

The Health Status of Gypsies & Travellers in England

Summary of a report to the Department of Health 2004

Glenys Parry,
Patrice Van Cleemput,
Jean Peters,
Julia Moore,
Stephen Walters,
Kate Thomas
Cindy Cooper

The University of Sheffield
School of Health and Related Research,
Regent Street,
Sheffield S1 4DA

The Health Status of Gypsies & Travellers in England

Advisory Group

This work was undertaken by a research team from the University of Sheffield School of Health and Related Research, supported by an advisory group; Ann Bagehot, secretary of The Gypsy Council, and Gypsy Travellers Richard O'Neill, Mally Dow, Mary Lee, Len Smith. Health Visitor members made the study possible by organising access to Gypsy Travellers and comparison groups and by their consistent support; Lynne Hartwell, Sarah Rhodes, Jackie Mosley, Teresa Murray, Rachael Wilson, and Val Dumbleton. Nick Payne and Paul Dolan helped to develop the protocol for the project and gave advice on health status measurement.

We should also like to mark our gratitude to Advisory Group members Tommy Doherty and Josie Lee, two Travellers who made significant contributions to this work, but who sadly died before the report

The Health Status of Gypsies & Travellers in England

Summary Report

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.

This report gives a summary of the research method and findings. The full report can be downloaded from www.shef.ac.uk/scharr/sections/ir/library/publications.html

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.

Current health policy places particular emphasis on reducing inequalities in health and targeting socially excluded groups although ironically a 1999 policy document, *Reducing Health Inequalities: an Action Report*, 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. 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. Our study excludes New Travellers, who have opted for an alternative lifestyle but are not of the same culture.

Specific research questions were as follows:

- 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?

Method

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. Details are given here:

EuroQol-5D (EQ-5D) questionnaire 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 study.

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, 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.

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.

Individual Travellers were interviewed in depth in their own homes or trailers, or other venue of their choice, to ensure privacy. A topic guide 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.

Interview Topic Guide

Icebreakers

How long have you lived here? (Leicester, Bristol etc). How long on site/road etc). How many of family around /with /near you?

Health experience

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)

Access & Use Of Health Services

GP registration, Use of GP service, Use of A&E, Hospital attendance- Outpatient; referrals-appointments.

Prevention

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

Knowledge

How knowledge is acquired. Extent of knowledge in relation to issues spoken of .

Impact Of Lifestyle on Health

Impact of travelling/ living in house/ on sites, Any other factors affecting health or access to care

Beliefs

Main reasons for illness and ill health? (*same for Gypsy Travellers as gorgios?*). 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?

If not raised and if appropriate to ask

Sexual health (STDs; contraception). Substance misuse, alcohol, smoking, drugs

Results: Health status survey

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.

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.

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.

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.

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.

Results: Qualitative study

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.

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. 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.

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.

Other results

Fewer than half of the Primary Care Trusts, Strategic Health Authorities and Public Health Observatories 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.

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.

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.

Implications for policy and health provision

Our findings demonstrate that the health needs of Gypsy Travellers are not being met through 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-ordinators. 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. 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". 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 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 al, 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 Community. A similar inter-departmental Task Force in England would command wide support.

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

The Health Status of Gypsies & Travellers in England

Acknowledgements

This study was made possible by the generous help of many individuals, for which we are very grateful. We should first like to thank our Advisory Group: Ann Bagehot, secretary of The Gypsy Council, and Gypsy Travellers Richard O'Neill, Mally Dow, Mary Lee, Len Smith. We should also like to mark our gratitude to Advisory Group members Tommy Doherty and Josie Lee, two Travellers who made significant contributions to this work, but who sadly died before the report was published. Health Visitor members made the study possible by organising access to Gypsy Travellers and comparison groups and by their consistent support; Lynne Hartwell, Sarah Rhodes, Jackie Mosley, Teresa Murray, Rachael Wilson, and Val Dumbleton. We should like to thank Nick Payne and Paul Dolan who helped to develop the protocol for the project and gave advice on health status measurement.

We are grateful to the other health visitors and members of Primary Care Teams who supported this work: Hilary Beach, Karen Crapper, Linda Wilson, Jenny Lewin, Maggie Harrison and Malcolm Price. Other field workers were: members of Haringey Travellers Team, Pat Webb, Michael Ridge and Janet Smith; Judy Bohan of Haringey Traveller Education Service; Lorna Daymund and Kerin Wright of Norfolk Traveller Education Service, and Norfolk Traveller Liason Officer Tony Lakey. We were fortunate in our project interviewers, Patricia Anderson, Jackie Gleeson, Becky Taylor, Rosemary Hasler, who were dedicated, sensitive and skilful. Other colleagues in ScHARR gave freely of their expertise, including Louise Hall and Trudy Coldwell. Teresa Hagan, Lucy Appleton and colleagues from Sheffield Care Trust's project on the mental health of Gypsies and Travellers kindly agreed to collaborate in Sheffield data collection. Bob Lewis was involved in the early stages of interviewing. Kate Gerrish shared information on ethnic minority health status. Anne Eden Green undertook the transcription of the qualitative interviews. Thanks are also due to Noelette Keane from the Irish Traveller Movement in Britain and Sinead Ni Shuinear for advice relating to Irish Travellers. We thank Gene Feder, Thomas Acton and an anonymous reviewer for their very helpful comments on the first draft of this report. Thanks to Jake Bowers for producing materials about the research for the Gypsy and Traveller community. We acknowledge the assistance of the Department of Health, and in particular, we should like to thank Christine McGuire and Clare Croft-White in the R&D Directorate for their role in project monitoring. The views expressed in this report are those of the authors and not necessarily those of the Department of Health.

Finally, we thank all those Gypsy Travellers and others who gave their time so generously by participating in the survey, with special thanks to the Travellers who gave extra time for the in-depth interviews.