}. Feder argued that “there is consensus among all those concerned with Travellers’ health ... that the main explanation [for ill health] lies in adverse environmental conditions and poverty”⁷. Many personal practice accounts cite health problems that are attributed partly to these adverse conditions: accidents, gastro-enteritis, upper respiratory infections, and otitis media^{24;25;26}. Substandard care was implicated in five of six maternal deaths examined in the Confidential Enquiry²³ and Durward²⁰ reports that harassment and eviction is especially problematic around the time of childbirth.

Gypsy Travellers’ own understandings of the causes of ill health have been explored. Heron et al²⁷ found that nearly a third of mothers in their study of psychosocial health felt that being a Traveller negatively impacted on their health. They strongly related this to their living conditions. An ethnographic study in Belfast by Ginnetty²⁸ explored the Travellers’ perceptions of factors having a negative impact on their health. Lack of education, changing work patterns, stereotyping and discrimination, harsh living environments and deprivation were implicated. Travellers in her study mourned their loss of a nomadic way of life. One Gypsy Traveller explained this cultural need by describing Travellers as “just like a bird in a cage”. They particularly perceived that mental ill health resulted from the many pressures they faced and saw this as a more recent phenomenon strongly associated with forced changes in lifestyle. They saw family solidarity as a positive cultural feature that enabled them to cope and help each other.

Access to services

In addition to health inequalities, there are good reasons to believe that Gypsy Travellers have unequal access to health services. Barriers to care most frequently highlighted were mobility – either as a cultural lifestyle pattern or enforced – “being moved on”. Other barriers cited, particularly in personal practice accounts, relate to cultural issues: negative attitudes to maternity services²⁵, mistrust of immunisations,

poor literacy levels²⁹. Feder⁷ gave evidence of large numbers of GPs who will not accept Travellers onto their practice lists, causing them difficulty in reaching 'sympathetic' GPs. Pahl and Vaile¹⁰ suggest that expectations and relationships with GPs are important, stating "Gypsies have strong loyalties and when registered with a sympathetic general practitioner are likely to be prepared to travel to see him or her". There are obvious repercussions, i.e. it may be necessary to camp in an unauthorised place to access this GP. Local studies¹² also suggest low registration with dental practitioners and unmet needs in dental health.

Health beliefs and attitudes have been found to influence health service use in a number of ethnic groups. For example, Goodwin³⁰ examined the health beliefs of 600 older Black, Hispanic and non-Hispanic White people in Texas, finding significant relationships between service use, and fatalism (seeing a health problem as inevitable) or nihilism (believing nothing can be done for it). British Bangladeshis' health beliefs about diabetes combined strong religious views in terms of 'God's will' with an acceptance of individual responsibility. These beliefs and the influence of lay sources of information determine health behaviours including use of health care³¹. The impact of health beliefs and attitudes of Gypsy Travellers has rarely been formally investigated, with the exception of beliefs relating to oral hygiene and dental health^{11;12}.

The factors affecting equity of access to health services are complex and interacting. Our research is designed to disaggregate the relative impact of Gypsy Traveller culture, accommodation conditions, ethnic minority group membership and socio-economic disadvantage. It is of greatest importance for developing sound policy, implementing existing policy and developing culturally competent services, that these global socio-demographic factors have their effect through specific circumstances which may vary between groups. For example, Morris and Clements³² show that Gypsy Travellers continue to face appalling conditions on some authorised sites and that not all Gypsy Travellers are provided with the basic amenities when parked on unofficial sites. Hawes³³ points out that nomadic Gypsy Travellers place greater priority on the practicalities of finding safe and well serviced stopping places, sanitation and water supply than on medical issues such as immunisations and cervical smears.

Hawes³³ has argued that more clinical research on a national basis ‘would not only help to legitimise often anecdotal evidence of the scale of deprivation among nomads but would be part of a wider attempt to reduce inequalities and advance social justice within the NHS’.

Methodological considerations

Policy objectives to reduce health inequalities and provide equitable services to socially excluded groups are impeded, in the case of Gypsy Travellers, by conceptual ambiguity and the absence of accurate health status data. The latter is at least partly due to methodological problems.

Obtaining accurate health status data for Travellers requires a) good access to Traveller communities through trusted intermediaries b) face to face interviews rather than postal questionnaires c) health status measures which are relevant, valid, reliable and which in total, do not place unrealistic demands on the respondent in terms of time taken or complexity. After gathering valid and reliable health status data, appropriate comparison groups are required, in order to understand the health inequities of this population. We have developed a method, shown to be feasible in pilot work, of addressing these challenges.

Conceptually, there is a fundamental ambiguity in the definition of ‘Gypsy Travellers’ used in official statistics and reports. Specifically, there is confusion over whether they are defined as a distinct ethnic group or whether the definition is solely based on a nomadic lifestyle. For this reason, although policy makers consider Black and ethnic minorities when assessing need, Gypsy Travellers have often been excluded. The Caravan Sites Act (1968)³⁴ defines them ‘as persons of nomadic habit or life whatever their race or origin’. The Department of the Environment, Transport and the Regions excluded them in their definition of black and ethnic minority groups in their document “New Deal for Communities: Race Equality Guidance”³⁵, on the basis of the definitions used in the 1991 Census classification, where Gypsy Travellers are classed as “White, other”. Department of Health guidance to the NHS on addressing inequalities in health in line with the “Our Healthier Nation” report (HSC 1998/129) did not accord Gypsy Travellers a distinct category in its breakdown of ethnic minorities.

On the other hand, Gypsy Travellers are recognised as a racial group for the purposes of the Race Relations Act 1976. The English Court of Appeal made a legal ruling that Romanies were an ethnic group, in a case brought by the Commission for Racial Equality (CRE v Dutton, 1989, 1 All ER 306). Irish Travellers were legally recognised for the purposes of the same Act following a judicial decision in London in August 2000. Okely³⁶ suggested that all Gypsy Travellers are primarily an ethnic group, with membership based on the principle of descent, i.e. status ascribed at birth.

Whilst mindful of the difficulties presented by the concept of ethnicity, we take this approach because it is more helpful in identifying a group with shared history and cultural tradition. Nomadism is part of their heritage, but many Gypsy Travellers live all or part of the time in houses. This is often due to the unavailability of places on authorised sites or the extreme difficulties associated with the travelling lifestyle. With rare exceptions, research has been confined to Travellers living in trailers, whether on sites or still mobile. However, we specifically include housed Travellers, who are often no longer viewed by authorities as belonging to their cultural group, or whose needs are assumed to be the same as the rest of the housed population. For example, many people, including some health service professionals, view housed Travellers as no longer being part of the Gypsy Traveller ethnic group and refer to them as ‘ex-Travellers’. On the contrary, Travellers argue that although nomadism is a feature of the Romany lifestyle, it refers to a state of mind, a pervasive way of seeing the world, rather than simply the physical act of moving^{6,37}. Cemlyn³⁸ in her study of social services work with Travellers, identified the extra difficulties of isolation, stress and racism faced by housed Gypsy Travellers and suggests that their health and social care needs are distinct.

In planning this research, we have been influenced by Bhopal’s searching critique of basic errors in epidemiological studies of ethnicity³⁹, and we have followed Senior & Bhopal’s recommendations to improve the value of ethnicity as an epidemiological variable⁴⁰. Specifically, we state explicitly the definitions used for ethnic group samples, we choose comparison groups to test whether associated factors, such as socio-economic differences, are a possible explanation of differences in health between ethnic groups. Rather than simply measure health inequalities between groups, which can itself contribute to social disadvantage, we illuminate the meaning

of these findings through a rigorously conducted qualitative study, and place both in the context of a survey of current provision in the English NHS. We hope in this way that the study will be of maximum use to health service planners and health policy makers in reducing the impact of social exclusion and improving access to health services to disadvantaged groups.

National strategies relating to Gypsy Traveller health

The Republic of Ireland has published a strategy, covering all aspects of Traveller life from culture, accommodation, and education through to sport and recreation. The national Traveller Health Strategy 2002-2005⁴¹ refers to a core value affirming the right of Travellers to “*appropriate access to health care services that takes into account their particular needs, culture and way of life*”. In recognition of the impact on their health of social exclusion, racism and living conditions it proposes a system of ‘Traveller proofing’ of national and regional health policy initiatives. Among its 122 proposals is the active partnership and participation of Travellers in planning and provision of services with emphasis on a community development approach, incorporating peer led services.

A report on meeting the health needs of Scotland’s ethnic minorities, Fair for All⁴², included a section on Gypsy Travellers. For this group it concluded “*the context of Travellers’ lives includes the stress generated by living in a hostile society where discrimination is a constant reality, and this is compounded by frequently enforced change in their way of life. This context impacts adversely on Travellers’ health*”. Amongst other recommendations, which included a need to change society attitudes, was the suggestion of an independent working party to oversee a resourced national health strategy to address the educational and health needs of Gypsy Travellers.

A report on the Welsh review of service provision for Gypsies and Travellers in 2003⁴³ also documents the level of discrimination and prejudice against Gypsies and Travellers in Wales and their lack of involvement in decision-making and policy development. It too recognises the impact of accommodation issues on their health. It discusses the various barriers to successful health service provision and outlines existing initiatives to overcome some of these.

1.2 Purpose of the research

This research was designed to provide the first valid and reliable estimate of the health needs of Gypsy Travellers in England. It examines socio-demographic correlates of health, makes appropriate health status comparisons with other low income and ethnic minority groups. It also explores culturally specific health beliefs, and attitudinal and practical barriers to accessing health services. Finally, it surveys the extent of health planning and provision for Gypsy Travellers in England.

- 1) *Primary research question:* Do Gypsy Travellers have significantly poorer health status and more self-reported symptoms of ill-health than other UK-resident, English-speaking ethnic minorities and economically disadvantaged White UK residents?
- 2) *Secondary research questions:*
 - a) What is the relationship between health needs and use of health and related services in Gypsy Travellers?
 - b) What is the scale of health inequality between the study populations and the UK general population?
 - c) What are the correlates of health status and symptoms with gender, age, types of accommodation, geographical locality and lifestyle factors such as smoking?
 - d) Which aspects of health show the most marked inequality?
 - e) What are the health beliefs and attitudes of Gypsy Travellers in relation to health service usage and access?
 - f) What are Gypsy Travellers' experiences in accessing health care and the cultural appropriateness of services provided?

1.3 Service user and practitioner involvement

Gypsy Travellers have been involved in developing and conducting this study, in the interpretation of results and in writing the report. Initial consultation on an informal basis with members of the Travellers' community was undertaken prior to the pilot work leading to this study proposal. The Gypsy Council (previously known as The Gypsy Council for Education, Culture, Welfare, and Civil Rights) was formally notified and sent details of the study at relevant stages. In contrast with many research

studies of this minority group, The Gypsy Council is strongly supportive of the study. A representative of the organisation was a member of the Project Advisory Group and Patrice Van Cleemput was elected to the Gypsy Council committee and has been able to liaise on implementation of the Project. Five Gypsy Travellers were also members of the project advisory group, and findings were presented to local groups of Gypsy Travellers in each of the study locations. A wider forum of Gypsy Travellers met in Sheffield in December 2003 to comment on the preliminary findings. Richard O'Neill, Mally Dow and Len Smith kindly commented on the draft report.

The study would not have been possible without the involvement of health service staff. Primary amongst these were health visitors specialising in Traveller Health who were the principal routes of access to Travellers living in trailers on sites, and who gave local support to the project interviewers. They were also members of the Project Advisory Group, and organised the practical arrangements for the validation phase of the project. Many other health service staff including GPs, health visitors and practice managers supported the research in terms of access to comparison groups.

2 Method

2.1 Sample and sample size

We sampled Gypsy Traveller populations across five locations in England, then contacted matched samples of the non-Traveller population for comparison purposes using an age- and sex- matched pairs method. These samples were chosen to make specific informative comparisons, rather than global ones. Gypsy Travellers' health status and access to health services may be influenced by many factors. Among these are: their nomadic lifestyle, their ethnic minority status, their social deprivation and educational disadvantages, or their socio-economic status. Rather than simply compare their health status to UK norms, we make planned comparisons, which allow these factors to vary systematically. The comparison group is also English-speaking, and consists of four subgroups:

- Low income white residents (English or Irish) in a socially deprived area
- English residents of mixed income levels from a rural community (of any ethnicity)

- British Muslim residents of Pakistani origin, of any socio-economic status
- British Black people of African Caribbean origin, of any socio-economic status

All the comparators were English-speaking, to match the Gypsy Travellers. In the absence of information about the total Traveller population size or age/sex statistics, we quota sample across five localities, male and female Travellers, both Irish and English/Welsh, across roadside, official and housed accommodation sites. ‘New Age’ Travellers, Roma refugees, and children under the age of 16 were excluded.

The size of sample required was calculated by a power analysis using data from a pilot study¹⁷, assuming similar levels of variability in the main study. This demonstrated that Gypsy Traveller subjects as well as comparison subjects could be recruited. Pilot response rates were 85% and 90% respectively. From this pilot study of 79 Gypsy Travellers, age sex matched to a control subject, the mean (standard deviation) scores on the EQ-5D utility index were 0.62 (0.40) and 0.76 (0.29) respectively. The observed paired mean difference between the Gypsy Traveller and comparison group was 0.14 (standard deviation of differences 0.48). The 95% confidence interval for the difference was 0.02 to 0.24. To have 90% power to detect a 0.10 difference in mean EQ-5D health utility scores between Gypsy Travellers and an age-sex matched comparison group as statistically significant at the 5% level (two-sided) would require 245 (say 250) Gypsy Traveller interviews paired with age-sex matched controls.

For secondary analysis of different subgroups, assuming equal numbers per category, 83 Gypsy Travellers will be required for the study to have an 80% power to detect a 0.15 difference in EQ-5D scores between the subgroups and their matched controls. From pilot work, we knew that it would be feasible to interview these numbers of Gypsy Travellers and comparison subjects in the time and with the resources specified.

It was therefore planned to interview a minimum of 250 Gypsy Travellers in Sheffield, Leicester, Norfolk, London and Bristol to obtain quotas (minimum n=83)

of male and female, Irish and British, across roadside, official and housed accommodation sites. Each Gypsy Traveller was paired (age/sex matched) with a comparison subject from:

- Sheffield – low income white populations, British or Irish
- London – mixed income white populations, British or Irish
- Norfolk – rural mixed income populations
- Leicester – British Muslim Pakistani mixed income population
- Bristol – British Black African Caribbean mixed income population

A small sub-sample of Gypsy Travellers with a health problem was recruited from the initial sample for the qualitative study. A form of purposive sampling, known as maximum variation was used⁴⁴. Sampling was undertaken in Leicester, Bristol, London and Norfolk* to include Gypsy 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 geographical origins, British or Irish Travellers.

2.2 Selection and recruitment

Samples were identified through the knowledge of local health visitors or other community services (e.g. Traveller education), and recruited at their site of residence. Dedicated Health Visitors were our primary access point because they see all Gypsy Travellers who arrive in their area to assess health needs, and they work very differently from generic health visitors who concentrate on families with small children. We specifically asked them to approach as wide a group as possible and not to target those with known ill health. Traveller education was a secondary source of access.

At each locality, a Health Visitor introduced the research interviewer to the local Gypsy Traveller communities. The research interviewer visited roadside and official sites in each locality, and was introduced to housed Gypsy Travellers by the Health

* Qualitative interviews were not undertaken in Sheffield because of a concurrent study of the mental health of Gypsy Travellers.

Visitor or in some cases through Traveller education or a Traveller social services team. Further introductions were made through networking within the community.

To take account of Gypsy Traveller population movement and seasonal variations to responses, each location within each District was visited in each of the four seasons over the fieldwork phase.

The sub-sample to be interviewed in depth was selected by interviewers in the quantitative survey asking those who fitted criteria for interview whether they were willing to be interviewed. If so, contact details were passed to the team member responsible for the qualitative aspects of the study (PVC). She then contacted these individuals and obtained informed consent before proceeding.

Comparison subjects from different socio-economic groups were identified by postal code within a GP practice. Comparison groups from ethnic minorities were recruited through participating general practices in those localities with high numbers of the required group. Letters of invitation were sent from the General Practice to individuals of the required age and sex, and in addition, they were invited by Health Visitors to participate in the research. This method was supplemented by invitation through researchers attending local community groups. If an individual declined to participate, a second matched control was substituted and so on.

2.3 Research governance and ethical approval, consent procedures

Ethics approval for the pilot study in Sheffield was granted in July 1998. MREC Approval for the main study was obtained in March 2002. The procedure for obtaining informed consent to participate in the research was as follows:

- a) For Gypsy Travellers, the health visitor approached individuals and families during routine site visits and mentioned the research. The researcher then visited the site and made contact with individuals who had expressed interest in participating, to explain the research fully and what would be required. An information sheet was read out and also left with the individual, although not all were able to read it.
- b) For comparison groups, an initial letter from the GP introduced the study to a target age/sex matched control, enclosing an information sheet and a brief inclusion

checklist with a stamped addressed envelope. Those indicating their willingness to be interviewed were visited at their home (or if they preferred, the GP's surgery), where consent was obtained and the interview carried out.

c) For those identified through local community functions, information sheets were provided with opportunity for questions and discussion before consent was obtained and interviews conducted.

The project received primary research governance approval and entry into the National Research Register through the Sheffield Health & Social Research Consortium, with secondary approval as participating sites from Primary Care Trusts where health visitors worked.

2.4 Health status survey: research measures

*EuroQol-5D (EQ-5D) questionnaire*⁴⁵ is a brief, generic, health status measure (sometimes described as a health-related quality of life measure). It defines health in terms of five dimensions, (mobility, self-care, usual activity, pain or discomfort, anxiety or depression) with each rated at one of three levels, (no problem, some problem, extreme problem). Each possible combination of levels from each dimension yields a total of 243 health states, which are scored on a tariff derived from a general population valuation study⁴⁶. The UK's National Institute for Clinical Excellence (NICE) is increasingly using this tariff in cost-utility studies. As a descriptive measure of health, the EQ-5D has been used in national health surveys in England, from which age/sex norms have been established for the general population⁴⁷, and comparative data are also available for different population sub groups⁴⁸. The questionnaire also includes the respondent's own perception of their overall health by use of a visual analogue scale designed to resemble a thermometer.

Socio-demographic characteristics and travelling patterns. Socio-demographic information included details of age, education (attendance at school, whether regular or not, age leaving school, and details of any post-school education), and smoking behaviour. The comparison group was also asked about their ethnicity (modelled on the census question) and current occupation. Gypsy Travellers were asked if they

travelled all year, rarely travelled or only travelled in the summer. For the latter option, they were asked if they spent the winter months housed or on a site.

Health symptoms and illnesses. Standardised measures were used, of anxiety and depression (HADS scale), joint pain/swelling, respiratory symptoms (MRC Respiratory Symptom Questionnaire), chest pain (Rose Angina Scale) and stroke. Data on all of these (with the exception of HADS anxiety) were available from the Sheffield Health & Illness Prevalence Survey^{49;50}, to allow comparison.

The census question on *limiting long term illness*.

Current use of medication and patterns of service use. Current medication was assessed by asking to see the medication and noting the label details. Questions were asked about the pattern of service use from a list of prompts.

2.5 Health status survey: data analytic methods

Univariate analysis

Frequency distributions were obtained for all categorical data and means and standard deviations or medians and interquartile ranges were calculated for continuous data. Statistical comparisons between groups were conducted using non-parametric tests such as chi square, and Wilcoxin matched pairs or McNemar's test for the age-sex matched data variables. Both unmatched and matched pairs T-tests were used.

To address the primary research question (*Do Gypsy Travellers have significantly lower health status and more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents?*) age-sex matched pair data have been compared on variables such as general health (EQ5D score), anxiety (HADS), depression (HADS), self-reported symptoms such as angina (Rose angina questionnaire), cough and wheeze, self-reported perceived health over the past year, self-reported long-term health problems or disability limiting daily activities or work.

In the result tables, data from both the age-sex-matched dataset and the larger Gypsy Traveller dataset are given. This is so that the level of agreement between the two

sets of Gypsy Traveller data is available, to justify our use of the full dataset in the multivariate analysis.

One of the secondary research questions (*Which aspects of health show the most marked inequality?*) is also answered with this analysis.

The secondary research question (*What is the relationship between health needs and use of health and related services in Gypsy Travellers?*) is addressed through data on use of health and related services, analysed in age-sex matched pairs to compare use of services between Gypsy Travellers and their comparators. Information on health and related service use in the Gypsy Travellers has also been compared with their health needs identified using their answers to the various health questions.

Health data on Gypsy Travellers and their comparators have been compared with data available from other studies such as the SHAIIPS study in Sheffield and with national data published by the Office of National Statistics. This provides an answer to a further secondary research question '*what is the scale of health inequality between the study population and the UK general population?*'

Univariate comparisons have also been made between the subgroups of both Gypsy Travellers and comparators to examine any differences in health status by, for example, ethnicity, location and socio-economic group. The two Gypsy Traveller ethnic subgroups used are British and Irish and the five comparator subgroups are Pakistani Muslim, African Caribbean, an inner city deprived population (Sheffield), a mixed rural population (Norfolk), and a mixed socio-economic multiracial city population (London).

Multivariate analysis

The final secondary research question (*what are the correlates of health status and symptoms with gender, age, types of accommodation, geographical locality and lifestyle factors such as smoking?*) has been examined using multiple linear and multiple logistic and regression. Independent and dependent variables are given in section 3.8. We also used the combined sample of Gypsy Travellers and controls and again looked for associations between the outcome variables of health status and

symptoms and gender, age, and lifestyle factors, using multiple linear and multiple logistic and regression. After the final model was selected, we added the group term (Traveller or comparison) to the model, to see whether or not there was a group (Traveller) effect on the outcomes after adjustment for the other explanatory variables in the model.

Data cleaning

Every tenth questionnaire was checked completely against its full data entry. Where any mistakes were found, the previous nine scripts were checked, in case of a systematic error, and all subsequent scripts until ten sequential scripts without errors had been processed. Checks then reverted to every tenth questionnaire until another error was identified, in which event, the process was repeated. Frequencies or maximum and minimum values were also obtained for each variable as a further check for inappropriate outliers. Seven typographical errors were found.

2.6 Qualitative study method

Individual Travellers were interviewed in depth in their own homes or trailers, or other venue of their choice, to ensure privacy. In all but one case, participants gave permission for the interview to be audiotaped, and these interviews lasted between one to two hours. In the exception, contemporaneous notes were taken during and after a short interview. A topic guide (see below) was developed from existing knowledge and from initial pilot interviews. Non-directive interview questions were used to foster exploration of health behaviours, beliefs and barriers to access and use of Health Services. Additional issues arising spontaneously, such as Gypsy Traveller identity and culture or suggestions for improved service provision, were incorporated into the topic guide. The participant guided the order of topics covered and the guide was only used as a prompt.

Interviews were transcribed. Qualitative data were analysed using the ‘framework’ approach⁵¹, which is specifically designed to answer policy related questions and allows for rigorous and transparent data management. A software package, Atlas Ti™, was used to enable more complex organisation and retrieval of data. After

familiarisation with the transcripts, recurring themes were noted from the early transcripts. Following coding of the first eight interviews, five broad themes were identified. The coding framework developed from the identified grouped themes was then applied to each transcript. Refinements were made during indexing of successive transcripts. On completion of indexing of all the transcripts, all the coded data for each theme was charted and sub themes were identified. When all the data had been charted, patterns, exceptions and associations were systematically examined as part of the final analytic process.

Interview topic guide	
<i>Icebreakers</i>	How long have you lived here? (Leicester, Bristol etc). How long on site/road etc). How many of family around /with /near you?
<i>Health experience</i>	How is your health at the moment/ how are you feeling? Do you consider yourself to be healthy? Could you tell me about the last time you had any health problems? (Best experience, worst experience, management of chronic illness, management of minor illness, cover attitudes; understanding; first line of action; differences in action when interviewee is unwell or their child)
<i>Access & Use Of Health Services</i>	GP registration, Use of GP service, Use of A&E, Hospital attendance- Outpatient; referrals- appointments.
<i>Prevention</i>	Ways that you try to keep self and family healthy? What do you think is bad for your health? Attendance for health screening for self (smears; flu vacs, dental etc) attendance for children (immunisations; hearing tests , dental etc) Ante-natal care
<i>Knowledge</i>	How knowledge is acquired. Extent of knowledge in relation to issues spoken of .
<i>Impact Of Lifestyle on Health</i>	Impact of travelling/ living in house/ on sites, Any other factors affecting health or access to care
<i>Beliefs</i>	Main reasons for illness and ill health? (<i>same for Gypsy Travellers as gorgios?</i>). Main health worries (i.e. illnesses / conditions most afraid of) What would most improve health of Gypsy Travellers? What advice you would give to friend/family member who had trouble with nerves, depression, mental problems and what would most help them?
<i>If not raised and if appropriate to ask</i>	Sexual health (STDs; contraception). Substance misuse, alcohol, smoking, drugs

The analysis was subjected to peer review at all stages of the process. Each transcript was read by a member of the research team (KT) experienced in qualitative methods. The coding, the framework, descriptive accounts and interpretative analysis were all

developed using continuous peer review. Following the initial analysis, the key findings were validated by presenting them to study participants and their peers in each of the study areas. This allowed for early interpretation of results to be tested or challenged by a wider group of Gypsy Travellers and for additional comments to be made.

2.7 Health services provision

Information was sought from the Directors of Public Health of 304 Primary Care Trusts, 28 Strategic Health Authorities and nine Public Health Observatories in England. A letter requested answers, including nil responses, to the following questions:

- Do you have, or could you obtain, any information on numbers of Gypsy Travellers and their location within your health district? (details to be provided if available)
- Do you have, or could you obtain, any information on health services usage for this group? (details to be provided if available)
- To your knowledge, is there any specific service provision for the Gypsy Traveller population within your health district?
- Do you have any policy statements or planning documents that specifically refer to Gypsy Travellers in the context of Fair Access and social inequalities?

2.8 Significant events during the study period

We became aware of a number of events during the time period of this research that may have had some impact upon the study outcomes and which need to be considered in the interpretation of the findings. For example, they are likely to have significance in relation to mental health scores and impact on GP attendance. At various times they affected access to sections of the community. Whilst the study did not monitor events over the entire period of the research, during the 9 months from May 2002 to January 2003, the following occurred. The events recorded during this time period are

likely to be representative of those that occurred, but were undocumented, over the full study period.

Norfolk

- PMS pilot established in Norwich. Significant re upturn in Traveller access to health care
- One site in Norwich closed due to refurbishment. The field that Gypsy Travellers temporarily camped in had become a quagmire, therefore most had moved away.

Sheffield

- Gun attack on Travellers- one murdered and one injured.

Leicester

- Recent stabbing to death of young male Traveller
- Extended family member killed by shooting in Manchester
- Unauthorised encampment – local farmer threatening vigilante action to muck spread the camp. Court hearing due re eviction.

London

- Council Site due for closure.
- Machete attack on family's caravan on site.
- Police raid on several Gypsy Travellers homes (houses). People arrested in connection with violence between two families
- Male Traveller, married with children, committed suicide in prison

3 Results: Health status survey

Primary results are presented, but for reasons of space, detailed analyses including results of all statistical tests are not included. Full details of analyses and tables can be obtained from [insert website address in published report].

3.1 Recruitment

Two hundred and ninety three Gypsy Travellers were recruited across the five locations: London, Bristol, Sheffield, Leicester and Norfolk. Quotas were met for ethnic group (English and Irish), sex, and accommodation (council or private caravan site, empty land, housed) with the exception of a shortfall of 3 housed Gypsy

Travellers. Recruitment of comparators was time consuming and a problematic for some groups. Limitations on time precluded the ability to recruit age-sex matches for all Gypsy Travellers. Of the 293 Gypsy Travellers recruited, 260 were age and sex matched with a comparator living in one of the five locations. We have no information on refusal rates for Gypsy Travellers as it proved impossible to determine reliably how many Travellers were initially approached. Table 1 shows the numbers of Gypsy Travellers recruited by ethnicity, location, and accommodation by quota required and by travelling pattern and comparators by ethnicity and location. No quota was pre-set for Private sites, or for specific locations, but numbers for these are recorded in the table below.

Table 1: Recruitment by quota variables

Gypsy Travellers		Norfolk	Leicester	Bristol	Sheffield	London	TOTAL	Quota
Sex	Male	23	33	15	18	13	102	83
	Female	43	24	41	42	41	191	83
Ethnicity	English/Welsh	44	22	25	41	7	139	83
	Irish	14	33	30	17	47	141	83
	Other	8	2	1	2	0	13	--
Site	Council	26	12	11	33	14	96	83
	Private	8	9	12	4	0	33	--
	Unauthorised	28	22	26	1	7	84	83
	Housed	4	14	7	22	33	80	83
Travel (miss=3)	Travel all year	28	15	21	1	6	71	--
	Travel in the summer	12	20	13	19	11	75	--
	Rarely travel now	26	22	20	40	36	144	--
TOTAL:		66	57	56	60	54	293	
Comparators	White	68			51	28	147	
	Pakistani		52		7		59	
	Black Caribbean			53			53	
	Other				2	1	3	
TOTAL:		68	52	53	60	29	262	

For the sub-sample selected for in-depth interview, 59 were approached who gave consent, and of these, 34 were subsequently unavailable, often for practical reasons, including health-related reasons. Table 2 shows the characteristics of the sub-sample

interviewed in depth compared with the full Gypsy Traveller sample. This is a good match with regard to socio-demographic characteristics, and as planned, is clearly weighted towards those with poorer health. The morbidity patterns are reflected in health related behaviour, such as smoking and accessing a GP. This sample is less mobile than the full sample, with a smaller proportion travelling all year and living on the roadside.

Table 2: Sub-sample selected for in-depth interview: sample characteristics in relation to full sample

	Interviewed Sample %	Whole Sample %
Characteristics	n=24	n=293
Gender: Male	29	35
Female	71	65
Age group: 16-25	17	24
26-45	42	51
46-65	29	21
Over 65	12	4
Attended school regularly as child	77	67
Age left school (mean years)	12.4yrs	12.6yrs
Accom (K5): Site	67	44
Empty land	4	29
Housed	25	27
In temporary (homeless)	4	
Children under 16yrs	88	85
Travelling patterns:		
All of the time	0	24
Part of the time	21	26
Rarely	79	49
Anxious or depressed today (EQ-5D)	50	28
Registered with any GP	92	84
Seen a GP in past year	96	79
Smoker (current)	75	57
Long-term illness, health problem or disability that limits daily activities or work	67	39

3.2 Demographic profile and socio-economic status

The demographic profile of the 260 age and sex matched Gypsy Travellers used in the age and sex matched sample does not differ significantly from the full sample recruited of 293. Although comparators were recruited to match existing Gypsy Traveller participants with respect to sex and age (within three years) in the final

sample, Gypsy Travellers were approximately four months younger. More Gypsy Travellers were main carers, predominantly of people aged between 17 and 64, compared to the comparator group where fewer carers were mainly caring for the elderly. In addition Gypsy Travellers had significantly larger families than their age-sex-matched comparators. Table 3 presents the demographic and socio-economic data for all subjects.

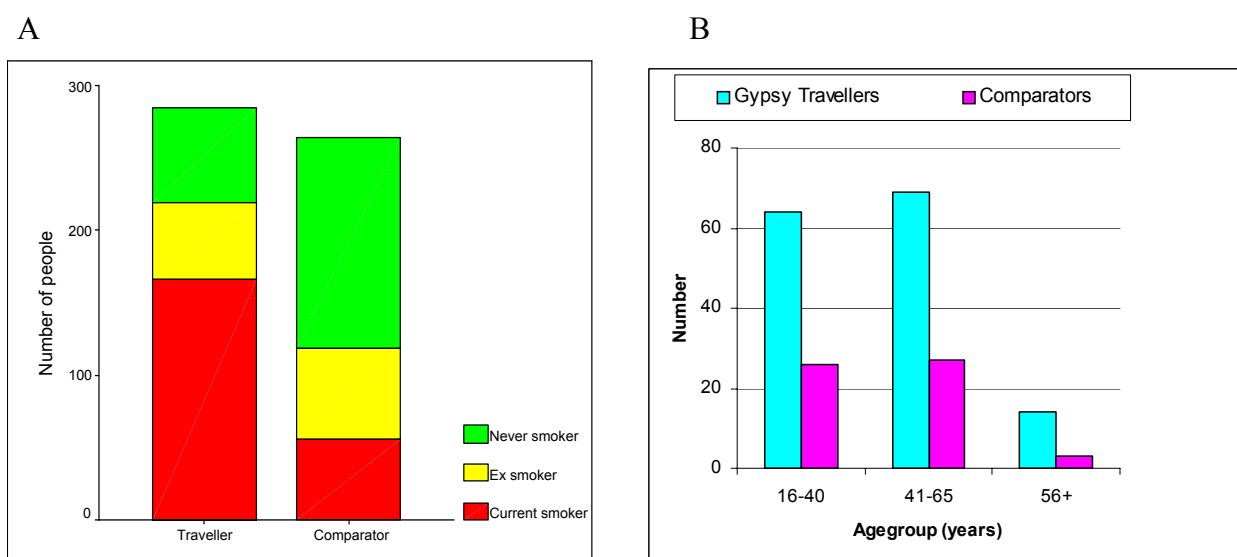
Table 3:
Demographic and socio-economic information on Gypsy Travellers and comparators

Variable		Gypsy Travellers N=293	Gypsy Travellers N=260	Comparators N=260	Age-sexed matched p
Age (years)	Mean±SD (range)	37.3±15.0 (16-87)	38.1±15.4 (16-87)	38.4±15.2 (16-82)	0.017
Sex	M:F	103:190	88:172	88:172	
School education	No. attended	196 (66.9%)	171 (65.8%)	228 (87.7%)	<0.001
	No. attended regularly after primary school	131 (44.7%)	115 (44.2%)	221 (85%)	<0.001
	Age stopped, mean±SD	12.6±2.6	12.6±2.7	16.4±1.5	<0.001
Further education	No. have	12	11	164	<0.001
	No. with degree/equivalent	0	0	101	
Smoking status	No. current: ex: never	166:53:66	147:46:60 miss 7	56;59;138	<0.001
Main carer	No. (<16:17-64:≥65)	51(15:30:6)	41(9:25:6)	21(5:6:10)	0.013
No of children: mean±SD (range)	Female responders	4.3±3.6(0-20)	4.3±3.6(0-20)	1.8±1.4(0-7)	<0.001
	Male responders	20	20	7	<0.001
		4.9±3.6 (0-18)	5.2±3.7(1-18)	2.6±2.0(1-13)	

Fewer Gypsy Travellers had attended school, either at all, or on a regular basis, or gone on to any form of further education. The type of further education also differed, with Gypsy Travellers attending adult literacy classes rather than degree courses, and there was no graduate Gypsy Traveller compared with 101 in the matched sample. There was no relationship between the age of the person interviewed and the age at which they left school, suggesting that school leaving patterns had not changed over time with changing legal requirement for school leaving age. Only 61% (115) of

Gypsy Travellers attended school regularly compared with 94% (221) of comparators, and some Travellers who attended regularly only attended for a very short period. The average age of leaving school was 12.6 years for Travellers and 16.4 for comparators. Many more Gypsy Travellers were current smokers than the age-sex-matched counterparts, and the proportion of smokers varied by age (see Figure 1).

Figure 1: Smoking status in Gypsy Travellers and age-sex matched comparators, prevalence (A) and current smokers by age group (B)



The ethnic origin of the two groups differed systematically, as intended. Gypsy Travellers were Irish or white British (mainly English) whilst the age-sex matched comparison group was predominantly English, Pakistani or African-Caribbean in origin (Table 1).

For the comparators, with respect to occupation, 23 were retired, 25 were students, 8 unemployed, 41 looking after their home and 10 disabled or sick. Of those working in the previous week, 112 were employed, and 24 self-employed. Information was missing for seven. Occupational status information was not obtainable for the Gypsy Traveller group.

Accommodation

We selected the study sample in terms of broad categories of living situations – Council sites, private sites, unauthorised encampments and housing. However, these categories mask significant variability in the types of living conditions within them. Unauthorised sites or encampments ranged between a group of caravans that had been unable to find anywhere other than empty land to stay and had no basic amenities, to a more semi-permanent ‘tolerated’ arrangement where some basic facilities were available. Private sites ranged enormously including those where Gypsy Travellers had bought their own land and obtained planning permission to live there. Council sites varied between those that had most basic facilities such as water, electricity, outbuildings with toilet, bathroom or laundry areas, rubbish collection and a recognised postal address for postal delivery, and those with few of these basic amenities. Very few sites of any type had safe play areas for the children or fire-fighting equipment. Many Council sites were located in extremely poor and hazardous environments, such as one located next to the Council tip and works department and a river with sewage outlet, causing a major problem with rats. Others lay between busy roads, next to sewage treatment plants and under electricity pylons. A few were in relatively more pleasant or desirable environments, for example, one next to a relatively quiet road, protected by thick hedge from the road, next to fields and under a mile from a new bypass and a supermarket. Tenure was usually insecure. Those living on unauthorised encampments, unless officially ‘tolerated’ were regularly moved on. Those who were not on a council or privately owned site found it difficult to obtain planning permission. Tenure on council sites was usually by licence agreement which, in contrast to a tenancy agreement, offers no protection against eviction. Several of the unauthorised encampments visited were disbanded in the course of the research, and one Council site has been closed since the fieldwork was undertaken.

3.3 Health status

General health

Gypsy Travellers reported poorer health status over the past year than their age-sex matched comparators ($z=-4.77$, $p<0.001$). The difference in proportions was 15% (95% confidence interval, 9, 22%). Overall Gypsy Travellers are significantly more likely to have a long-term illness, health problem or disability which limits their daily activities or work ($\chi^2=6.25$, $p=0.009$), compared with their age-sex matched comparators (Table 4). The difference in proportions was 11% (95% CI 3,19%). The Gypsy Travellers had a slightly higher prevalence of accidents in the previous six months (that had caused them to see a doctor or go to hospital) but this was not statistically significant.

In terms of their health on the day of completion of the questionnaire, Gypsy Travellers had more problems with mobility, self-care, usual activities, pain or discomfort, and anxiety or depression as assessed using the EQ5D than their age-sex matched comparators. Mean scores in the overall tariff for the EQ5D were 0.75 for Gypsy Travellers and 0.87 for the comparators, a mean difference of 0.12 (95% Confidence Interval [CI] 0.07 to 0.16) where 0 represents death and 1 is equivalent to optimum health. Therefore, the Gypsy Travellers reported statistically significant worse health status than their age-sex-matched comparators ($t=4.93$, $p<0.001$). Scores ranged from -.35 to +1 for Gypsy Travellers and -.09 to +1 for comparators.

Similar differences were seen between the two groups using the EQ5D visual analogue scale (VAS).

Table 4: Comparisons between Gypsy Travellers and age-sex matched comparators on standardised general health status measures.

Health variable		Gypsy Travellers N=260	Comparators N=260	Age-sex matched p	
Health status over past year	Good	103	147		
	Fairly good	80	76		
	Not good	77	37	<0.001	
Long-term illness	Yes	101	75	0.009	
Number having accidents		34	22	0.112	
Health on day of interview	Mobility	- no problems	196	222	
		- some problems	64	38	
		- confined to bed	0	0	
	Self-care	- no problems	232	250	
		- some problems	17	7	
		- unable to	11	3	
	Usual activities	- no problems	203	227	
		- some problems	46	28	
		- unable to perform	11	5	
	Pain/ discomfort	- no pain	173	188	
		- moderate pain	50	60	
		- extreme pain	37	12	
	Anxiety/depression	- not anxious	186	218	
		- moderately anxious	52	36	
		- extremely anxious	22	6	
	Total score (EQ5D tariff) mean±SD		74.9±36.1	86.6±23.1	<0.001
	Total score (EQ5D VAS) mean±SD		67.7±26.8	76.4±17.0	<0.001

Specific illnesses or problems

On a list of specific illnesses or problems both groups were asked to identify one or more of these as the health problems or disabilities that limited their daily activities or work. For most conditions, the prevalence was significantly higher for Gypsy Travellers compared with their age-sex matched comparators (Table 5). Exceptions were diabetes, stroke and cancer.

Table 5:
Numbers of Gypsy Travellers and age-sex matched comparators
reporting specific illnesses and problems

Illness or health problem	Gypsy Travellers s N=260	Comparators rs N=260	Age-sex matched p	% difference (95% CI)
<i>Illnesses/ problems reported after prompting</i>				
Nerves	73	10		
Arthritis	57	25		
Asthma	56	14		
Eye/vision problems	28	9		
Bronchitis/ emphysema	27	5		
Heart disease including angina	20	9		
Hearing problems	16	8		
Rheumatics	15	3		
Diabetes	11	9		
Stroke	3	2		
Cancer	2	6		
<i>Illness/problems identified from specific question(s)</i>				
Chest pain/discomfort	88	57	0.002	12 (4,20)
Possible angina	78	51	0.008	10 (3, 18)
Chronic cough	127	43	<0.001	32 (25,40)
Chronic sputum	119	38	<0.001	31 (24, 39)
Bronchitis	107	26	<0.001	31 (24, 38)
Asthma	168	105	<0.001	24 (16, 33)
Anxiety	100	33	<0.001	26 (19, 33)
Depression	55	20	<0.001	14 (8, 20)

Gender differences in health status

We examined the extent to which men and women had similar or different health status. Broadly, there were very few such differences, with the important exception of mental health indices.

There were no differences between the two groups with respect to health in the past year ($\chi^2=1.95$, $df=2$, $p=0.38$) or limiting long term illness ($\chi^2=1.35$, $df=1$, $p=0.15$). Similar percentages of men and women reported their health as good, fairly good or not good, and likewise had or did not have a limiting long term illness. From the questions specific to each condition, there were no statistically significant differences

(all $p > 0.05$) in the numbers reporting nerves, stroke, cough, sputum, asthma, or pain in the chest although more women (64%, 120) reported having shortness of breath than men (50%, 50) ($\chi^2 = 4.85$, $df = 1$, $p = 0.02$).

With respect to an accident in the last six months, 18 (18%) men and 25 (13%) women reported one that required a doctor or hospital visit but the difference between the sexes was not statistically significant ($\chi^2 = 0.99$, $df = 1$, $p = 0.20$).

There were no differences between the sexes in any of the five separate components of the EQ-5D. Overall scores ranged from -0.349 to 1 and the mean scores were $.76$ (SD $.34$) for men and $.75$ (SD $.36$) for women ($t = 0.26$, $df = 291$, $p = 0.8$). However the visual analogue scale (VAS) was statistically significantly different between the two sexes. The mean score for men was 73.25 (SD 23.7) and for women 65.32 (SD 28.0) ($t = 2.56$, $df = 241.4$, $p = 0.011$ (equal variances not assumed)). There may therefore be a systematic difference in recording on the 'thermometer' between the two sexes, compared with the standardised questions.

However, there were sex differences in anxiety and depression. In relation to anxiety, this was found whether measured in terms of mean HADS scores or in the numbers defined as 'definite cases' of anxiety, using a cut-off score on the anxiety scale of the HADS of ≥ 11 . Between Gypsy Traveller men and women there were significant differences with 44% of the women but only 30% of the men having anxiety problems (scores of ≥ 11) ($\chi^2 = 4.21$, $p = 0.02$). The difference in proportions was 14% (95% CI 2,26%). In both groups, anxiety scores correlated closely with the answers given to the anxiety question in the EQ5D questionnaire ($r = 0.52$ in both groups, $p < 0.001$). Anxiety problems were present in 74 Gypsy Traveller women compared with 27 comparators (difference in proportions = 28%, with 95% CI 19, 37%; $\chi^2 = 28.99$, $p < 0.001$). For men, 26 Gypsy Travellers had anxiety problems compared with 6 comparators (difference in proportions = 23%, with 95% CI 12, 34%; $\chi^2 = 12.03$, $p = 0.001$).

There were also significant differences between Gypsy Traveller men and women on reported problems with depression on the HADS, with 27% of the women but only 11% of the men having problems with depression (scores of ≥ 11) (difference=16%, 95% CI 6, 25%, $\chi^2 = 7.17$, $p=0.003$). This sex difference was only found in the GT group.

The differences between Gypsy Travellers and comparators in those reporting clinically significant levels of depression were therefore accounted for by the number of Gypsy Traveller women reporting depression on the HADS ($n=45$) compared with their counterparts ($n=16$; difference in proportion = 18%, 95% CI 10,25%; $\chi^2=17.42$, $p<0.001$).

Maternal health

More Gypsy Traveller women had children than their age sex matched counterparts, so by definition are more likely to have problems reported in childbirth if all comparators were included. We therefore only examined the rates in the two groups with children: 150 Gypsy Travellers and 141 comparators, although within these groups, the Gypsy Traveller mothers had more pregnancies and deliveries. There was no significant difference between the number of Gypsy Travellers and comparison women reporting a number of problems with pregnancy or childbirth, such as morning sickness, pre-term birth, breech presentation, or post-natal depression. However, more Gypsy Travellers experienced one or more miscarriages – 43 (29%) and Caesarean sections – 33 (22%) Gypsy Traveller women compared with 18 (16%), and 20 (14%) respectively of the non-Gypsy Traveller group with children. Conversely, hypertension was less commonly reported by the Gypsy Traveller women – 2 (1%) compared with 11(8%) of comparators.

Premature death of offspring

In response to the question “Are all your children still living?” 25 of 142 Gypsy Traveller women (17.6%) had suffered the death of a child (of any age but excluding miscarriages) compared with one of 110 matched comparators (0.9%) ($\chi^2=16.9$, $p<0.001$). Information was missing for two Gypsy Travellers and six comparators.

Eight Gypsy Travellers but no comparators reported one or more stillbirths or death of a neonatal infant, with one woman experiencing multiple stillbirths.

3.4 Health correlates: accommodation type and travelling patterns

Gypsy Travellers with long term illness are more likely to be living in a trailer on a Council Site or in a house, than on a private site or on empty land ($\chi^2 = 9.14$, $p = 0.03$). The same pattern is found for the EQ5D tariff scores, with those on private sites or empty land reporting better health status ($F = 4.33$, $p = 0.005$). There is a significantly higher level of anxiety symptoms reported by those living in houses compared with trailers, comparing scores on the HADS anxiety scale ($F = 4.43$, $p = 0.005$). Other health problems do not differ significantly by accommodation.

Travelling patterns showed an even stronger relationship with health, with those who rarely travelled having the worst health status, in terms of health in past year ($\chi^2 = 34.57$, $p < 0.001$), long term illness ($\chi^2 = 15.04$, $p = 0.001$), chronic cough ($\chi^2 = 8.34$, $p = 0.02$), HADS depression score ($F = 4.17$, $p = 0.02$), EQ5D tariff ($F = 13.09$, $p < 0.001$) and VAS scores ($F = 6.76$, $p < 0.001$).

It is not possible from these data to determine whether accommodation and travelling patterns have an impact on health or vice versa. Those with poorer health status may choose or be constrained to live in a house or travel rarely. On the other hand, living in a house or on a Council site, and travelling rarely, may have a negative effect on health.

3.5 Health correlates: Gypsy Travellers' ethnic subgroup

Before making specific comparisons between Gypsy Travellers and other social and ethnic groups, it is important to clarify whether there is significant variation between the different subgroups of Travellers – in particular between Irish Travellers and English Gypsies. There were no statistically significant differences in health between the ethnic subgroups of Gypsy Travellers (Irish compared with English, Scottish and Welsh), over a range of symptoms (depression, angina, chronic cough, chronic sputum, bronchitis, and asthma). Nor did health status in the past year and numbers

with long term illness differ between Gypsy Traveller ethnic subgroups. There was one statistically significant difference between Irish Travellers and English, Scottish or Welsh Gypsies, and that was with respect to being anxious: 47% of Irish and 31% of the others reached case criteria for anxiety (diff = 16%, 95% CI 4, 28; $\chi^2=7.19$, df=1, p=0.007). There were no differences between the Irish and other Gypsy Travellers in any of the five separate components of the EQ-5D with the exception of anxiety/depression, where 25% and 18% of Irish and the others respectively were moderately anxious and 12% and 5% extremely anxious ($\chi^2=7.27$, df=2, p=0.026).

3.6 Health comparisons: Gypsy Travellers and other ethnic and social groups

The health status of Gypsy Travellers was compared with that of three sub-groups matched for age and sex: British African-Caribbean (n = 51), British Pakistani Muslim (n = 57) and White English or Irish (n = 148). The Pakistani and Black African-Caribbean groups were urban dwellers of mixed socio-economic status. The White population was further broken down into inner city deprived (Sheffield), socio-economically mixed rural (Norfolk) and socio-economically mixed urban (London). Data for four comparators and their age-sex matched Travellers were excluded from this analysis as their ethnic status did not fall within the three groups listed. Data for a further six White comparators and their age-sex matched Travellers were excluded from this analysis, because their place of residence was outside the three localities.

The Gypsy Travellers' health was poorer on all indices than that of their White counterparts (greatest p=0.01) with one exception. There was no significant difference between the number of Gypsy Travellers and the number of White counterparts reporting long term illness.

Gypsy Travellers compared with the White non-Traveller population showed the same significant demographic differences described above: much less formal education, larger family size, and greater prevalence of smoking.

Compared with the British Muslims of Pakistani origin, the Gypsy Travellers had more children, were more likely to smoke and less likely to have attended school, although the two groups did not differ significantly on how regularly they attended

school. Most health measures showed Gypsy Travellers to have poorer health than Pakistani Muslims, although on three indices the differences between the two groups did not reach statistical significance: self reported health status, chest pain and depression.

Compared with the British Black African-Caribbean group, despite age matching within 3 years, the Traveller group was on average two years younger. They had a relative lack of formal education and larger families, although the difference in smoking status was less marked. Fewer differences in overall health were seen between Gypsy Travellers and Black African Caribbean comparators. However, more Gypsy Travellers reported respiratory problems (such as chronic cough, bronchitis, asthma), and mental health problems (anxiety and depression).

We made a planned comparison between Gypsy Travellers and different socio-economic groups within both rural and urban White populations. Even compared with those White comparators living in socially deprived urban areas, Gypsy Travellers reported significantly poorer school education, greater smoking prevalence, and larger family size. In general the health of the Gypsy Travellers was found to be poorer than that of white residents living in all the areas surveyed, i.e. whether living in a deprived inner city area or a rural area.

3.7 Comparison with national and local health status information

As the ethnic minority groups in our study were concurrent comparators, selected to match the Gypsy Traveller sample, they were not systematically sampled to be representative of their populations. It is therefore important to check whether our results on their reported health status are broadly as expected, compared with national statistics. We checked in relation to the census question on 'limiting long term illness'. Using 2001 census data, the proportion of the Pakistani population (all ages) with limiting long term illness is 14.4%, compared with 21.6% in our survey and for the Black Caribbean population, 17.8% compared with 27.3% in our survey.

The lower proportions seen in the census data may reflect the predominantly younger age distribution in these groups. However for our study, for which age and sex matched data was required, the black and ethnic minority sample identified tended to be of older people for which a higher prevalence of limiting long term illness would be expected.

One of the secondary research questions in this study (*'what is the scale of health inequality between the study population and the UK general population?'*) requires comparisons between national data and those collected from this survey. In the 2001 census, the proportion of the population overall (all ages) reporting limiting long-term illness is 18.2% compared with 41.9% in the Gypsy Traveller group.

A further comparison can be made with UK normative data for the EQ-5D VAS score. These are as follows:

UK general population sample (n=3392)	EQ5D = 0.86 (s.d. 0.23)
Social class IV and V (n=1505)	EQ5D = 0.82 (s.d. 0.26)
Gypsy Traveller sample (n= 260)	EQ5D = 0.68 (s.d. 0.27)

Within Sheffield, it is possible to make a more detailed comparison between the reported health status of Gypsy Travellers and a local population, as the Sheffield Health and Illness Prevalence Survey (SHAIPS⁴⁹) included many of the same measures. On the basis of reported symptoms, the prevalence of chronic bronchitis in Sheffield overall was 8.5% (95% CI 8.0, 9.0) compared with 41% in the Gypsy Traveller population; of asthma-like symptoms 25.6% (95% CI 24.8, 26.4) compared with 65%; of stroke 3.8% (95% CI 3.5, 4.1) compared with 1.1%; and of possible angina 12% (95% CI 11.4, 12.6) compared with 30%.

3.8 Multivariate data analyses

The analyses reported in sections 3.3 to 3.6 show a number of factors that correlate with health status. In this section we examine these factors in relation to each other, to understand more fully which combination of factors are the most important

predictors of health in the Gypsy Traveller population. Having done this, we explore whether these factors alone are enough to account for the observed health differences between the Travellers and their counterparts, or whether factors specifically associated with being a Gypsy Traveller over and above other factors (e.g. education, smoking) carries health risks. Finally, we examine the extent to which the observed differences between the health of Gypsy Travellers and the non-Traveller population can be accounted for by other factors.

To examine the relationship of health status and symptoms with sex, age, types of accommodation, geographical locality and lifestyle factors such as smoking, a number of different multivariate models were developed. As the full sample of 293 Gypsy Travellers were in every respect very similar to the subgroup of 260 who were matched to comparators, we used the full sample to address research question 2c (see section 1.2).

The following categorical variables were included as ‘predictors’ in the regression models: sex, education (did not attend school), current smoker, registered with a GP, main carer for a dependent relative, ethnic subgroup (Irish/not), accommodation (housed/not), and travel pattern (rarely/summer/all year). Age was the only explanatory variable that was continuously distributed.

Multiple regression models were fitted for the following binary health outcomes: anxious (HADS ≥ 11), depressed (HADS ≥ 11), chest pain or discomfort, cough, sputum, bronchitis, asthma, and the following continuously distributed variables: EQ-5D tariff score, EQ-5D VAS, HAD anxiety score, HAD depression score.

Table 6 summarises the results of the multiple regression models across all outcome variables (full results, in tables giving beta co-efficients, their standard errors, and 95% confidence intervals, are available from the authors). For example, health status as measured by the EQ-5D was significantly associated with age, sex, and school attendance. When these variables were entered into the model, there was no reliable evidence for a relationship with smoking status, ethnic group, travelling pattern and accommodation. Overall 16.4% of the variability in EQ-5D scores in the sample was

explained by the three predictive variables of sex, age, and school attendance. Age had the most consistent relationship with poorer health status. Women were more prone to anxiety and depression. Smokers were more likely to be anxious, depressed, or to have respiratory problems.

For explanatory variables specific to Gypsy Travellers, the only robust association was that housed Travellers were more likely to be anxious than those living in trailers, irrespective of sex, age, education, or smoking status.

For all of the models, the majority (76%) of the variation in the outcomes was not accounted for by the explanatory variables.

Odds ratio regression coefficients were calculated for the explanatory variables with dichotomous health outcome variables. In this analysis, accommodation type was analysed in terms of 1. housed or temporary accommodation, 2. private or council site, and 3. roadside site, trailer on empty land. This analysis confirmed the multiple regression findings, for example, women were twice as likely as men to be anxious (HADS anxiety score ≥ 11), other factors such as smoking status and accommodation being the same. Travellers living in houses were most anxious – more than twice as likely to be anxious as those living in trailer on a site, and about one and a half times as likely as those living in a trailer on empty land, other factors being equal.

To examine whether the poorer health of Travellers compared with non-Travellers could be accounted for by these explanatory variables, we fitted multiple linear and logistic regression models to the health outcome data for the full sample. The results are summarised in Table 7 (further tables giving beta co-efficients, their standard errors, and 95% confidence intervals are available from the authors). The explanatory variables were age, sex, attending school, current smoker, registered with a GP, whether or not a carer, and finally, whether or not a Traveller. As before, these variables only account for a proportion (at most 28%) of the variance in health. The group term (i.e. Traveller or Comparator) was entered after all the other explanatory variables, yet was still a significant predictor of health status. This shows that the

poorer reported health of Travellers cannot be accounted for by their poorer education, smoking prevalence or carer status.

Odds ratio regression coefficients were again calculated for the explanatory variables with dichotomous health outcome variables, for the whole sample. These showed that Gypsy Travellers were nearly three times more likely to be anxious than their counterparts, and just over twice as likely to be depressed. They were over three times more likely to have a chronic cough or bronchitis, even after smoking had been taken into account.

3.9 Use of health and related services

Contact with health professionals

Gypsy Travellers were much less likely than their counterparts to be registered with a GP; 41 (16%) were not registered with a GP either where they were living or elsewhere, but only one comparator. Six were unsure and a further nine only had temporary registration, in contrast to the comparison group, where only one was unsure and none had temporary registration. Travellers living on sites or in houses were most likely to have a GP. Of those living in trailers on empty land, 38% were not registered, and of those who travel all year, 37% were not registered.

In terms of contact with specific health (or health-related) professionals in the past year, Gypsy Travellers were less likely to visit the GP, practice nurse, a counsellor, chiropodist, dentist, optician, or alternative medical workers, or to contact NHS Direct for advice, than their counterparts. Conversely more of the Travellers had spoken to health visitors, social workers and midwives, or used Accident and Emergency services or a hostel in the past year. It is of note that the latter health workers are usually visitors to the home, and therefore initiating the contact. Table 8 shows details of the use of health and health related services in the past year.

Table 6: Exploring health status in Gypsy Travellers: summary of results from multiple regression models

Outcome	N	R ² as %	Explanatory variables								
			Age	Sex	No school	Smoker	GP register	Carer	ethnic sgrp	housed	Travel pattern
<i>Continuous outcomes</i>											
EQ5D - tariff	265	16.4	X		X						
EQ5D - VAS	263	9.6	X	X							
Anxiety	263	10.6		X		X				X	
Depression	260	9.5	X	X		X					
<i>Binary outcomes</i>											
Anxious	268	12.7		X	X	X				X	
Depressed	260	14.1	X	X	X	X					
Chest pain	265	3.4	X								
Cough	265	23.8	X		X			X			
Sputum	265	17.8				X					
Bronchitis	265	20.4				X		X			
Asthma	265	16.3	X		X	X		X			

Note:

Multiple linear regression models were fitted for continuous outcomes and multiple logistic regression models for binary outcomes. Statistically significant explanatory variables were selected using a forward stepwise selection method, with a p-value of less than 0.05 for entry into the model and a p-value of greater than 0.10 for removal from the model. A cross indicates that the explanatory variable was statistically significant and included in the multiple regression models.

Table 7: Exploring health inequalities between Gypsy Travellers and Comparators: Summary of significant associations between the outcome variables and potential explanatory variables from a series of multiple linear (continuous outcomes) and logistic (binary outcome) regression models

Outcome	N	R ² as %	Explanatory variables					
			Age	Sex	School at all	Current smoker	Any GP registration	Carer
<i>Continuous outcomes</i>								
EQ-5D	496	18.7%	X		X	X		
VAS	493	14.7%	X	X	X	X		
Anxiety (HAD)	491	16.5%		X	X	X	X	X
Depression (HAD)	488	17.9%	X	X	X	X		X
<i>Binary outcomes</i>								
Anxious(HAD) (Y/N)	491	19.7%		X	X	X		
Depressed (HAD) (Y/N)	488	18.7%	X	X	X	X		
Chest pain (Y/N)	496	3.3%				X		
Cough (Y/N)	496	27.2%	X			X		
Sputum (Y/N)	496	25.2%			X	X		X
Bronchitis (Y/N)	496	27.9%			X	X		X
Asthma (Y/N)	496	21.2%	X		X	X		

Note: Statistically significant explanatory variables were selected using a forward stepwise selection method, with a p-value of less than 0.05 for entry into the model and a p-value of greater than 0.10 for removal from the model. A cross indicates that the explanatory variable was statistically significant and including in the multiple regression models. The group term was added last to the model.

Table 8

Health/health-related professional or service	Gypsy Travellers N=260	Comparators N=260	Age-sex matched p
GP	205	222	0.04
Health Visitor	124	36	<0.001
District Nurse	26	21	0.41
Community Psychiatric Nurse/ other members of Mental Health Team	7	5	0.56
Practice Nurse	86	128	<0.001
Social Worker	22	3	<0.001
Counsellor	8	19	0.03
Midwife	46	30	0.02
Chiropodist	8	24	0.005
Dentist	122	186	<0.001
Optician	37	113	<0.001
Alternative medical worker	7	48	<0.001
Chemist for advice	50	87	<0.001
Other healer	20	27	0.30
Health or Social Services Day Centre	3	1	0.32
Hostel	4	0	0.05
NHS Direct	9	32	<0.001
Walk-in Centre	13	18	0.34
Accident and Emergency	63	38	0.004

Significantly fewer Gypsy Travellers than comparators kept their own ($p<0.001$) or their children's ($p<0.001$) health records. Gypsy Traveller women were much more likely to keep their records or their children's records than men ($p=0.014$) in contrast to the comparison group, where there was no significant difference between men and women.

Use of medication

Few of those surveyed claimed to take medication for their health problems. The commonest medication is taken for asthma (21 Travellers and 17 non-Travellers). Statistically more non-Travellers were taking medication for anxiety or depression, both absolutely and relative to those with HADS anxiety or depression above the threshold ($p=0.03$). Fewer Gypsy Travellers take vitamins or tonics, only 58 Gypsy Travellers stated

that they took vitamins or tonics compared with 84 age-sex matched comparators ($\chi^2=6.25$, $p=0.012$).

Forty five Gypsy Travellers and 60 age-sex matched comparators said they had decided not to use one or more medicines that their GP had advised for them ($p=0.14$) and 18 Travellers and 44 comparators had not taken one or more of their GP prescriptions to the chemist ($p=0.001$). Reasons for not using medication that had been advised by the GP were very varied for the Gypsy Travellers, including reluctance to take antibiotics or anti-depressants and dislike of side effects. For the comparators, reluctance to take antibiotics or anti-depressants and the fear of becoming addicted were the main reasons. For medication which was prescribed but for which a prescription was not redeemed at the chemists, the reasons were also variable. Distrust of the GP was a reason given by Gypsy Travellers (this was confirmed in the qualitative study) as well as not wanting the prescription in the first place. Four Gypsy Travellers also raised non-health reasons that included being moved on in the meantime, it being too far to get to a chemist, embarrassment about literacy skills, and not being bothered. Comparator non-medical issues were around cost, not being bothered and deciding not to take the medication prescribed.

The use of medication was examined matched against disease prevalence and/or disease severity, after adjustment for a number of other variables. For example, although Gypsy Travellers were only slightly more likely to take medication for chest pain, the prevalence of chest pain or discomfort among Travellers is significantly higher. We fitted a multiple logistic regression model to examine whether the consumption of medication for chest pain different between the Gypsy Traveller and comparator groups after allowing for (i.e. adjusting for the prevalence of) chest pain? Similar models were fitted to the data on medication use and prevalence of cough, wheezing, shortness of breath, stroke, anxiety and depression.

The results suggest that consumption of medication for these specific conditions is not significantly different in Gypsy Travellers compared to their counterparts, after adjusting for the prevalence of the condition in each group.

4 Results: Qualitative study

A full report of the findings from the qualitative study is precluded by space limitations. What follows is a highly condensed summary of findings within each theme, divorced from the verbatim accounts. Whilst this gives an adequate overview for policy purposes, it can not convey the ‘voices’ of the Travellers or provide a deeper understanding of their beliefs and attitudes. A fuller report is available on [insert website address in published report].

4.1 Cultural beliefs and attitudes

Identity

Travellers see themselves primarily as a separate ethnic group beyond their national identity determined by country of origin. This aspect of their identity is viewed as inherited and not chosen. Fear of losing the culture through forced change of lifestyle was evident. Cultural ‘rules’ exist. Breaking the ‘rules’ entailed the risk of being ‘outcast’. Keeping a separate existence from non-Travellers was an important aspect of maintaining a strong cultural identity and passing it on to the children.

Racism and discrimination

The experience of racism and negative stereotyping was pervasive and was automatically anticipated as a result. Most described a feeling of complete rejection by society. There was conflict between pride in identity and a felt need to hide identity to avoid discrimination. Prior experience and expectation of racism was closely associated with mistrust of non-Travellers in general that leads to defensive hostile behaviour and avoidance of unnecessary encounters with non-Travellers. It also results in resourcefulness in avoiding discrimination (including hiding Gypsy Traveller identity)

Travelling (nomadism)

Nomadism was seen as a central feature of Traveller identity and the inability to maintain a Travelling lifestyle was frequently mourned. Freedom, choice and socialising were seen as the most important benefits of travelling, but also a necessity for men to obtain employment. Travelling was seen as much more of a hardship today, and many abandoned it for this reason. Since nomadism is associated with freedom, the sense of loss of freedom was described as having a profound effect on the psyche of Gypsy Travellers. There were mixed views on the preference for houses or living on a site as an alternative to travelling. For some the idea of house-dwelling was completely alien and also experienced as very isolating.

Kinship and the Family Community

Many large Traveller families are inter-connected by marriage. The value of extended family (particularly kin) is very important to Travellers. Close family network is important but close living can also be seen as a threat to personal privacy. Bereavement is a major life-changing event. Grief and mourning may continue for many years, with self-destructive consequences, for example, abuse of alcohol. There is an accepted responsibility for Travellers to care for their own family and for this to be shared among family members. Children are extremely important to Travellers and for many a 'raison d'être.' There are clearly understood roles in families which it is important to display; women should be good mothers and men should be good providers. Respect and regard for older relatives are maintained as they age.

Self Reliance

Self reliance is seen as resulting from adversity and exclusion. Self-reliance is also construed as another aspect of privacy and not involving others in one's troubles. Both men and women showed a pride in being 'tough' and resourceful. Some Travellers felt that this trait started to be lost when Travellers moved into houses and away from the more traditional cultural lifestyle. Men had an independent work ethic – working for themselves rather than being employed by others.

Motivation and accomplishment

A prime purpose in life for men and women is to raise the family. There is a strong role expectation and sense of duty in being a good parent. Men are highly motivated to provide for the family and there is pride in the strong work ethic of both sexes. It is seen as important to demonstrate outward signs of success ('flash and show'). Personal appearance and presentation of the home are further outward signs of self worth and pride. Time was viewed as an important concept. Time spent with people and particularly listening to them was highly valued. Time in respect of urgency was also very important. It was suggested that this urgency was related to the travelling lifestyle and the need to attend to problems immediately. Keeping busy and being self-reliant were also used as coping mechanisms for displacing anxiety or grief.

Education

A lack of formal education and illiteracy was common, particularly amongst adult Travellers. Reasons given for lack of education were varied, but largely lifestyle (e.g. mobility) and cultural (roles within the family) or due to experience of, and anticipation of, racism. Inability to read and write was invariably regretted, but also often seen as an inevitable consequence of being a Traveller. The regret was both from a practical point of view, but also because of shame and embarrassment. Some were concerned that their illiteracy would identify them as Travellers and were anxious about poor ability to communicate effectively with non-Travellers, including health care workers. There was concern that the younger generation needed a formal education to 'get on' in a changing world, but few saw Traveller youth as possibly benefiting from further education or being enabled to move beyond present day occupations and patterns of employment.

Religion

Religion is an integral part of the experience of the lives of many Travellers, particularly Irish Traveller Catholics and evangelical Christians across all groups. Some Catholic Irish Travellers believe in religious 'curing people' (healers). Most Catholic Travellers also described deriving strength and comfort from visiting 'holy people' or holy places of pilgrimage for intercession when they, or someone close to them, are sick. Whilst prayer and belief in God's intervention is a source of comfort and strength in the face of adversity for many Gypsy Travellers, others see it as an act of desperation or hope rather

than faith. Many Travellers of either religious persuasion feel that their destiny is determined according to 'God's will.' The evangelical Christian Travellers feel a strong need for other family members to be converted in order to be 'saved'. Other Travellers were very sceptical of the 'born again' movement, and it sometimes caused friction within families because of the 'rules' associated with being a 'born-again' Christian.

Privacy

The need for privacy was identified by Travellers as a very important requirement and was seen as a result of their upbringing. For women in particular, the need was strongly associated with 'cultural rules' concerning behaviour with the opposite sex. Privacy was closely linked to social and personal embarrassment, and there was concern that non-Travellers did not understand this aspect of Travellers' culture. Privacy was also related to avoidance of being the subject of gossip within a close community and the need to be perceived in a positive light. As a result, family problems that may be perceived as shameful were kept hidden rather than shared.

Cleanliness and pollution concerns

The importance of cleanliness and hygiene is a notable feature of Gypsy Traveller life, associated with their self-identity. Some 'cultural rules' enshrined around this concept were alluded to rather than specifically mentioned. For women, the act of cleaning was an accepted important role. Interviews were often timed to make sure they did not interfere with this daily task. It was considered essential to be seen to have a clean home. Concerns about additives and 'unnatural' foods and remedies (including medication) were expressed. These may be linked to pollution beliefs that were much stronger in Gypsy Traveller culture in the past.

Pride in home and personal appearance

Presentation and appearance are important aspects of psychological well being for many Gypsy Travellers. Personal appearance and the appearance of the home are both important in this respect. The centrality of cleaning is emphasised by several respondents who mention the ability to continue the cleaning tasks as an important aspect of keeping healthy. The pride in having a presentable home and appearance are consistent with the

dignity and resilience that Gypsy Travellers value in themselves and each other. To fail to maintain these standards would be consistent with 'giving in' or losing control.

Food and appetite

Providing food was seen as an important nurturing role for mothers and an important aspect of being a good parent. 'Big' children were viewed as 'healthy' children and poor appetite was seen as worrying with a need to give tonics to ensure adequate intake. Quantity was largely seen as more important than nutritional quality of food, and there was limited knowledge and understanding of nutrition. Adult Travellers were concerned with body image and did not want to be over weight for this reason. Natural foods (without additives) were valued and seen as healthier. Older Travellers viewed mass-produced food with more suspicion. Conversely, younger Travellers were part of the 'fast food' generation.

4.2 Health-related beliefs and attitudes

Attitudes to health services

The general mistrust of non-Travellers in wider society described in 4.1 includes health staff. The everyday experience of racism and the defensive expectation of it underlie this widespread mistrust and give rise to low expectations of staff and service provision. The common experience of difficulty in gaining access to GP's and being registered is frequently attributed to racism, as is poor care. Mistrust is frequently manifested as fears, either of investigations, procedures or treatments. Close community and large family networks ensure stories of unpleasant experiences, medical mishaps or adverse outcomes are frequently recounted and so make the incidence of negative events appear higher. The reverse is also true with good reputations being well circulated. Avoidance behaviour is a common outcome arising from lack of trust. Lack of accurate information is compounded by usually poor communication with health staff and leads to reliance on trust rather than informed decision-making about health related options. A trusted member of health staff is highly valued and efforts are made to maintain continuity with that person. The most important factor influencing the outcome of health service encounters is whether the person is treated with respect and empathy. Anticipation of

discrimination can lead to hostile and demanding behaviour from Gypsy Travellers, particularly if it concerns anxiety at being unable to obtain treatment for a child.

Attitudes to illness

Self-reliance and a cultural pride in being tough and resourceful clearly impact on health beliefs. Stoicism, along with self-reliance, underlies a tendency to denial and delay in presentation for health care. Men take pride in being 'fit' and strong. Particularly when travelling, it is thought rarely possible to 'give in' to health problems for purely practical reasons. A fear of being perceived as weak by others, as well as not wishing to cause distress to close relatives, often results in conditions such as depression being kept secret or minimised. Cultural pride in being resilient and self-reliant led people to dismiss health complaints that were deemed minor.

Restricted autonomy for Gypsy Travellers generally and particularly for women, with their strong cultural role expectations, appears associated with a strong need to retain control. The inability to exercise some control over situations adds to the burden of stress that many Gypsy Travellers experience. Anti-depressant medication is sometimes resisted because it is viewed as interfering with self-control. There were generally low expectations of health attainment. Lack of accurate health information precluded awareness of the significance of some symptoms, with the result that some endured untreated health conditions unnecessarily. There is a strong expectation that the wider family is involved in caring for and supporting a sick member in preference to outside support, even in situations where this places extreme burdens on the carers.

Beliefs about and attitudes to death and dying

There is a strong fear of terminal illness and death associated with dread of separation from close others. The important cultural ritual of showing respect and solidarity in attending the funerals of associates, as well as those of usually many extended family members, result in attendance at a large number of funerals. Fear of bereavement and its impact is intense. Most Gypsy Travellers have witnessed or experienced overwhelming and enduring grief reactions and responses in family members. The grief of bereavement

is perceived as a cause of illness and often as an indirect cause of death. Bereavement is described as a precipitating factor in the use of harmful health behaviours such as smoking and excessive alcohol intake. The memory of the dead person is kept alive through regular grave visiting and naming of subsequent children born in to the family after the deceased. This is in conflict with the need to avoid the grief reactions that are stirred by association with the place of death. The urge to move away is a common coping reaction, but there is also an apparent superstitious fear of staying in a place where someone has previously died. Those who hold religious beliefs, whether Catholic or evangelical Christians, describe great comfort as a result of their belief that helps them to cope with their grief.

Attitudes to screening and diagnosis

Death is seen as inevitable following a diagnosis of cancer and some view the diagnosis itself as being implicated in the prognosis. Many avoid the opportunity of diagnosis because of this fear. A fatalistic attitude of many Travellers is associated with a lack of conviction in the purpose of screening and other preventative health measures. This belief is compounded by fears of a potentially fatal diagnosis. However, an alternative religious viewpoint was expressed that it is a duty to take preventative health measures in order to stay well.

4.3 Health experience

Maternal Health

Many women are multiparous because of a cultural desire for large families. Women often described avoiding early antenatal care and others had difficulty in accessing care. Those interviewed had experienced a variety of poor pregnancy or childbirth outcomes. Many first-time mothers experienced extra stress during pregnancy and childbirth due to fear of the unknown and lack of cultural understanding from staff. Hospital births were welcomed but there a preference was expressed for having a longer period of postnatal care to rest before the exhaustion of going straight back to daily duties of managing the home and caring for the family. Within living memory, postnatal women were not

allowed to do anything for some weeks apart from nursing the child, and indeed, were seen as ‘unclean’, needing to be ‘churched’.

Chronic ill health

The experience of chronic ill health was marked but understated. Many affected by chronic ill health suffered polymorbidity. Examples of poor continuity of care and information, resulting in sub-optimal management of ill health, were described. The family role in caring for chronically ill member is an important cultural expectation. Individuals affected by chronic illness are concerned about being a burden to family and try to be as independent as possible. Immediate symptom relief in order to continue performing usual responsibilities assumes more importance than long term outcomes. Stress and pressure were seen as predisposing factors to certain illnesses, particularly cancer, but chronic ill health was rarely seen as a cause of depression.

Depression and psychological health

Poor psychological health was seen as a result of difficulties and hardships faced. Depression was perceived to be common, but seen as shameful and something that should be kept hidden. There is a stigma about being labelled ‘mentally ill’. Denial of depression resulted in delay or absence of help seeking and also resulted in increased suffering. Known suicides were referred to in this context. There was a distinction made between the ‘depression that everyone suffers from’ that could be resolved by self-help, and ‘real depression’ that required medical intervention. ‘Real’ depression was feared due to its visible increase among families and its apparent intractability.

Immediate family members were strongly affected by the behaviour of a depressed relative, particularly when alcohol was consumed as a coping strategy. Bereavement was a very common precipitating factor in depression or other manifestation of psychological ill health. Grief or depression resulting from bereavement was profound and prolonged.

Substance and Alcohol Misuse

It was reported that depression was often associated with excessive alcohol consumption and that this often began as a coping strategy following bereavement. There was a recreational drinking culture among male Traveller youths, but it was culturally unacceptable for girls to join this social scene.

Drug use among Traveller youths was widely reported and a source of great concern. To have a family member who was using drugs was shameful and something to be kept secret. This resulted in family isolation. Some parents would go to desperate lengths to get their affected child away from drugs, without the help of outside support. There was insufficient knowledge about drugs and resulting increase in fear of drugs. Most described feelings of despair and helplessness over the problem of drug use and saw it as an insoluble problem for those affected.

Other health issues

Experience of trauma, accidents and infectious disease were all mentioned but not given prominence. Certain conditions such as cancer were reported as prevalent among families and extremely feared, but none of those interviewed had personal experience of suffering with cancer.

4.4 Use of health care

Communication

Communication difficulties with health staff are common, particularly where the professional does not understand Gypsy Traveller culture. Poor literacy increases the lack of confidence. This, and fear of being scorned for ignorance, makes it more difficult to ask for clarification when explanations from health professionals are not understood. These difficulties appear to contribute to reduced compliance with prescribed treatments. Family members or a trusted health worker are often brought to act as intermediaries to facilitate understanding in medical consultations.

There is a strong preference for continuity of care from a culturally congruent health worker who knows the family history so that a need to explain their situation can be

avoided. Dedicated health visitors are valued for this and are often sought out as back up to a doctor, sometimes taking on roles more usually performed by other members of a health care team. Trust in the health worker has to be earned, but is an essential prerequisite for engagement. A fear of loss of continuity of care due to lack of available up to date health records results in Gypsy Travellers preferring to return to known GPs even when they have moved on.

Importance is attached to physical examination as part of the overall consultation and this appears to be linked to the perception of the extent of true care and attention being given by the doctor. Embarrassment, especially about examination of or discussion about intimate areas of the body or discussion of health concerns relating to sexual health, is a common reason for avoiding access to health care. The need for privacy is important and efforts would be made to avoid others knowing that a consultation is taking place. Men are considerably more reluctant to attend health care and are reported to suffer more difficulty in discussing health concerns

Impact of lack of knowledge

Lack of knowledge creates heightened fears that are not necessarily perceived by health staff. It can reduce attendance and result in late presentation for care. The main source of health knowledge is from peers and family or from the media. Family experience of illness in such large extended families increases fears and skews the perception of prevalence and risk of feared conditions such as cancer. Uncommunicated fears can result in unnecessary conflict between health staff and Gypsy Travellers about the urgency to be seen. Lack of explanation and misunderstanding can result in inappropriate use of medication. Fears about the clinical process of delivery of care can result in reduced access.

4.5 Environmental factors

Living arrangements

Accommodation was the overriding factor, mentioned by every respondent, in the context of health effects. These effects are seen to be far reaching and not exclusively concerned with actual living conditions, although these are clearly seen as crucial.

Other issues include security of tenure, access to services and ability to register with a GP, support and security of being close to extended family, a non-hazardous environment and the notion of freedom for the children. There are also other factors aside from health considerations that come into play such as availability of work and access to education.

For most respondents the ability to choose their style of accommodation and to decide for themselves whether, or how, they continue to live a traditional travelling lifestyle is of fundamental importance and crucial to their sense of independence and autonomy. Many talk in terms of a 'Hobson's choice'. The lack of choice or the intolerable conditions, mentioned by the majority of respondents, are an indication to them of the negative way in which they are viewed by the non-Traveller society. It is this feeling of injustice and persecution that is often forcibly expressed as much as concern about the adverse effects of the conditions per se.

Virtually all respondents, irrespective of current accommodation, have experienced the 'traditional' travelling lifestyle in a trailer, either in the distant or more recent past. Almost without exception it is the traditional travelling lifestyle that is still craved, "the travelling way", although with qualifications, "as long as you had water and toilets and showers". One of the most frequently mentioned health benefits, and often the first called to mind by respondents, is the freedom associated with being out doors. The importance of close kinship relations is one of the major considerations. The chance to meet different people and socialise with other Gypsy Travellers is also an important requisite.

Respondents spoke despairingly of the stress arising from a lack of choice in being able to stay anywhere before they are forcibly moved on. However, there are many Gypsy Travellers who are compelled to continue travelling because they are unable to gain one of the limited available places on a permanent site.

The travelling lifestyle was also seen as potentially hazardous in view of limited safe stopping places. The hardship entailed in accessing basic facilities was also cited as a motivation for abandoning a travelling lifestyle.

Today, the benefits of a travelling lifestyle were, for most, now outweighed by the difficulties but the loss was greatly mourned and underpinned the stress and isolation described by respondents.

The perceived impact on health varied according to the type of site, conditions and geographical location, but also whether the site was privately owned or managed by others and rented out. The overwhelming disadvantages to living on a site, reported by many, were the site conditions and the surrounding environment where they were located. Hazardous location of a site was a major cause of concern to families with young children. Access to amenities, including health services, otherwise unavailable when stopping on unauthorised sites or poorly serviced transit sites was also a factor.

The main advantage to living on a site was the option to live amongst other Gypsy Travellers and, where possible, amongst other family, but for some respondents the lack of choice of close neighbours on a site was viewed as a drawback. For many respondents, particularly older ones who had longer prior experience of the 'freedom' of travelling, the feeling of being confined and bound by strict site rules was a source of real distress and there was more than one reference to a feeling confined as if in a prison.

Costs of living on a rented site were another disadvantage. In contrast to renting a council house where structural maintenance is included in the rent, the high rent for a council site only includes the pitch and any outbuildings and services. The family is responsible separately for providing and maintaining their trailers (owned or privately rented).

Housed respondents spoke of their decision to live in a house as being forced by circumstances rather than preference. Several spoke of those they know who could never settle in a house. The feeling of confinement mentioned by some respondents living on sites was also mentioned by those living in a house. This was particularly highlighted by the behaviour of children who had not previously been used to this style of living.

A significant disadvantage and cause of distress is isolation and the feeling that cultural values will be destroyed. This failure to continue living the same cultural lifestyle is seen as a severe loss that can precipitate depression, and to have damaging effects on the motivation, resourcefulness and ambition of Travellers.

Other respondents refute that house dwelling is a threat and are quick to argue that identity is not dependent on where you live “we’re the one people”. However, the perceived erosion of the culture and adoption of damaging lifestyle habits from their closer associations with non-Travellers, is seen as the risk to the young.

Some respondents talked of a small privately owned family site as the ideal living situation if they can no longer travel. The importance of having a secure base for family to come to, if in need, was an important feature of this desired option. It was conceded that there is very little opportunity of such an option for most at present.

The difficulty in obtaining suitable accommodation is a cause of insecurity for many Gypsy Travellers. Whenever respondents felt compelled to move onto a site or into housing, sometimes for health or related reasons, the process was often lengthy and very stressful, requiring intervention and support from advocates in order to succeed. The obstacles, particularly legal ones, are seen as indicative of society’s discriminatory attitude towards them.

Work

Reduced opportunities for self-employment result in stress for the family and anxiety for the future of the next generation. Awareness of discrimination in the job market and the fear of erosion of culture intensify these fears if ‘forced’ to move into a house and resort to waged employment among non-Travellers. There is reduced availability for work for those who are carrying out roles as carers within the family, but there is also lack of awareness of rights and entitlements to appropriate benefits.

Hostility and fear of violence

Experience of racist hostility was described, particularly by respondents in houses. This is felt to be particularly intolerable when it was directed at the children. There was also fear of aggression from other Gypsy Travellers, with long-term feuds between certain families. There was allusion to domestic violence, with the suggestion that this is concealed or denied. In addition, the level of violent crime in certain neighbourhoods was also expressed as a fear about living in housed accommodation.

4.6 Verification phase

Preliminary results of both the health survey and the qualitative study were presented to local Travellers in Bristol, Norwich, Leicester and London, with the organisational support of the health visitors. A total of 34 Travellers and some accompanying children attended these. Almost all of those attending were women. A larger event was organised in Sheffield, both for local Travellers and for a wider audience of Travellers and those working with them, e.g. in Traveller education, support groups and specialist health services. Twenty-one Travellers attended the Sheffield forum, including six men. A further eleven people working with Travellers attended.

There was a general consensus that findings rang true. Everyone agreed that the findings would be transferable and nobody raised any concerns about confidentiality. A number of the themes described above were confirmed or elaborated. What follows is a summary of the main elaborations.

Cultural beliefs

In relation to cleaning, there was agreement about its importance but a consensus that it was not the process of cleaning that was enjoyable so much as the end result – *“everything all bright and shiny”*. An observation at one of the sessions confirmed a strong concern of Travellers relating to hygiene that had also been mentioned before by an advisory group member. When the health visitor at one session brought in a selection of clean coffee mugs she was questioned by one of the Travellers about whether they had been in general circulation and whether they had been scoured clean (with bleach). The advisory group member had made the point that this hygiene issue was sometimes a concern for Travellers about using communal crockery if they had to go into hospital.

The need for privacy about female matters and the particular importance of keeping such matters from male children was confirmed by an observation during one of the sessions. One boy, aged about 10 years, picked up a poster showing different stages of foetal growth during gestation and showed his mother. She quickly removed it from him saying it was 'dirty'. Whilst there was agreement about the general mistrust of society, those present spoke of their trust in specialist health visitors—*'they are the only ones who want us'*.

Health beliefs

There was strong agreement that drugs as a health issue were a serious concern. Travellers were against drugs "*splits families up*", "*It's a killer*". It was stated that it is mainly lads taking drugs. 'Dope or hash' but also smack and heroin were specifically mentioned. Younger Travellers were said to mix more with people in houses now and '*young boys go clubbing and get drugged up*'. There was particular concern about lack of knowledge of symptoms and what to do. A strong need was expressed for more information.

There was agreement that depression is a major issue, but some disagreement that it was a matter of shame – some people present admitted to being on treatment for depression and felt no shame. Some took a long time to go to the Doctor and talked to a nurse or a health visitor first. There was agreement that many Travellers are reluctant to go to Doctor and some non-verbal agreement that others would think there was weakness in admitting to depression. Concern was also expressed that a Doctor will just write out a prescription rather than discuss the problem. It was agreed that some Travellers do warn each other that if they admit to depression, their children may be taken away because they may be seen as unfit mothers.

There was no surprise that women report more anxiety than men, with a general view that they 'take things on board' more than men. In relation to the higher levels of anxiety in Traveller men than their comparators, a male Traveller described always feeling wary, and that men felt the pressure of *having to "go out and work and earn the money"*.

There was strong confirmation of the deep and lasting impact of bereavement. The particular dread of cancer was confirmed, with admission of avoidance of cancer

screening because of being *'scared of what they might find'* and also not wanting to create fear and worry on their behalf in close relatives – *"I get smear test letters but I rip em up and put em in the bin"*. *"I wouldn't want to put my kids through hell"*. We noted at one venue there was clear distraction when cancer was mentioned – at that point in the presentation people started moving around and changing the subject.

Experience of hardship and social exclusion

There was clear agreement about the preference for travelling and with the experience that it was too difficult now. The comment was also made that 'shifting' is very stressful *"every time I shift I have an argument with my husband – cos you get stressed"*. The point was also made that there is a need for more site provision and if this need were met there would be less stress.

There was agreement with situation concerning existing sites *"feel like a pig in a pen."* The adverse positioning of sites in unhealthy and unsuitable environments was emphasised *"great big stinky dump next to us"* – *"near a swamp, we got the flies and the rats"*. Discrimination was mentioned as arising from having a site address- *"if you do apply for a job, once they know you're on a site, they won't give you a job"*. Some had lived in both caravans and houses, but houses were generally viewed as a poor option. It was agreed that people do not choose houses as a preferred way of living. In a house *"You miss camp life, when you close that door you're on your own, you miss the company."* Camp life was seen as preferable – *"You get out and talk to one another, but you have to have a bit of land with it"*. There was a general view that Travellers in houses are 'forgotten' and feel isolated. A feeling was also expressed that a lot more is done for Travellers on sites. On the other hand, participants stressed the negative impact of evictions (and the fear of evictions) on health, particularly mental health.

There were several stories reinforcing blatant discrimination in pubs, shops, employment etc. *"Hasn't changed, it's got worse"* Discrimination was blamed on negative media stereotyping and ignorance. Racism and social exclusion were thought to be barriers to access to schools and accommodation.

Health service use

In relation to using health services, communication with staff was endorsed as a most important issue. Communication with receptionists may be particularly important for Gypsies and Travellers as they often attend in person to get an appointment if they do not know the surgery phone number. When receptionists are immediately hostile, it has a marked impact. People spoke of not wanting to have to tell the receptionist about health problem (i.e. their reason for wanting to see doctor) “*why do they need to know, they aren't a nurse or a doctor!*” Several examples were given of doctors failing to communicate adequately and to give proper attention. People felt that doctors often can't understand what Travellers are saying; and in turn Travellers can't understand what doctors say. Stories were told of negative experiences with doctors who treated them dismissively or disrespectfully. Women felt more able to speak up for others than for themselves, in challenging negative staff attitudes or asking questions if things were unclear. People preferred to see the same doctor each time, and women preferred to see a female doctor, but explained that it is difficult to ask for a ‘lady doctor’ because of embarrassment about explaining why. However, women Travellers who had a male doctor who they trusted were happy. Men were also said to prefer male doctors, but were also said to rarely go to doctors.

In relation to accessing GP services, many reported that doctors are scared to visit sites, giving excuses, e.g. fear of dogs. It was reported that ‘*they tell you to go to casualty*’ (although sometimes the out of hours service was misunderstood as casualty). Travellers stated that they will go to the A&E department if a child is not well ‘*You have to wait a week for an appointment at doctors – no good if you are travelling*’. Access to doctors was reported by some to be easier than in the past “*I'm on a private site- health visitor makes it better to get access to doctors. Having mobile phones makes it easier to get in touch with us*”.

Some Travellers don't register with GPs by choice whereas others found it hard to get registered on a doctor's list because they live on a site; this was an explanation given for not being registered locally. In one location a local doctor was reported as saying that he would take them on, “but I won't come out, you have to go to casualty”. The health

visitor explained that the doctor who says this does so because he takes Travellers on from outside of his boundary, but they still go to him because he prescribes what they ask for without question.

There was no surprise at the finding that only 3% had seen a mental health team “*we can't get to a GP – they won't see us – so never mind a psychiatrist*”; “*There would be a long wait anyway*”. NHS Direct was not seen as a good option for Travellers who rely on mobile phones as it would be very expensive (unless they will phone back).

Options to improve health service provision

The following options either came from Travellers during original interviews or are initiatives that are in place elsewhere. At each presentation Travellers were asked to give their views but not to make either /or choices.

Dedicated Traveller health teams were seen to be a good idea, particularly health visitors, but mixed feelings about whether the team should include a doctor. Some thought it would be good to have a lady doctor (for the women) who would visit the site. The point was also made that the men would want a male doctor. (GP's are usually reluctant to visit sites). This was also seen as an option for those who don't like to go to a doctor's surgery. Others made the point that all doctors should be trained to respect people (then there would be less need for dedicated doctors). Where there were dedicated Health Visitors and health assistants for Travellers this was clearly valued.

There were mixed responses to the idea of *Travellers trained as health care workers*, some thinking it a good idea whereas others disagreed and would be afraid of other Travellers knowing their business. There was also a view that Traveller should not be treated differently to everybody else.

The idea of *Regional health centres for Travellers* was generally less popular – either it wasn't felt to be needed or they would not want to feel different by going to somewhere especially for Travellers. There would also be an access problem for women who couldn't drive. It was also seen as an unachievable idea.

Some liked the option of *mobile outreach services to Travellers* on sites, because of difficulty in accessing existing services (particularly in rural areas such as Norfolk).

Others raised the same objections as with earlier specialist options. Certain types of outreach were favoured above others – for example, dental outreach was seen as a good idea but breast screening was not because of the privacy issue.

Despite some earlier expressed needs and desire for special services there was a widespread belief that if you set up special provision it would make prejudice worse. There was an expressed view that people did not want to feel different and they should be treated the same as others.

Whilst there were mixed views about *Travellers trained as advocates*, the idea of *Travellers trained to give cultural awareness training to health staff* was generally supported.

There were no strong feelings about a policy of *ethnic monitoring* within health and social care to include Gypsy Travellers, and very little response to the idea of *Traveller health units within Strategic Health Authorities*.

Other comments

A comment was made that we didn't compare Travellers and non-Travellers regarding single teenage parents, with the implicit suggestion that this would have been a favourable comparison among the largely less positive ones.

Scepticism was also expressed about whether this research would make a difference to anything, based on previous experience of people coming out to carry out research and no results or benefits ever seen afterwards.

At the Sheffield forum, concern was raised about the ownership of, and access to, the information in this report, and whether it would be widely available.

5 Results: health service planning and provision

Of the 336 Primary Care Trusts, Strategic Health Authorities and Public Health Observatories approached, 98 (29%) responded to the invitation to submit information.

Of these, 90 were PCTs, 7 were SHAs and 1 was a PHO. Of the 98 who responded, 43 (43.9%) had or could obtain information on numbers of Gypsy Travellers and their location within their health district. Many fewer, 18 (18.4%), had, or could obtain, any information on health services usage for this group. Nineteen (19.4%) knew of any specific service provision for the Gypsy Traveller population within their health district. Only 10 (10.2%) had policy statements or planning documents that specifically referred to Gypsy Travellers in the context of Fair Access and social inequalities.

6 Summary of results

The primary research question in this study

'do Gypsy Travellers have significantly lower health status and more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents?'

can be answered as follows: This sample of Gypsy Travellers had significantly poorer health status and significantly more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents.

In summary, the health status of these Gypsy Travellers, using standardised measures (EQ5D, HADS anxiety and depression) as indicators of health, is worse than that of their age-sex matched comparators. Self reported chest pain, respiratory problems, arthritis were also more prevalent in the Traveller group. For Gypsy Travellers, living in a house is associated with long term illness, poorer EQ-5D health state and anxiety. Those who rarely travel had the poorest health; or conversely, those with the poorest health travel rarely.

Secondary research questions can be answered as follows:

There is some evidence of an inverse relationship between health needs and use of health and related services in Gypsy Travellers, with fewer services and therapies used by a community with demonstrated greater health needs.

The scale of health inequality between the study population and the UK general population is large. There was more than twice the prevalence of limiting long-term illness and significantly poorer reported health in Gypsy Travellers. Bronchitis, asthma and angina were much more prevalent. For example, nearly five times as many Gypsy Travellers reported symptoms of chronic bronchitis than a general population in Sheffield, and over twice as many reported asthma-like symptoms or symptoms of angina.

Health status in the Gypsy Traveller group is correlated with those factors that are recognised as influential on health: age, education and smoking. However the poorer health status of Travellers can not be accounted for by these factors alone. One major gender difference was found; women were twice as likely as men to be anxious, even when education, smoking and carer status was taken into account.

The aspects of health that show the most marked inequality are self-reported anxiety, respiratory problems including asthma and bronchitis, and chest pain. There was less inequality observed in diabetes, stroke and cancer.

Travellers' health beliefs and attitudes to health services demonstrate a cultural pride in self-reliance. There is stoicism and tolerance of chronic ill health, with a deep-rooted fear of cancer or other diagnoses perceived as terminal and hence avoidance of screening. Some fatalistic and nihilistic attitudes to illness were expressed; that is, illness was often seen as inevitable and medical treatment seen as unlikely to make a difference. There is more trust in family carers rather than in professional care.

In relation to Gypsy Travellers' experiences in accessing health care and the cultural appropriateness of services provided, we found widespread communication difficulties between health workers and Gypsy Travellers, with defensive expectation of racism and prejudice. Barriers to health care access were experienced, with several contributory causes, including reluctance of GPs to register Travellers or visit sites, practical problems of access whilst travelling, mismatch of expectations between Travellers and health staff, and attitudinal barriers. However, there were also positive experiences of those GPs and health visitors who were perceived to be culturally well-informed and sympathetic, and such professionals were highly valued.

Fewer than half of the PCTs, SHAs and PHOs responding to our survey had knowledge of the numbers or location of Gypsy Travellers locally. Information on Gypsy Travellers' use of services was more rarely available and only a fifth had any

specific service provision. Only one in ten had any policy statement or planning intentions that specifically referred to Gypsy Travellers.

7 Discussion and recommendations

7.1 Methodological limitations

The biggest challenge to representativeness of our sample is that Gypsy Travellers were contacted through Health Visitors, and it is important to consider potential bias introduced. These Health Visitors see all Gypsy Travellers arriving in their locality, and we took great care to ensure they did not pre-select on the basis of known health problems. However, there may be structural reasons why people available and willing to be interviewed could have poorer health, with the exception of those who were acutely ill. On the other hand, compared to those who live in or spend time in areas that are not served by specialist health care professionals, our sample probably had better access to health care provision and hence potentially better treatment. This suggests the opposite bias, although the nomadic nature of our sample means that many will have lived in areas that are less well served. In any case, alternative procedures for gaining access to the study population would, in our judgement, have created even more problems with representativeness. For example, primary contact through Traveller education would tend to exclude men and the elderly, and would be sporadically unavailable – although we did use this as a secondary source. Attempting to contact the sample without trusted intermediaries would have resulted in very severe problems. On balance, for policy purposes, the results do not overestimate health difficulties and problems with access to services for the population as a whole.

A related methodological limitation is that we found it impracticable to obtain accurate information on the numbers of people approached informally, and within these, who were unwilling to be interviewed. Several expressed willingness but were later unavailable for interview, and we do not know if this was in fact a form of refusal. There is almost certainly a bias in that the participants were if anything more trusting of outsiders than

those who refused. This means that the findings on mistrust of health staff are, if anything, an underestimate of the extent of distrust.

The ethnic composition of the age and sex matched sample is not exactly analogous to the ethnic categories of English Gypsy or Irish Traveller. For example, there is no one Pakistani or Black Caribbean language. Also, the ethnic minority samples were heavily localised, making it hard to disentangle the effects of ethnic group membership from local factors, e.g. living in Leicester. However, key similarities for our purposes were to belong to an English-speaking non-White ethnic minority group with strong cultural identity, importance of family networks, and potential difficulties in access to services, including communication difficulties and experience of racism.

Although we used validated health status measures, our results are based on self-report rather than objective measures such as forced expiratory volume or blood pressure. However, given the qualitative findings on stoicism and understatement of health problems, we think it is unlikely that the quantitative results are an artefact of reporting style, if anything, the reverse.

Men were under-represented, particularly in the qualitative research, although the quota was met for valid subgroup analysis. The preponderance of women in the qualitative study, in both the in-depth interviews and the validation phase, implies that some topics and issues may be under-represented in the results, for example, paternal roles, male health attitudes, and other experiences which are more prevalent in male populations, such as those relating to violence, alcoholism and heart disease.

The response to the survey of health provision was extremely disappointing, possibly because of the many administrative and information demands on PCTs and SHAs and the fact that we did not follow up with reminders. However, since those who did respond were more likely to have some knowledge of or interest in the topic, the survey is very unlikely to *under*-represent the extent of provision and planning. We therefore see these figures as overestimates of the national picture.

Finally, limitations imposed by the design of this research should be recognised: it is not designed to address issues of life expectancy or provide Standardised Mortality Ratios for the Gypsy Traveller group, nor is it able to address child health. The standardised health survey could not address every health problem, and some (e.g. dental ill health, gynaecological problems other than associated with pregnancy and childbirth) were omitted, although there was opportunity to discuss them in the qualitative interviews. A limitation of the qualitative study is that we did not undertake these interviews with the comparator groups, so it is difficult to be sure when particular beliefs or experiences are specific to the Travellers and when they may be more broadly applicable.

7.2 Discussion of results

Our findings confirm and extend the practice-based evidence on poorer health in Gypsy Traveller populations. There is now little doubt that health inequalities exist between the Gypsy Traveller population in England and their non-Gypsy counterparts, even when compared with other socially deprived or excluded groups, and with other ethnic minorities. The difference of 0.12 in average index values on the EQ-5D needs to be placed into context. This translates into important differences in expectancy of quality-adjusted life years (QALYs) between the two groups. Assuming that people in each group experienced the average index value of their group and that, on average, people lived to be 75, the Gypsy Traveller group would enjoy 62.25 QALYs in their lifetime, compared with 56.25 QALYs in the Gypsy Travellers group. This difference of nine QALYs is slightly larger than the difference which exists between the highest and lowest social classes in the UK⁵². Of course, the difference would be even larger if account is taken of the lower life expectancy of Travellers.

The range of health outcomes for which a difference was found is extensive, but not universal. The baseline frequency of some conditions such as stroke was low in both populations. In the light of the qualitative findings, it is possible that the lack of difference in relation to cancer may be partly an artefact of under-diagnosis and excess mortality because of late diagnosis.

The impact of smoking, education and access to GP service is important. The educational disadvantage of the Travellers was extremely striking, and the single most marked difference between Gypsy Travellers and other socially deprived and ethnic minority populations. Age is also inversely correlated with health status, with the possibility that ageing may bring particular health hazards in this community, due to the hard nature of the life and the lack of services. However, these factors do not account for all the observed health inequalities. The roles played by environmental hardship, social exclusion and cultural attitudes emerge from the qualitative study, and are consistent with the finding there is a health impact of factors associated with being a Gypsy Traveller, over and above other measured socio-demographic variables. For example the qualitative study suggests the possibility that the higher levels of anxiety in the Gypsy Traveller population may be linked to experience of, or fear of, hostility, racist attack or violent eviction from unauthorised sites. The anxiety levels of housed Travellers is even greater, supporting Cemlyn's³⁸ report of greater levels of stress due to isolation from their cultural networks and fears or experiences of neighbourhood hostility. The perception of Gypsy Travellers that they are one of the most alienated groups in society fits with Nazroo's⁵³ description of the relationship between perceptions of racial discrimination and a range of health outcomes across ethnic groups.

Heron et al in their study of the psychosocial health of Irish Traveller mothers point to the importance of family to the Travelling community and explain that "historically, Travellers' survival has depended on the group's solidarity and cohesion, their acceptance of each other as similar, their sense of belonging and their unwillingness to conform to the lifestyle of the dominant society."²⁷ This study too points to the importance of close family networks and also demonstrates the negative impact on health for many Travellers when these networks are eroded without choice, often as a result of accommodation policy.

Gypsy Travellers spoke of their fear of a policy of assimilation and the threat that this brings, both to their culture and to their general health and well-being. They see the purpose of policy that seems to 'force them' to adopt a settled lifestyle as one which is

attempting to make them the same as ‘settled people’ (or “gorjerfy” them) rather than accept them as one of many distinct groups in society. Social inclusion is a different concept and has much more to do with balancing power relations in society. Social inclusion is implicit in the concept of cultural safety – an ethical standard that has emerged from the New Zealand nursing profession. As Polaschek explains, in describing cultural safety with regard to Maori, this concept goes beyond the notion of cultural sensitivity; “It is how this group is perceived and treated that is relevant rather than the different things its members think or do”⁵⁴. This resonates well with a speech by Mary Robinson when she was Irish President, talking about Irish Travellers. She describes the fact that they want their culture recognised and their dignity respected, over and above practical provision, and concludes her speech by saying “ the most important thing is that we value them as a distinct community within our larger community”⁵⁵

The qualitative study also helps to interpret the health survey findings. For example, there is quantitative evidence of an excess prevalence of stillbirth and neonatal death. The qualitative study suggests that several factors may be implicated: lack of health knowledge, difficulties in access and negative attitudes to ante-natal care, and bad experiences of health care based on a lack of ‘cultural safety’ and mutual misunderstandings. The qualitative findings sometimes suggest caution in interpreting the survey results. For example, the lesser use of medication for anxiety and depression, among Gypsy Travellers may be partly a result of under-reporting, since medication use is a source of minor shame in itself, and many deny this for that reason. In some areas, the qualitative results suggest other important mechanisms, for example, the avoidance of preventative health screening because of extreme cancer fear, or the impact on mental health of multiple bereavements. However, the limitations of the qualitative method described in section 7.1 imply that one can only provisionally attribute these to Gypsy Traveller culture specifically, and further research is required, to examine these processes in cross-cultural studies.

The overall picture of engagement with health service personnel that emerges from this study is strongly related to problems in patient satisfaction⁵⁶. Collins et al point out, in their study of patient’s perceptions of physician communication regarding cardiac testing, that fewer studies have focussed on differences in patient satisfaction by ethnicity⁵⁷.

Their study highlighted four major issues concerning satisfactory communication with health service providers:

Substance of the information communicated (i.e. clarity of explanation):

Prior experiences of patients (particularly traumatic experiences):

Patient's expression of the need to be convinced (of the need for the procedure):

Patient's desire for a relationship with the physician (i.e. trust).

Of these four areas, it was the need for trust that strongly featured among the black ethnic group, in contrast to a stronger need for explanatory evidence and the need to be convinced among white patients. This strong need for trust in the health service provider is also a significant finding among Gypsy Travellers in this study.

The poor response to our survey of Strategic Health Authorities and primary care trusts requires these results to be treated with caution. However, an informative comparison can be made with a well-conducted survey of eight Regional Health Authorities in the South West of England in 2001⁵⁸, where seven responded after postal and telephone follow up. This study found similarly low levels of activity in data collection, health service delivery, or strategic planning in relation to Gypsies and Travellers.

7.3 Implications for research

As with any major study, as many research questions are raised by this work as answered. Whilst this study moves the field forward in a number of ways, further topics remain to be examined, or topics addressed in this report require specific detailed study. These include:

- the impact of ageing and premature mortality among Gypsy Travellers compared with other groups
- evaluation of effectiveness of cultural awareness training and advocacy projects
- impact of accommodation and cultural lifestyle factors on health
- new methods of service delivery e.g. training health workers from within the Traveller community to work with health professionals

- men's perceived health needs and barriers to meeting the needs – pilot initiatives aimed at addressing men's health
- sexual and gynaecological health needs and indicators of health
- effective and acceptable means of introducing ethnic monitoring in order to collect vital health data.
- addictive behaviours, plus effective support, treatment and prevention
- use of specific secondary and tertiary services and take-up of referrals
- case study research into suicides
- effective means of support and service provision in relation to violence (both racist violence towards Gypsies and violence between Gypsies, including gender violence),
- piloting of effective targeted health promotion initiatives and systematic evaluations of local policy initiatives.

Future research focussing on ethnic group comparisons could select less broad and more culturally homogeneous samples. For example, one wonders whether the results would have been different if Bangladeshis had been selected instead of Pakistanis. Bangladeshi Sylhetis in particular have a history over some centuries of being a disadvantaged linguistic minority population similar to Gypsy Travellers which might make this a particularly informative comparison.

Some of the policy implications outlined below apply equally to the evidence base for improving Traveller health; for example, the lack of basic data on service usage (because of the invisibility of this group in NHS ethnic monitoring) severely hampers research.

7.4 Implications for policy and health provision

Our findings demonstrate that the health needs of Gypsy Travellers are not being met through PCT and SHA current plans and provision. The general implication for policy and health provision is therefore that methods are needed to improve access and services. Options include working in partnership with Gypsy Traveller communities in the delivery of health care, commissioning dedicated or specialist health workers, improving the

cultural competence of health service staff and better coverage of Gypsy Travellers in NHS ethnic monitoring.

An example of a partnership model was developed in the form of a pilot primary health care project in 1994 in Ireland. Traveller women were given training to develop their skills in providing community based health services to their own community in partnership with public health nurse co-ordinators⁵⁹. Partnership models also imply that Gypsy Travellers be actively consulted and involved in local health planning and service development. We are aware of examples of good practice such as in Cambridge, Newark and Leeds where Gypsy Travellers are working in community development and in close partnership with health workers. (Gypsy Travellers from these areas attended our verification forum). A further way to ensure the voice of the Traveller community is heard is where Black and Ethnic Minority forums exist; Gypsy Travellers should routinely be invited to participate.

The proportion of PCTs offering specialist provision is at present small, but is the most straightforward way to achieve local awareness of health provision to Travellers whether housed or on a site. It was clear from the study findings that dedicated health visitors for Travellers were highly valued and played an important role in facilitating access to other health services. Targeted service provision has long been a practice for a range of groups. For example, specific socio cultural contexts of smoking identified in the Bangladeshi community in one particular Trust led to a specially targeted smoking cessation project that considers socio-cultural contexts⁶⁰. The resource may also include liaison work with mental health services, antenatal care and hospitals. There appears to be a strong need for targeted service provision in order to meet policy imperatives of patient involvement in care. Specialist provision would address inequities, involve capacity building and support community development, and should include housed Travellers in the job descriptions, as these needs are so often overlooked.

A valid point was made at one of the road shows that if all doctors and health staff were “*trained to respect people*” then there would be less need for dedicated services. Some

participants were quite emphatic that there should be no specialist provision and that Gypsy Travellers should be treated with the same respect and care as others in the population.

The trust and value placed by these Gypsy Travellers in specialist workers and their ready acceptance of the option of dedicated services for Travellers, reinforces the suggestion that one of the most important considerations in the experience and use of health care services is cultural safety. The ideal of a generalist service achieving this aim appears to be a long way from being met and in the meantime it appears necessary to expand and develop existing valued dedicated service provision. However, there should ideally be an aim within this specialist provision to expand efforts to improve capacity building in a community development approach that involves Gypsy Travellers participating in an equal partnership in their health care.

As a basic step, Primary Care Trusts may value advice on overcoming the difficulty faced by Gypsy Travellers in obtaining GP registration. PCTs have a duty of care to ensure that Travellers with temporary registrations receive the full range of primary care services. Patient-held records would also improve the continuity of care.

Health service information is now routinely translated into ethnic minority languages, and in a similar way, materials should be provided for a population at severe educational disadvantage and poor levels of literacy, for example in the form of audio tapes or audio CDs.

There is also a need for local interagency working in relation to Travellers. For example, Directors of Public Health could be routinely invited to participate in Local Authority forums that have an impact on Traveller health, for example, in planning accommodation for Travellers, and deciding on site evictions.

There was general consensus that cultural awareness training is a useful way of trying to improve current services, and involving Gypsy Travellers in the design and delivery of

such training was supported. Health services also need to be provided in a way which is sensitive to age and gender issues in the Gypsy Traveller population. For example, evidence from the qualitative interviews suggests that these are communities in which gender roles are strongly delineated. Women's access to health care including mental health services may be affected by restrictions on their autonomy, so that gender awareness is an important part of cultural diversity training. Provision of sensitive and culturally appropriate services relating to sexual and reproductive health and gender violence also need attention. However there is little or no evidence to support the efficacy of cultural awareness training currently provided, so that any such development should be evaluated in terms of its effectiveness at changing negative attitudes that are at the root of much discrimination.

Planning for improvement of health service provision and access is likely to be ineffective until the central problem of the 'invisibility' of Travellers is tackled. Health Needs Assessments require knowledge of the size and whereabouts of Gypsy and Traveller population. In the Race Equality Guidance for the New Deal for Communities issued by DETR in 2000, the definition of Black and ethnic minority groups, based on the 1991 census, is "all non- white groups." They state that "excluded from this definition are distinctive cultural groups such as Gypsy Travellers ... though Gypsy Travellers are recognised as a racial group for the purposes of the Race Relations Act"⁶¹. While local information about the Gypsy Traveller population and their health needs is not sought they are more likely to remain invisible to policy makers. However, including a category for Gypsies and Travellers on ethnic monitoring forms should be done in consultation with their communities, and requires careful staff training,

The Priorities and Planning Framework 2003-2006 requires that Primary Care Trusts and SHAs conduct Health Equity Audits* to inform NHS service planning and commissioning. This is a good opportunity to recognise Gypsy Travellers as a socially excluded group suffering from health inequalities. The HEA process and subsequent

* Health Inequity refers to health disparities that are unfair and avoidable

service development is most robust when Gypsy Travellers are actively consulted and involved.

If improvements are to be made in Gypsy Traveller health, clearer lines of responsibility and accountability are needed, as currently there is lack of central guidance, fragmentation of services, and a low priority given to Gypsy Traveller health. This point has already been made by Doyal et al⁵⁸, but is reinforced by our study. As many of the determinants of health status are outside the remit of the Department of Health, inter-Departmental co-ordination with regard to Gypsy Traveller health seems advisable. The Traveller Health Strategy 2003-2005 of the Republic of Ireland is an example of such an approach, developed in response to a key recommendation of the Report of the Task Force on the Travelling Community⁴¹. A similar inter-departmental Task Force in England would command wide support.

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