Health ASERT Programme Wales

Enhancing the health promotion evidence base on Minority Ethnic Groups, Refugees/Asylum seekers, and Gypsy Travellers

2. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Gypsy Traveller Population, and of Appropriate Health Care Interventions

Health Challenge Wales
Her Iechyd Cymru
Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Foreword for series

As Minister for Health and Social Services, I am pleased to present the Health ASERT Programme Wales report series to you. This report series details the findings and the recommendations arising from this important research programme examining health promotion issues for minority ethnic groups, refugees/ asylum seekers and Gypsy Travellers living in Wales.

This research programme demonstrates the commitment shown by the Welsh Assembly Government to promoting equality of opportunity in all aspects of Welsh life and reducing inequalities in health faced by ethnic minority and marginalised groups. In order for us to meet this commitment and develop appropriate policies and practices, it is imperative that we have access to a solid evidence base, drawn from the available literature and the views of those directly affected by our policies. The research reported here involved community members as well as key stakeholders at the national and local levels. This input, combined with the extensive review of the literature on the health beliefs and health status of these groups and their use of services and on appropriate health care interventions has culminated in a comprehensive piece of work.

One of the key conclusions of the research is that promoting good health is the responsibility of individuals, communities and Government. I wholeheartedly endorse this sentiment, which forms the approach behind the recent launch of Health Challenge Wales, a call to all people and organisations in Wales to work together for a healthier nation.

I trust that you will find this report series both enlightening and thought provoking, as indeed the Deputy Minister and I have. Furthermore we hope that you will use the report series as a source of reference material for your work.

Brian Gibbons AM
Minister for Health and Social Services

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Deputy Minister with responsibility for older people

Health ASERT Programme Wales Report Series

Health ASERT Programme Wales. Enhancing the health promotion evidence base on Minority Ethnic Groups, Asylum Seekers/Refugees and Gypsy Travellers.

1. Main Findings and Recommendations.
2. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Gypsy Traveller Population, and of Appropriate Health Care Interventions.
3. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Minority Ethnic Group Population, and of Appropriate Health Care Interventions (to be published 2005).
4. A Review of the Literature on the Health Beliefs, Health Status, and Use of Services in the Refugee and Asylum Seeker Populations, and of Appropriate Health Care Interventions (to be published 2005).
5. A Review of Databases and other Statistical Sources Reporting Ethnic Group and their Potential to Enhance the Evidence Base on Health Promotion (to be published 2005).
6. Summary Primary Research Report (to be published 2005).
7. Full Length Primary Research Report (to be published 2005).

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The views expressed in this report are those of the author and not necessarily those of the Welsh Assembly Government

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Preface

The Health ASERT Programme Wales is a research programme commissioned by the Office of the Chief Medical Officer, Welsh Assembly Government, to investigate health promotion issues among Minority Ethnic Groups, Refugees/Asylum seekers, and Gypsy Travellers. The acronym ASERT stands for Asylum Seekers, Ethnic minorities, Refugees and Travellers. Research was undertaken by the Research Centre for Transcultural Studies in Health, Middlesex University and the Centre for Health Services Studies, University of Kent at Canterbury between February 2003 and March 2004. The study aimed to enhance the evidence base on health promotion issues related to minority ethnic groups, refugees/asylum seekers and Gypsy Travellers in Wales in order to inform policy and programme development in the Welsh Assembly Government's Health Promotion Division and elsewhere in the Office of the Chief Medical Officer. The study objectives were to: identify gaps in the existing evidence base of health needs and health promotion issues for the study groups; identify existing good practice of health services and promotion for the study groups; explore ways of delivering health promotion policy/programmes targeting these groups in a culturally and socially sensitive manner and identify issues for further research.

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Executive Summary

I. Health Status, Behaviour, Wider Determinants of Health, and Use of Services

1. Background and policy

The size of the Gypsy Traveller population in Wales is difficult to establish as Wales discontinued the twice-yearly caravan count. However, a recent study identified around 2,000 travelling children in Wales, twice as many as the last Government count. A survey, undertaken for the Welsh Assembly Government's Equality of Opportunity Committee (National Assembly for Wales, 2003b), enumerated around 1,400 Gypsy Travellers (54 per cent children), although only half the unitary authorities in Wales replied. Of this population, 28 per cent (but 37 per cent of children) lived in houses. In the absence of any systematic enumeration, there is a dearth of evidence on the location of the Gypsy Traveller population in Wales. The main findings of the Welsh Assembly Government's review on the health of the Gypsy Traveller population were: difficulties in establishing numbers in particular areas; the diversity of the Gypsy Traveller Community; problems of continuity of care; and the lack of a formal structure for liaising between health and other professionals.

2. Health status and life expectancy

There are very few studies that have systematically compared the health status of the Gypsy Traveller Community with the population in general using generic health status measures. The only exception found the self-assessed health status of Gypsy Travellers was significantly poorer than that in the lower socio-economic UK population group. A number of studies in the UK, Ireland, and Europe have reported significantly lower life expectancy amongst the Gypsy Traveller population than the general population. Perinatal and infant mortality rates are reported to be higher. Studies in Kent and Ireland, for example, found stillbirth rates 1.7 and 2.8 times higher, respectively, than in the general population. These studies also report a perinatal mortality rate 1.2 and 2.8 times higher in the Gypsy Traveller population and an infant mortality rate 1.5 and 2.4 times higher. Only one study was identified, of the incidence of Sudden Infant Death Syndrome (SIDS) in the Gypsy Traveller population, and it reports a figure 12 times higher than the general population.

3. Women's health

Much of the literature on the health of Gypsy Traveller women has focused on the low uptake of antenatal and postnatal care, family planning services, cervical cytology, and other preventive health care. Again, however, there is a lack of robust evidence. According to one English study, significantly lower cervical screening rates are found in the Gypsy Traveller Community. Others have reported relatively low levels of registration with GPs, low contraceptive usage, and high levels of smoking. There are no specific studies of domestic violence in the Gypsy Traveller Community, although voluntary agencies identify barriers to women seeking help.

The mobility of the Gypsy Traveller Community and the threat of eviction are likely to contribute significantly to the low use of antenatal and postnatal care. However, lack of adequate service provision and the concern of some Gypsy Travellers only with their direct health needs may also explain low uptake.

4. Children's health

Gypsy Traveller children probably have the poorest health of any minority ethnic group. A wide range of factors contribute to this situation, including the mobility of the community, poverty, poor environmental conditions, and lack of access to services. Rates of serious injury amongst Gypsy Traveller children appear

to be higher than in the general population, although there is a paucity of robust studies. Higher infection rates have also been reported that are probably linked to poor sanitation, lack of water, and other site conditions. However, evidence on the prevalence of asthma in the Gypsy Traveller population is inconsistent.

Some studies report that dental care for Traveller children is non-existent and most find lower uptake rates of immunisation than in the general population (although there are exceptions). The use of child health screening and developmental assessments also appears to be lower.

Finally, the literature contains some evidence of a highly significant increase in the prevalence of congenital anomalies amongst Gypsy Travellers compared with the general population; high rates of consanguinity have been found with some evidence of a trend towards higher prevalence of congenital anomalies in the offspring of first cousins. Care needs to be taken in interpreting this evidence and in placing the findings within an informed and culturally sensitive context.

5. Mental health

There is a paucity of robust evidence on the level of psychiatric morbidity in the Gypsy Traveller Community but much anecdotal evidence of poor mental health linked to poverty, racism/discrimination, site eviction and threat of eviction. Only one study reports evidence-based findings. This study reports that research in Sheffield found prevalence rates for anxiety and depression in the Gypsy Traveller population 2.9 and 6.8 times higher than in the general population. Presenting problems included cumulative stressors, family relationships, societal stereotypes, and communication issues.

6. Cardiovascular disease and cancer

While cardiovascular disease and cancer are likely to be the major causes of death in the Gypsy Traveller Community, as in the wider population, there are virtually no studies of these conditions (a situation resonant of minority ethnic health in general in the 1980s). There is also very little robust evidence relating to the well-established risk factors such as poor diet, lack of exercise, smoking, and alcohol misuse. The few evidence-based studies of the Roma population indicate significantly higher rates of these conditions in the Gypsy Traveller Community.

7. Communicable diseases and other conditions

While the literature on the health of Gypsy Travellers has traditionally focused on communicable diseases and infections at the expense of major causes of morbidity and mortality, there is a paucity of robust epidemiological evidence (although more on the Roma in Europe). Studies from eastern and southern Europe report hepatitis A, poliomyelitis, and tuberculosis amongst Gypsy Travellers. Lower uptake of immunisation amongst Gypsy Traveller children has been widely reported, although rates vary across studies and high uptake rates have been achieved with health promotion/intervention initiatives.

8. Access to and use of services

Many studies have reported low uptake of services, including primary care, dental services, family planning, cervical screening, routine antenatal and postnatal care, and immunisations. There also appears to be a low uptake of available aural, speech, and language services by the Traveller Community. Varying rates of registration with GPs are reported in the literature, as low as 50 per cent in two studies. A range of factors have been implicated in this pattern of health care use. The mobility of the community is undoubtedly an important factor, a Scottish study reporting that over two-fifths of Gypsy Traveller families were receiving care at the time they were moved on. This study also found that two-thirds of health professionals identified racist attitudes of other health professionals as the primary obstacle to Gypsy Travellers trying to access health services. Other studies have identified barriers of poor staff attitudes,

GPs refusing to register Gypsy Travellers, the refusal of treatment, the lack of transferable medical records, low levels of literacy amongst Gypsy Travellers, and cultural attitudes within the Gypsy Traveller Community (e.g. the concern with immediate needs and social construction of hygiene practices, etc.).

9. Lifestyle factors

There are reports of high prevalence of smoking amongst Gypsy Travellers (around 70 per cent), although there are few robust studies. There is also a dearth of information on the prevalence of alcohol consumption and on dietary intake.

10. Oral health care

A consistent picture emerges from the few studies of oral health care of high rates of dental caries, low registration and use of dental (including preventive) services, and mobility and the threat of eviction as major determinants of access.

11. Wider determinants of health

The poor location of sites (on derelict or contaminated land; close to main roads; on or near rubbish tips, with poor sanitation; proximity to power cables; lack of access to clean water), low levels of provision of services on sites (especially transit sites), poor site management and facilities, and differences in pitch fees and issues of affordability are all regarded as detrimental to the health of Gypsy Travellers, although few studies have established the links epidemiologically. There is anecdotal evidence (but a paucity of robust studies) that blood lead levels may be higher in Gypsy Traveller children than in those in the general population. There is, too, a dearth of information on the employment rates and experiences of Gypsy Travellers and no studies that report reliable information on income levels and poverty. Research studies suggest high levels of absence from primary schools, non-attendance at secondary school, and low educational attainment levels. Policy reports identify a wide range of barriers to accessing education.

II. Health and Social Care Interventions

Most reported interventions for Gypsy Travellers are small-scale and short-term. Moreover, there is a paucity of robust and systematic evaluations undertaken independently of project workers that focus on outcomes rather than process. This review, too, found a paucity of health care interventions that had been subject to rigorous and independent evaluations.

While there is strong support for the development of hand-held patient records for Gypsy Travellers in Scotland and a number of authorities in England are addressing this issue, no studies of evaluations of pilot schemes have been identified. There is descriptive evidence that supports the use of specialist health visitors but, again, no robust evaluations. There are a few examples of mobile dental and health clinics, a pilot scheme in Herefordshire being described by the Commission for Health Improvement (CHI) as an example of good practice '…that the rest of the NHS can learn from'. The model of community health workers recruited from the Traveller Community has been implemented in Ireland and reported to bring substantial benefits to the Traveller Communities in these areas. There is some evidence that outreach programmes by community health workers are effective at increasing immunisation rates in the Gypsy Traveller Community. Peer-conducted health education by members of the Traveller Community to reduce smoking in children/young people has been used amongst Roma children. There is evidence, too, of benefit to the Gypsy Traveller Community of structured local partnerships, both representative organisations/agencies and liaison posts.

III. Recommendations

Based on this review of the literature on the health beliefs, health status, and use of services in the Gypsy Traveller population, and of appropriate health care interventions, a number of recommendations for policy and practice are put forward.

1. Ethnic monitoring should be mainstreamed – including primary care population profiling and hospital episode statistics – using categorisation that includes at least Gypsy/Roma and Travellers of Irish Heritage.
2. Hand-held records for Gypsy Travellers should be mainstreamed.
3. There is an urgent need for a health and lifestyle survey of minority ethnic groups – with enhanced sample for Gypsy Travellers – to establish baseline rates of health status, health-related behaviours, use of services, etc.
4. Gypsy Traveller health should be embedded in mainstream service planning (health equity audits, provision, etc.).
5. The small-scale, short-term, and champion-dependent nature of many projects needs to be addressed through funding and links to/integration with mainstream provision.
6. Specific projects/initiatives require robust independent evaluations that address outcomes as well as process.
7. There is a need to build on the evidence that use of trained workers from the Gypsy Traveller community works, including peer-conducted health education.
8. Some effective interventions – the Community mothers' programme, outreach programmes for immunisation, etc. – offer examples of potentially replicable good practice.
9. Particular attention needs to be accorded to environmental factors: the poor location of sites, low levels of provision of services on sites (especially transit sites), poor site management and facilities, differences in pitch fees, and issues of affordability which are all regarded as detrimental to the health of Gypsy Travellers.

I. Health Status, Behaviour, Wider Determinants of Health, and Use of Services

1. Background and policy

1.1 The size of the Gypsy Traveller population in Wales

The size of the Gypsy Traveller population in Wales is difficult to establish for a number of reasons. Firstly, Wales discontinued the twice-yearly caravan count which England continues to undertake, a step which has '…deprived Wales of important information' (National Assembly for Wales, 2003a). Some local authorities in Wales have continued to undertake counts but there is no pooling of this data for all of Wales and no standard data collection format. Secondly, even in settings where such counts are undertaken, the size of the Gypsy Traveller Communities is notoriously difficult to establish. For example, the Scottish Executive's Central Statistics Unit carries out a half yearly count of Gypsy Travellers and estimates that there are about 500 Gypsy Travellers living in caravans. The Scottish Gypsy Travellers Association has strongly contested this figure on the grounds that it excludes Gypsy Travellers who live in housing for part of the year and many of those who live on the side of the road. The Association believes that there are around 15,000 Gypsy Travellers living in Scotland, 30 times the Scottish Executive's estimate (Scottish Executive, 2001a). Thirdly, the Gypsy Traveller population is diverse and includes Irish Travellers, English, Scottish, and Welsh Travellers, and "New" (New Age) Travellers, who live in a wide variety of settings, including authorised and unauthorised public and private sites and settled accommodation. Fourthly, there was no predesignated category for Gypsy Travellers in the England and Wales and Scotland 2001 Census schedules and a count of those who used the free text fields in the ethnic group questions to declare that they were Gypsies or other travelling people is likely to be substantially incomplete. Only in Northern Ireland was there enumeration of this community, specifically Irish Traveller, 0.10 per cent of the population (of 1,685,267) being in this ethnic group, varying from 0.01 per cent – 0.32 per cent across Local Government Districts (Northern Ireland Statistics and Research Agency, 2003).

The evidence on the size of this group in Wales is limited with respect to the following sources:

(i) The Welsh Office ceased to undertake the biannual count of caravans in 1997, and there is no national co-ordination or standardised reporting of ad hoc surveys in those authorities that have continued to record a count.

(ii) A recent study of Traveller children (Morgan, 1998), for the Save the Children Fund Wales Programme, identified about 2,000 Travelling children in Wales, twice as many than did the last Government count. As in Scotland, it is likely that many Travelling children in housing are not included in official estimates.

(iii) In 1998 there were reported to be 20 public sites in Wales (Morris *et al.*, 2001, citing RSL Social Research, 1998).

(iv) A variety of reports provide information on specific sites. According to the Cardiff Local Health Action Plan (cited by Mogie, 2002 and Cardiff Local Health Group, 2001), Cardiff has two official Gypsy Traveller sites, one being the largest local authority site in the United Kingdom. There are official pitches that provide for a total of 77 families and 60 Gypsy Traveller families are housed around the Cardiff area. Approximately 12 to 15 families are living on unofficial roadside sites at any one time.

Because of deficiencies in statistical sources for this group, a pro-forma was designed to collect basic information on the Gypsy Traveller population in Wales and mailed to the Chief Executives of all (22) unitary authorities for onward transmission to relevant departments. The response rate for Gypsy Travellers was very poor (1/22, 4.53 per cent), less than for refugees and asylum seekers. The respondent for Neath Port Talbot County Council was unable to report the number of Gypsy Travellers in the area. Since this survey was undertaken, the findings of a similar Gypsy and Traveller Survey of unitary authorities, undertaken on behalf of the Equality of Opportunity Committee (National Assembly for Wales, 2003b), have been published. Eleven unitary authorities provided information on the number of Gypsy Travellers living in their area (Table 1).

Table 1. Number of Gypsy Traveller adults and children living in Welsh unitary authorities.

Unitary Authority	Number of Adults	Number of Children
Cardiff	202	419
Merthyr Tydfil	20	8
Torfaen	None given	None given
Monmouthshire	None given	None given
Caerphilly	None given	None given
Swansea	48	37
Gwynedd	20	8
Carmarthenshire	148	85
Bridgend	3	2
Neath Port Talbot	146	147
Wrexham	55	64
TOTAL	**642**	**770**

Source: Adapted from: Review of Service Provision for Gypsies and Travellers. (National Assembly for Wales, 2003b p25).

This table shows a total of 1,412 Gypsy Travellers in the 11 unitary authorities, of whom over half (54.5 per cent) were children. The number of children recorded in these returns (for only half the unitary authorities in Wales) is likely to be an under estimate. Although the last Welsh Office survey of Gypsy Travellers, in January 1997, estimated 846 Gypsy Traveller children in Wales, the Cardiff University and Save the Children Fund report of 1998 (*Traveller Children and Educational Need in Wales*) (Morgan, 1998) put the figure substantially higher at 1,809 Traveller children. The 2003 Pupil Level Annual School Census recorded 782 Gypsy Traveller children but this, too, is likely to be an underestimate of school-aged children.

The Equality of Opportunity Committee's survey also reported on number of Travellers by type of accommodation (Table 2).

Table 2. Number of Gypsy Traveller adults and children living in Welsh unitary authorities by type of accommodation.

Type of Accommodation	Number of Travellers		
	All Travellers	Adult Travellers	Child Travellers
Local Authority Sites	834	412	422
Privately Owned Sites	130	84	46
Unauthorised Sites	48	29	19
Living in Houses	400	117	283
All Accommodation	**1,412**	**642**	**770**

Source: Review of Service Provision for Gypsies and Travellers. (National Assembly for Wales, 2003b p27).

More than two-thirds of Gypsy Travellers (68 per cent) were living on authorised local authority or privately owned sites, although 28 per cent were living in houses. The proportion of Gypsy Traveller children in houses (36.8 per cent) was higher than for adults (18.2 per cent).

1.2 The location of the Gypsy Traveller population in Wales

Again, in the absence of any systematic enumeration, there is a dearth of evidence. Of the total number of Gypsy Travellers identified in the Equality of Opportunity Committee's survey (1,412) (National Assembly for Wales, 2003b), 44.0 per cent were on sites in Cardiff, the other main communities being found in Neath Port Talbot (20.8 per cent), Carmarthenshire (16.5 per cent), Wrexham (8.4 per cent), and Swansea (6.0 per cent). It is likely that Travelling people are to be found in most of the unitary authorities in Wales, if in small numbers in some areas. Certainly, the evidence from Scotland and England suggests wide dispersal. Applications for Section 488 grant for the education of Gypsy Travellers provide the only other information on the distribution of this population. To October 2001 only 10 authorities in Wales had applied for the grant. Their geographical distribution corresponds to the traditional routes followed by Gypsy Travellers into and out of Wales, along the A55 corridor in north Wales and the M4 corridor in south Wales. The Equality of Opportunity Committee similarly concluded that beyond the general statement that 'Gypsies and Travellers are concentrated along the key transport routes in the North and South of Wales', exact information on distribution of this predominantly mobile population was limited.

1.3 Policy issues in Wales

The National Assembly for Wales started to address the needs of the Gypsy Traveller population in Wales in 2001 by publishing an issues paper for the National Assembly's Equality of Opportunity Committee (National Assembly for Wales, 2001). The paper highlighted the requirement under Section 120 of the Government of Wales Act 1998 that the National Assembly have regard to the principle of equality of opportunity for all people. The Equality of Opportunity Committee identified the need to clarify whether

there was a need for specific provision to meet the needs of Gypsy Travellers across the different areas of government. The areas considered were education, employment, health, accommodation, and policing. The Committee argued that some policies treated Gypsy Travellers like other disadvantaged groups within the general population, while others recognised the distinctive needs of Gypsy Travellers. Given the support for the latter view, there was consequently a need for a more integrated approach to Gypsy Travellers across the Assembly.

In October 2002 the National Assembly's Equality of Opportunity Committee took evidence in a Gypsy Traveller Review on Health from a number of experts (National Assembly for Wales, 2003c). The main findings of this review were:

- difficulties in establishing the number of Gypsy Travellers in particular areas as no statistics were collected;
- the diversity of the Gypsy Traveller Community, including settled families, 'visiting families' who stayed for 4-6 months, and families in transit;
- problems of continuity of care including the resourcing of site visits and the failure to do recalls;
- the lack of a formal structure for liaising between health professionals, social services, and child protection;
- high morbidity due to environmental circumstances, including unsafe play areas and sites that were insanitary and in dangerous locations;
- lack of sites;
- low levels or lack of literacy;
- lack of services, both medical (especially health visitors) and dental;
- lack of trust and the importance of continuity of staff to allow this to develop;
- the importance of consulting Gypsy Travellers directly;
- the importance of culturally sensitive health promotion based on the experiences of the Gypsy Travellers themselves;
- lack of agreement across GP practices on the range of services to provide to the Gypsy Traveller Community;
- the importance of informal networks, for example, in securing referrals for Gypsy Traveller families in transit;
- the importance of informal postal services to ensure that Gypsy Travellers were informed of medical referrals;
- high levels of disability (including mobility issues) requiring welfare benefits advice;
- late and ad hoc immunisation and some resistance by GPs to having Gypsy Travellers on their lists for immunisation as this incurred a loss of funding;
- local discrimination against Gypsy Travellers, including that by health workers;
- the importance of culture-specific training for health care workers, including an understanding of the health beliefs of Gypsy Traveller families;
- difficulties in managing chronic conditions;
- lack of cultural acceptability of breast feeding among Gypsy Traveller families;
- the importance of self-advocacy through community education.

In 2003 the Equality of Opportunity Committee (National Assembly for Wales, 2003b) published a comprehensive review of service provision for Gypsies and Travellers, based on public hearings, evidence sessions, site visits, and expert advice. The review addresses accommodation, health, education, and a range of cross-cutting issues. The needs of Gypsy Travellers have also been addressed in a further Welsh Assembly Government publication: Health Needs of Disadvantaged Groups: *Travellers report prepared for the subgroup of the Service Development Task and Finish Group of the NHS Implementation Plan* (National Assembly for Wales, 2003a) which states: 'The task for the new (NHS) corporate bodies (in Wales) is to identify, target resources, and facilitate improved health outcomes for Gypsies and Travellers'.

1.4 Stakeholders

There are a wide range of stakeholders involved in providing services for Gypsy Travellers: The Welsh Assembly Government itself and Local Health Boards (as successors to Health Authorities), Welsh NHS Trusts, unitary authorities (housing, planning, and social services departments and local education authorities), the Welsh Planning Officer's Society, the Welsh Local Government Association, Police, Save the Children, Children in Wales, Association of Directors of Social Services, Gypsy Traveller Liaison Officers, Travellers' Law Research Unit (Cardiff Law School), Cardiff Gypsy Sites Group, and The Gypsy Council. Other bodies such as the Advisory Council for the Education of Romany and other Travellers (ACERT), Friends and Families of Travellers, Bias, Pavee Point Travellers' Centre, Dublin, and experts play a key role in identifying and supporting the needs of Gypsy Travellers.

2. Health status and life expectancy

Most of our knowledge of the health of the Gypsy Traveller population is based on small-scale research studies that generally eschew robust methodologies. However, quantitative assessment of health status in the Traveller Community using standardised generic measurement instruments has been shown to be feasible in a small number of studies (Van Cleemput and Parry, 2001).

2.1 Generic health status

An English study showed that the self-assessed health status of Gypsy Travellers is significantly poorer than in the lowest socio-economic UK population group but was not very different from a concurrent, matched, socially deprived resident group (Van Cleemput and Parry, 2001). However, Gypsy Travellers did have poorer health status than matched comparators in relation to mobility, activity, and perception of overall health.

Although there are several studies on the health of Travelling People, many are based on small local samples and frequently do not draw comparisons with a reference population. Furthermore, few make use of standardised and validated health instrumentation. Van Cleemput and Parry's (2001) study, one of the few to do so, seeks to compare the health status of traditional Gypsy Travellers with norms from the UK population and with a concurrent comparison group using the EuroQol EQ-5D health status measure administered by interview. In this study, 87 adult Gypsy Travellers were matched for age and sex with English or Irish residents registered with an urban general practice in an area of high social deprivation. Travellers had poorer health status than their settled counterparts in socially deprived areas on two of the five dimensions of Euroqol (mobility and activity) but not on the overall summary score. However, Travellers reported significantly poorer health than the matched comparison group on the EQ-5D visual analogue scale. Both the Travellers and the comparison group had much poorer health status on the EQ-5D index than the UK population norms, even when comparisons were made with the lowest socio-economic group. Work is now underway by a research team in Sheffield on a much more comprehensive assessment of the generic health status of Gypsy Travellers in England which will provide the first comprehensive picture of their health status using standard health instruments. (Since the completion of this review, this work has been published; Parry *et al.,* 2004 and Van Cleemput *et al.,* 2004).

The only other study that has been identified that systematically reports on generic health is that undertaken by Nesvadbova *et al.* (1999), although no information on age was reported. The investigators studied the self-reported health of 432 adult Roma from several districts in the Czech Republic in 1998. The study subjects assessed their current status as 'completely healthy' in 50.1 per cent, 'not completely healthy' in 26.1 per cent, and as 'not healthy' in 23.8 per cent. The most frequently mentioned illnesses reported by the subjects 'in the past' were diseases of joints, muscles and heart (15 per cent), diseases of the digestive system (12 per cent), gynaecological disease (10 per cent), respiratory diseases (9 per cent), and diabetes (5 per cent). In addition to this, 40 per cent of the study group reported that they were currently suffering from a condition requiring medical treatment: disease of the joints and muscles (22 per cent), cardiovascular diseases (22 per cent), diseases of digestive system (13 per cent), respiratory diseases (10 per cent), and diabetes (10 per cent).

2.2 Life expectancy

There is much anecdotal evidence in the United Kingdom and Ireland that Travellers have a shorter life expectancy than the general population but there is a paucity of robust studies. The most recent vital statistics on the health of Travellers in Ireland was that commissioned by the Health Research Board in the mid 1980s (Barry *et al.,* 1989). This analysis included statistics on life expectancy and showed that Travellers then were only reaching the life expectancy that settled Irish people attained in the 1940s.

The statistics showed that Travellers of all ages had much higher mortality rates than people in the general population, that Traveller women live on average 12 years less than women in the general population (65 years vs. 77 years), and that Traveller men live on average 10 years less than men in the general population (62 years vs. 72 years)[1]. There has been no subsequent study. Given continuing levels of disadvantage, there is unlikely to have been significant improvement since 1987.

There is also anecdotal evidence of low life expectancy in Scotland. In the Scottish Parliament's Inquiry into Gypsy Travellers and Public Sector Policies, evidence was submitted of a large extended family of Gypsy Travellers in North Argyll whose members have a life expectancy of 55 years, compared with mid or late 80s for women and early 80s for men in the settled community in this part of Scotland (Scottish Parliament, 2001). The last time average male life expectancy was 55 years in Scotland was 1932. There are some sociological studies that suggest that life expectancy at birth of Romas in Hungary is about ten years less than the Hungarian average (which, is itself, not very high) (Puporka and Zadori; Nemenyi, 1998). A government survey in Hungary also reported that life expectancy of the country's Roma is 10 to 15 years lower than that of the general population (71 years), citing unemployment, poor nutrition (cheap foods rich in fat and carbohydrates), substandard housing, environmental pollution, and workplace hazards (Kovac, 2002). A study of 121 Gypsy patients in Castellon, Spain, revealed that the mean age of death among Gypsies was early (40.6 years) vs. 73 years of age in a control population (Garcia *et al.,* 2000).

2.3 Stillbirths and perinatal and infant mortality

A large number of studies report poor outcomes for the offspring of Gypsy Traveller mothers, including high rates of stillbirths, infant deaths, and early childhood mortality, although there is a dearth of robust studies. Such outcomes have been linked to poverty, site evictions during pregnancy, lack of access to antenatal and postnatal care including community midwives and health visitors, and hazardous environmental conditions.

Stillbirths

A survey by Linthwaite *et al.* (1983) of 265 mothers showed a stillbirth rate[2] 19 times greater than that in the population as a whole. Pahl and Vaile (1988) report a stillbirth rate of 12.0 for Kent travellers (1984), compared with 7.2 in the general population (England and Wales 1980). The stillbirth rate among Travellers in Ireland was 19.5 per 1,000 in the Traveller population vs. 7 per 1,000 in the general population (Barry *et al.,* 1989).

Perinatal mortality

The perinatal mortality rate[3] was 16.0 in Kent Travellers (1984) compared with 13.3 in England and Wales (1980). A perinatal mortality rate of 28 per 1,000 in the Traveller population vs. 10 per 1,000 in the general population was reported in Ireland (Barry *et al*., 1989). A study in the Roznava Region in Slovakia found a perinatal death rate among Roma that was 1.5 to 2 times higher than among non-Roma in 1996-1997 (Seres, 1998). Low birth weight may have been one reason for the higher rates among Roma.

1. Life expectancy at various ages for Travellers and the Irish population (1987) were: Men – at 0, 61.7 vs. 71.6, at 15, 48.9 vs. 57.4, at 45, 21.3 vs. 28.8, at 65, 10.1 vs. 13.1; Women – at 0, 65.3 vs. 77.2, at 15, 52.1 vs. 62.9, at 45, 25.1 vs. 33.6, at 65, 10.4 vs. 16.4.

2. Stillbirth Rate, calculated as the number of stillbirths (a baby born dead after 24 weeks of gestation) per 1,000 live births and stillbirths.

3. Perinatal Mortality Rate, calculated as the number of stillbirths plus the number of liveborn babies who die before the end of the first seven days of life per 1,000 live births and stillbirths.

Infant mortality

The infant mortality rate[4] among Kent Travellers (1984) was 17.5, compared with 11.9 in England and Wales (1980) (Pahl and Vaile, 1988). The infant mortality rate in 1987 for Travellers in Ireland was 18.1 compared to a national figure of 7.4 (Barry *et al.,* 1989).

Evidence from continental Europe supports these findings of very high infant mortality rates. A quantitative and qualitative study of the network ROMEurope-health, carried out in France, Spain and Greece, reported a neonatal mortality index in these populations of about 19 per 1,000 (as against 2.2 per 1,000 in France in 1996) and infant mortality reaching about 23.5 per 1,000 (as against 4.8 in France in 1996) (Medicins du Monde, Secrétariat International, 2001).

Early childhood mortality

Koupilová *et al.* (2001) report that death rates in early childhood also appear to be high. Between 1981 and 1990 death rates of Roma children under 3 years in three different regions of Slovakia, Bystrany, Spisske Tomasovice and Spissky Stvrtok, were 47.1, 40.9 and 32.0 per 1,000, respectively (Mann, 1992), considerably higher than the under 5 mortality rate of 15.8 per 1,000 in Slovakia in 1989 (UNICEF, 2003).

Sudden Infant Death Syndrome (SIDS) and Traveller children

Only one report of the incidence of SIDS in the Traveller population has been identified. The occurrence of SIDS among Traveller families in Ireland in 1999 was twelve times the national figure (8.8 vs. 0.7 per 1,000 live births) (Irish Sudden Infant Death Association, 2000), based on approximate estimates of the total number of live births among Traveller families in 1995. The absolute annual number of cases of SIDS among Traveller families is small. However, from 1992 to 1999 the rate of occurrence of SIDS in the Traveller Community was higher than the national rate and in 1999 11.4 per cent of SIDS cases occurred in Traveller families.

4. Infant Mortality Rate, calculated as the number of deaths of infants in the first year of life per 1,000 live births.

3. Women's Health

3.1 Maternal health and use of maternity services

A number of studies report relatively high fertility rates in the Gypsy Traveller Community and this contributes to a high utilisation rate of obstetric services in some areas (Barry *et al.,* 1989). However, there is much anecdotal evidence, but few robust studies or statistical evidence, that use of maternity services is low.

The Department of Health and Children (2002) in Ireland reports a poor understanding of the value of antenatal and postnatal care among Travellers, including a low uptake of antenatal classes, a low uptake of antenatal and postnatal check-ups, a low uptake of family planning services, and a low rate of breast feeding. The key source of evidence was research undertaken by the National University of Ireland's Centre for Health Promotion Studies for the Mid-Western Health Board (2002) on Travellers' perceptions and experiences of maternity and child health services. Interviews were carried out with 52 Traveller and 41 non-Traveller women, as well as 58 GPs, public health nurses, district midwives, hospital based midwives, and others. Self-reported obstetric history revealed more pregnancies and at a younger age in Travellers than non-Traveller women. High overall levels of satisfaction with maternity and child health services were reported in both groups, although the Traveller women were less satisfied with their experience in hospital and postnatally from their GP (including some sense of perceived discrimination due to their Traveller status). Travellers depended on peers and family for antenatal support rather than traditional classes, and also in relation to breastfeeding practice. Traveller women were more likely to have visited their GP or hospital with a sick baby, less likely to attend for antenatal care and less likely to breast-feed their babies. For Travellers it was especially important that health professionals showed an understanding of their living conditions and way of life. Also, experiences were poor if health professionals were hurried, impersonal, used technical language, or did not offer enough information.

In Lloyd and Morran's (1999) study of Scottish Travellers' health, 27 per cent of new mothers reported seeing a health visitor and 31 per cent had been issued with hand-held records. Some 48 per cent of women had been evicted or moved on whilst pregnant. Only 46 per cent of women attended antenatal classes and 20 per cent breastfed, stating that their lifestyle and the lack of privacy made this difficult. No information on denominators is available. There is a dearth of evidence relating specifically to Wales. However, the Equality of Opportunity Committee's (2003) *Review of Service Provision for Gypsies and Travellers* (National Assembly for Wales, 2003b) reported the testimony of an experienced health professional working with Gypsy Traveller families in the Swansea area that most women took up antenatal care and that low birth weight had not been a problem.

The wider evidence base suggests that maternity services may not be meeting the needs of Gypsy Traveller women. The Confidential Enquiry into Maternal Deaths Report found that a disproportionate number of women from the traditional Travelling Community died in pregnancy or after childbirth (Royal College of Gynaecologists, 2001). The House of Commons Health Committee's report on inequalities in access to maternity services (House of Commons Health Committee, 2003) reported that those from the Travelling Community faced a number of barriers: the lack of continuity in antenatal or postnatal care when women move from one official stopping place to another; health professionals' lack of access to the woman's medical records; Gypsy Travellers' experience of hostility from the local population; hostility from some health professionals when Gypsy Traveller women seek maternity care; their perception as 'resistant to services'; and a lack of trust of health professionals perpetuated by prejudice on the part of health service staff. The maternity module of the Children's National Service Framework (for England) is currently examining how to make services more accessible for Gypsy Traveller women.

Current initiatives to address the use of maternity services by the Gypsy Traveller Community include a

Department of Health funded project by the Maternity Alliance (2003-2005) on service take-up (Select Committee on Health, 2003). This will work with Gypsy Traveller groups, consult with women and health professionals, and produce guidance on service delivery and information materials to encourage the community to more fully use maternity services. The Department of Health is also funding the organisation Action on Pre-Eclampsia (APEC) to deliver the Pre-Eclampsia Advice for Travellers and Gypsies Project. This will result in an easy to understand leaflet aimed at Gypsy Travellers with information on the signs and symptoms of the condition and where help can be sought and a pamphlet for community health workers and support groups involved in the welfare of this community.

3.2 Cervical and other screening

Only one study has been found that reports cervical screening rates in the Gypsy Traveller population. In this hard to reach population on whom routine information was not available, Adcock (1999) carried out a linkage study to investigate screening coverage in West Sussex. Women were identified from a list of children known to a Traveller education worker using the GP registration database. The screening histories of women aged 20 to 64 years were collected from the cervical screening database. The crude coverage rate for the 128 women aged 25 to 64 years ranged from 25 per cent (using the estimated eligible Traveller population as denominator) to 73 per cent (using the sample number as denominator, based on the method used in Department of Health statistics on Cervical Screening). These rates were significantly lower than the district level of 87 per cent. Clearly, these data are restricted to women registered with a GP and a reluctance to share information between agencies was encountered, despite data protection and local ethics committee clearance.

However, in a survey of attendance at screening (dental, gynaecological, pulmonary screening, etc.) in a national representative sample of 1,599 subjects selected from women aged 18 to 24 years in Hungary (Gyukits *et al.,* 2002) – which included 69 women (4.3 per cent) who self-identified as Gypsies – marked differences were found between Gypsy and other respondents. In all cases the Gypsy women had less favourable attendance rates. Of particular concern is the case of pulmonary screening because of the increased risk in this population.

3.3 Family planning and contraception

Most studies have found that Gypsy Travellers tend to have larger families and to marry younger than the general population. However, there are no specific studies of family planning and contraception use (for both women and men) in the Gypsy Traveller Community. Little information is available on levels of contraception use. Hawes (1997) has reported that this is low and Pahl and Vaile (1988) found that only 16 per cent of Traveller women were taking the contraceptive pill. In East Sussex, Brighton and Hove (East Sussex, Brighton and Hove Health Authority, 2001), 44 per cent of a sample of 73 women in contact with the health visitor were using some kind of contraception.

European evidence also suggests poor use of contraception. Hajioff and McKee (2000) cite two studies that provide information on contraceptive use amongst the Roma in Europe. A study of the sexual culture of Roma women in Bulgaria found that only 61 per cent used contraception regularly, that abortions were more common than in the majority population – 2.41 abortions per woman, with 33 per cent of women having had more than 3 – and that Roma women had their first pregnancy earlier. A study of contraceptive practices in Spain found that Roma women knew significantly less about barrier methods of contraception, about vasectomy and tubal occlusion, and about periodic abstinence, their primary form of contraception being coitus interruptus. They were also less likely to seek contraceptive advice than non-Roma women. The reasons for low levels of contraceptive use have not been investigated. Crout (1987) and Moreton (1988) have suggested that religious beliefs may influence the methods of contraception used and Smart *et al.* (2003) also suggest that clinics are often not available at times that are convenient for Gypsy Traveller women.

3.4 Domestic violence

Doyal *et al.* (2002) contrast the attention the maternal role of Gypsy Traveller women has received with the neglect of hidden problems such as gender violence. While few specific studies have been identified of violence against Traveller women, Pavee Point (a voluntary organisation campaigning for human rights for Travellers) has described a number of issues (Department of Health and Children, 2002). These issues include: difficulties Traveller women have in accessing mainstream services (GPs, Accident and Emergency (A&E) services, crisis services, refuges and related support services) for reasons of institutional and individual discrimination; difficulties in accessing information and legal options due to preliteracy or illiteracy; and the often conflictual relationship between the police and the Traveller Community makes it difficult for Traveller women to access help via this route. The Northside Travellers Support Group (1994), too, have recommended that the refuge needs of Traveller women be addressed.

The only study to provide empirical evidence is by the Mid-Western Health Board (2003). Among two service providers for women who have experienced violence, 42 per cent and 52 per cent, respectively, of women using these services were Travellers, suggesting a high incidence of violence against women in the Traveller Community. The approaches of these service providers include, the adoption of anti-racism codes of practice, employment of outreach workers with particular emphasis on Traveller women, the training and employment of Traveller women as support workers, and a training for trainers programme for Traveller project co-ordinators and support workers in the area of violence against Traveller women.

4. Children's health

Gypsy Traveller children are widely reported to experience poorer health than their counterparts in the general population, although there is a paucity of robust evidence. A number of studies report a higher rate of congenital anomalies, although the contribution these make to overall childhood morbidity needs to be seen in context. There is also evidence of higher rates of childhood injury related to the often hazardous environmental conditions in which Gypsy Travellers live. Findings on the prevalence of asthma amongst children are inconsistent. Finally, infection rates may be higher than in the general population. One study reported that 30 per cent of children below 12 years of age in contact with the health visitor had a current infection affecting their skin, eye or chest (East Sussex, Brighton and Hove Health Authority, 2001). There is little in the literature on looked after Gypsy Traveller children or child abuse. Reported low levels of uptake of immunisations (see 7.2) and of developmental examinations (e.g. Save the Children [1983] found that 66 per cent of children had not received such examinations) are consistent with the wider under-utilisation of health care services.

4.1 Congenital anomalies

There is anecdotal evidence of a high prevalence of congenital anomalies in the Traveller population but few robust studies. Similarly, anecdotal evidence suggests a high consanguinity rate[5] in this population but few studies have attempted to determine such rates using rigorous methods. Care needs to be taken in interpreting this evidence, including the contribution of consanguinity to the prevalence of congenital anomalies, and in placing the findings within an informed and culturally sensitive context. Robust studies have reported a highly significant increase in the prevalence of congenital anomalies, mostly attributable to metabolic conditions with autosomal recessive inheritance. High rates of consanguinity have been found with some evidence of a trend towards higher prevalence of congenital anomalies in the offspring of first cousins.

The population based research evidence on congenital anomalies in the Gypsy Traveller population is very limited. In a national study of the health of Irish Travellers, Barry and Kirke (1997) compare the prevalence of congenital anomalies in this population to the general population in the Eastern Health Board region of Ireland. The study collected information on congenital anomalies and parental consanguinity at birth and at public health nurse visits in the immediate postnatal period and at the first birthday, for all Traveller children born in the Irish Republic in 1987. Use was also made of the registry of congenital anomalies in the Eastern Health Board region for validation. The prevalence of congenital anomalies in Travellers was 5.5 per cent (31/564 births), compared to 2.9 per cent in the Eastern Health region (Odds Ratio: 1.95). When metabolic conditions were excluded (n=7) there was no significant difference. There was a trend (not statistically significant) for the prevalence of congenital anomalies among Travellers to be greater in the children of first cousin marriages (6.5 per cent) than in those born to unrelated parents (3.8 per cent) (Odds Ratio: 1.73, 95 per cent CI 0.50-5.71). However, consanguinity status was missing for 20 per cent of Traveller mothers.

Few other findings are available. A study of the health of Traveller's children (n=350) aged under 16 years in Northern Ireland (Gordon *et al.*, 1991), using data gathered by community health doctors and health visitors, revealed a high degree of consanguinity in this community, which '…points to higher levels of congenital abnormalities than in the settled community'. Williams and Harper (1977) and Harper *et al.* (1977) report a high incidence of phenylketonuria along with other recessively inherited disorders in a south Wales Gypsy kindred of Romany origin (n=84), in which there was a high rate of consanguinity

5. 'Consanguinity' refers to a situation in which a couple are 'blood' relatives, i.e., they share a common ancestor. An example is a couple who are first cousins. Consanguinity is common in many cultures and can have a number of social benefits. In genetic counselling, consanguinity is important because it increases the risk of certain genetic disorders called autosomal recessive disorders.

(F=0-017). A number of recessively inherited disorders have been recorded in other Gypsy Traveller and Romany Gypsy populations. Martinez-Frias and Bermejo (1992) found a relative risk of 7.0 for autosomal recessive conditions in Spanish Gypsies compared to non-Gypsies in a hospital-based, case-control study and surveillance system, a finding attributed to consanguinity found in Roma families, twelve times more common than in the majority population. However, they reported relatively few cases of chromosomal and autosomal dominant disorders (ratios of 0.68 and 0.80, respectively). In a study in Boston, Massachusetts, medical data on 58 Gypsies were analysed together with a pedigree linking 39 of the subjects in a large extended kindred (Thomas *et al.*, 1987). Hypertension was found in 73 per cent, diabetes in 46 per cent, hypertriglyceridaemia in 80 per cent, hypercholesterolaemia in 67 per cent, occlusive vascular disease in 39 per cent, and chronic renal insufficiency in 20 per cent. Of 21 marriages, 12 were consanguineous '…yielding an inbreeding coefficient of 0.017'.

There is, in addition, an extensive literature that has focused on genetic studies of the Roma across Europe. Kalaydjieva *et al.* (2001) report a range of mendelian disorders of the Roma caused by private founder mutations: primary congenital glaucoma, galactokinase deficiency, polycystic kidney disease, hereditary motor and sensory neuropathy-Lom, and others. Reported carrier rate for some Mendelian disorders are in the range 5-15 per cent, sufficient to justify newborn screening and early treatment, or community-based education and carrier testing programmes where no therapy is currently available.

Studies of the relationship between consanguinity and congenital anomalies are fraught with problems. Firstly, there are difficulties in establishing the rate of consanguinity in the Traveller population. In Barry and Kirke's (1997) study reliable information on consanguinity was only available for 452 (80 per cent) of Traveller mothers. This was obtained at the postnatal public health nurse visit and full pedigrees were not taken. Moreover, data on consanguinity status were more complete for those without (82 per cent) than those with (55 per cent) congenital anomalies. Flynn (1997) suggests that the figure of 19 per cent of marriages being first cousins given by Barry and Kirke is much too low. In a study of the vital statistics of 180 Traveller families of Westmeath (Ireland) origin (Flynn, 1986), the genealogies of 141 married couples and their blood relationships were constructed: first cousins, 55 (39 per cent); first cousins once removed, 16 (11 per cent); second cousins, 30 (21 per cent); third and fourth cousins, 20 (14 per cent); and no traced relationship, 20 (14 per cent). Flynn (1997) suggests that seeking information on blood relationships solely from Traveller mothers in the postnatal period is likely to underestimate the true rate of consanguinity. It is clear, however, that the rate of first cousin marriages in this population is substantially higher than in the general population. A rate of 0.16 per cent in the settled population is reported in a study carried out between 1958 and 1966 in Ireland (Masterson, 1970). High rates of consanguinity have also been reported for Roma populations in the United States (Thomas *et al.,* 1987) and eastern Europe (Ferak *et al.,* 1987). Based on the results of their study, Barry and Kirke argue that vigorous efforts should be made to ensure that Traveller babies are included in neonatal metabolic screening programmes.

Secondly, consanguinity is a culturally sensitive issue for Gypsy Travellers and it is important that its health consequences are placed in context and not given disproportionate importance. While there is an obligation upon health professionals to explain the risks of consanguinity, respect must be preserved for the place of (and reasons for) first cousin and other close relative marriages in the Gypsy Traveller Community.

4.2 Injury in children

Around half a dozen studies have been identified that address the issue of injuries in the children of Gypsy Travellers and suggest a higher prevalence rate, although there is much additional anecdotal evidence. Most of these studies implicate the often hazardous environmental conditions in which children are brought up. For example, almost three-fifths of Gypsy Traveller mothers interviewed in one study (Pahl and Vaile, 1988) identified problems in caring for their children, including dirty environments, lack of safe play areas, and proximity to fast traffic.

A Cardiff based study set out to test the hypothesis suggested in anecdotal and empirical evidence that Gypsy Traveller children have a higher accidental injury rate than the general population and to use the information to inform recommendations for appropriate and culturally sensitive strategies to reduce accidental injuries in this community. Visits to A&E Departments were used as a proxy for injury rates. The study found a higher attendance by children living on Gypsy Traveller public sites, even when compared to a control group from an area scoring relatively highly on deprivation indices (Kemp, 2003; Beach, 1999).

Health visitor contact with local Traveller children in East Sussex, Brighton and Hove found that 16 per cent of children below 12 years of age reported an accident in the last year (trauma, burn or scald) (East Sussex, Brighton and Hove Health Authority, 2001). In Pahl and Vaile's (1988) study, 11 per cent of children under five years of age suffered serious injuries (like lacerations, scalds and burns) in the previous 5 years. An earlier study (Lawrie, 1983) highlighted the hazards of open fires and faulty wiring. High levels of childhood injury are also reported by Save the Children (1983) and Ginnety (1993).

Evidence from European studies corroborates some of these findings. In an interview study of 239 children who presented with a burn injury at the Emergency Department of a teaching children's hospital in Athens during a twelve month period and 239 gender- and age-matched controls with minor non-injury ailments, children from families of Gypsies and recent migrants were at substantially higher increased risk for burns (17 cases, 7.1 per cent, vs. 2 cases, 0.8 per cent in controls) (Petridou *et al.,* 1998).

4.3 Asthma

Evidence on the prevalence of asthma in the Gypsy Traveller population is inconsistent. An Irish study compared the prevalence of asthma in a sample of 6 to 12 year old Gypsy Traveller boys in Cork (n=54) with a settled control population of schoolboys (n=129) to test the hypothesis that the travelling lifestyle is a protective factor in the development of asthma (Kearney and Kearney, 1998). The parent reported prevalence of wheeze and related symptoms were more common in the control subjects compared with the Gypsy Traveller boys. The values were significant for wheeze in the last year (31.3 per cent vs. 14.8 per cent, Odds Ratio: 5.6, p=0.025) and for doctor diagnosed asthma (25.6 per cent vs. 11.1 per cent, Odds Ratio: 5.1, p=0.04), suggesting that the travelling lifestyle may be a protective factor.

However, in Feder's (1989) study, the prevalence of asthma and chronic bronchitis was higher among Gypsies than in a control group. Anderson (1997) also reported a higher incidence of asthma. A high prevalence of asthmatic diseases was demonstrated in a group of Gypsies (5 families comprising 87 individuals) residing in the North of Spain (Cardaba *et al.,* 2001). The study suggested the existence of multiple genetic influences on the allergic response in these families.

5. Mental health

While there are many general references to poor mental health in the Traveller Community (often made in the context of discriminatory behaviour by the wider society), there is a paucity of well-designed studies that seek to assess psychiatric morbidity using well-validated instruments. Doyal *et al.* (2002) comment, for example, that 'mental health has…been largely ignored except for very general references to the negative impact on Travellers of discriminatory behaviour by the wider society'. There is general agreement that the Gypsy Traveller Community's (anecdotally) reported high levels of poor mental health are a result of multiple stressors, including discrimination, eviction or the threat of eviction, poor living and environmental conditions, poverty, and inequity of access to services.

Work undertaken by a Sheffield team (Appleton and Welton, 2002) provides the only robust findings on mental health in this group. Using a questionnaire containing the Hospital Anxiety and Depression Scale (HADS) [which detects anxiety and depression better than non-psychiatric physicians], EuroQol EQ-5D, and questions on use of services and medication, they report findings from 60 Gypsies and Travellers in Sheffield (42 female and 18 male). The prevalence of anxiety was around 35 per cent among Gypsies and Travellers, compared with 12 per cent in the general population. The prevalence of depression was around 27 per cent amongst the Gypsies and Travellers, compared with about 4 per cent in the general population. A SF (Social Functioning) score was also used, Gypsies and Travellers scoring just over 100 (that is, a lower level) compared with over 130 in the Sheffield population. The study also undertook in-depth interviews with 17 Gypsies and Travellers and 5 focus groups with health and social care professionals to explore issues around Gypsy and Traveller experience and understanding of mental health and their use of mental health services. Emerging findings include the often complex nature of the presenting problems (cumulative stressors, family relationships, societal stereotypes, fear and rejection), communication issues, and the acceptability only of medication.

6. Cardiovascular disease and cancer

A number of commentators have drawn attention to the absence of literature on major causes of death – such as cancer and heart disease – compared with the focus on such issues as infectious diseases or the condition of mothers and babies (Vozarova de Courten *et al.,* 2003; Doyal *et al.,* 2002; Koupilová *et al.,* 2001). This has resulted, for example, in a dearth of evidence on the main health problems that affect male Gypsy Travellers. There are no epidemiological studies of these major causes of death in the Gypsy Traveller community in the UK.

6.1 Cardiovascular disease

There is virtually no literature on cardiovascular disease and its risk factors in the Gypsy Traveller population. This appears to apply equally to studies of the Roma in Europe. For example, Koupilová *et al.* (2001) found 'very few reports on cardiovascular disease in Roma'. In one of the few UK studies to mention cardiovascular disease, an interview survey of 171 Traveller families in North Derbyshire, 31 per cent of respondents reported that they either lived with someone who had heart disease or had it themselves (Macredie and Taylor, 1995).

In a study of self-reported health among Czech adult Roma, 22 per cent of the study subjects reported that they were currently suffering from cardiovascular diseases (Nesvadbova *et al.,* 1999). Nozdrovicky (1991) [cited by Koupilová *et al.,* 2001] followed a community of Roma in the village of Rakusy, Slovakia, from the late 1980s and reported that cardiovascular diseases were the most common cause of death among this Roma Community. Risk factors identified included high consumption of animal fat, low consumption of fruit and vegetables, obesity, high prevalence of smoking (often from an early age), lack of physical activity, and very high consumption of alcohol. One small US study reported a high prevalence of obesity, type 2 diabetes, hyperlipidemia, dyslipidemia, chronic renal insufficiency, occlusive vascular disease, and hypertension in 58 Gypsies living in Boston, Massachusetts (Thomas *et al.,* 1987).

The only robust data come from a recent study (Vozar *et al.,* 2002; see also Vozarova de Courten *et al.,* 2003) that has reported higher prevalence rates of cardiovascular disease (self-reported history of ischaemic heart disease, myocardial infarction, stroke or peripheral vascular disease) in Gypsies compared to Caucasians in Slovakia. The investigators examined 156 Gypsies (76 male, 80 female, aged 49 +/- 11 years [mean+/-SD]) and 501 Caucasians (230 male, 271 female, aged 51 +/- 0.6 years) who participated in a population survey. Age- and sex- standardised prevalence of cardiovascular disease was 35 per cent (95 per cent CI, 28 per cent to 43 per cent) and 26 per cent (22 per cent to 29 per cent, p=0.004 for comparison of ethnic groups) in Gypsies and Caucasians, respectively. Cardiovascular disease was reported in 80 per cent of Caucasians and 100 per cent of Gypsies who had all five features of the metabolic syndrome (comprising type 2 diabetes, obesity, hyperlipidemia, hypertension, and elevated albumin/creatinine ratio [ACR]).

Specifically, the following age- and sex- standardised prevalence rates were reported:

- Type 2 diabetes – 30 per cent (95 per cent CI 22 to 39) and 10 per cent (95 per cent CI 8 to 13, p=0.0001) in non-Gypsies
- Obesity – 65 per cent (95 per cent CI 56 to 74) and 30 per cent (95 per cent CI 26 to 34, p=0.0001)
- Hypercholesterolemia – 69 per cent (95 per cent CI 61 to 76) and 59 per cent (95 per cent CI 54 to 63, p=0.04)
- Hypertriglyceridemia – 66 per cent (95 per cent CI 59 to 74) and 39 per cent (95 per cent CI 35 to 43, p=0.009)

- Hypertension – 49 per cent (95 per cent CI 42 to 56) and 43 per cent (95 per cent CI 39 to 47, p=0.1)
- Hyperinsulinemia – 33 per cent (95 per cent CI 26 to 50) and 8 per cent (95 per cent CI 2 to 14, p=0.002)
- Elevated ACR – 16 per cent (95 per cent CI 9 to 22) and 5 per cent (95 per cent CI 3 to 7, p=0.0001)
- Metabolic syndrome – 20 per cent (95 per cent CI 12 to 27) and 4 per cent (95 per cent CI 3 to 6, p=0.0001)

These much higher prevalences of type 2 diabetes, metabolic syndrome, and cardiovascular disease are likely to contribute to the high mortality rate in this group.

Vozarova de Courten *et al.* (2003) characterise the Gypsy population as one that has recently experienced a rapid transition from a traditional lifestyle (involving high levels of physical activity and a low energy but high nutrient density diet) to a more sedentary lifestyle with high caloric intake. The consequences of such transition are frequently seen in extreme rates of obesity, type 2 diabetes, and cardiovascular disease. The investigators further invoke the hypothesis of Neel *et al.* (1998) that the high prevalence of a 'thrifty genotype' in these populations is due to a selective advantage in the 'feast and famine' conditions that historically characterised the traditional environment of these populations.

6.2 Cancer

A low incidence of cervical carcinoma in women of Gypsy origin was found in the Karlovy Vary district of the Czech Republic (Hrajdek and Petr, 1981) but no other studies were identified. This gap in the epidemiological record is of concern, given the low utilisation of preventive health care (such as breast and cervical screening) and the high prevalence of some health related behaviours that carry risks for cancer such as smoking and drinking.

7. Communicable diseases and other conditions

7.1 Communicable diseases

The literature on the health of Gypsy Travellers has traditionally focused on communicable diseases and immunisation at the expense of other major causes of morbidity and mortality. Yet there are few studies that report detailed epidemiological data on communicable diseases in the Gypsy Traveller population in the United Kingdom. Several studies report seropositive rates for *hepatitis A* (HAV) in Gypsy populations. In Spain, Morales *et al.* (1992) found a 63 per cent anti-HAV positive rate among Gypsy children aged 1 to 14 years, compared with 46 per cent for children in an orphanage and 23 per cent for non-Gypsy families. There have been a number of reports of *poliomyelitis* among Gypsy children in Bulgaria over the last ten or twelve years, where effective vaccination has been difficult because of the Roma's transient lifestyle (Schrope, 2001). In a study of 126 Gypsy patients aged 15 or more and registered with *tuberculosis* for over two years in Bucharest, the risk of the disease was twice as great in men and the age group most affected was 30 to 49. The successful outcome of chemotherapy was low (48 per cent) and two-thirds of the subjects had associated diseases (Dediu *et al.,* 2000). A microepidemic of tuberculosis was reported in Gypsy children in the Czech Republic in 1990 (Trnka and Hejdova, 1993).

7.2 Immunisation rates

Low rates of immunisation uptake have frequently been reported in the literature since the early 1980s and are consistent with low levels of utilisation of health care services generally. However, in areas where health care workers have sought to increase uptake, rates of 87-90 per cent have been achieved. Indeed, other research suggests that Gypsy Travellers may have concerns about the safety of childhood immunisations and that such concerns can be addressed through culturally appropriate health promotion work.

Feder *et al.* (1993) investigated the immunisation status of the children of Traveller Gypsies presenting to two general practices and a paediatric accident and emergency department in east London between July 1988 and February 1990. Findings were compared to a control group presenting to the same services. Based on an investigation of parental reports and other records for 72 Traveller Gypsy children and 106 control children aged 10 months to 6 years, Traveller Gypsy children had significantly lower completion rates for pertussis, measles, diphtheria/tetanus, and poliomyelitis vaccines than the control group. Moreover, the difference between the uptake of the first and third diphtheria/tetanus, pertussis and poliomyelitis vaccines was significantly greater among the Traveller Gypsy children than among the control group.

Recent studies report variable rates of immunisation uptake but with some examples of good uptake. Health visitor contact with about 60 local Traveller children in East Sussex, Brighton and Hove under 5 years of age suggested that uptake of immunisation in this group may not be quite as low in this area as reported rates in earlier studies: 65 per cent were fully vaccinated, although, of course, this figure relates to those coming into contact with the health visitor (as opposed to a population-based sample of Gypsy Travellers) (East Sussex, Brighton and Hove Health Authority, 2001). The Nottingham Traveller Team (Warriner and Gregory, 2002) report that 87 per cent of children are fully immunised in their study, although no figures are supplied on the size of the sample and method of selection. Nelson (2003) reports immunisation uptake rates among Gypsy Travellers in the Ferryhill area of County Durham of around 90 per cent following health visitor health promotion work.

Many of the earlier studies report low rates of uptake amongst Travellers. Lloyd and Morran (1999) report from their study of Scottish Travellers' health that 43 per cent of children had not received pre-school immunisations, although no information is given on the size and composition of the sample. Gordon *et al.* (1991) reported that uptake of immunisation (DPT, pertussis and measles) was less in a sample of 350 Traveller children aged under 16 years in Northern Ireland than in the settled community. A report

by University College Galway/McCarthy (1995) in Ireland identified an immunisation rate of 52 per cent for MMR (mumps, measles and rubella) as against a national uptake of 75 per cent. The Kent study (Pahl and Vaile, 1988) also found a very low uptake of childhood immunisations (one quarter of the England rate in the mid 1980s). Save the Children (1983) reported non-completion of immunisation for diphtheria/ tetanus in 90 per cent of cases.

A range of studies of the Roma people (including those cited by Hajioff and McKee, 2000) report low immunisation coverage from studies in Europe and elsewhere. Garcia *et al.* (2003) report vaccine coverage for children under 15 years of age of 41 per cent for polio, diphtheria and tetanus, 24 per cent for pertussis, and 36 per cent for MMR in a marginal Gypsy Community in Alicante. A study in Jordan reported only a 9 per cent immunisation rate amongst Roma (Reichler *et al.,* 1997) and one in Italy reported 26 per cent coverage (Aylward *et al.,* 1997).

A variety of reasons have been advanced to explain the reluctance of Gypsy Traveller mothers to take up immunisations, including practical barriers such as enforced mobility, low literacy levels, absence of postal addresses, and discrimination from healthcare staff (Feder *et al.,* 1993) and cultural factors (Bunce, 1996; Streetly, 1987). However, other studies suggest that Gypsy Traveller mothers are concerned about the potential side effects of certain vaccinations (Edwards and Watt, 1997a) and that their concerns may not be that different from non-Gypsy Traveller mothers (Smart *et al.,* 2003).

7.3 Other conditions

No studies on the subject of occupational hazards have been reported (Hajioff and McKee, 2000). Some specific medical conditions have been reported in the literature. For example, in Hungary, *multiple sclerosis* prevalence ranged from 32 per 100,000 to 79 per 100,000 in the period 1992-1996. However, prevalence rates for Gypsies varied, from 5 per 100,000 in Baranya County Gypsies to a rate of 98 per 100,000 in Gypsies from Fejer County, a rate similar to that for the general population in Hungary (Pugliatti *et al.,* 2002).

8. Access to and use of services

Most of the literature on the utilisation of services has focused on primary care (especially registration levels with GPs) and relatively little attention has been accorded to community health and social care services, A&E services, and the use of outpatient and inpatient care.

8.1 Primary care

Varying rates of registration with GPs are reported in the literature:

(i) The Kent study (Pahl and Vaile, 1988), based on interviews with 263 Traveller women, found 85 per cent of women registered with a GP but 33 per cent attending A&E for primary care, in a population of Travellers 30 per cent of whom had not moved for over 5 years. The investigators also found that 19 per cent of their sample lived more than 5 miles from their practice.

(ii) Based on interviews with 88 Travellers in 5 London boroughs – 54 on authorised and 34 on unauthorised sites – Hyman (1989) reported that 96 per cent of Travellers on authorised sites and 56 per cent on unauthorised sites were registered with a GP within the borough (based on self-reports), 81 per cent overall or slightly less than reported by Pahl and Vaile (1988).

(iii) Barnett (1995) interviewed 79 Gypsy Traveller families in mid-Kent and found 91 per cent were registered with a GP, a significant association being reported between long-term residence and GP registration.

(iv) In East Sussex, Brighton and Hove (East Sussex, Brighton and Hove Health Authority, 2001), health visitor contacts with Gypsy Traveller women (n=70) showed that 51 per cent were not registered with a GP. The report concluded that primary health care needed to be made more accessible. While Travellers experienced difficulties registering, they preferred to register themselves rather than be registered via the Health Authority, so that they would know where the surgery was.

(v) The Nottingham Traveller Team (Warriner and Gregory, 2002) reported 50 per cent of families registered with a GP, although no figures are supplied on the size of the sample and method of selection.

(vi) Lloyd and Morran (1999) report from their study of Scottish Travellers' health that 86 per cent of Travellers surveyed by the Save the Children Fund were registered with a GP (no information is given on denominators).

In addition, a small number of studies report registration refusals. A London survey (Feder, 1989) found that 10 per cent of GPs would not accept Travellers. Lloyd and Morran (1999) report that 27 per cent of Gypsy Travellers surveyed stated that they had been refused registration on one or more occasions. According to the Save the Children (1983) survey of 265 Traveller mothers in East Anglia, a high number claimed GPs refused them treatment at their surgeries. Problems registering with GPs were also reported by Streetly (1987) and Barnett (1995).

A qualitative research study in York, involving in-depth interviews with 20 Travellers and 5 interviews with providers (Carlisle and Hutton, 1998), provides valuable information on barriers to access. The majority of Travellers were registered with a local GP (a benefit of living on an official site and having a permanent address); those that were not used the A&E department. Different medical practices in the city operated different policies towards Travellers with respect to home visiting. Isolated instances reported included the offer only of temporary registration to a settled Traveller, the threat of removal from the register because a complaint was made, and misdiagnosis by GPs that was corrected by specialists. The attitude of health professionals was generally felt to be good, with health visitors doing onsite checks on children at 3 years of age. The health professionals reported difficulties of access to primary care for young families who did not own a car and concern amongst health visitors and district nurses at visiting isolated sites after dark.

8.2 Secondary and community care services

Very little is known about Gypsy Travellers' use of other services. Few studies have been identified that report the use of A&E services or in-patient care. As noted, a third of the Traveller women interviewed by Pahl and Vaile (1988) attended A&E for primary care. Streetly (1987) and Northside Travellers Support Group (1994) also reported use of A&E and secondary care services because of problems registering with GPs. Similarly, little is known about the uptake of family planning services, although a study of health visitor contacts with Gypsy Travellers in East Sussex, Brighton and Hove (East Sussex, Brighton and Hove Health Authority, 2001) reported that 44 per cent of women were using some kind of contraception.

8.3 Aural and speech and language services

As with other services, there appears to be a low uptake of available aural, speech, and language services by the Traveller Community, the early identification of such disorders in children and their appropriate treatment being important to children's quality of life and reduction in secondary disability.

A study carried out in the Western Health Board region in 1999 found that a significant number of the pre-school Traveller children assessed presented with delayed speech and language skills (Western Health Board, 1999). A need was identified for the implementation of a programme targeted at the stimulation of speech and language skills in pre-school children. Ireland's Department of Health and Children (2002) has responded with proposed action to develop new initiatives to increase the uptake of aural screening services during the first two years of a Traveller child's life and the implementation of a national training programme in the pre-school setting targeted at the stimulation of speech and language skills in pre-school children.

The York Study (Carlisle and Hutton, 1998) reports a case of speech therapy needs undetected in primary care and only recognised by a specialist.

8.4 Barriers to access

Gypsy Travellers have a right to registration with general practitioners and those who refuse to offer temporary or permanent registration to Travellers in their area can be challenged with a Race Relations Questionnaire (RR65) procedure (Charing, 2002).

Few studies have explicitly sought to identify barriers to access to health services and much of the evidence is anecdotal. Research by Save the Children (Scotland) and Dundee University Law School (1999) investigated two barriers: the health impact of being forcibly moved on; and institutional discrimination. Their main finding was that 43 per cent of families were receiving healthcare at the time they were moved; as regards follow-up, treatment stopped completely for half the respondents and for the other half treatment was interrupted or delayed. In the same study, 66 per cent of the health professionals interviewed identified racist attitudes of other health professionals as the primary obstacle to Gypsy Travellers trying to access health services.

Institutional discrimination (poor staff attitudes, GPs refusing to register Gypsy Travellers, and refusal of treatment) and the funding system of remuneration were identified as barriers in the evidence given at a Scottish Inquiry. A Highland Health Board stated in oral evidence:

'We are aware that Travellers find it difficult to register with primary care and with general medical practitioners. Some surgeries openly discriminate against them and say that they do not want Travellers to register. That is partly because Travellers are considered to create an excessive workload… That attitude also comes partly from the system of remuneration of general practitioners. Much weight is given to

achieving targets, including those for immunisation and cervical cytology. If a woman registers with a practice but…then disappears, and the practice cannot prove that she has had a smear test, the practice's percentage up take drops, and so its income drops. Much subtle discrimination is happening for various reasons, but in primary care, much of the explanation is financial'. (Scottish Parliament, 2001: col. 1143).

Studies of the use of GP services by Travellers in Ireland (Mid Western Health Board, 2003; O'Donovan *et al.,* 1995) have reported similar findings. Travellers' perceptions of GP services include consultations of inadequate length, lack of consideration of the educational levels of Traveller patients in explaining an illness, lack of physical examinations before medicine is prescribed, the need to make an appointment and wait to see a GP, a reluctance of GPs to make home visits during out of surgery hours, and a lack of understanding of Travellers' circumstances and culture. GPs' perceptions of Travellers include high utilisation of GP services but low uptake of preventive services such as immunisations and developmental paediatric clinics, poor continuity of care arising from difficulties in transferring records, issues around reimbursement, inappropriate use of prescribed medication, disruption to surgery waiting rooms and inadequate facilities to accommodate families, problems with illiteracy, and safety issues with regard to 'halting site' visits.

There may also be specific cultural issues surrounding Gypsy Travellers' approach to, and use of, GP and other services. Lehti and Mattson (2001) reported that Gypsies seldom attended primary care services alone, but were generally accompanied by one or more relatives, friends, or companions. Wetzel *et al.* (1983) also reported that the Gypsy approach to acute medical care consisted of the presence of a large extended family.

9. Lifestyle factors

9.1 Smoking

There is a lack of comprehensive data on smoking in the Gypsy Traveller population as the large national health and lifestyle surveys, such as the Health Survey for England and the Policy Studies Institute's Fourth National Survey of Ethnic Minorities (1993-1994), do not separately identify this group. Reports in a few local research studies suggest very high rates. In East Sussex, Brighton and Hove (East Sussex, Brighton and Hove Health Authority, 2001) 75 per cent of women in contact with the health visitor smoked. Among 171 Traveller families in North Derbyshire (Macredie and Taylor, 1995) 70 per cent of respondents reported that they smoked. The Nottingham Traveller Team (2003) estimated that 80 per cent of Traveller men and 60 per cent of Traveller women smoked. Significantly lower rates of smoking prevalence are reported for the 239 Travellers attending the Rathkeale Triage Clinic in Ireland's Mid Western Health Board Region: 110 (46 per cent), comprising 53 per cent of men and 43 per cent of women (Mid Western Health Board, 2003). This compares with 57 per cent in Parry *et al.*'s (2004) national survey of 293 Gypsy Travellers.

In a non-representative survey conducted within the frame of a WHO-financed project, 70 per cent of young Roma adults were found to be regular smokers, the youngest regular smoker in the evaluated group being 9 years old (WHO/EURO, Soros Foundation, 1998-1999). This compares with a prevalence of 46 per cent (95 per cent CI 42.4 per cent to 49.5 per cent) among 2,410 secondary school students aged 14 to 18 in Budapest, Hungary in 1999 (Centers for Disease Control, 2000). In a survey of Czech and Gypsy ethnic groups in the Czech Republic, about 78 per cent of Gypsy mothers admitted smoking compared with 31 per cent of Czech mothers (Dejmek *et al.,* 2002). Vozarova de Courten *et al.* (2003) have reported higher smoking rates in a sample of 105 Slovakian Gypsies than 501 non-Gypsies (42 per cent vs. 21 per cent, respectively, p=0.001). In a study of the relationship between lung function and smoking and dietary habits in 121 Gypsies (62 males and 59 females aged 14 to 70 years of age) living in Greece, approximately 70 per cent of subjects were smokers (Gourgoulianis *et al.,* 2000). Finally, a particularly high rate was found in a study of 58 Gypsies in the area of Boston, Massachusetts, 39 of whom were linked in a large extended family, 86 per cent smoked cigarettes (Thomas *et al.,* 1987).

9.2 Alcohol use

While there are many anecdotal reports of high drinking levels in the Gypsy Traveller Community, there is a dearth of robust data. In the north Derbyshire study of 171 Traveller families (Macredie and Taylor, 1995), 54 per cent of respondents said that drinking alcohol caused difficulties for them in some way. Only one other study has been identified that reports on the use of alcohol. Of the 241 Traveller attendees at the Rathkeale Triage Clinic in the Mid Western Health Board Region, Ireland, who provided information on drinking, 61 per cent said that they consumed alcohol, 83 per cent of men and 51 per cent of women. The difference between adult men and women was striking in those aged 15 to 34, in men alcohol consumption being high from an early age whilst in women it peaks in mid-life. (Mid Western Health Board, 2003).

9.3 Diet and nutrition

Nutrition is an important issue in the Gypsy Traveller Community because of reported (but poorly documented) higher than average levels of diabetes, coronary heart disease, stroke and obesity. Edwards and Watt (1997b) mention the high sugar diets of Gypsy Travellers and that many of the foods perceived as being healthy are too expensive for Travellers (although there is a dearth of statistical data on the extent of poverty in the Gypsy Traveller Community and on the income range of its members). There are no comprehensive studies of nutritional issues in this community and only anecdotal evidence. For example, based on health visitor research in County Durham, Nelson (2003) mentions the high salt content of broths and soups prepared by older Gypsy Traveller women and the reliance on fast food amongst younger women. Hawes (1997) also highlights insufficiency of breast milk volume for babies. Doyal *et al.* (2002) refer to the high fat diets of Gypsy Travellers. Dietary factors and lack of physical exercise are likely to be the main contributors to the reported high prevalence of obesity in the Gypsy population (Vozarova de Courten *et al.,* 2003; Nozdrovicky, 1991; Thomas *et al.*, 1987). In a comparison of Gypsy and non-Gypsy populations in Slovakia, for example, Vozarova de Courten et al. (2003) found Gypsies had a higher body mass index (32 vs. 28 kg/m^2) and reported less physical activity. Fewer Gypsies reported exercising more than twice a day compared with the non-Gypsies (3 per cent vs. 14 per cent, p=0.001).

10. Oral health care

There are very few studies of oral health care in Travelling People. Of the few that have reported findings, a consistent picture emerges of high rates of dental caries, low registration and use of dental (including preventive) services, and mobility and the threat of eviction as major determinants of access. Also, Nelson (2003) has suggested that caring for teeth to ensure they last a lifetime may not be considered important in the Gypsy Traveller Community, although they are interested in avoiding toothache and the inconvenience of finding emergency dental treatment. One solution may be the use of mobile dental units, as has happened in the Bristol Traveller Health Project (Rhodes, 1998).

A study of Gypsy Travellers' perceptions of dental health and service use in Hertfordshire (Edwards *et al.,* 1997a, 1997b), in which information was obtained from semi-structured interviews with 43 Gypsy Travellers, a questionnaire survey and clinical screening of 72 Travellers, found a high level of unmet need, low dental registration, and very little use of preventive services. However, the Travellers had adopted many of the health beliefs and attitudes of the general population and no cultural barriers to dental care were identified, although dental health professionals need to be aware of their cultural characteristics in relation to food and hygiene. With respect to access to education and health services, the investigators reported that control of their travelling was the major determinant.

A small scale survey (information on sample size is not supplied) undertaken in East Sussex, Brighton and Hove (East Sussex, Brighton and Hove Health Authority, 2001) found that over 70 per cent of Traveller children had dental caries, one third of Travellers had never seen a dentist, and the threat of eviction was a major factor determining access to health services. The report concluded that 'dental care for local Traveller children is non-existent and innovative ways to provide a child-friendly service need to be found'. The Cambridgeshire Family Health Services Authority (FHSA) issued a policy paper on Travellers in 1991, which stated that dental health was thought to be very poor (Cambridgeshire County Council, Cambridgeshire Travellers Research Group, 2002). Observations made in other local studies confirm that a high proportion of children seen by health visitors have visible dental decay and of problems in accessing dental care due to mobility.

The prevalence of dental caries was also found to be very high in a Spanish population of Gypsies (Mora and Martinez, 2000). Among 173 children aged 2 to 5 years old in a deprived community, the prevalence of caries was 37 per cent in the patients but 58 per cent in the Gypsy group, compared with 29 per cent among the majority population.

11. Wider determinants of health

11.1 Environmental factors including sites/accommodation

There are many anecdotal reports of the effect of the environment in which Gypsy Travellers are forced to live upon their health. These include the location of sites (e.g. on derelict land, close to sewage plants, tipping areas/landfill sites, contaminated or poor quality land, proximity to overhead power lines, proximity to busy roads or motorways, and areas that lack traffic calming), poor sanitation, problems with infestation by vermin, lack of safe play areas for children, lack of safe access to shops, schools, and other services, poor access to public transport, and lack of/problems with on site water supplies, amongst others. These conditions have been linked to high rates of accidents on sites, road related injuries and deaths, and illnesses due to the environment (such as diarrhoea, asthma, parasites, skin conditions, hepatitis A, and enteric infections). However, there have been few studies that have systematically evaluated the health impacts of Gypsy Travellers' living environments.

The provision of sites and associated services

One of the most comprehensive surveys of sites and associated provision for Gypsy Travellers is that undertaken by Communities Scotland, in association with Heriot-Watt University (Communities Scotland, 2002; see also Lomax *et al.,* 2000, for Travellers' views). While the research found isolated examples of good practice, weaknesses were frequent across key areas of policy: the lack of robust information on the needs, preferences and aspirations of Gypsy Travellers, the absence of long-term planning for site improvement, the absence of effective financial planning for sites, limited information for Gypsy Travellers on using pitches and site services, the lack of defined service standards, and lack of evidence on the affordability and comparability of current rents. Some councils had provided facilities such as community meeting places, play facilities, barrier-free site access and adapted amenity chalets and access to such provision was regarded as essential. Many of the sites were not in ideal locations and amenity units were of a standard that failed to meet the current needs of site residents, notably, inadequate heating and unsuitability for cooking. Pitch rents were found to be generally high in comparison with mainstream housing and there was little evidence to demonstrate affordability. Very limited information was given to Gypsy Travellers on finding pitches and on the range of services available and many councils did not have a documented policy on allocating pitches. Only a few councils were formally making efforts to encourage the Gypsy Traveller Community to participate in effective planning and service provision and there was little evidence of feedback to the community from consultation.

A similar assessment has been made of the provision and condition of local authority Gypsy Traveller sites in England (Niner, 2002). No clear, widely understood national policy towards accommodation for Gypsy Travellers in England was found. Some sites were below standard and others currently closed and extensive funding was needed to maintain the network that could be met from site income. An estimate of an additional 1,000-2,000 residential pitches was needed over the next 5 years and, in addition, between 2,000-2,500 additional pitches on transit sites or stopping places to accommodate nomadism. As in Scotland, the need for intensive site management was identified, including performance monitoring. Also, in some cases large differences were found between the pitch fee charged and the amount payable by housing benefit, raising issues of affordability.

Clearly many of the circumstances related to site location, provision, and condition impact significantly on the health of the Gypsy Traveller Community. Some of the hazards relating to location have already been mentioned. In Scotland, for example, there are nine sites built on or near old council rubbish tips and the proximity of some sites to pylons has been highlighted (Lloyd and Morran, 1999). The shortage of official sites and of transit sites force many families into unauthorised camping where facilities and essential services are often absent, including refuse collection and the provision of water supply and toilets.

There are problems around forced eviction, including the constant threat of this and disruption of everyday life. Where school-aged children are involved there may be difficulties in maintaining continuity of education.

The 1994 Criminal Justice and Public Order Act repealed those parts of the Caravan Site Act 1968 which placed a duty on local authorities to provide Gypsy Traveller sites. There is evidence that since then conditions and facilities on sites have deteriorated and that very few authorities have programmes of further development. In particular, there are very few formal transit sites but a widely acknowledged need for such provision. Furthermore, the 1994 Criminal Justice and Public Order Act has increased the power of local authorities to evict Gypsy Travellers and this has been reported to have had damaging effects on the Gypsy Traveller population (Niner *et al.*, 1998).

Lead poisoning

There is anecdotal evidence (but a paucity of robust studies) that blood lead levels may be higher in Gypsy Traveller children than those in the general population. Only one report has been identified. A study of differences in average blood lead levels between iron-deficient children of both Gypsy (n=25) and Caucasian origin (n=64) and 41 iron-sufficient children (11 Gypsies and 30 Caucasians) was undertaken in Spain (Redondo and Guisasola, 1995). The average blood lead levels in iron deficient children (14.25 vs. 7.25 micrograms/dl ($p<0.01$)) and the prevalence of iron-deficient children with toxic blood lead levels (24 per cent vs. 1.5 per cent) was significantly higher in Gypsies. A difference in average blood lead levels between the two groups was also seen in children with normal iron metabolism (10.23 vs. 5.65 micrograms/dl ($p<0.001$)).

11.2 Socio-economic factors: employment, income and poverty

There is a dearth of literature on the employment rates and experiences of Gypsy Travellers and no studies that report reliable information on income levels and poverty. Bancroft *et al.* (1996) report that Travellers prefer self-employment rather than wage employment and, consequently, value the transfer of skills across generations.

Webster and Millar (2001) provide the only research findings on the nature and extent of employment among the 'New' Traveller Community through in-depth interviews. Employment was found to be common among New Travellers, with about half working at the time of the interview. Seasonal agricultural jobs, temporary jobs and self-employment accounted for most of the work. Mobility was important in giving access to seasonal agricultural employment. New Travellers with good health, portable skills, transport, bank accounts, and mobile phones were most likely to be in paid work; lone parents were least likely to have access to paid employment. Most of the Travellers had claimed income support at some time, although difficulties in claiming and obtaining benefits were commonly experienced. The investigators identified as key priorities for policy: improving access to employment programmes and making these sensitive to the particular needs of New Travellers, more flexible benefits which can support temporary and seasonal employment, and access to stable and secure sites.

11.3 Educational factors

Research studies report high levels of absence (59 per cent) from primary schools and non-attendance at secondary school (80 per cent) (Bancroft *et al.,* 1996). Low educational attainment levels are consistently found (Liégeois, 1998). A government report found that Gypsy Traveller pupils were the group most at risk in the education system. Although some make a reasonably promising start in primary school, by the time they reach secondary level their generally low attainment is a matter of serious concern (OFSTED, 1999). However, the only area where Morris and Clements (2001) suggest there is a dearth of research evidence concerns the extent of unmet (or over-met) need by Traveller children in respect of Special Educational Needs (SEN) assistance.

A more robust evidence base has recently become available on the position of Gypsy Travellers in schools as a result of the inclusion of categories for Gypsy/Roma and 'Travellers of Irish heritage' in the Pupil Level Annual School Censuses (PLASC) of 2003 and 2004. The most recent collection for England (National Statistics and Department for Education and Skills, 2004) provide information on 3,920 Travellers of Irish heritage (2,900 in maintained primary schools and 1,020 in secondary schools) and 6,410 Gypsies/Roma (4,660 in primary and 1,750 in secondary schools).

In maintained primary and secondary schools in England, 64.0 per cent and 52.6 per cent of pupils who were Travellers of Irish heritage were known to be eligible for free school meals and 54.8 per cent and 52.5 per cent, respectively, of Gypsy/Roma pupils. Only Bangladeshis in secondary schools had a higher proportion and the percentages are substantially higher than the 15.9 per cent and 12.2 per cent, respectively, among white pupils. Only small proportions of these groups had a first language known or believed to be other than English: 1.5 per cent and 1.7 per cent, respectively, among Travellers of Irish heritage but 12.1 per cent and 16.8 per cent, respectively, amongst Gypsy/Roma. The percentage of the school population in maintained primary, secondary and special schools who were permanently excluded was 0.51 per cent in Travellers of Irish heritage (the highest of any ethnic group) and 0.36 per cent amongst Gypsies/Roma (the second highest), substantially above the 0.12 per cent of white pupils. Among pupils in maintained primary schools 53.9 per cent of Travellers of Irish heritage and 50.1 per cent of Gypsy/Roma were Special Educational Needs (SEN) pupils, proportions that were more than twice those of white, mixed, and Asian pupils. Of those in maintained secondary schools, 48.6 per cent Travellers of Irish heritage and 47.1 per cent Gypsy/Roma, were SEN pupils, three times the proportion in the white and Asian groups. These statistics show that Gypsies/Roma and Travellers of Irish heritage are the most socially excluded of any ethnic group, frequently by a wide margin.

Broadly similar findings are reported for Wales, where 279 Travellers of Irish heritage and 366 Gypsies/Roma were enumerated in the 2004 PLASC collection (National Statistics, 2004). Of Travellers of Irish heritage and Gypsies/Roma, 65.8 per cent and 54.7 per cent, respectively, were entitled to free school meals, the highest with black Africans (55.3 per cent) of all ethnic groups. Further, 39.6 per cent of Travellers of Irish heritage and 53.3 per cent of Gypsy/Roma had SEN status, substantially higher than the next group (Bangladeshis, 23.3 per cent) and the white group (19.3 per cent). Again, the statistics provide a profile for this community of substantial disadvantage.

Most policy reports identify a wide range of service issues relevant to Gypsy Travellers and their children in accessing education:

- difficulties experienced in accessing educational services when travelling and managing interrupted learning;
- poor provision of pre-school and special education;
- problems with school catchment areas and acceptance into particular schools;
- poor provision of transport for children from sites or unauthorised camps to school;
- difficulties of transition from primary to secondary school;
- the relevance of the school curriculum and the need for more flexible provision in relation to vocational and work based learning;
- the need for flexibility in the delivery of educational services, including distance learning and outreach support;
- access to computer technology for home education;
- the building of links between schools and Gypsy Traveller families;
- building awareness of Gypsy Traveller lifestyles in school policies;
- the need for monitoring of anti-bullying strategies;
- provision for lifelong learning and training through further education institutions;
- the inclusion of Gypsy Travellers as a separate ethnic group in all systematic ethnic monitoring of educational services.

II. Health and Social Care Interventions

A recent review of the literature on the health of Travellers (Doyal *et al.,* 2002) found an absence of interventions that had been rigorously evaluated. Those undertaken by health care workers associated with particular projects were only rarely well designed, measuring success through process rather than outcome measures. The investigators concluded that '…they cannot provide concrete evidence of improvements in the health status of Travellers'. Moreover, in a survey of south west health authorities, none claimed to be able to identify examples of good practice with respect to Travellers. Doyal *et al.* (2002) conclude that systematic and independent evaluations of local policy initiatives are needed and recognise the cost implications of their recommendation. In this study few examples of well documented good practice have been identified. The small number of local policy initiatives that are reported are patchy geographically and often short-term. Moreover, as reported by Doyal *et al.* (2002), there is a lack of formal evaluations of interventions, most reports being descriptive of process but lacking outcome measurement. While such studies sometimes provide insight into ways that culturally competent services can be delivered, their findings need to be treated with caution.

Examples of innovative service provision (usually only summarily reported) are numerous. They include health needs assessment studies in the Gypsy Traveller Community which have been undertaken in a few localities in Scotland and elsewhere. Culturally specific health education work with young Gypsy Travellers has also been developed, again with examples from Scotland. Collaborative health projects with the Gypsy Traveller Community are frequently cited as good practice. For example, North Staffordshire Health Authority won one of the NHS Equality Awards for best practice innovative projects that involved gaining the confidence of Traveller families through the development of a uniquely shared ownership of the problems, needs and responses (NHS, 2000). The initiative was said to provide 'an excellent model for replication nation-wide'. In addition, North Staffordshire Health Action Zone (HAZ) has sought to make access to GPs and other services much easier for Gypsies and Travellers by improving information (North Staffordshire HAZ, 2003). The Integrating and Modernising Services for Gypsies and Travellers Project, managed by the Stoke-on-Trent Citizens Advice Bureau (CAB), manages access and support information posted on notice boards and on tape at Stoke-on-Trent Travellers' sites. Experienced CAB Advisers also host an outreach advice clinic for members of the Travelling Community, including assistance and advocacy on racial discrimination and advice on benefit entitlements and help with claims. Other services have been introduced, including carers support, play services, and adult education.

These aside, the number of examples of generic interventions (e.g. hand-held patient records, specialist health visitors, mobile clinics, and the like) are few and the evidence-base for their success largely anecdotal.

The following interventions have been graded according to the strength of evidence for them. A number of schema are available, the most widely recognised being those based on the Agency for Health Care Policy and Research (AHCPR, 1992; Petrie *et al.*, 1995). The former, resulting in a grade of A, B or C (see Appendix 3), has been used.

1. Hand-held patient records

Many studies of the health of Travellers have recommended the use of hand-held patient records (Save the Children, 1983; Lawrie, 1983; Cornwell, 1984; Crout, 1987; Streetly, 1987; Pahl and Vaile, 1988; Feder, 1989; Durward, 1990; Feder *et al.,* 1993; Neligan, 1993; Acton *et al.,* 1994; and Bunce, 1996). However, there are few descriptions of pilot schemes to implement this intervention and a dearth of formal evaluations.

In Scotland, pilot schemes on hand-held records have been undertaken in Dumfries and Galloway and Forth Valley. Strong support was expressed in the Official Inquiry (Scottish Parliament, 2001) to roll out the system across Scotland to help Gypsy Travellers access services and maintain continuity of care. The Scottish Parliament's Equal Opportunities Committee recommended that resources should be made available to Health Boards to develop the use of patient hand-held records. The Scottish Executive's response to the Equal Opportunities Committee Report of 2001 (Scottish Executive, 2001b) on this matter is that the use of patient hand-held records will be considered as part of the planning necessary to meet the Scottish Health Plan commitment. Save the Children Scotland (2000) cite patient-held records as one of a few examples of good practice. The Scottish Executive's Race Equality Advisory Forum (REAF, 2003), in their Health and Social Care Action Plan, also recommend that for Gypsy Travellers the Scottish Executive Health Department give early consideration to the feasibility of developing patient-held health records throughout Scotland.

A number of authorities in England are addressing this issue. East Sussex, Brighton and Hove Health Authority recommend the development of hand-held family records. A conference exclusively on Traveller health issues, held at Wisbech, Cambridgeshire in March 1995, identified as a main issue the reluctance of some GPs to register Travellers as patients and the need for hand-held records, a recent report stating that a hand-held medical records system would be piloted with GPs in the near future (Cambridgeshire County Council, Cambridgeshire Travellers Research Group, 2002). Herefordshire Primary Care Trust (PCT) is developing patient-held records (as part of a more general service innovation) (Commission for Health Improvement [CHI], 2002).

In its National Strategy for Traveller Health, Ireland's Department of Health and Children (2002) recommended the introduction of patient and family held records for Irish Traveller families, including a pilot project to identify how a patient and family held record system would work for the Traveller Community. The Department suggests that such records might contain information on a patient's medical history, all general practice and hospital consultations, obstetric history, and details of prescribed medicines, the use of which by Travellers would be voluntary. A Working Group of Traveller organisations, members of the Traveller Health Advisory Committee, the Irish College of General Practitioners, and Public Health Nurses working with Travellers, are drafting the content and design of a durable and user friendly patient and family held record to be used by all Health Boards and the Department stated that the introduction of the new record on a nationwide basis should commence not later than June 2003.

Although there are reports of effective pilots of a system of patient held records for use by Traveller families in the UK, no evaluations of these pilot schemes have been identified. However, the strength of support for this practice across many statutory and other agencies suggests that it is an effective intervention. The National Association of Health Workers with Travellers (NAHWT) is reported to be seeking government backing to launch and promote the use of a national client-held record for Travellers (Van Cleemput, 2000). The use of patient-held records by the refugee population has been recommended (Jones and Gill, 1998). Support for patient-held records has also come from the Welsh Institute for Health and Social Care (Hart, 2002) and the principle of moving towards patient-held records was accepted at a policy forum of the Wales Labour party, with the prospect of a working party to take this forward (Labour Party Wales Policy Forum, 2001). In evidence given to the Welsh Assembly Equality of Opportunity Committee's Review of Service Provision for Gypsies and Travellers (National Assembly for Wales, 2003b), health professionals reported the successful use by Gypsy Traveller families of parent-held child health records and of the development in Wrexham of an adult health passport to record medical details.

A research review of the practical problems surrounding patient-held records and ethical arguments for and against them (Gilhooly and McGhee, 1991) concluded that 'there are no substantial practical drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical records'. Further, a pragmatic Randomised Controlled Trial (RCT) of a patient-held record used by the patient and healthcare professionals, with around 500 patients living in the environs of Swansea, found that the record was significantly helpful to patients preparing for appointments, reducing difficulties in monitoring their own progress, and helping them to feel more in control (Williams, Cheung, *et al.,* 2001). The investigators recommended that it should be made available to patients on request and used by them according to need.
(all Grade C)

2. Specialist health visitors

The use of specialist health visitors to meet the health care needs of Gypsy Travellers is one of the most frequently reported interventions. In Scotland this has in the past consisted of small numbers of staff with specialist knowledge of working with Gypsy Traveller Communities who have taken the initiative rather than Trust or Health Board planning. Save the Children (Scotland) (2000) cite this as one of a few examples of good practice. East Sussex, Brighton and Hove Health Authority (2001) have named health visitors that have a responsibility for Gypsy Traveller families, the latter comprising one health visitor with one day per week dedicated to this work. Doyal *et al.* (2002) and others cite the Bristol Traveller Health Project as one of the more substantial examples of good practice. This was established by a health visitor in 1990 (Neligan, 1993) and continues to be run by a specialist health visitor. The different initiatives of the project have included a mobile dental unit and a Well Woman service with monthly clinics for screening and health promotion as well as the treatment of chronic problems, the latter ending in the late 1990s through lack of funding (Rhodes, 1998). The success of the project is attributed to its response to Gypsy Traveller needs as they themselves see them.
(all Grade C)

3. Mobile health and dental clinics

No evaluations of the effectiveness of mobile dental and health units have been identified. However, the Department of Health has funded the setting up of a pilot scheme to provide Travelling families in Herefordshire with their own personal, GP-led mobile health service. Some £900,000 will fund Herefordshire PCT to provide the project for 3 years and it is estimated that 1,200 Travellers will register. The team will comprise a GP, a lead nurse, a practice administrator, and two health visitors. As well as a Travelling families GP surgery, a bus equipped as a mini-health centre will be used like a mobile library, regularly visiting Travelling families wherever they are based. One of the main aims is to improve access to health care as many of the Travellers in the county are reported not to be registered with GPs and some visit A&E departments in Hereford hospitals as a source of primary care. The Commission for Health Improvement's Clinical Governance Review for Herefordshire Primary Care Trust (Commission for Health Improvement, 2002) states: 'A personal medical services scheme for travelling families is an example of best practice. This much appreciated scheme was developed with considerable input from the Traveller Community. The trust should continue to develop the patient public involvement programme further and ensure that the patient's voice is heard in policy and planning of services'. The CHI felt this innovation was one of two things in their inspection '…that the rest of the NHS can learn from'.

There are few other examples. The Irish Government's Department of Health made the necessary funds available to the Eastern Health Board in the mid-1980s to set up a mobile health clinic for the Travelling Community, stating: 'The clinics are on an experimental basis and will provide a number of services but with a particular emphasis on expectant mothers and infants. If the clinic is a success in the Eastern Health Board area the concept will be extended to other areas where there are large numbers of travellers'

(Dáil Éireann, 1985). The Northern Area Health Board's mobile health service for Travellers comprises a mobile clinic providing services to more than 40 'halting sites' and roadside stops 4 days a week, including a full immunisation service and counselling service for Traveller children (Northern Area Health Board, 2002). The Bristol Traveller Project has reported the successful operation of a mobile dental unit, popular with Gypsy Traveller children, that grew from an identified need at roadside and transit sites used by Gypsy Travellers (National Assembly for Wales, 2003b).
(all Grade C)

4. Community mothers' programme

This was a specific intervention to see whether the community mothers' programme – using lay volunteer mothers to deliver a childhood development programme – could be successfully extended to the Travelling Community in Ireland (Fitzpatrick *et al.,* 1997). The Travelling Community were studied prospectively in a regional health authority in Ireland, comparisons being made with the results of a previous randomised trial of settled mothers. The participants comprised 39 Traveller and 127 settled intervention mother/ infant pairs (RCT intervention), settled community mothers, and 105 settled control pairs (RCT control). All mothers received standard support and Traveller and RCT intervention groups also received the services of a community mother.

There were some benefits to be found at the end of the study. Traveller and intervention children were exposed to more cognitive games and nursery rhymes. The diet of Traveller children surpassed that of the RCT controls in all food groups except fruit but they were less likely to begin cow's milk before 26 weeks of age. Traveller mothers' diet was better than that of RCT controls and similar to RCT intervention mothers. Traveller and RCT intervention mothers were less likely to feel tired, miserable, and want to stay indoors than RCT control mothers. However, there were significant differences between the groups in immunisation uptake, with Traveller children doing least well.
(Grade B)

There are examples of successful community mothers' programmes in the Traveller Community, including that in the Northern Area Health Board, where nursing staff call to 'halting sites' to provide a shared child rearing programme (Northern Area Health Board, 2002). A number of trained family workers from the Travelling Community provide an essential service in developing relationships with Travelling Communities and ensuring that services are accessible and acceptable to Travellers. The Mid Western Health Board (2002) has recommended the expansion of the community mothers' programme for Travellers to address such needs as more dedicated and outreach maternity services, the promotion of breast feeding amongst Traveller mothers, and provision of antenatal support/outreach antenatal classes.

5. Community health workers recruited from the Traveller Community

The best example of this practice can be found in Ireland. A notable feature of Ireland's first Primary Health Care for Travellers Project, established as a pilot initiative in 1994 in Dublin as a joint partnership agreement between the Eastern Health Board and Pavee Point, is the recruitment and training of community health workers drawn from the Traveller Community. Similar projects have been set up and operated successfully in many other areas and have been reported as bringing substantial benefits to the Traveller Communities where they are located: 'Working with public health nurses, dentists, dental nurses, and other health professionals, the Community Health Workers have been responsible for remarkable improvements in levels of access to child health services including immunisation, women's health services, family planning and oral/dental health services' (Department of Health and Children, 2002).

The original project included a training course which concentrated on skills development, capacity building and empowerment of Travellers. As a result 16 Traveller women have received accredited training as

community health workers and are currently employed on the project. The Department of Health and Children's Strategy concluded that '…it is imperative that the replication strategy is supported to facilitate the development of these projects and maintain standards in Community Health Worker training'. The action it proposed was that Primary Health Care for Travellers Projects be developed in conjunction with Traveller organisations in all Health Board areas where there is a significant Traveller population by the end of 2005, each Project to have a community health worker employed by the Traveller organisation and be periodically evaluated.
(all Grade C)

6. Outreach immunisation programmes

There is some evidence that outreach programmes by community health workers are effective at increasing immunisation rates in the Gypsy Traveller Community, especially when such workers are drawn from the Gypsy Traveller Community.

Moreton (1992) reported on the uptake of a new immunisation (Hib) in the early 1990s that offers protection against the commonest cause of bacterial meningitis in the under fives in Oxfordshire, where the development and implementation of health education programmes achieved a 90 per cent take-up in the first year, even among Traveller Gypsies. Nelson (2003) reports immunisation uptake rates in the Ferryhill area of County Durham of around 90 per cent following health visitor health promotion work in the Gypsy Traveller Community (although the mainstream media reports on whooping cough and MMR vaccines had a major influence on Travellers' views of immunisation).

The effectiveness of a health education intervention to increase the vaccination coverage of the Gypsy child population in the Cartuja and Almanjayar areas of Spain, using community health workers (n=4) belonging to the Gypsy Community, has been reported by Camara *et al.* (1994). The patients comprised the whole of the Gypsy population aged less than 14 years (1,073 children). The intervention comprised health education for mothers and carers by means of home visits carried out by the health workers who had been trained for this purpose by a School of Public Health. Vaccination coverage in September 1988 was 42.2 per cent, at the start of the intervention in March 1990 it was 46.2 per cent, and at the end of the programme in March 1991 it was 68.2 per cent. While the health centre had increased vaccination coverage by 4 per cent in 18 months, the intervention increased it by 22.2 per cent in 12 months.
(Grade B)

A similar improvement is reported by Garcia *et al.* (2003) amongst 463 children younger than 15 years of age in a marginal Gypsy Community in Alicante. The intervention comprised an educational programme and health care actions by means of home visits performed by Gypsy educators specially trained for such intervention. Before the intervention the vaccine coverage was 41 per cent for polio, diphtheria and tetanus, 24 per cent for pertussis, and 36 per cent for measles, mumps and rubella. After the intervention the overall coverage increased to 53 per cent, 45 per cent, and 54 per cent, respectively.
(Grade B)

7. Peer conducted health education by members of the Traveller Community to reduce smoking in children/young people

Only one intervention has been found that seeks to raise awareness on smoking issues and to reduce teenage smoking in the Traveller Community. Szilagyi (2002) reports on peer education with respect to smoking issues in Hungarian communities of disadvantaged Roma children. Eight secondary school pupils aged 14 to 18 (6 of whom were Roma) were selected to constitute the peer educator group, members of which participated in a three-day training programme. A total of 174 students (55.5 per cent boys), 56 from intervention classes and 118 from control classes, were involved in the study. Two types of

interventions were performed: school-based interventions consisting of six lessons given by peer educators on various topics; a one-day 'School No Smoking Day' intervention to inform children on the effects of smoking and also to show a healthy alternative to smoking. The baseline survey showed that 34.5 per cent of children were regular smokers, the interventions resulting in a decrease in smoking rates to 27.1 per cent. When asked, 37.5 per cent of the students said they knew of a peer who had decided to give up smoking as a result of the programme. Furthermore 57.4 per cent of pupils said that they now felt second-hand smoke as more disturbing than previously. An awareness of the relationships between smoking and different diseases had also increased. There was also a notable change in the children's opinion on who should be viewed as the more trustworthy mediators of information related to smoking. While peer educators had been ranked fifth in the order of trustworthiness in the baseline survey, they had advanced to third place in the rank order by the end of the programme (no change being found in the order of the control classes). Finally, the satisfaction of participants with the activity of peer educators was shown in the 86 per cent of the students in the intervention classes who reported at the end of the programme that they would like to participate in such programmes as peer educators. The investigator recommends creating a peer education network in schools where Gypsy children are in the majority.
(Grade B)

Peer education is a traditionally used method in health education in Hungary. Peer educator groups were first organised in 1989 to disseminate health related information on HIV/AIDS, and school-based education on tobacco issues was started in1993. However, Szilagyi's demonstration programme was the first to use minority group secondary school students as peer educators to reach Roma communities in Hungary. Other studies (Mellanby *et al.,* 2000; Perry *et al.,* 2003) have shown that the peer teaching method is effective in promoting healthy behaviours in school settings.

8. Structured local partnerships: Gypsy Traveller representation agencies and liaison posts

Given the large number of factors that impact on health, including racism, site evictions, and environmental conditions, there is evidence of benefit to the Gypsy Traveller Community of both representative organisations and liaison posts (European Commission against Racism and Intolerance, 2001). In the County of Cambridgeshire, for example, the East Anglian Gypsy Council (EAGC) was formed to represent this group and by 2001 had a membership of around 700 families and represents the interests of many more. In 1988 Peterborough City Council formally established the post of Gypsy Traveller Liaison Officer. The post involves liaising with the full range of public and voluntary sector organisations on behalf of members of the local Gypsy and Traveller population. The scope of the Liaison Officer's work includes provision of advice to Gypsies and Travellers regarding employment, education, housing, planning and environmental issues, health, policing, and the courts. The Liaison Officer acts as an adviser to and representative of individual Gypsy Travellers and their families and also advises the public authorities directly on policy and practice. Although a member of a local authority team, the postholder is an established resident on a local Traveller site and remains firmly a member of and a leader within the Gypsy Traveller Community, thus enabling representation of the interests of this community to be effective and of high credibility.

The European Commission against Racism and Intolerance (ECRI) (2001) found this form of structured local partnership, rooted in the community development approach, to be a model of good practice within the UK for managing the relations between the civic authorities and the Gypsy Traveller Community. ECRI (2001) cites two further examples of good practice in combating racism and intolerance against Roma/Gypsies, both in Non Governmental Organisations (NGOs). Opera Nomadi, based in Rome, has long experience of acting as a mediator between the state agencies and Roma Communities to protect their rights and to promote interventions by public authorities to improve conditions. Pavee Point Traveller Centre, based in Dublin, provides a mediation service set up to resolve disputes between Travellers and

the general population. It brings together the various stakeholders, seeks to develop innovative approaches, and provides educational and training workshops.
(all Grade C)

9. Development of health promotion materials/resources for the Gypsy Traveller population

Although there is a paucity of evaluative studies, a number of reports have highlighted good practice. Several workers have commented on the limited value of much current health promotion literature for the Gypsy Traveller population. Barriers include poor reading skills, materials that are too wordy or too complicated for the needs of Gypsy Travellers (Nelson, 2003), the potential for diagrammatic information to be misunderstood (Rose, 1993), and the lack of appropriate positive images of Traveller culture, including pictures of people living in caravans to which members of the community can relate (Davis, 1999; Nelson, 2003).

A collaborative project in County Durham between a health visitor and the Gypsy Traveller Community resulted in the production of *Be Happy, Be Healthy* (Salkeld, 2002), a 16-page picture board book promoting the health of children and adults, the recipient of the Association of Healthcare Communicators (AHC)'s Communicating Health Award in the inequalities and public health category and publicised by the Health Development Agency. The specific issues covered by the book were dental health, poor uptake of child health surveillance and immunisation opportunities, home safety, diet, the limited opportunities for children to develop gross and fine motor skills, and the depression and isolation experienced by some mothers. The key components of success were: the involvement and support of Gypsy Traveller families themselves, including the creation of a positive and strong relationship with families during the production of the book; building on the skills, knowledge and expertise of families and taking into account their perceptions of health, disease, and health care needs; accessibility regardless of families' literacy skills; advice from the local education authority on the words in the book; and dissemination which included an audio tape and provision of cassette recorders.

A similar approach has been used in Kingston upon Hull and East Riding, where the Gypsy and Traveller Participation Project has brought together members of the community and service providers to improve the health and quality of life of members of the community (Regan, 2002). This has included a 'Whole System Event', developing a working relationship with the Gypsy Traveller Community, developing the confidence of the community to actively engage in local democratic processes, enabling the community to identify their own needs and solutions and to improve their quality of life, a photo-documentary research project to gather community perceptions of their history, culture, and current conditions, and appointment of a community apprentice. Again, a link has been established between the impact of the project and the role of the Gypsy Traveller Community as a driver of activity. The North Staffordshire Inter-Agency Group on Gypsies and Travellers (recipient of one of the 2000 NHS Equality Awards) similarly utilised a model based on confidence-building with the Gypsy Traveller Community and a shared ownership of the problems, needs and responses (North Staffordshire Gypsy and Traveller Project Advisory Group, 2004).
(all Grade C)

10. Play bus visits and other initiatives

A number of health authorities/PCTs have used play bus visits to cater for the health and other needs of Gypsy Traveller children. In Brighton, for example, a nursery nurse and a health visitor go with education staff to visit up to three Brighton and Hove sites with the play bus once a week (although this is considered to be insufficient). Although they spend less than an hour at each site, there may be up to 20-30 children and the play bus has proved to be a way of building up trust with the community. In Hailsham a play bus (funded by Sure Start) makes 1-4 visits per month. In Ferryhilll, County Durham, a Sure Start van visits a Gypsy Traveller site once a week, offering play facilities and childcare for the children. This is seen as important as Gypsy Traveller children are reported to have few opportunities to develop fine motor skills. A different approach was adopted by Sure Start in partnership with the West Midlands Consortium for the Education of Traveller Children: the first purpose-built play area on a Travellers' site (for Traveller children in Ketley, Telford). In addition Traveller Education Services operate in about 130 Local Authorities in England and have developed good practice models. In Norfolk, for example, the Traveller Education Service has worked with parents to demonstrate the importance of pre-school activity including "play" as a medium for learning. Traveller parents are consulted and involved in the provision.
(all Grade C)

11. Coronary heart disease and Travellers: redressing the balance

This project has been included as it represents a specific type of intervention that has been conducted in Wales, funded by the National Assembly for Wales' Inequalities in Health Fund (which is supporting, in total, 62 projects at a cost of £5 million in 2004-2005), and initially planned to run for three years from January 2002 (now extended for a further two years to facilitate a planned merger into mainstream funding based on robust evidence). The project's staff include two full-time workers: a health worker and a researcher. It was set up in recognition of the significantly worse health profile of Travellers compared with the settled population, including poor access to care, lack of continuity of care, inappropriate use of health services, poor general health, low immunisation rates, low screening rates, and less preventive care. The aims of the project, located in Wrexham, are to improve appropriate access to health care services, to describe the coronary heart status of the Travellers, and to evaluate the impact of the project. Components of the work include a mobile health unit on site to provide a private and safe environment for people to discuss their health concerns, preventive work undertaken by a health visitor, an assessment of the CHD status of the Travellers, a qualitative evaluation of the initiative, and in-depth interviews with the community in order to gain insight into their culture, lifestyle, and health beliefs. More than 95 per cent of Travellers involved with the project are now registered with a GP and to date, 130 adults and 129 children had been reached by the project. The Chief Medical Officer for Wales (2004) has reported that the Travellers have now been provided with risk screening and advice in a form that is accessible and acceptable. The project is the first in Wales to undertake an in-depth study of coronary health in the Gypsy Traveller community and may serve as a model approach nationally in this much neglected area.
(**Grade C)**

Culturally competent components of good practice in health promotion, preventive care and treatment interventions

Although there is a lack of robust evaluations of health and health care interventions for Gypsy Travellers, there is sufficient evidence from reported examples of good practice and service reviews to be able to identify culturally competent components of such programmes that contribute to successful implementation.

1. Direct involvement of Gypsy Travellers in decisions about their health and health care and their patterns of access to services and the incorporation of their views into the policy development process to avoid the perception that Gypsy Travellers are the "object" of health and health care initiatives.
2. Sensitivity to the cultural diversity within the Traveller Community which may include Irish Travellers, Scottish Gypsies/Travellers, English Gypsies, Romanies, Welsh Gypsies, New (Age) Travellers, and fairground, circus and waterway communities. Health beliefs, needs, and desires may vary within and across these communities.
3. Awareness of issues of trust within the Gypsy Traveller Community where experience of sustained discrimination and prejudice in the wider society may require strategies based on confidence building, advocacy, and continuity of care at the level of the individual team. Many local projects emphasise the need for trust to be established and for partnership arrangements with the Gypsy Traveller Community.
4. Cultural awareness training for service providers in contact with Gypsy Travellers.
5. Dedicated and outreach health services aimed at Travellers. Many of the health-related issues affecting the Gypsy Traveller population – poor access to antenatal and postnatal care, low uptake rates of childhood immunisations, child health screening, developmental assessments, and dental health care, and frequently low levels of registration with general practitioners – arise from the mobility of the community and the threat of eviction. Service provision should be responsive to the needs of a mobile population.
6. The employment of trained workers recruited from the Gypsy Traveller community to ensure that services are accessible and acceptable to Gypsy Travellers. Some of the most successful health care interventions have recruited workers from the Gypsy Traveller Community or closely collaborated with the community in developing services.

III Recommendations

Based on this review of the literature on the health beliefs, health status, and use of services in the Gypsy Traveller population, and of appropriate health care interventions, a number of recommendations for policy and practice are put forward.

1. Ethnic monitoring should be mainstreamed – including primary care population profiling and hospital episode statistics – using categorisation that includes at least 'Gypsy/Roma' and 'Travellers of Irish Heritage'.
2. Hand-held records for Gypsy Travellers should be mainstreamed.
3. There is an urgent need for a health and lifestyle survey of minority ethnic groups – with enhanced sample for Gypsy Travellers – to establish baseline rates of health status, health-related behaviours, use of services, etc.
4. Gypsy Traveller health should be embedded in mainstream service planning (health equity audits, provision, etc.).
5. The small scale, short-term, and champion-dependent nature of many projects needs to be addressed through funding and links to/integration with mainstream provision.
6. Specific projects/initiatives require robust independent evaluations that address outcomes as well as process.
7. There is a need to build on the evidence that use of trained workers from the Gypsy Traveller community works, including peer-conducted health education.
8. Some effective interventions – the 'community mothers' programme', outreach programmes for immunisation, etc. – offer examples of potentially replicable good practice.
9. Particular attention needs to be accorded to environmental factors: the poor location of sites, low levels of provision of services on sites (especially transit sites), poor site management and facilities, differences in pitch fees, and issues of affordability which are all regarded as detrimental to the health of Gypsy Travellers.

Appendix 1: A note on terminology

A wide range of terminology is used to describe Gypsy Travellers. 'Gypsy Traveller' is perhaps the salient generic term and is used in this report. Some investigators use the term 'Travelling People'. Where findings have been cited from research studies the terms used by the investigators have been retained to avoid confusion and misinterpretation.

Appendix 2: Literature search strategies

Some 40 databases were searched using a variety of search strategies, including hierarchical search algorithms, Boolean searches, use of database thesauruses (MESH, Emtree thesaurus), and keyword searches: Contents First; Electronic Collections Online, Index to Theses; PapersFirst; Proceedings; UnCover; Web of Sciences Proceedings; Zetoc; ArticleFirst; Best Evidence; CHID; Cochrane Library Databases (CDSR, DARE, Cochrane Controlled Trials Register; NHS Economic Evaluation Database; Health Technology Assessment Database); EMBASE; HealthPromis; HMIC; HSTAT; Medline; PubMed; National Electronic Library for Health; PsycInfo; Science Citation Index; ASSIAnet; EconLit; Social Science Citation Index; Social Services Abstracts; Sociological Abstracts; British Nursing Index; CINAHL; ENB Health Care Database; CRER; National Research Register; Regard; and HARPWeb (Health for asylum seekers and refugees portal).

The review was undertaken between February 2003 and March 2004. In a small number of cases, updates have been provided prior to publication.

Appendix 3: Evidence grading of interventions

Levels of evidence and grading of recommendations

Level	Type of evidence
Ia	Evidence obtained from meta-analysis of randomised controlled trials
Ib	Evidence obtained from at least one randomised controlled trial
IIa	Evidence obtained from at least one well designed controlled study without randomisation
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study
III	Evidence obtained from well designed non-experimental descriptive studies such as comparative studies, correlation studies, and case controlled studies
IV	Evidence obtained from expert committee reports of opinions and/or experiences of respected authorities

Grade	Type of recommendation
A (levels Ia, Ib)	Requires at least one randomised controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation
B (levels IIa, IIb, III)	Requires availability of well conducted clinical (health services) studies but no randomised clinical trials on the topic of recommendation
C (level IV)	Requires evidence from expert committee reports or opinions and/or clinical (health services) experience of respected authorities. Indicates absence of directly applicable studies of good quality.

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