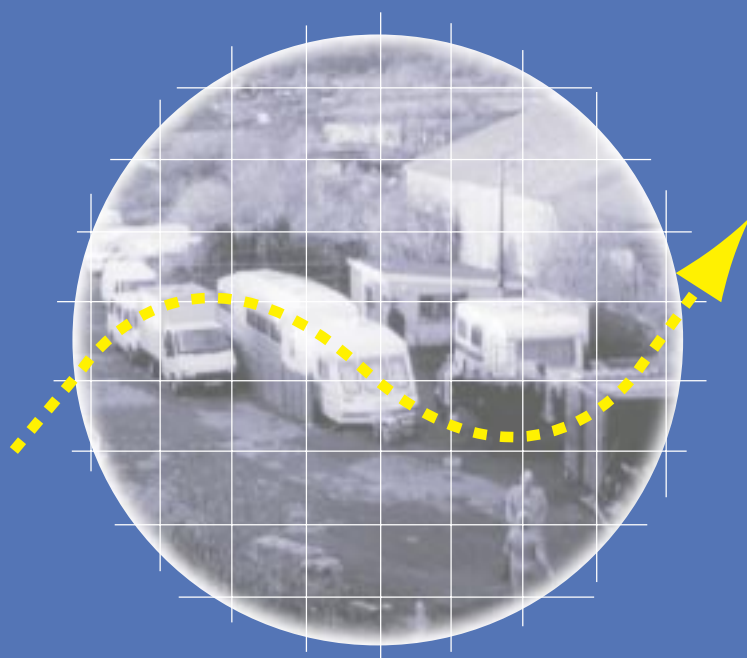




South West Public Health Observatory

The health of Travellers in the South West region



The health of Travellers in the South West region:

a review of data sources and a strategy for change

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This report has been prepared by the South West Public Health Observatory and the School for Policy Studies, University of Bristol.

The South West Public Health Observatory is part of a national network of eight regional public health observatories, funded by the Department of Health. These were established in 2000 as outlined in the Government White Paper *Saving Lives: Our Healthier Nation*. Key tasks include: monitoring health and disease trends; identifying gaps in health information; advising on methods for health and health impact assessment; drawing together information from different sources and carrying out projects on particular health issues.

The South West Public Health Observatory also forms a key part of the developing South West Regional Observatory. This is a wider regional intelligence function, currently supported by the Department of Health, Government Office for the South West, the South West of England Regional Development Agency, the Regional Assembly and the Environment Agency.

Further information about the work of the South West Public Health Observatory can be found at www.swpho.org.uk.

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Foreword

There is no other group in our population that is so marginalised and disadvantaged as Travellers. Their culture and lifestyle is often at variance with that of the settled population amongst whom they live. This can sometimes create tension and misunderstanding. There is no doubt however that, whilst the health of the population as a whole continues to improve, the health of Travellers remains a major concern.

This valuable report highlights the difficulties in making accurate assessments of the health of the travelling population and the comparative poverty of research on the health experience of this extremely

important minority group. Part of our task in helping Travellers to live full and healthy lives must be to improve substantially the information that is available. This will enable us not only to develop a clearer picture of the health experience of Travellers but also to work with them to produce solutions to the many threats to their health and well-being.

Health inequalities, quite rightly, is at the very top of the health agenda and there can surely be few other groups whose needs require such urgent attention.

Dr Gabriel Scally

Regional Director of Public Health

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Summary

There are estimated to be 120,000–150,000 Travellers in the UK of whom approximately half live in caravans and half in houses; many move in and out of housing.

Around 10% of the total number of Travellers live in the South West. A greater proportion of Travellers in the South West region live on unauthorised sites (36.6%) compared to the rest of England (22.4%).

Evidence suggests that Travellers and their children experience worse health than the general population, and that accessing health care is problematic.

However, the research on this topic has a number of limitations:

- Travellers are not counted in the Census or other routinely collected data sources.
- Travellers are not included in studies of ethnicity and health, despite Romani Gypsies being defined as an ethnic group in the Race Relations Act of 1976.
- The bi-annual DETR/DLTR Count of Travellers counts the number of caravans rather than the number of people, and excludes Travellers living in houses.

The only source of data on Travellers' health is one-off studies, which suffer from a range of weaknesses:

- Most are small-scale, many are anecdotal, few compare Travellers to the general population.
- Those looking at health service use focus almost exclusively on primary care.
- Evaluations of interventions lack rigour and impartiality.

Health and local authorities in the South West region reported relatively little activity directed

specifically at Traveller communities in terms of data collection or needs assessment, with only a few exceptions.

As local authorities have a statutory responsibility to provide education services provision in this area is far more complete; this may provide a form of contact that could be developed for the additional provision of health services.

Improving the knowledge base on Traveller health faces a number of challenges, including:

- Addressing the process and politics of definitions and classifications of 'Travellers'.
- Cultural and behavioural factors affecting traveller health need to be distinguished from material factors.
- The effects of low socio-economic position, a highly mobile lifestyle and marginalisation from mainstream society need to be disentangled.

Moving towards a more effective evidence base will assisted by:

- Acknowledging Travellers as an ethnic minority
- Including Travellers in routine monitoring
- Ensuring studies are culturally sensitive
- Systematically evaluating local policy initiatives
- Attempting to understand the determinants of Traveller health
- Addressing issues of responsibility and accountability
- Considering ethical issues specific to researching this group.

1 Introduction: what is this report about?

This report is concerned with the range and quality of evidence available on the topic of the health of Travellers. There is a relatively small amount of research which suggests that Travellers experience worse health outcomes than the general population, and that they experience a range of problems in accessing health care services. However, this research has a number of limitations. This report addresses the current state of this area of knowledge, and suggests strategies which might lead to a more evidence-based approach to health and health care issues for Travellers. The focus is upon, but not exclusive to, Travellers in the South West region of England.

As with all research, issues of definition and terminology are at the forefront. After consideration it was decided that the research would relate to those who define themselves as English/Welsh Gypsies, Irish Travellers and Scottish Travellers. The inclusive term 'Travellers' is used throughout to cover all these groups and is used as a generic term to refer to people who have a historical and cultural tradition based on a mobile lifestyle. In the process of this research some sources were also uncovered relating to those communities known as 'New Travellers', referring to people who have opted for a similar nomadic lifestyle but have very different social and cultural backgrounds. However it was decided to exclude this latter group from the main analysis since the differences between the two groups were deemed likely to be confusing rather than helpful.¹

The report is presented in five parts:

1. A review of national data sources on Travellers' health.
2. A methodological review of recent studies on Travellers' health in the UK.
3. A survey of relevant health and local authorities in the region on data sources and activities related to Travellers.
4. Methodological critique of strategies for the creation of a better evidence base on Travellers' health.
5. Conclusion: towards a more effective, and ethical, evidence base.

Who is this report for?

The aim of this report is to provide information on the extent and quality of the evidence-base relating to Travellers' health for those whose work relates to providing health and other services for this group of people, as well as for those in policy-making positions regarding the distribution and utilisation of resources. More generally, it will also be of interest to anyone concerned with understanding issues of health inequality and social exclusion, particularly those with responsibility for developing effective strategies for tackling health inequalities and improving the health of the worst off groups in society.

¹ Further information on 'new Travellers' can be found in Webster and Millar (2001).

2 Review of national data sources on Travellers' health

2.1 Travellers' health

A review of national data sources was conducted and sources were assessed for their potential value in understanding the realities of Traveller health in the region. Similar to the conclusions of earlier researchers the results of this review suggest that sources in this area are very limited (Chartered Institute of Environmental Health, 1995; Feder, 1989; Hajioff and McKee, 2000; McKee, 1997; Morgan and McDonald, 1999; Morris, 1998; Van Cleemput, 2000; van Cleemput and Parry, 2001). Despite many commentators having identified huge gaps in the available knowledge on this group of people, very little has been done to fill these gaps.

The lack of well-designed research on Travellers makes it difficult to draw overall conclusions but the general findings suggest that the health of Travellers is markedly worse than the national average (van Cleemput, 2000; van Cleemput and Parry, 2001). Studies of Traveller children have suggested that they experience high infant mortality and perinatal death rates as well as low birth weight and a high child accident rate (Feder, 1989; Hajioff and McKee, 2000). Very few studies in the UK have examined the health status of adults in the Traveller population but a study of Irish Travellers showed a higher mortality rate across all cause groups (Barry et al., 1987). Many studies have shown that Travellers often live in extremely unhealthy conditions while at the same time using health services much less often than the rest of the population (Hawes, 1997).

2.2 Enumerating Travellers: exclusion from routine data sources

The Census remains the most basic source of information for local authorities and health authorities on the population groups for whom they are responsible. However, Travellers have never been separately identified in the Census. Although there was some debate about their possible inclusion in the 1991 Census – when the question on ethnicity was first included – they were not actually allocated a separate category in the final survey. Despite the 'Count me in' rhetoric of the 2001 Census, Travellers were again excluded. A question was added on caravan dwellers, but the results are unlikely to be published and Travellers will remain unidentifiable. This group is also absent from other key data sources, such as the Labour Force Survey, the National Dwellings and Household Survey and the General Household Survey, which have included questions on self-defined ethnicity since the late 1970s (Smaje, 1995).

Given their invisibility in these broader data sets it becomes all the more important that specific groups such as Travellers should be identifiable in the routine monitoring of health and social services. But again there are considerable lacunae here. This reflects the situation of most other minority groups but is exacerbated in the case of Travellers for whom there no separate ethnic category is used. Despite a frequently expressed commitment to the elimination of inequalities in health and health care, successive governments have so far done little to address the issue of ethnicity in data collection. This is true both of routine mortality and morbidity data and also of statistics relating to service use.

2.3 Surveys including ethnicity, but not Travellers

One of the main projects undertaken to remedy this deficit was the special survey of minority ethnic groups in the 1999 Health Survey for England (Erens et al., 2001). Significantly, this did not include Travellers. Nor was there any mention of this group in the Guidance on Assessing the Health Needs of People from Minority Ethnic Groups issued by the Department of Health in 1998 or in the Action Guide on Health Inequalities (DoH, 1999). One justification for these exclusions might be that Travellers make up only about 5% of the ethnic minority population in the UK. However, this is around the same size as the Chinese population. Moreover, a number of studies have suggested that Travellers are among the most unhealthy of all minority ethnic groups (Bunce, 1996; Hawes, 1997; van Cleemput, 2000; van Cleemput and Parry, 2001).

2.4 The national data source on Travellers, and its weaknesses

The only national data source on Travellers remains the biannual DETR/DTLR Count. This survey is carried out by local authorities on behalf of central government and has been widely criticised by those concerned with the interests of Gypsies and Travellers (Green, 1991; Kenrick and Clark, 1999; Drakakis-Smith and Mason, 2001). The most immediate deficiency with the Count is that it estimates the number of caravans rather than the number of people. It also excludes those Travellers living in houses (estimated to be about 50% of the total, see below) and those living on temporary sites. The methodological rigour with which the survey is conducted also leaves much to be desired. Though OPCS made recommendations for a standard methodology across local all authorities few attempts have been made to implement this (OPCS, 1997).

Because of their timing, these surveys do not measure seasonal variations in numbers, which can be very large in particular areas. Above all, they do nothing to assess any of the needs of Traveller communities. This reflects the fact that the Count was originally designed to assess the number of caravans for planning and environmental control purposes rather than to measure the circumstances of the people living in them. Hence it remains an extremely rudimentary source of information. For purposes of this report the Count was useful only as a data set from which estimates of the number of Travellers in the South West region could be drawn and for offering some indication of their distribution between authorities.

The best estimates of the total number of Travellers in the UK is between 120,000–150,000 of which around 50% now live in houses (Morris and Clements, 1999; Kenrick and Clark, 1999). In July 2001 the DETR count showed 13,802 caravans in England, 44.9% on authorised council sites, 30.8% on authorised private sites and 24.2% on unauthorised sites elsewhere. In the

South West the total figure was 1,758 caravans (12.7% of the national total) with 34.7% on authorised council sites, 26.8% on authorised private sites and 36.6% on unauthorised sites. Caravans in the South West are therefore more likely to be on unauthorised encampments (chi-squared = 177.179, significant at $p < 0.001$). (See Table 1 for full information from the DETR count which shows the uneven distribution of sites across the South West region.) There is appreciable variation between the proportion of unauthorised sites of the total in different parts of the south West ranging from 35/263 (13.3%) of sites to 268/325 (82.5%) in Dorset. A total of around 12–15,000 Travellers can therefore be assumed to live in the South West.² Anecdotal reports suggest that there are likely to be seasonal variations in this number both because of migration from and to other parts of the country and also because some Travellers spend the winter in houses and are thereby excluded from counts based on caravans. However, there are no available figures on the extent of these variations.

² This total does not include New Travellers.

Table 1: Count of Gypsy caravans on 16th July 2001 by types of site, total for England and figures for the South West region

	Total	Unauthorised encampments	Authorised sites: council	Authorised sites: private
England	13802	3346	6201	4255
South West	1758	644	611	503
Unitary/Local Authority within county				
Bath & NE Somerset UA	2	2	0	0
Bournemouth UA	0	0	0	0
Bristol UA	31	12	19	0
Cornwall (County of)	98	15	79	4
Caradon ¹	10	0	10	0
Carrick ¹	28	0	24	4
Kerrier ¹	59	14	45	0
North Cornwall	0	0	0	0
Penwith ¹	1	1	0	0
Restormel	0	0	0	0
Devon (County of)	212	72	21	119
East Devon	19	11	8	0
Exeter ¹	13	0	13	0
Mid Devon	30	1	0	29
North Devon	0	0	0	0
South Hams	43	17	0	26
Teignbridge	92	28	0	64
Torridge	14	14	0	0
West Devon	1	1	0	0
Dorset (County of)	325	268	45	12
Christchurch	17	14	0	3
East Dorset	178	178	0	0
North Dorset	76	51	17	8
Purbeck ¹	20	5	14	1
West Dorset	14	0	14	0
Weymouth & Portland	20	20	0	0
Gloucestershire (County of)	300	41	101	158
Cheltenham	1	1	0	0
Cotswold	15	6	9	0
Forest of Dean	37	6	0	31
Gloucester	0	0	0	0
Stroud	40	0	0	40
Tewkesbury	207	28	92	87
Isle of Scilly UA	0	0	0	0
North Somerset UA	46	1	14	31
Plymouth UA	13	13	0	0
Poole UA	11	0	11	0
Somerset (County of)	263	35	119	109
Mendip	48	2	31	15
Sedgemoor	54	13	16	25
South Somerset	47	9	31	7
Taunton Deane	96	11	23	62
West Somerset	18	0	18	0
South Gloucestershire UA	191	69	60	62
Swindon UA	85	40	42	3
Torbay UA¹	1	1	0	0
Wiltshire (county of)	180	75	100	5
Kennet	0	0	0	0
North Wiltshire	49	24	23	2
Salisbury	76	13	60	3
West Wiltshire	55	38	17	0

Notes: ¹ Some data estimated using previous counts.

Source: DETR 2001

3 A methodological review of recent studies on Travellers' health

Given the lack of routine data collection on Travellers' health, policy makers and practitioners are forced to rely on the results of one-off studies. In recent years these have been reviewed by a number of commentators, all of whom have pointed to their limitations. The aim of the survey of research presented was to move the debate one step further through focussing not on the substantive results of these studies but on their methods. The intention is to highlight some of the underlying reasons for the unsatisfactory nature of much of the existing literature.

Box 1: Databases included in the search strategy

The **MEDLINE** database is produced by the U.S. National Library of Medicine. It encompasses information from *Index Medicus*, *Index to Dental Literature* and *International Nursing*, as well as other sources of coverage in the areas of allied health, biological and physical sciences, humanities and information science as they relate to medicine and health care, communication disorders, population biology and reproductive biology.

PubMed – A service of the National Library of Medicine, provides access to over 11 million MEDLINE citations back to the mid-1960s and additional life science journals. PubMed includes links to many sites providing full text articles and other related resources.

Ovid – Over 90 commercial databases are available through Ovid. They include the definitive bibliographic resources in many research areas. For research in medicine and allied health, Ovid offers **MEDLINE®** and **EMBASE**; in nursing, **CINAHL**; in bioscience, the **BIOSIS** databases; for general reference, **Current Contents®**, **Newspaper Abstracts** and **Wilson Reader's Guide Abstracts**; and so on in business, humanities, engineering, agriculture, science & technology, and social sciences.

Health Promis (HEA) – National health promotion database for England, which contains references and links to a range of sources. These include official publications, surveys, reports, books, journal articles and resources. Previously maintained by the Health Education Authority (HEA).

CINAHL – The Cumulative Index to Nursing & Allied Health (CINAHL) database provides authoritative coverage of the literature related to nursing and allied health. Virtually all English-language publications are indexed along with the publications of the American Nurses Association and the National League for Nursing.

In order to carry out this review, searches were conducted on five computerised databases: Medline,

PubMed, Ovid, CINAHL and the HEA (see Box 1). Search terms included Gyps*, Traveller*, health* and Roma* and searches were limited to articles published in English since 1980. In addition, Internet search engines were used to find local organizations involved with Traveller and Gypsy issues in the UK. This was followed up by contacting people at the Traveller Law Research Unit at Cardiff University, who provided further information on the 'grey' literature. The regular newsletter "Travellers' Times" was also searched. These various search strategies, as well as hand searches, yielded a range of relevant articles and a total of 105 were put into a Reference Manager database. The research team then read all of these articles and completed data extraction sheets which included a review of sources of evidence.

Those articles which made little use of empirical evidence were set aside and the rest were classified into those which had collected primary data (32) and those which relied on secondary data (26). The team then reviewed the methods used for primary data collection as well as examining the ways in which earlier data were cited by later commentators. The 58 articles reviewed are summarised in Appendix 1, which includes the findings and the recommendations (if any) of each study, as well as a range of methodological details.

Overall the review indicated that studies in this field were largely small scale and anecdotal. Many had been carried out by health care workers directly involved with Travellers. Health visitors in particular have been very active in documenting the needs of this group (Anderson, 1997; Batstone, 1993; Kargar, 1992; Lawrie, 1983; Ormandy, 1993; Rose, 1993; Sadler, 1993; Taylor, 1991; Tylor, 1993; Vernon, 1994). These authors are highly motivated but unfortunately rarely have either the research training or the resources to undertake robust studies which would stand up to wider scrutiny.

Studies which focus on health status or social determinants of health are mostly concerned with infectious diseases or with the condition of mothers and babies (Cornwell, 1984; Feder et al., 1989; Feder and Hussey, 1990; Feder and Vaclavik, 1991; Feder et al., 1993; Durward, 1990; McKenzie, 1990; Save the Children, 1983; Webb, 1996 and 1998). Some interest has been shown in dietary issues and in dental health (Edwards and Watt, 1997a and 1997b). However very few studies have explored major non-communicable diseases such as cancer and heart disease and no studies on the topic of occupational hazards were found (Hajioff and McKee 2000).

As a result of this relatively narrow focus, there is very little evidence on the main health problems experienced by men. Women's problems have received more attention but only those associated with their role

as mothers. Very few references are made in the literature to 'hidden' problems such as gender violence and child abuse. Mental health has also been largely ignored except for very general references to the negative impact on Travellers of discriminatory behaviour by the wider society.

The impact of poor quality sites on both physical and mental health has received attention in a few studies but, surprisingly, there has been no detailed examination of potential links (Chartered Institute of Environmental Health, 1995). Many studies refer to the damaging effects of the 1994 Criminal Justice and Public Order Act which increased the power of local authorities to evict Travellers (Niner et al., 1998; Morris and Clements, 1999; Webster, 1995). At the same time there are a number of references to the harm done to those Travellers who cannot move around and are forced to live in houses (van Cleemput, 2000). These complex relationships between travelling *per se* and health require further investigation if their interactions and implications are to be properly understood.

Very few studies have attempted any systematic comparison of the health status of Travellers with the wider population. The only real exception to this is an important pilot study carried out in Sheffield in 1995 (van Cleemput, 1995). In this investigation 87 Travellers were matched for age and sex with working class members of a socially deprived area. The results showed statistically significant differences between the two groups in certain dimensions of wellbeing and significant associations between frequency of travelling, smoking and health status. A larger study based on this pilot is now underway and should provide valuable information on the socio-demographic correlates of Traveller health compared with other materially disadvantaged groups in the population.³

Moving on from health status to health services, most studies have concentrated on issues relating to primary care (Feder, 1989; Hussey, 1988; Hennink et al., 1993). Reflecting current moves towards joint working, several comprehensive studies have examined Traveller use of local community health services as well as their use of social care (Cemlyn, 1994; Cemlyn, 2000a and 2000b; Harvey et al., 1999; Hawes, 1996; Hawes and Perez, 1996; Morris and Clements, 1999). While these are clearly important areas for investigation, they leave a number of other health care arenas largely unexplored. Very little indeed is known about Traveller use of accident and emergency services or in-patient care, for example (Beach, 1999). A few studies have examined the links between Travellers and public/environmental

health services but these are very few in number despite the obvious significance of such initiatives for mobile populations (Chartered Institute of Environmental Health, 1995; Hussey, 1998; Redondo and Guisasaola, 1995).

Most importantly, the literature does not include examples of interventions which have been evaluated with any degree of rigour. There are many cases of projects which have been documented by the health workers involved. These reports usually focus on the positive aspects of their interventions and offer useful suggestions for those wishing to do similar work. However, they are rarely well designed and tend to use process rather than outcome measures as indicators of success. Such accounts can give important indications of ways of avoiding culturally inappropriate approaches to service delivery. However, they cannot provide concrete evidence of improvements in the health status of Travellers.

Despite the weak methodological foundations of the data reported in many of these studies, they are frequently cited in subsequent articles with little or no recognition of their limitations. In a number of cases it was evident that the informal and anecdotal observations of individuals had a tendency to be transmuted into empirical 'truths' over the course of repeated publication. This may be understandable in the context of a desire to improve the circumstances of a group which has been largely ignored. However, it is of little value in building a scientific foundation for evidence-based practice. Since very few of these findings can be directly compared with those concerning other groups, they remain outside broader public health debates. According to one recent commentator, the available literature 'does not represent a picture of "evidence piling up" so much as a patchy and ill-understood phenomenon whose complexity is matched by its marginality to the mainstream health structure' (Hawes 1997: 17).

The overall conclusion from these reviews of national data sources and of recent studies was that they could contribute relatively little to the search for better sources of information on Travellers in the South West region. The DETR/DLTR Count measures the numbers of caravans and their location across the region but does not give any indication of the needs of individuals. The findings of one-off studies from other parts of the country give some indication of topics needing further investigation but offer little in the way of new data sources or innovative approaches for developing a more robust evidence base.

³ Further information on this study can be obtained from Professor Glenys Parry at SchARR (Sheffield Centre for Health Related Research).

4 Survey of South West health authorities and local authorities

A recent report on Inequalities in Health (South West Region, 1999) highlighted the plight of local Travellers but gave no further information on their circumstances or needs. This third component of the research outlined in this report was designed in part to fill this gap through identifying relevant data sources and activities. It was carried out in 2001 mainly through the use of postal questionnaires mailed to the Directors of Public Health at each of the eight health authorities in the region and the Chief Executives of all of the 51 local authorities with the request that they be passed on to the most relevant person in the organisation. Respondents were also asked to send on any relevant documentation relating to their work with Travellers. Follow up letters were sent to non-respondents after eight weeks and telephone calls were made as a final reminder. This produced a response rate of 80.4% from local authorities and 87.5% from health authorities. The questionnaire used is presented in Appendix 2. The research team also received around fifteen documents illustrating work on Travellers carried out by responding authorities.

In order to complement the questionnaires, both face-to-face and telephone interviews were carried out with individuals identified as key stakeholders in relation to Traveller health in the region. These included the health visitor responsible for running the Travellers' Health Project in Bristol (see Box 2) as well as a number of individuals responsible for providing education for Traveller children. Members of the research team also attended a workshop to meet with local Traveller representatives and colleagues from Ireland.

Box 2: Bristol Traveller Health project

One of the more substantial examples of good practice uncovered during this research was the Traveller Health Project which was set up in Bristol by a health visitor in 1990 and continues to offer care. A very positive report on the first two years of the project (Neligan, 1993) led Avon Health Authority to offer further funding and in 1994 Sarah Rhodes took over the post of specialist health visitor. Over the years the work of the project has involved a number of different initiatives including a mobile dental unit. One of the most popular initiatives was a Well Woman service with monthly clinics for screening and health promotion as well as the treatment of chronic problems. However, this part of the project ended when Avon Health Authority declined to give further funding (Rhodes 1998). The Bristol Traveller Health Project has lasted longer than other initiatives in the region and has achieved considerable success by responding to the needs of Travellers as they themselves present them.

The results from both health and local authorities showed what appeared to be a relatively low level of

activity with regard to both data collection and service delivery directed towards Travellers. Among the local authorities only four identified an individual charged with the task of liaising with Travellers. A few local authorities cited examples of what they defined as good practice. These consisted mainly of specialised needs assessments and audits but the details were often unclear. Most energy appeared to be going into educational initiatives, reflecting the statutory responsibilities of authorities in this area as well as the availability of earmarked funds (NATT, 1999). Not surprisingly, claims of good practice coincided with the appointment of a specific liaison person.

In the case of the health authorities, three out of the seven who responded had a named individual with responsibility for Travellers but only one out of the seven reported that they regularly collected specific data on this group. Four reported specialist services for Travellers and three had published reports. No health authorities claimed to be able to identify examples of good practice with regard to Travellers.

These results from both local authorities and health authorities need to be treated with some caution. In the case of the local authorities there was considerable complexity in the devolved/delegated nature of various responsibilities which impacted on work with Travellers. It was sometimes unclear at which level (if any) responsibility lay and hence there was some doubt about whether the questionnaires were reaching the right people. However, the surprisingly high response rate did suggest that they were arriving on the desk of an appropriate person who had the knowledge and the authority to answer.

Care also needs to be exercised in interpreting the time frame of the responses given. Most people included in their returns any interventions carried out over the last few years. These were rarely dated and it was not always clear whether or not they were still in operation. Hence the findings could not be used as evidence of activities being undertaken currently. Rather they seemed to reflect the work of the past five years or even longer. This problem of timing was exacerbated by the fact that many of the interventions appeared to be short-term and lack of continuity was a major problem.

The findings did indicate major variations in the levels of activity carried out by different authorities. But again these need to be interpreted with caution. Evidence from the DETR Count indicated a very uneven distribution of Travellers around the region. This was also evident in the replies to the survey. Some of the smaller authorities reported no Travellers in their population while some of the larger county councils had many. Indeed the respondent from Somerset reported that Travellers were the largest ethnic minority group in the area. Under these circumstances, the

appropriateness of the spending levels of different authorities can only be assessed in the context of the numbers of Travellers involved. In general the high rates of activity did seem to coincide with the largest numbers of Travellers and low levels of activity often reflected the absence of a Traveller population.

As well as variation between authorities the survey also suggested fragmentation within them. In some authorities there was evidence of tension regarding where responsibility for Travellers lay and the context within which they were to be treated. It was clear, for example, that workers in education, housing, environmental health and social services could all have a professional interest in Travellers. However, their concerns might be very different and might sometimes

have little to do with promoting the health of Travellers themselves. For some, their mandate necessitated that Travellers be seen mainly as a problem from which others should be protected rather than a group whose own needs should be met.

Overall then, the regional picture was one of relatively little activity directed specifically at Traveller communities. With the exception of those authorities with specialist liaison workers, there were few examples of specialist services or of dedicated systems for data collection or needs assessment. The remainder of this report therefore focuses on the challenges faced in improving the evidence base for this group both regionally and nationally.

5 Improving the knowledge base for Traveller health: conceptual challenges

Any attempt to improve the knowledge base on the health needs of Travellers will need to be preceded by a conceptual as well as technical debate about the most appropriate methods to be deployed. Discussion is needed about the definitions to be used and also about the best ways of investigating the social determinants of Travellers' health. In particular, much more thought is needed regarding how Travellers can most appropriately be placed within current discourses on inequality and social exclusion. Both have been used to frame the health problems of Travellers but as we shall see, neither is entirely appropriate.

The first problem to be tackled is that of definitions and classifications. Who should be included in the group to be investigated? Work in this area is strewn with debates about categorisation and naming, many of which are essentially political rather than scientific in nature. Travellers themselves, and those concerned with their interests, have highlighted the importance of allowing individuals and groups to name themselves as part of the process by which they shape their own identity (Acton, 1997; Feder, 1990; Hancock, 1996; Turner, 2000). This is entirely understandable from a political point of view, but self-definition can lead to confusion if it is used as the basis on which to design a study.

Much of the literature refers to the fact that Travellers (or more specifically Romani Gypsies) have been granted 'ethnic minority' status for the purposes of the Race Relations Act 1976.⁴ Indeed it is this legal judgement which is frequently brought forward as an argument for capitalising the terms 'Gypsy' and 'Traveller'. This decision was clearly an important tool in the campaigns waged by both Travellers and their supporters to protect these groups from discrimination.⁵ However, it does not follow that ethnic minority status is also useful as an analytic category in either epidemiological studies or needs assessments.

There is now an extensive debate on the problems of using ethnicity as a variable in health and health services research (Bhopal and White, 1993; Bhopal, 1997; Bhopal and Donaldson, 1998; Smaje, 1995). In many cases the term is used incorrectly as a euphemism for 'race', raising all the problems associated with the deployment of biological categories to explain social phenomena. More appropriately, the term 'ethnic group' is sometimes used to refer to 'a group of people that belong together because of shared characteristics including ancestral and geographic origins, cultural

tradition and language' (Bhopal 1997:1751). This can be a valuable tool in the planning of sensitive and effective services. However, its utility depends on a clear definition of who is included in the group and the rationale for their inclusion as well as criteria for the exclusion of others.

This issue of defining group membership has been a continuing problem in the context of Traveller research. Should traditional and 'New' Travellers be regarded as members of the same research population, for example? Both are nomadic in similar ways but their cultures are very different. Even amongst traditional Gypsies/Travellers there are cultural differences which need to be taken seriously. Should those who define themselves as Romani, English or Welsh Gypsies be included in the same study as those who define themselves as Scottish Travellers or Irish Travellers? Similarly, should those Gypsies and/or Travellers who travel, those who remain in one place and those who travel occasionally be grouped together despite the fact that the material and environmental influences on their health may be very different? Gypsies/Travellers are a very diverse group of people characterised by a 'continuity rather than community of culture' (Hawes 1997) and this has major implications for the development of sensitive and appropriate research designs.

The issue of definitions and boundaries is especially difficult in the context of epidemiological studies exploring the causes of health and illness. Bhopal and others have used the term 'black box' to apply to the many studies which use ethnicity as a key variable (Bhopal, 1997; Bhopal and Donaldson, 1998). Too frequently such studies are entirely descriptive, with no attempts to produce causal explanations. This is characteristic of much of the current literature on Travellers. A range of potential influences on health are identified and described but no attempt is made to elucidate their relative importance or the links between them. This amounts to a serious methodological constraint on the creation of an appropriate evidence base for practice.

The first set of influences referred to in the literature are what could be called behavioural or cultural factors. Here studies have identified a diverse group of factors that are assumed to have an impact on Travellers' health. These include high fat diets, what are referred to as 'alternative' hygiene practices (Acton et al., 1994; Okley, 1983), young age at marriage and large family size, lack of education and low levels of literacy especially among women, risk taking behaviours including smoking and drinking among men, and an 'innate' reluctance to use health services. These are clearly important areas for investigation but they need to be much more clearly delineated and understood. In particular we need to know how important each of these

⁴ CRE v Dutton (1989) 1 All ER 306. This was extended to Irish Travellers in an unreported court case in London in August 2000 (for details visit www.cre.gov.uk).

⁵ More details of these various campaigns can be found in Turner (2000) and in Morris and Clements (1999).

are, how they relate to each other and how they impact differently on men and women and on older and younger people within Traveller populations.

At the same time it is also important to be able to separate these cultural/behavioural factors from the more material ones. How far are Travellers' health problems related to their low socio-economic position, how much to the poor quality of the sites they often inhabit and how much to travelling itself? And how far do these problems reflect their experiences of discrimination and rejection? There is now a growing literature on migrant health from different parts of the world which poses very similar challenges. Many studies have emphasised the need to disentangle the effects of poverty and low socio-economic position from the

effects of a highly mobile lifestyle, from the effects of marginalisation from mainstream society. Yet very few insights from such wider studies have been incorporated into work on Traveller health. Cross fertilisation of this kind could play an important part in bringing these issues into the wider public health arena.

There are therefore serious problems involved in any attempt to draw firmer conclusions about the determinants of health among Travellers. If the gaps in current knowledge are to be filled, much more thought will need to be given to the ways in which the different groups are defined and to the different elements of the causal model to be deployed in explaining their health status and in planning for change.

6 Towards a more effective evidence base

6.1 Acknowledging Travellers as an ethnic minority

Bearing these conceptual challenges in mind, we can identify certain key policies that will need to be put into practice if a better knowledge base is to be developed. The first is that Travellers will need to be properly acknowledged in the wider debate on the health of ethnic minority groups. This will provide an essential starting point for ensuring that they are made visible in the collection of national data, including the Census, and also in the routine monitoring of health status and service delivery. As part of this process, the DETR Count could be replaced or complemented by an assessment of Traveller needs as part of local authority housing strategies.

6.2 Including Travellers in routine monitoring

Initiatives of this kind would be in line with current policies for dealing with inequalities in health. Under section 25 of the Health Act 1999, for example, health authorities are required to prepare Health Improvement Plans in conjunction with local authorities. These plans require the collection of accurate data on the health status and health needs of all relevant communities, particularly those deemed to be at greatest risk. This should include Travellers, despite the obstacles posed by their low levels of registration with general practitioners.

6.3 The need for culturally sensitive studies

Alongside this routine monitoring there is also the need for individual studies to explore the circumstances of particular groups of Travellers. The cultural dimension of preferences in service delivery require that individuals' perceptions of their health care needs are sought. This will necessitate the development of more creative techniques for ensuring that Travellers themselves (and subgroups within the Traveller population) are more active participants in the research process. This will not be an easy task since there is often considerable reluctance on the part of Traveller communities to talk to researchers. However, local authorities need to take seriously their responsibility to optimise consultation and levels of participation.

6.4 Systematic evaluations of local policy initiatives

More work is also needed on the evaluation of local policy initiatives. As we have seen, the literature is now full of accounts of small scale interventions, often carried out by primary care workers. Because very few have included an independent evaluation, there have been few opportunities for critical learning. If appropriate lessons are to be drawn from these initiatives, more systematic evaluations will be required. There are obvious difficulties in putting this into practice, not least of which is the increased cost. These projects are usually conducted with very few resources and adding to the price tag may mean that they do not happen at all. But if they are to be given the value they deserve then this must be taken seriously as part of the broader pursuit of quality evidence.

6.5 Understanding the determinants of Traveller health

Alongside needs assessments and evaluations of service delivery there is also a need for research to provide a clearer understanding of the determinants of health in Traveller communities. Starting from the important work being undertaken by researchers at SCHARR (van Cleemput and Parry, 2001) more detailed studies are needed to make sense of the complex mix of factors shaping the well-being of particular groups of Travellers and of individuals within those groups. This will not be achievable at local level but will need a commitment from central government to ensure that adequate resources are available.

6.6 Addressing responsibility and accountability

If improvements are to be achieved in the evidence base for Traveller health, much clearer patterns of responsibility and accountability will need to be established for the commissioning of research and for routine data collection. The current situation is one where lack of central guidance, fragmentation of services and the sometimes conflicting aims of different parts of the same authorities mitigate against effective evidence gathering. Unless these functions are clarified and Travellers are given greater visibility, their health will continue to be very low on the public health agenda both locally and nationally.

7 Closing notes on ethical dilemmas

In carrying out this review, the research team has identified a number of ethical dilemmas that need to be considered in developing research strategies for this particular group. These generally relate to the issue of 'mainstreaming' (encouraging minority groups to participate fully in existing services) versus what we might call 'separate development'. There is a general presumption in the planning of welfare that all groups will wish to participate equally in whatever society has to offer. The issue is how this can be achieved without compromising the autonomy either of the group as a whole or of individuals within it. In the case of Travellers these issues are very complex.

The frequently expressed desire of many Traveller communities to remain 'outside' society is not merely an understandable response to discrimination. Rather it is an important element in how they define their own identity. They are socially excluded but they also exclude themselves. Hence policies designed to meet their needs by 'mainstreaming' them into existing services are liable to be met with resistance – even when they are prepared with sensitivity. This raises the question of what the needs and rights of such a group actually are. Separate services may be the only appropriate option but this may increase their isolation still further.

To make matters even more complicated, it is also necessary to consider the rights of sub-groups and individuals within the Traveller community. What are the duties of the wider society towards those who may be denied rights because of the cultural context in which they are living? The high levels of illiteracy among young people in Traveller communities is a case in point here. Lack of education is a serious constraint on any individual's ability to realise their potential. How far is it the responsibility of the rest of society to ensure that the needs of Traveller boys and girls are effectively met even when this comes into conflict with the values of their cultural group?

At the same time we need to ask: what are the duties of the Travellers themselves? It is increasingly accepted that in the context of citizenship, rights can only be understood alongside corresponding duties. These duties or social responsibilities are clearly problematic in settings where some members of the group involved wish to remain separate. Of course the desire for 'separateness' will vary between individuals and will depend in part on the sensitivity with which they are approached. However, important questions remain about how the duties of Travellers themselves towards the rest of society are to be defined, especially when the perceived needs of the two groups may often appear to be in conflict.

These concerns are of obvious relevance in the context of service delivery but they are also central to the ethical conduct of research. The most important question relates to the moral status of research itself. Should we be trying to carry out research in situations where the subjects are reluctant participants? These ethical dilemmas underlie much health work but have particular significance in the case of Travellers. Is it possible to reconcile the desire of Travellers to have a degree of separation from the rest of society with the collection of health data for wider social use? How much effort should researchers put into undertaking needs assessments if their efforts are not seen as appropriate or welcome? Can health promotion research and interventions be justified if the subjects of these activities are ambivalent or resistant to them? These questions will need careful consideration and resolution if an appropriate knowledge base is to be developed for improving the health of Travellers.

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Appendix 1: Articles reviewed

Table 1A: Articles with primary research

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Save the Children (1983), <i>The Health of Traveller Mothers and Children in East Anglia</i> . Save the Children.	<p>Location: East Anglia (Cambridgeshire, Norfolk, and Suffolk).</p> <p>Survey of Traveller mothers experiences of obstetric care. Also surveyed local GPs and health professionals re Travellers and provision on services.</p> <p>Research conducted over 8 months, 1981-1982.</p> <p>Focus: Mother and Child Health</p>	<p>265 Traveller mothers with children under 5 were interviewed on family history, GP registration and attendance, access and availability of services, ante- and postnatal care received for each of their children, preventive and curative health services, details of accidents and injuries. Also recorded details of environment of sites (access to water, sanitation etc.).</p> <p>Questionnaire survey of GPs (39), and health professionals (33) in the region re problems of providing care.</p>	<ul style="list-style-type: none"> • Birth weight • Immunisation rates • Perinatal mortality <p>'Divergence' from the national norm as an indicator of 'disadvantage'.</p>	<p>Findings:</p> <p>Found Traveller children to have lower birth weights, higher perinatal mortality, greater prevalence of 'disability' than settled communities.</p> <p>Childhood injury and illness levels high (55%). Immunisation rates for DPT - non-completion in 90% of cases. 66% of children had not received developmental examinations.</p> <p>Difficulties of access to care, poor water and sanitation facilities.</p> <p>High number of Traveller mothers claim GPs refused them treatment at their surgeries.</p> <p>Agreement by health professionals surveyed that Travellers do not receive adequate preventive care. Mobility cited as 'a cause of poor uptake of services'.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Use of personally held records • Employment of outreach health visitors specifically responsible for Travellers • Simpler registration system • Easier access for temporary treatment • Use of Mobile clinics • Better resourced sites (water, sanitation etc.).
<p>Pahl and Vaile (1986), <i>Health and Health Care Among Travellers</i>. University of Kent at Canterbury MSc Thesis.</p> <p>Pahl and Vaile (1988), <i>Health and Health Care Among Travellers, J Social Policy</i> 17[2]: 195-213.</p>	<p>Location: Kent</p> <p>Survey of health histories of Traveller women and children.</p> <p>Focus: Traveller women and children under 5 years old.</p>	<p>Questionnaires distributed by Health Visitors to all sites in Kent over a 2-week period in 1985 and interviews with 263 Traveller women were held. Data on facilities available at each site, safety conditions, illness and accidents over last 5 years, use of GP services, dentists and family planning, problems obtaining care. For children information on accidents, immunisations, disabilities and developmental surveillance was collected.</p>	<ul style="list-style-type: none"> • Access to water, electricity, sanitation and rubbish disposal. • Assessment of site safety (good, moderate, poor) by respondents. • Use of GPs, dentists. • Sources of primary care. • Information on pregnancy - pre and antenatal care, birth weight, foetal and infant mortality rates. • Immunisation rates. 	<p>Findings:</p> <p>Found Travellers more settled than expected. (30% not moved for over 5 years) - allows for continuity of care.</p> <p>42% lived on local authority sites, 18% on 'private' sites, and 29% on unauthorised sites. Poor amenities and facilities.</p> <p>85% of women registered with GP. 40% had no dental care in previous 5 years. 14% said they had psychosocial illness in last 5 years.</p> <p>33% attended A&E for primary care. 70% received antenatal care from GP or hospital.</p> <p>Higher infant mortality rate.</p> <p>16% on the Pill.</p> <p>11% of children had had a serious injury in last 5 years.</p> <p>3% reported to have mental/physical disability.</p> <p>Very low immunisation rates.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • HAs should include statement on healthcare of/for Travellers in strategic plans. • Use of personal records to facilitate continuity, provision of mobile services • Appointment of Health Visitor responsible for Traveller and Gypsy health • Need for inter-agency working • Promotion of Traveller and Gypsy culture to raise awareness and sensitivity.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Streetly (1987) Health Care for Travellers: One Year's Experience, <i>BMJ</i> 294: 492-494. Ref. ID 45	Location: Kent Describes work of clinical medical officer, put in post to address issues raised by Pahl and Vaile (1986). Focus: Service provision. Initially families with young children then scaled up to include Travellers of all ages and sexes.	2 Health Visitors, 1 CMO and a mobile clinic visited site formally at least twice a month. Further 'informal' visits were made when problems arose. Provision of preventive services, information on local welfare services, immunisation, advice on feeding, family planning. Use/provision of patient-held record cards.	<ul style="list-style-type: none"> Numbers of consultations made Uptake of preventive services (developmental screening, hearing/sight tests). Appointments made for dental, chiropody and physiotherapy treatment 	<p>Findings: 2 groups of Travellers identified. Those dependent on social security (the old, disabled, ill) who remain on permanent sites, and those with younger families who respond to seasonal work, more mobile and more likely to park illegally and thus have less access to care/services. Both groups had similar health problems.</p> <p>Low literacy among Travellers made finding info on services difficult. Postal service refusing to deliver mail meant making hospital appointments was difficult.</p> <p>Poor understanding by health workers of Travellers' cultural beliefs.</p> <p>Problems with registering with GPs, therefore use A&E.</p> <p>Liaison with different agencies (education etc.) made health services more acceptable and sensitive to Traveller needs. "Uptake has improved as the team has been accepted".</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Regular monitoring by Health Authority of Travellers, including illegal encampments or environment and facilities available. Specify Health Visitor for Traveller health matters. Establish a national network of Health Visitor working with Travellers. Health Visitor to reach Travellers of all ages and both sexes. Outreach approach needed for mobile young families. Use of patient held cards. Intra-agency working important, esp. health education.
Hussey (1988) Travellers and Preventive Healthcare: What are Health Authorities Doing? <i>BMJ</i> , 296: 1098	Location: None specified. Results of a survey sent to community nursing directors requesting information on prevention policies and details of known Travellers. No primary research done with Travellers. Focus: Provision of Services for Travellers.			<p>Findings: Only 5/168 districts had policy statements mentioning Travellers. 81/168 districts had Health Visitors with a special responsibility for Travellers (only 22 offered training re Travellers). 11 districts claimed to have special outreach facilities for Traveller mothers and children.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Need for general rather than specific preventive measures. Need for better liaison channels. Suggested running of demonstration health promotion projects for Travellers.
Barry et al. (1989) The Travellers' Health Status Study - Vital Statistics of Travelling People, 1987. Dublin HRB.	Location: Republic of Ireland. Describes fertility and mortality rates and life expectancy of Travellers based on births and deaths in 1987, using the 1986 Census of Travelling People as a denominator. Focus: Fertility and mortality rates, congenital health problems.	Community care study teams (CCSTs) in each health board recorded Births/deaths for 1987. CCSTs included an area medical officer, public health nurse(s) and a social worker. Use of interviews with public health nurses for accommodation status, mother's age, marital status, and age at marriage. Health board social workers used as sources for data on Traveller deaths.	<ul style="list-style-type: none"> Crude birth rate General fertility rate Total fertility rate Standardised mortality rate Life expectancy. 	<p>Findings: Importance of accommodation status for health. From census, age structure of Traveller population is skewed to younger age groups, with relatively few in older age groups. Explanations vary. Higher than national average CBR, GFR and TFR. Higher than average stillbirth rates, perinatal, neonatal and infant mortality rates much higher than national average. High mortality from congenital anomalies and accidents. Life expectancy for Travellers much lower than rest of the population.</p>

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Hyman (1989) <i>Sites for Travellers - a Study of 5 London Boroughs</i> . London Race and Housing Research Unit.	Location: 5 London boroughs. Examination of health/health care issues as part of a wider study on Travellers. Identifies disparity in access to care between Travellers on authorised/unauthorised sites. Focus: None specified.	88 Travellers interviewed on authorised (54) and unauthorised (34) sites. Information collected on 'nerves'/depression, chronic illness, disability, birth, infant and child mortality. Access to health care - GP registration, health records, use of hospitals for general check-ups, because "if you go to the doctor he just looks at the part you complain about".	<ul style="list-style-type: none"> Responses re illness, accidents, infant and child mortality. Length of stay on site. Data compared with that from Pahl and Vaile (1986) study. <i>'the numbers of respondents...were too small to make meaningful comparisons'</i> .	Findings: Findings were similar to those in Pahl and Vaile (1986). 96% of Travellers on authorised sites and 56% on unauthorised sites said they were registered with a GP within the borough. 81% of Travellers on both types of sites were registered with a GP (slightly less than Pahl & Vaile (1986) found). Health records were kept at GP surgeries, but this was less often the case with Travellers on unauthorised sites. Low rates of disability (polio, epilepsy, and congenital heart defect). No mental handicaps mentioned.
Feder, Salkind and Sweeny (1989) <i>Traveller-Gypsies and General Practitioners in East London: the Role of the Traveller Health Visitor, Health Trends</i> , 21: 93-94.	Location: East London. Questionnaire survey of general practitioners in East London. Focus: service provision	Questionnaire sent to 103 general practices (100 responded) to determine: <ul style="list-style-type: none"> What proportion accepted Traveller patients Which practices knew that the Traveller Health Visitor existed What problems (if any) GPs faced in providing care for Travellers. 	<ul style="list-style-type: none"> What proportion accepted Traveller patients Which practices knew that the Traveller Health Visitor existed What problems (if any) GPs faced in providing care for Travellers 	<i>"Transitional nature of out-reach services detracts from their long-term efficacy...there is a need to integrate Travellers into established primary care networks."</i> Findings: 10% of GPs didn't accept Travellers. Most GPs ignorant of specialist Health Visitor service. Poor continuity of care and follow up. Lack of past medical histories. <i>"The survey shows that the appointment of a Traveller health visitor does not automatically improve access to primary care."</i> Recommendations: <ul style="list-style-type: none"> Improved access of Travellers to GP services Identification of barriers to access and GP perspectives. Greater publicity of the existence and role of specialist Health Visitors essential. Improve record keeping systems to allow for greater continuity. More training/awareness raising of Traveller issues for trainee doctors/GPs. Need for Travellers to be taught what services are available and what may be expected.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Durwood (1990) <i>Traveller Mothers and Babies - Who Cares for Their Health?</i> , London: Maternity Alliance.	Location: UK general. Review of issues affecting health of pregnant women and new-born babies, including discrimination, lack of sites, lack of facilities, eviction, local and health authority policies. Brief review of health literature and presentation of 7 examples of health initiatives for Travellers. Focus: Mothers and babies.	Questionnaire sent to 67 members of the Association of Metropolitan Authorities. 43 responded (64%). Information sought on Travelling families in their areas, council sites, facilities, monitoring, enforced mobility, liaison with local health authorities to provide ante- and postnatal facilities, other liaison arrangements with health authorities.	Traveller responses to questionnaire: <ul style="list-style-type: none"> Provision of facilities Monitoring methods Would Authorities enforce mobility on pregnant women, pregnant women close to birth or mothers with newborns Liaison with health authorities and provision of ante- and postnatal services. 	Findings: 13/43 respondents would evict/move on pregnant women. 15/43 authorities would evict/move on mothers with newborns. 21/43 liaised with local health authorities, through health visitors, midwives, doctors, district nurse, etc. 28/43 had other liaison arrangements with health authorities. Recommendations: <ul style="list-style-type: none"> Local authorities should urgently accept their responsibilities to provide permanent and temporary sites for Travellers, with basic environmental health facilities (water, sanitation etc.). Local authorities to work with health authorities to develop policies to promote maternal and infant health. Also to obtain and update information on sites regularly. Collaboration and consultation with representatives of Traveller organisations prior to development of services. Consultation and involvement in planning, design and evaluation of initiatives. Training for personnel working with Travellers. Health Authorities to include statements on proposed actions regarding Travellers. Liaison with family practitioner committees and agencies to obtain and update information on Travellers in their areas. Designate person to co-ordinate information re Travellers, including the transfer of health records when Travellers move across authority boundaries. National system of Traveller-held health records. Evaluation of most useful format and content of personal records. Elimination of discriminatory practices. Specialist training and induction for all personnel working with Travellers.
Gordon et al. (1991) <i>The Health of Travellers' Children in Northern Ireland. Public Health</i> 105[5]: 387-391.	Location: Northern Ireland Study examining aspects of health status of children in a group of Travelling people in Northern Ireland. Focus: 'Children' (no age range mentioned) of all people who defined themselves as Travellers.	Structured questionnaire seeking demographic data concerning the family and other information about child morbidity and uptake of child health services sent out and completed by Senior Clinical Medical Officers and Health Visitors familiar with each group of Travellers. Use of medical records and interviews with families 'whenever possible'. Info collected on 203 families; 52 families resident in public rented/legal serviced sites, 151 families on illegal sites. Questionnaires completed on 350 children.	<ul style="list-style-type: none"> Accommodation status Congenital abnormalities Immunisation status Hospital admissions. 	Findings: High level of consanguinity (38% children born to parents who were related). High rate of congenital abnormalities and recessive genetic disorders. Sites reported as public health hazards, often overcrowded and without clean running water or adequate drainage and toilet facilities. Frequent admission of children to hospital with infectious diseases. Low uptake of DPT, Pertussis and Measles vaccinations. Recommendations: <ul style="list-style-type: none"> Need to raise immunisation rates, particularly Pertussis immunisation. Need to improve accommodation by providing better-serviced sites. Need for HAs to examine how services can be targeted to Travellers appropriately to encourage uptake of preventive and primary care medical services.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Feder, Vaclavik and Streetly (1993) Traveller Gypsies and Childhood Immunisation: a Study in East London, <i>British Journal of General Practice</i> 43[372]: 281-284.	Location: East London (London borough of Hackney). Study compared immunisation status of children of Traveller Gypsies (72) and control group (106). Focus: Paediatrics (children aged 10 months to 6 years).	Consecutive Gypsy children presenting at A&E and at 2 GP practices were recruited. Selection of control group. Doctors and nursing staff were asked to take immunisation history of the children from the parents at next consultation. Further data for immunisation status were collected from computerised records, practice-based child health records, and records kept by specialist Health Visitors.	· Completion rates for DPT, Pertussis and Measles vaccination courses.	Findings: Gypsy children had significantly lower completion rates for all vaccinations. Significant difference between Gypsy children and control children having received first immunisation but not completing primary course of immunisation. Low rates among Gypsy children due to poor access to services due to involuntary mobility, "as well as rejection of certain vaccines by Traveller Gypsies" (measles and Pertussis) due to fears they may be harmful to the children. Measles and Pertussis are considered to be "normal" or even "strengthening" for children. Recommendations: · Systematic outreach clinics to bring immunisation and preventive services to caravan sites · Parent-held records · Funding of specialist Health Visitors · Production of "appropriate health education material".
Neligan (1993) <i>Report of a Specialist Health Visitor for Travelling Families</i> , Bristol UBHT.	Location: Avon County Council Area Report of work of a specialist Health Visitor for Travelling families. Focus: Maternal and child health, access, and environment.	Data collected by Health Visitor through interview and medical records on family size, maternal age, infant/neonatal/child mortality - but small numbers made comparisons with other studies/national rates problematic. Information collected on contraceptive methods, child health, immunisations (found refusal of MMR and Pertussis vaccines), accidents and injuries.	None specified. Report is more of an account of Health Visitor's experiences. Comparisons with other studies (Pahl and Vaile 1986; Feder 1989).	Findings: Health needs identified: Safe stopping places with adequate facilities (water, sanitation, electricity). Access to primary preventive health services and screening for early detection of disease. Improved access to secondary care. Access to 'user-friendly' health information esp. on smoking, alcohol and drug abuse, nutrition advice. Hand-held health records. Outreach benefits advice worker to provide information/advice/support when necessary. Recommendations: · Provide specialist team to co-ordinate health services · Provision of mobile clinic to visit unauthorised sites regularly · Nominated physician in public health responsible for liaison with Local Authority re Traveller health needs · Encourage Local Authority to adopt policy of non-eviction if pregnant mother or new-born is on site.
Noonan (1993) <i>Travelling People in West Belfast</i> , SCF.	Location: West Belfast. Discusses denial of rights to health, education and welfare services for Travellers. No real primary research re health and health care. Standard treatment of poor access, disadvantage and resulting problems. Focus: general health, access issues, deprivation.	Relies on other studies for data. Interviews with GPs re immunisation targets		

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Hennink, Cooper and Diamond (1993) <i>Primary Health Care Needs of Travelling People in Wessex</i> , Wessex Institute of Public Health Medicine.	Location: Wessex Regional Health Authority area Study to identify primary health care needs of travelling people. Focus: family planning, antenatal care, and service delivery	Review of the literature, consultations with key informants, practitioners (liaison officers, health visitors, teachers, education welfare officers), NGOs (Save the Children, Maternity Alliance) and the Gypsy Sites Branch of the Department of the Environment. Use of question framework for interviews.	None clearly specified. The literature review is discussed in relation to findings from reviewed primary research.	Findings: Varying degrees of tolerance by local authorities for New Age travellers. Cultural beliefs of Gypsies impact on their use of health services, as will illiteracy and unfamiliarity with the health system. Health problems of Gypsies and New Age Travellers stem from poor environmental conditions and poor uptake of preventive health care. New Age Travellers tend to have some understanding of the health care system. General Traveller attitudes to health care and preventive health care are not given high priority. Lack of awareness/information, mobility and cultural beliefs identified as major barriers to accessing health services. "The differing demographic composition of Gypsies and new age travellers suggests that Gypsies have a greater likelihood of requiring child health care while new age travellers may have a greater need for health care related to young adults (i.e. family planning, antenatal care, sexual health, drug awareness)" Low use of condoms among New Age Travellers, contraception largely the woman's responsibility in Gypsy communities. Recommendations: <ul style="list-style-type: none"> · Training for health workers to improve cultural awareness and understanding · On-site health care provision, outreach workers · Further study (long term) of heart disease among Gypsies, also mental illness · Need for project evaluation and monitoring · Good practice guidelines to be developed and disseminated · Importance of inter-agency co-operation.
Ginnety (1993) <i>A Report on the Health of Travellers Based on a Research Study with Travellers in Belfast</i> , EHSSB Belfast.	Location: Belfast Report on the health experience and attitudes of Travellers based in Belfast over the period 1991-1992. Extensive coverage of all health issues. Focus: All aspects of health.	Ethnographical approach used to ascertain Traveller views on health and services. Participant observation and informal interviews used. 55 respondents (17 men and 38 women, aged 18 to 73, representing 16 Travelling families) interviewed.	Traveller responses on a wide range of issues. No specific outcome measures specified.	Findings: Main factors negatively influencing health and social well-being of Travellers included <i>'poor environmental conditions, poor access to mainstream service provision (due partly to inflexible service delivery and partly to widespread social prejudice against Travellers), a lack of awareness by service providers of the needs of Travellers and their nomadic culture, and the absence of a comprehensive strategy to overcome the problems of poor health, literacy, unemployment, racism and discrimination faced by Travellers'</i> . Cancer was the most feared disease among Travellers, and as a taboo subject is rarely discussed with health workers. High rate of accidents (especially for children) and injury. Importance of punctuality for Travellers (leading to reluctance to wait for scheduled appointments). Recommendations: <ul style="list-style-type: none"> · Ensure that Travellers are included and identifiable in population censuses · Health authorities and Trusts to review policies and plan to address identified areas of need · Work to fully integrate Travellers into mainstream services. Sensitise health workers to needs of Travellers.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Davis, Grant and Locke (1994) <i>Out of Site, Out of Mind - New Age Travellers and the Criminal Justice and Public Order Bill</i> , The Children's Society.	Location: West of England Report on the work of the Children's Society with New Age Travellers. Sought to understand the lifestyle and needs of New Age Travellers. Focus: homelessness, poverty, stress, and impact of the CJPOA.	Interviews with 98 New Age Travellers at 20 unauthorised sites in Somerset and South Avon. Comparative visits were made to unauthorised sites in Cornwall and Bristol.	Information on <ul style="list-style-type: none"> • why people became New Age Travellers • whether they could opt out of travelling • what kinds of sites were available and • the likely impact of new legislation on their lives. 	<p>Findings: Push factors far more important than pull factors in decision to become a New Age Traveller - two thirds of respondents said they were forced into travelling (homelessness, family breakdown, leaving care/prison, insecure housing).</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Duty of local authorities to provide sufficient sites of reasonable quality to be retained (after CJPOA) • Reinstatement of 100% Exchequer grants (as laid down in 1968 Caravan Sites Act) • Development of new sites should take more account of Traveller needs, including establishment of small transit sites with basic facilities • Special planning considerations should be retained to ensure Travellers receive fair treatment and respect • Development of partnerships with local housing association to develop transit sites • Introduction of Toleration policies for unauthorised sites.
Northside Travellers Support Group (1994), <i>Travellers' Health and Accommodation Status in the Coolock Area</i> , Northside Travellers' Support Group.	Location: Coolock area in Dublin Case study of Traveller health and accommodation status Focus: Environmental conditions, access to services, incidence of disability.	Questionnaire distributed to and completed by 68 Traveller families. Focussed interviews conducted with service providers including area medical officer, public health nurse, GP and consultant in A&E. Group discussions held with 2 Traveller groups, and detailed interviews with 3 Travellers.	<ul style="list-style-type: none"> • Facilities/services provided • Sources of care • Accommodation type • Length of time on site • Traveller perceptions of health and use of health services 	<p>Findings: No provision of play facilities on sites for children Poor environmental conditions on all sites, with little or no maintenance of facilities. 65% of women did not attend for a postnatal check-up. 95% of families said poor living conditions and a lack of essential services were the main cause of sickness. 67% of Travellers belief in 'cures'/faith healers. Use of hospital services because of problems with GP.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Improvement of environmental conditions • Provision of central heating to Traveller houses. • Greater Traveller consultations when designing group housing schemes. • Provision of medical cards honoured by all GPs in the GMS scheme. • Provision of a second mobile clinic • Penalise doctors who refuse services to Travellers. • Positive action to train Travellers as health workers. • Training of health personnel re Traveller issues. • Refuge needs of Traveller women to be addressed.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Barnett (1995) <i>The Heath and Health Needs of Travellers in Mid-Kent, West Kent Health Authority.</i> Robertson, Hyder and King (1995) <i>Health Care for Travellers in Mid-Kent Health Care NHS Trust.</i>	Location: Mid Kent Department of Health funded study of health and health needs of Travellers in Mid Kent. Focus: Women, men, children, elderly.	Project staff interviewed Traveller families on site by site basis in 1993/4 using an interviewer-administered questionnaire. Included questions from the 1986 Travellers survey, the 1992 Census and 1992 South East Thames HealthQuest Survey. Mothers responded on behalf of themselves and children (and husbands - if husbands were unavailable or unwilling to participate). 79 families interviewed, with 216 Travellers. Site conditions examined. Interviews with GPs, other agencies.	<ul style="list-style-type: none"> Length of stay on site Site conditions Access to amenities Heating methods Non-availability of amenities Travellers' rating of site conditions Need/use of medical/dental service Last consultation with GP/practice nurse Illnesses/accident/operations Self reported health status. 	Findings: <ul style="list-style-type: none"> Women control response to health issues of the family ("women's work"). High proportion of single women and younger age groups. Site conditions poor, with little provision of water/heating/electricity/sanitation facilities. 91% registered with a GP, significant association between long term residence and GP registration. Women more likely to have consulted GP in previous year. 24% reported illness/accident in previous year. Most common conditions reported included hypertension, diabetes, epilepsy, asthma. Diseases of genito urinary and respiratory systems common. "A small but significant proportion of families reported difficulties obtaining care from a GP or dentist."
Van Cleemput (1995) <i>Report on Traveller Health Survey in Sheffield 1995.</i> (Unpublished)	Location: Sheffield Evaluation of mobile health clinic and survey of Travellers' views of factors affecting health and perceived needs. Focus: Traveller women, service provision.	Questionnaire and interviews of 23 Travellers (22 women, 1 man): 19 women resident on permanent sites; 2 women from unofficial sites; 1 woman with 3 children squatting on site until eviction having been refused an official place on the permanent site. Interviews conducted by teachers from the Sheffield Traveller Education Service. Housed Travellers not included in survey.	<ul style="list-style-type: none"> Traveller satisfaction Use of services 	<p><i>"the sole male respondent did not want advice on men's health problems".</i></p> <p>Findings: Most Travellers found the mobile clinic important. Travellers identified GP as source of care if mobile clinic unavailable. Demand for welfare benefits, keep fit and first aid advice. Group work not considered a popular concept. Advice sought on women's health problems, prevention of heart disease and cancer. Least popular topics were sexual health, AIDS and mental health.</p> <p><i>"56.5% felt their health would be better if they were able to travel freely, whereas 52.5% felt it would be better if settled on a site"</i> (as cited in original).</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Purchasers and providers need to be aware of the specific health needs of Travellers when planning services. Consultation with Travellers re aspects of site planning or improvements. Inter-agency co-operation and co-ordination. Further research to incorporate a wider representation of the Travelling community and to document morbidity and mortality for whom no data exists to compare with other groups.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Webster (1995) <i>Report for the Children's Society on the Impact of the CJPOA on the Lives of Travellers and Their Children</i> , Children's Society, London.	Location: South West England Report exploring the impact of the implementation of the CJPOA 1994 by local authorities and police on Travellers access to stable and secure sites and services. Focus: Children, access to services, impact of CJPOA.	Information collected from 80 families (157 adults, 139 children), all with children. 100 interviews conducted using a structured questionnaire, 80 questionnaires completed with different families and 20 with families who experienced repeated evictions. Sample population divided into 3 groups to compare abilities to access essential services. 3 groups were (a) families who had not been evicted since November 1994; (b) families who had been evicted since November 1994; and (c) families experiencing multiple evictions since November 1994.	<ul style="list-style-type: none"> • Times evicted since November 1994 • Access to services • Planning application outcomes. 	<p>Findings:</p> <p>Traveller children in families who had experienced evictions were unable to access stable and secure sites or essential services.</p> <p>Children in families trying to establish legal sites are at risk of losing them since a majority of planning applications are refused.</p> <p>Some local authorities implement a co-ordinated policy toward Travellers, although this approach is not often matched by Police forces.</p> <p>Authorities adopting a multi-agency approach to eviction achieve the best outcome in that families' circumstances are taken into account.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Local authorities should implement policies for site provision. • Home Office Guidance should become statutory. • Police should allow Travellers a set period of time on each site. • Planning authorities should show commitment to private site provision by identifying suitable and available land, and by working collaboratively with Travellers who wish to establish legal sites.
Hawes (1996) <i>Delivering Health and Welfare Services to Gypsies and Travellers - the effectiveness of inter-organisational working; innovative approaches and the impact of the Criminal Justice and Public Order Act 1994</i> , NHS Executive (South and West).	Location: Avon County Council, Cornwall, Dorset and Hampshire. Project to examine the effectiveness of delivery of health services to traditional and "new" Travelling families, with particular reference to the quality of inter-professional and inter-agency collaboration. Focus: Access, service provision, environmental problems	Structured and semi-structured tape-recorded interviews with a range of professional people who worked with Travellers. Less formal discussions held with Traveller families. Postal survey of all English and Welsh local authorities to identify policy responses to the introduction of the Criminal Justice and Public Order Act 1994 re eviction, provision of sites, establishment of inter-agency liaison. Use of DETR biannual caravan counts and DfEE information.	No outcome measures specified.	<p>Findings:</p> <p>As Criminal Justice and Public Order Act 1994 has removed duty of Local Authorities to provide sites for Travellers, leading to increased confrontation and poorer access to services.</p> <p>Privately financed sites expensive.</p> <p>Continuing relative deprivation, mental and physical ill health of Travellers.</p> <p>Survey of all Local Authorities indicates "that a majority have established some form of rudimentary liaison structure with other agencies and with the police; but most are ad hoc groups whose main task is to co-ordinate removals, re-siting or prosecution of unauthorised encampments, rather than establish a comprehensive corporate policy to provide services".</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • NHS Executive and regional offices should emphasise to providers the need to improve access. • In locations where Travellers stop, Health Authorities and providers should consider appointment of specialist Health Visitors for Travellers and patient-held records. • Further training for existing Health Visitors re Travellers, Joint Training initiatives etc. • Adoption of recommendations in the "Working Together Under the Children Act 1989". • NHS Executive to require annual reports, community care plans and strategic planning documents with reference to needs, numbers and target strategies for improving Traveller access to services. • Incentives for GPs to register itinerant families. • Development and use of appropriate media for health education and promotion.
Hawes (1997) <i>Gypsies, Travellers and the Health Service - A Study in Inequality</i> . The Policy Press, Bristol.				

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Anderson (1997) Health Concerns and Needs of Traveller Families, <i>Health Visitor</i> 70[4]: 148-150.	<p>Location: Leicestershire</p> <p>Examines health concerns of Traveller parents, and health perceptions of young families with different lifestyles (i.e. Travellers and settled populations).</p> <p>Focus: Young Traveller families with children.</p>	<p>Opportunistic interviews with Travellers during site visits. Selection of 50 Traveller families. "Random number tables from Health Visitor case records were used to select 50 families from an affluent estate and 50 families from a deprived inner-city estate." 38 Traveller, 44 inner city and 44 affluent families interviewed.</p> <p>Use of a questionnaire to ascertain health needs of the settled and Traveller population. Issues covered:</p> <ul style="list-style-type: none"> child health problems potential health problems for parents potential health concerns of parenting (child education, injury etc.) concerns re health care delivery. 	<ul style="list-style-type: none"> Identification of parental concerns for child health Immunisation rates Use of health services (antenatal services, health screening, and GP registration). 	<p>Findings:</p> <p>High levels of concern among Traveller parents re children's health (illnesses), education and play needs.</p> <p>Concerns re unsafe environments need to be considered when planning health care delivery.</p> <p>Adult health concerns re depression, maternal ill health, and diet.</p> <p>Desire for education and access to health information, a nurse they could trust.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Need for health service offering more personal contact, responsive and sensitive to Traveller views and lifestyle.
<p>Edwards and Watt (1997) Diet and Hygiene in the lives of Gypsy Travellers in Hertfordshire, <i>Community Dental Health</i>, 14: 41-46.</p> <p>Edwards and Watt (1997) Oral Health Care in the Lives of Gypsy Travellers in East Hertfordshire, <i>British Dental Journal</i>, 183: 252-257.</p>	<p>Location: Hertfordshire</p> <p>Study to investigate aspects of food and hygiene in lives of Travellers within context of culture and environment.</p> <p>Focus: diet, hygiene.</p> <p>Location: East Hertfordshire</p> <p>To explore Traveller's perceptions of dental health and dental service use within the context of culture, environment and use of other services.</p> <p>Focus: oral health and hygiene.</p>	<p>Semi-structured interviews with 43 Travellers (11 men, 32 women). Issues covered:</p> <ul style="list-style-type: none"> Travelling Education Health Oral health care Food and hygiene. <p>Interviews supplemented by a questionnaire and clinical screening of 72 Travellers (12 adults, 59 children).</p>	<ul style="list-style-type: none"> Place of residence Registration with GP and Dentist School attendance Caries Normative and perceived barriers to care. 	<p>Findings:</p> <p>Inequity of dental health and dental service use with more disadvantages experienced by Travellers on unauthorised transit sites.</p> <p>Major barriers to dental health and health care were environmental (e.g. control of mobility) rather than cultural (e.g. hygiene concepts).</p> <p>Use of services low but needs high. High caries rate, high sugar diets.</p> <p>Travellers aware of their dental treatment needs but treatment not sought because of fear or lack of perceived benefits.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Transport, literacy and lack of postal address need to be taken into account when providing services. Need for respect of Travellers' environment and cultural beliefs.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Barry and Kirke (1997) Congenital Abnormalities in the Irish Traveller Community, <i>Irish Medical Journal</i> , 90(6): 233-234.	<p>Location: Republic of Ireland</p> <p>Study comparing prevalence of congenital anomalies in Traveller community with general population.</p> <p>Focus: Congenital anomalies, metabolic defects.</p>	Information on congenital anomalies and parental consanguinity was collected at birth and at public health nurse visits in the immediate postnatal period and at first birthday, for all Traveller children born in the Irish Republic in 1987. Prevalence of congenital anomalies in the Traveller community was compared with the general population of the Eastern Health Board region.	<ul style="list-style-type: none"> Metabolic defects Prevalence per 1000 births of congenital anomalies. 	<p>Findings:</p> <p>Found "a highly significant increase in the prevalence of congenital anomalies, mostly attributable to metabolic conditions with autosomal recessive inheritance".</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Balance needs to be sought between sensitivity to cultural reasons for consanguinity and providing information to communities about the negative health consequences of certain cultural practices. Strong case for ensuring Traveller babies are included in neonatal metabolic screening programmes.
Rhodes (1998) <i>Travellers Health Project - Women's Health Report</i> , UBHT.	<p>Location: Bristol, South Gloucestershire, North East Somerset, part of Bath.</p> <p>Report of a one-year pilot project offering Traveller women health services from a mobile clinic.</p> <p>Focus: Women's health, Traveller opinions of services.</p>	Questionnaire administered verbally to 41 Traveller women on 11 sites (one permanent council site, 10 unauthorised, temporary encampments).	<ul style="list-style-type: none"> Services provided Use of health services Health problems reported. 	<p>Findings:</p> <p>High level of urinary tract infection among women and children.</p> <p>Prejudice of GPs not tackled by health authorities.</p> <p>Preference by women for a female doctor.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Travellers on sites should have the same rights to choose a GP as the settled population. Action by health authority to tackle prejudice of GPs.
Beach (1999) <i>Injury Rates in Gypsy-Traveller Children</i> , University of Wales College of Medicine.	<p>Location: Cardiff</p> <p>Explores levels of accidental injury in Traveller children, demonstrating the high correlation between high rates of injury and socio-economic deprivation.</p> <p>Focus: Child injuries, socio-economic deprivation, and health status.</p>	<p>Comparison of levels of attendance of Traveller children from 2 Local Authority Gypsy sites at A&E between 1993/1996 with levels of attendance of children from the 2 wards where sites were located. Injury profiles developed for both areas/groups and compared to a deprivation index.</p> <p>Use of data from All Wales Injury Surveillance System (AWISS), A&E records, Cardiff Research Centre (Cardiff City Council), Bro Taf Health Authority, Traveller Education Service, Welsh Office.</p>	<ul style="list-style-type: none"> Comparison of injury/non-injury attendance at A&E departments Diagnoses made. 	<p>Findings:</p> <p>Found a higher rate of A&E attendance by Traveller children compared to control group. It is therefore likely that injury rates for Traveller children are far higher than in children in social classes I - V.</p> <p>Study confirmed anecdotal evidence that Travellers use A&E to access primary care services.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> Widening of the study to include Traveller children in families not on permanent sites. Consultation with Travellers to develop a safety agenda. Explore why Travellers use A&E departments to access primary care. Compare injury rates in Travellers with other social deprivation groups. Provide evidence and rationale for funding a dedicated community health worker or project. Work to ensure equity of access to mainstream services and health promotion. Raise awareness among service providers of the issues contributing to high accidental injury rates.

Table 1A: Articles with primary research (continued)

Study title	Study location, description and focus	Description of evaluation methods	Outcome measures used	Findings and recommendations
Kearney and Kearney (1999) The Prevalence of Asthma in Schoolboys of Travellers Families, <i>Irish Medical Journal</i> , 91(6).	Location: Cork, Republic of Ireland. Study comparing the prevalence of asthma between Travelling schoolboys and settled controls to determine whether a travelling lifestyle may be a protective factor in the development of asthma. Focus: Asthma, travelling boys aged 6-12 years.	Information collected by parental response to the International Study of Asthma and Allergies in Childhood (ISAAC) questionnaire. Study population was 6-12 year old school boys living in Cork. Parents of 54 travelling children interviewed, as were parents in a control group of 119 settled children.	<ul style="list-style-type: none"> • Wheezing (attacks in previous year) • Wheezing during sleep • Wheezing during exercise 	<p>Findings:</p> <p>Parent reported prevalence of wheeze and related symptoms were all more common in controls compared with the travelling boys. But note: <i>"The lifestyle of Travellers exposes them to considerable health risks ...the health status of Travellers is lower than the national average, and Traveller children are known to have a higher prevalence childhood infection"</i>.</p> <p>Recommendations: None made.</p>
Lomax, Lancaster and Gray (2000) <i>Moving On: A Survey of Travellers' Views</i> , Scottish Executive Central Research Unit, Edinburgh.	Location: Scotland Survey of Travellers views on sites, facilities, travelling, housing, work, prejudice, harassment and other issues. Focus: Sites, work, travelling	Focus group interviews followed up by 83 face to face interviews with Travellers using a semi-structured questionnaire. New Age Travellers and Travellers living permanently in houses who did not travel at all were excluded. 41 respondents from local authority sites, 18 from private Traveller sites and 24 from roadside camps in local authority areas. Respondents 70% women, 30% men	<ul style="list-style-type: none"> • Length of stay on site • Facilities on site • Distance to facilities • Experience of housing • Time spent travelling in the previous 12 months • Agencies contacted for advice • Experience of prejudice/harassment 	<p>Findings:</p> <p>Importance and use of informal networks for advice and information.</p> <p>Concerns on health and safety varied depending on site location.</p> <p>Most related to proximity of busy roads or rivers.</p> <p>Concerns about the safety of children.</p> <p>Concerns with lack of adequate sanitation and sewage facilities.</p> <p>Regular experience of harassment and prejudice from the local community, police, local council officials.</p> <p>Recommendations: None made.</p>
Van Cleemput and Parry (2001) Health Status of Gypsy Travellers, <i>Journal of Public Health Medicine</i> .	Location: Sheffield Report of a pilot project to measure and compare the health status of Travellers with norms from the UK population and a concurrent comparison group. Focus: Health status measurement, inequality.	87 Travellers matched for age and sex with English or Irish residents registered with an urban GP practice in an area of high social deprivation. Both groups complete EQ-5D questionnaire by interview. Comparison made with normative data from UK general population.	<ul style="list-style-type: none"> • Health status measures • Mobility • Self-care • Usual activity • Pain or discomfort • Anxiety or depression • Visual analogue scale 	<p>Findings:</p> <p>Compared with the UK general population a significantly greater proportion of Travellers reported problems on all dimensions, except pain and discomfort.</p> <p>The proportion of Travellers reporting problems with 'nerves' was significantly greater than the matched population.</p> <p>Traveller health status is poorer in terms of mobility and usual activity and perceived overall health problems.</p> <p>Traveller health status is poor, even when compared with the lowest UK socio-economic groups.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Planning fair access at the health authority level will require culturally appropriate health services, including mental health services, in liaison with local authorities. • Need to establish basic epidemiological data on health of Travellers

Table 1B: Articles with secondary research

Title	Summary	Recommendations
Lawrie (1983) Travelling Families in East London - Adopting Health Visiting Methods to a Minority Group, <i>Health Visitor</i> 56: 26-28.	Description of work by a Health Visitor in East London, who worked exclusively with Travellers. Improved immunisation rates and communication with Travellers. Mothers reluctant to pass family planning advice to daughters, "so ignorance is perpetuated". Few Traveller babies are breast-fed. Use of modified milk. Children involved in accidents - playing in dangerous places. High incidence of inherited disease. Dental problems, especially caries.	<ul style="list-style-type: none"> Travellers should be given their own health records to carry with them. Importance of a designated Health Visitor to work specifically with Travellers. Importance of better health education for Travellers (to find and access services). Prevalence of infectious and communicable disease appeared to be linked to living conditions.
Peck (1983) Gypsies - A Sheffield Experience, <i>Health Visitor</i> , 56: 385.	Report of a Health Visitor experience on unofficial sites in Sheffield.	<ul style="list-style-type: none"> No evaluation of services. Endorses Lawrie (1983) re health needs of Gypsies.
Cornwell (1984) <i>Improving Health Care for Travellers</i> , London: King's Fund Centre.	Report of a conference to discuss Linthwaite (1983) report on maternal and perinatal health amongst Travellers.	<ul style="list-style-type: none"> Need to dismantle traditional barriers to care (e.g. discrimination and hostility) rather than provide separate services to sites. Use of hand-held medical records. Financial support for specialist posts. Acceptance of the statutory responsibility of the NHS to provide same standard of care to Travellers as is provided to other patients. Consultation with Travellers when planning sites. Need for sufficient numbers of pitches for Travellers on official sites. Importance of outreach work, continuity of care, specialisation and health records.
Crout (1987) Walsall Traveller Health Project.	Collection of papers associated with the Walsall Traveller Health Project.	<ul style="list-style-type: none"> Client held records considered essential. Individual health authorities should investigate what provision they make for Travellers' health needs. Traveller issues should be included in training for all health workers. Develop co-operation with local authority agencies to improve environmental conditions that affect health.
Feder (1989) Traveller Gypsies and Primary Care, <i>J Royal College Gen. Practitioners</i> , 39: 425-429.	General discussion of health of Gypsies and Travellers. Maternal and perinatal, child and adult health issues examined. Access problems, role of Health Visitors, challenge to GPs. No mortality data. Identifies a lack of effectiveness evaluations of Health Visitor services to Travellers.	<ul style="list-style-type: none"> Support demands for secure and safe caravan sites. GPs with Traveller patients should request appointment of a designated Health Visitor. Use of Traveller held records - GPs tend not to know about their existence or expect them. Implementation of opportunistic screening by GPs when Travellers present. Integration of Travellers into normal health care system when appropriate. Training of health professionals dealing with Travellers, and co-ordination of activities. Implementation of preventive or promotion initiatives after consultation with Travellers.
Feder and Hussey (1990) Traveller Mothers and Babies - Health Authorities Need to Provide Better Care, <i>BMJ</i> , 300: 1536-1537.	Discusses report by the Maternity Alliance (1990) on inadequacy of sites and poor provision of facilities, and council policies on evicting pregnant women.	<ul style="list-style-type: none"> Development of non-harassment policies for pregnant/newly delivered mothers. Inclusion of Traveller needs in planning of services. Inform Travellers of individuals in council responsible for them. Regular liaison with Local Authorities, GPs etc. Need for research on Traveller's health needs and perceptions. Need for evaluations of interventions (patient held record cards, educational initiatives etc.)

Table 1B: Articles with secondary research (continued)

Title	Summary	Recommendations
<i>Safe Childbirth for Travellers - Joint Action to Stop Eviction of Traveller Mothers and Babies</i> (1992)	Focus of campaign on needs of pregnant women, mothers and babies not to be evicted. Background on the campaign re site availability, legal duties etc.	
Moreton (1992) <i>Educating Parents and Professionals, Health Visitor</i> 65(8): 266-267.	Report by a specialist health visitor of a health education programme for Hib in which Traveller Gypsies were included.	Importance of one to one health education for Traveller communities. Importance of educating health professionals re Traveller culture/attitudes to immunisation. <i>"Health education is not a random process but is dependent on the perceptions of the potential recipients".</i>
Batstone (1993) <i>Meeting the Health Needs of Gypsies, Nursing Standard</i> , 7; 17:30-32.	Health Visitor description of providing community based multidisciplinary services to Gypsies and Travellers. Use of patient held records with information on vaccination status, GP details, social service and Health Visitor contact details.	· Importance of team work involving GLO, site wardens, liaison teachers, speech therapist, special needs teachers etc. - an inter-link approach.
Tyler (1993) <i>Travellers Tale, Nursing Times</i> , 89; 33: 26-27.	Description of the Partnership Project which aimed to make long-term improvements to Traveller health. Conducted in Walsall.	· Importance of training and advice for health staff working with Travellers.
Reid (1993) <i>Partners in Care, Nursing Times</i> , 89(33): 28-30.	Account of a weekly clinic run for Travellers, providing well women, child and baby, adult immunisation, dental and chiropody services. Hearing tests.	· Use of videos for health promotion to avoid problem of high illiteracy rates. · Provision of information for healthy eating/cooking. · Identification of clinic for everyone NOT just Travellers - to make Travellers feel they are able to access services available to everyone. · Importance of inter-authority liaison with Health Visitors.
Acton, Caffrey, Dunn and Vinson (1994) <i>Gender Issues in Accounts of Gypsy Health and Hygiene as Discourses of Social Control</i> , Paper presented to British Sociological Association.	Discusses the relationship between scientific, epidemiological and policy literature re Gypsy health and health concerns, beliefs and practices. Review of anthropological and sociological debate re historical and contemporary origins and significance of Gypsy health practices.	· Need for more detailed research, working with Travellers, to identify elements in travelling life which promote health. · Review of recommendations from health projects showed repetition (hand held records, better training of health workers etc.). · Importance of seeing Gypsy women as change agents rather than victims. · Need for dialogue between Gypsies and health professionals and researchers.
Cemlyn (1994) <i>Health and Social Work: Working with Gypsies and Travellers, Practice</i> , 6(4): 246-261.	Practise account of a Specialist Education Welfare Officer who worked with Travellers between 1988 and 1991.	<i>"Compared to the oppression and hardship Travellers experience, and their achievements in survival and struggle, the contribution of any workers with Travellers to their struggle has to be seen as very small..."</i> · Importance of inter-agency liaison and co-operation. · Value of health education and promotion <i>"Acknowledging the presence of Traveller children whose development is systematically undermined by conditions imposed on them and are therefore 'in need' can open the way for more imaginative and culturally appropriate services for these children."</i>
Vernon (1994) <i>The Health of Traveller Gypsies, British Journal of Nursing</i> , 3(18): 969-972.	Reviews the prevalent health care needs of Travellers from the perspective of client factors and service factors.	· Important to recognise the cultural and legislative context in which Travellers live.

Table 1B: Articles with secondary research (continued)

Title	Summary	Recommendations
Chartered Institute of Environmental Health (1995) <i>Travellers and Gypsies: an Alternative Strategy</i> , London.	Report to provide an objective view of travelling life and to give practical advice to Local Authorities developing plans to provide sites and services for Travellers. Criticism of DETR bi-annual count.	<ul style="list-style-type: none"> Discontinue bi-annual 'Gypsy count'. Introduction of a Needs Assessment which looks at quality of service provision as part of Local Authorities' housing investment strategy. To be integrated into local planning process. Establishment of national advisory committees, including representatives of central government, local authorities, Traveller groups and NGOs. Reintroduction of subsidy payable to Local Authorities for site provision (removed under CJPOA 1994). Subsidy payments to be linked to site provision targets. Availability of subsidy should be flexible so that registered housing authorities, private enterprise or recognised Traveller's groups can provide services and manage sites. Compilation of a register of available land by central government to assist the identification of possible permanent, transit, emergency and gathering sites. Encourage use of 'suitable land' for staging of festivals and raves. Adoption of a formal toleration policy nationwide, to allow Travellers to remain on certain categories of land subject to non-availability of authorised sites. Local Authorities to facilitate officer training in Traveller culture and needs. Regular meeting between those responsible for service provision to Travellers. Provision of sites with basic sanitation, safe water and refuse collection.
Bunce (1996) Travellers are the unhealthiest people in Britain, <i>BMJ</i> , 313: 963.	Comment on report by Hawes (1996) Ref. ID 33.	<ul style="list-style-type: none"> Provision of safe, well serviced stopping places for Travellers. GP practices and Purchasers annual reports and other strategic planning documents to set targets and strategies for improving Travellers' access to services. Provision of "positive financial incentive" to register itinerant patients. Care agencies (police, NHS, social and education services) to work together when planning and implementing care for Travellers.
Bunce (1996) A Hard Road to Travel, <i>Nursing Times</i> , 92; 49: 34-36.	Account of problems Travellers face, in terms of health and politics. Impact of CJPOA 1994 on health. Description of Travellers Health Project in Bristol.	<ul style="list-style-type: none"> Importance of Health Authority stressing to Local Authority need to provide safe, well-serviced sites. Importance of collaborative planning. Setting of targets and strategies to meet Traveller needs in planning documents. Issuing postcodes to sites to allow tracking through health system. Patient held records. Information on sources of health information. Use of community nurses and Health Visitors to liaise with Travellers.
McKee (1997) The Health of Gypsies, <i>BMJ</i> , 315: 1172-1173.	Editorial on health of Gypsies, with European comparison. Notes lack of research on health of Roma, even in the UK.	<ul style="list-style-type: none"> Importance of sensitivity to historical and political environment when conducting research concerning Gypsies.
Matthews (1998) The Outsiders, <i>Nursing Times</i> , 94; 37: 26-27.	Broad discussion of social determinants of ill health and social exclusion.	<ul style="list-style-type: none"> Funding for community development projects. Need to develop analysis of social determinants of ill health for marginalised communities. Importance of multidimensional holistic approaches rather than narrow biomedical focus. Need for systematic analysis of impact on socio-economic, environmental and cultural processes imposed by the dominant culture.
Webb (1998) Children and the Inverse Care Law, <i>BMJ</i> , 316: 1588-1591.	Thought-piece on marginalised groups (including Travellers) and access to services.	<ul style="list-style-type: none"> Unstudied phenomenon but they have not given up their rights to statutory services. Need for pro-active Specialist Health Visitors. Increased involvement of public health doctors. Inter-agency collaboration.

Table 1B: Articles with secondary research (continued)

Title	Summary	Recommendations
Acton, Caffrey, Dunn and Vinson (1998) Gendered Health Policies and a Women's Movement: the Gypsy Case, <i>Health and Place</i> , 4; 1: 45-54.	Sociological discussion of relationship between non-Gypsy health research and practice relating to Gypsies, and Gypsy health and hygiene practices. Discusses growth of the Gypsy women's movement and links with initiatives promoting MCH.	<ul style="list-style-type: none"> · Need to reconceptualise Gypsy women as effective change agents rather than victims and for a more holistic approach to Gypsy health. · Need for increased attention to men's health rather than narrow focus on women and children. · Use of videos as means of health promotion, which are gender targeted and prepared by Gypsy community workers. · Greater involvement of Travellers in research. · "the 1989 Education Act has led to the collection of relatively useful and reliable national statistics on resources, and to some extent, outcomes. No such official statistics are available for Gypsy health." · Criticisms of other work done on Gypsy culture and health as being unrepresentative, patronising, exaggerated etc.
Binnie (1998) The Health of Gypsies, <i>BMJ</i> , 316: 1824.	Letter. Comments on McKee (1997), and raises issue of disadvantage and oppression of Gypsies in the UK.	None.
Morgan and McDonald (1999) The Invisibility of Gypsies and Travellers, <i>Journal of Social Welfare and Family Law</i> , 21; 4: 397-404.	Discusses TLRU 1994 Report on health, educational and social welfare needs of Gypsies and Travellers. Discusses problems of data collection and negative image in the British Press.	<ul style="list-style-type: none"> · Provision of 'Gypsy' as an ethnic group on national census.
Van Cleemput (2000) Health Care Needs of Travellers, <i>Archives of Disease in Childhood</i> , 82: 32-37.	Review of health care needs of Travellers. Health care issues, causes of poor health, education, access to services, role of health visitors.	<ul style="list-style-type: none"> · Health authorities to name health visitor for care of Travellers, with adequate training re Traveller issues. · Establishment of inter-agency forums to co-ordinate policies re Travellers, e.g. needs assessments as part of Health Authority business plans. · Involvement of Travellers organisations, local pediatricians. · National network of health visitors for Travellers. <p>Follow precedent set by education system where authorities are required to submit needs document re Travellers.</p>
Hajioff and McKee (2000) The Health of the Roma People: a Review of the Published Literature, <i>Journal of Epidemiology and Community Health</i> , 54: 864-869.	Literature review of health of Roma people (internationally). Six articles concerning Traveller health in the UK. Focus areas of papers reviewed included child health, communicable disease, general health care, reproductive health and anthropometry.	<ul style="list-style-type: none"> · Published research on health needs of Travellers is fragmentary. · Need for further research with greater emphasis on non-communicable disease and effective interventions and less on issue of 'contagion'. · Need to evaluate interventions for Traveller health.

Appendix 2: Questionnaire sent to local authorities

Traveller and Gypsy Health Information Project – 2001

- Q1. Does your Authority have a specific person designated to deal with Traveller/Gypsy health issues? If YES please provide contact details.
- Q2. What data sources do you use when assessing the needs of Traveller/Gypsy communities?
- Q3. Does your Authority collect data on Traveller/Gypsy communities? If YES please describe.
- Q4. Does your authority provide any specific services for Traveller/Gypsy communities? If YES please describe what these are.
- Q5. Has your Authority published any specific policy statements relating to the health and/or provision of services to Traveller/Gypsy communities? If YES could you please provide us with copies.
- Q6. Has your Authority produced any formal/informal reports relating to the health of Traveller/Gypsy communities? If YES could you please provide us with copies.
- Q7. Is your Authority involved in partnerships with your local Health Authority and/or other local authorities in the region to meet the health needs of Traveller/Gypsy communities? If YES please describe.
- Q8. Are you aware of any specific local examples of 'good practice' relating to the provision of health services to Traveller/Gypsy health communities? If YES please describe.
- Q9. Does your Authority have any links/project work with the Local Education Authority regarding services for Traveller/Gypsy communities? If YES please describe.