



All Ireland Traveller Health Study Our Geels

Summary of Findings

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September 2010



All Ireland Traveller Health Study Team

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Region	Traveller Org/Project	Research Coordinators	Peer Researchers
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Note:

The previous census of Travellers took place in November 1986 (Barry and Daly, 1988) and the component Traveller vital statistics were calculated for the calendar year following the census (Barry *et al.*, 1989). As appropriate this study is referred to in this report as the 1986 or 1987 study.

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Foreword

by Minister Mary Harney T.D.

I am very pleased to welcome the findings of the All Ireland Traveller Health Study which marks the culmination of a long journey which began in 1986 with the first Travellers' Health Status Study. In 2001 the Health Strategy, *Quality and Fairness: A Health System for You*, specifically identified Travellers as a group at significant disadvantage in health status, and remarked on the findings of the Travellers' Health Status Study which had shown that life expectancy at birth in 1987 for Traveller men was 9.9 years less than for settled men and 11.9 years less for Traveller women than for settled women. Shortly thereafter, the Traveller Health Advisory Committee produced *"Traveller Health – A National Strategy 2002-2005"* which was published in February 2002 with the aim of improving the health status of Travellers. The All Ireland Traveller Health Study, which I launched in 2007, was one of the recommendations of the 2002 Traveller Health Strategy. It has taken three years to complete this huge undertaking which has been jointly funded by the Department of Health and Children, the Department of Health, Social Services and Public Safety, Northern Ireland and the HSE.



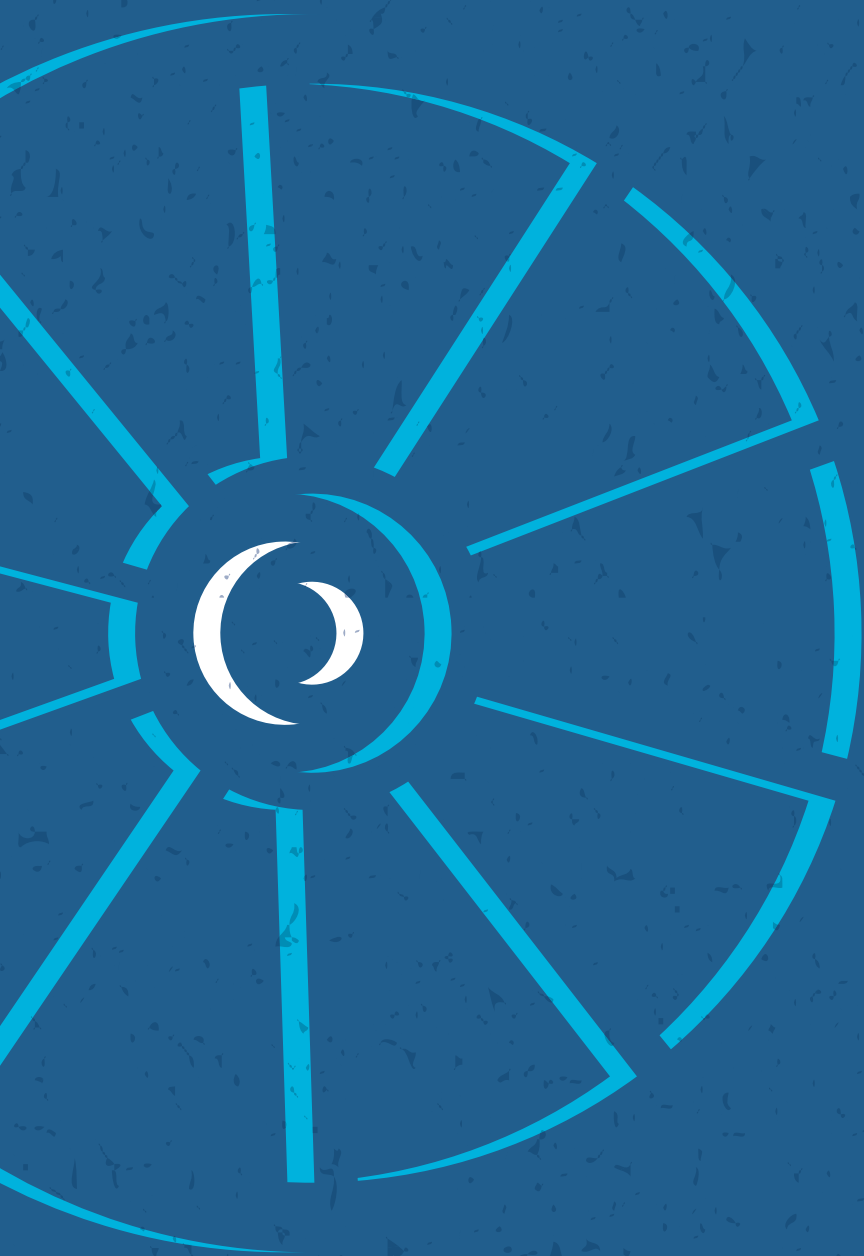
The involvement of Travellers themselves in the delivery of health services is considered crucial in bridging the gap between the Traveller Community and the health services. Such an approach was also adopted in this research. Regrettably, in spite of significant investment in the area of Traveller health, the findings contained in this report do not show the improvements hoped for in life expectancy in the Traveller community, particularly among Traveller men. The Study has identified ongoing problems but it also provides the evidence base to help develop solutions.

I would like to note my appreciation of the contribution made to this Study by Professor Kelleher and the UCD Study Team, the members of the Technical Steering Group, the Health Service Executive and to all the Stakeholders who engaged so positively with the Study. Particular mention must also be made to the members of the Travelling community who, by their participation in the Study, have made these findings possible. As the Study has been carried out on behalf of Travellers, for and by Travellers, the results are more robust and will be all the more useful to policy makers and service providers as a result.

Mary Harney T.D.

Minister for Health and Children

The All Ireland Traveller Health Study



Introduction

The All Ireland Traveller Health Study (AITHS) is a very large-scale and ambitious undertaking and represents a major commitment by the sponsoring stakeholders to Traveller Health. The census of families North and South marks the completion of the first stage of this exercise. Following on from this report is the vital statistics report and the consultative process with both Travellers and Service Providers, employing both qualitative and quantitative interview methodologies. The birth cohort study is still in follow-up stage, and is a major prospective issue for the future. This final report assimilates findings from all stages of the project together with recommendations.

This is the first descriptive report based on the census survey and has 3 important characteristics. First, it is comprehensive in that every single identifiable Traveller family on the island of Ireland was approached as a potential respondent in this study following a comprehensive scoping and mapping exercise.

Second, it achieved a very high response rate for a survey of this kind, at 80% so its findings should be representative. The cooperation of the Travellers themselves was in fact not alone critical to obtaining usable data but demonstrated the high level of trust and commitment in the process, recognition by respondents themselves that data were needed to inform future policy.

Third, the innovative methodology afforded a very detailed interview not otherwise achievable. The challenge in devising a research instrument for this study was to capture the complex whole that is the modern Traveller community, both the positive and negative aspects, and at the same time compare and contrast that experience with the general population. By developing an oral-visual electronic questionnaire, delivered by trained and committed Peer Researchers, we were able to transcend problems of literacy, collect in-depth data across a range of health topics, contextualised by state-of-the-art literature on health determinants. Unusually perhaps for a survey, we were able to empower the Peer Researchers with skills and competencies transferable to other future situations.

What are the important findings of this report? We capture the complexity and heterogeneity of the modern Traveller community in Ireland as well as its commonalities currently and its links with the past. There is evidence of disadvantage, not a universal blanket picture but certainly a poorer health profile than the general population. In the 22 years since the last study the community has enlarged considerably but still has relatively modest numbers of people aged 50 years and upwards. We examine in more detail in the vital statistics report both the exact numbers in the current population and the patterns of mortality contributing to that population profile.

Background to the All Ireland Traveller Health Study

Overview

The All Ireland Traveller Health Study (AITHS) is the first study of Traveller health status and health needs that involves all Travellers living on the island of Ireland, North and South. It arose from a recommendation in the Department of Health and Children's National Traveller Health Strategy - 2002-2005 (Department of Health and Children, 2002): *'A Traveller Needs Assessment and Health Status Study to be carried out to develop and extend the indicators collected in the last survey of Travellers' Health Status (HRB, 1987) and to inform appropriate actions in the area of Travellers' Health.'*

Following the publication of the National Traveller Health Strategy, the Institute of Public Health (IPH) was commissioned by the Department of Health and Children in the Republic of Ireland (ROI), and supported by Pavee Point, a national Traveller Organisation in ROI, to undertake a comprehensive consultation process throughout Ireland to ascertain the views of Travellers, Traveller organisations, the HSE and health personnel in relation to the scope and conduct of the AITHS. This consultation involved over 600 people throughout the regions and was completed in December 2003 with a national conference (McMahon, 2003).

The IPH then submitted a report to the Department of Health and Children, which was developed into a scoping document for an All Ireland Traveller Health Study (AITHS) and was put out to tender. The AITHS is jointly funded by the Department of Health and Children and the Department of Health, Social Services and Public Safety (NI), with fieldwork funding support by the HSE and FAS.

In June 2007 the School of Public Health and Population Science, University College Dublin, was awarded the contract for the AITHS. The study team worked in collaboration with the HSE and Travellers and Traveller organisations throughout the island of Ireland to conduct this research.

Launch of Study

The All Ireland Traveller Health Study was launched formally by the Minister for Health, Mary Harney T.D on 10th July, 2007 and was attended by statutory and voluntary Traveller organisations, from throughout the island of Ireland. It was by then 20 years since Traveller health had been last examined in ROI by the Health Research Board (Barry and Daly, 1988; Barry *et al.*, 1989). Those findings highlighted that Travellers of all ages have much higher mortality rates than the general population, with differentials in life expectancy averaging 11 years less than the general population.

Minister Harney stated at the launch in 2007:

'...Traveller Health is a priority area and considerable work has been undertaken, in consultation with the interest groups, in commissioning this study. The purpose of the Study is to examine the health status of Travellers, to assess the impact of the health services currently being provided and to identify the factors which influence mortality and health status. It will provide a framework for policy development and practice in relation to Travellers.'

Study Aims and Principles

Study Aims

- To count the number of Travellers living on the island of Ireland
- To document fertility rates, the number of births (prospectively) and deaths (retrospectively) of Travellers over a period of one year on the island of Ireland
- To follow a birth cohort of Traveller infants over a period of 1 year prospectively documenting outcomes, and uptake of services including vaccinations
- To document the health status of Travellers living on the island of Ireland
- To determine the factors influencing the health status of Travellers and their access to social and health services currently available/utilised by Travellers on the island of Ireland
- To document qualitatively the attitudes/perceptions of Irish Travellers to health services

Study Principles

During the consultation process for the AITHS a number of principles were proposed that were to guide all stages of the study. These were endorsed by the study team tender to form the rationale and basis for the study:

- Key local, regional and national Traveller policies, strategies and programmes.
- A holistic model of health and a broad view of the factors that affect and impact on Traveller health. These factors include education, accommodation, the experience of racism and discrimination, health and social services and lifestyles.
- Principles of equality, human rights, social inclusion, anti-racist, anti-sexist, anti-discriminatory and anti-poverty values.
- Respect for Traveller values, beliefs and perceptions as well as other parts of Traveller culture including nomadism.
- Training and resourcing to ensure that Travellers and Traveller organisations build their research capacity to participate fully in all stages of the study.
- Support to ensure participation of relevant health and social service providers in all relevant stages of the study.
- Confidentiality for all participants, with proper procedures that adhere to data protection legislation and established frameworks for research ethics.
- Appropriate qualitative and quantitative methods to collect, analyse and interpret data.
- Linkages to ongoing international research with ethnic minorities.

Rationale for the Study

Process

The study accordingly adopted a holistic approach to health, using a social-determinants model that acknowledges the broader impact of social, economic, environmental and political policy on health (Figure 1) (Dahlgren and Whitehead, 1991). This strategy is in keeping with public policy on health in the Republic of Ireland dating back to 1986 when *Health: the Wider Dimensions* (Department of Health, 1986) was published. Successive strategies in the 2 decades since then for health promotion, disease prevention and provision of care have emphasised the importance of contextualising health experiences of groups and individuals and facilitating health choices. This led to the adoption in *Quality and Fairness, a Health System for You* (Department of Health and Children, 2001) of a focus on social inclusion, at policy and delivery level. The Traveller community presents a particular challenge, exemplifying as it does an identifiable group in Irish society with complex health needs and service delivery challenges.

The international literature on health inequalities increasingly acknowledges the need to take account both of material factors such as access to education, housing and other amenities and so called psychosocial factors that can work either positively or negatively at the level of individuals or groups, such as social support, networks or engagement (Mackenbach *et al.*, 2008; Berkman and Kawachi, 2000; National Economic and Social Forum, 2003). Successful health choices, whether in lifestyle or access to care, are contingent on empowerment, a fundamental principle of the *Ottawa Charter for Health Promotion* (WHO, 1986). It is increasingly clear also that a life-course perspective is essential to the understanding of how groups or individuals maintain wellness, or conversely, develop ultimately disease-specific outcomes.

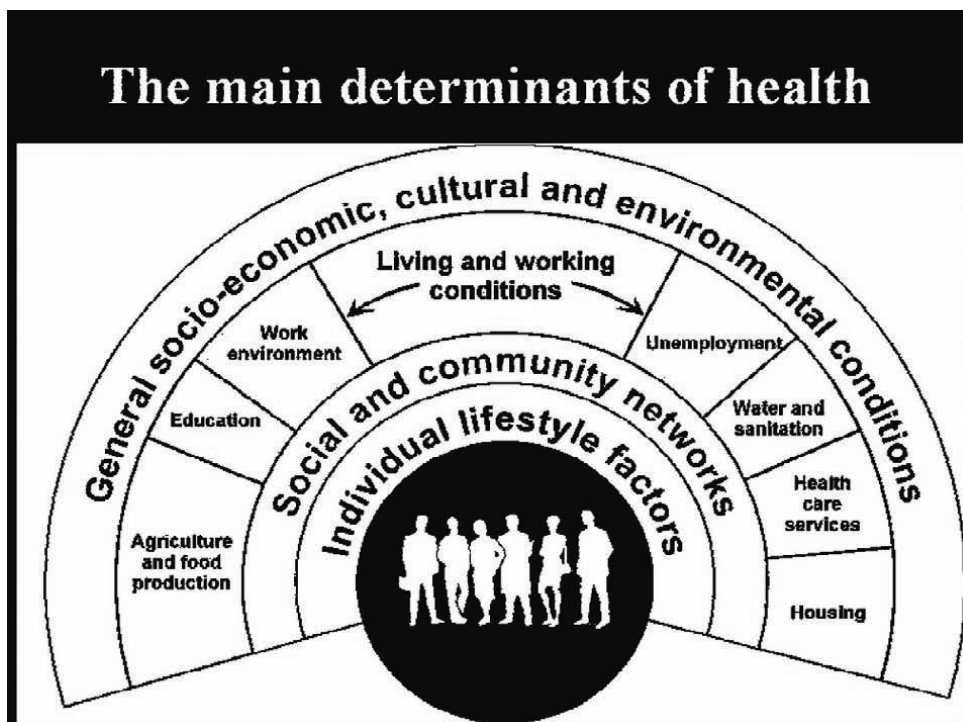
In 2007 the findings of the 7-year Health Research Board (HRB) of Ireland-funded Unit for Health Status and Health Gain were published (Kelleher, 2007). The outcome of this work programme corroborated that of others in Ireland, including the Institute of Public Health (Balanda and Wilde, 2001), that there is significant health inequality in Ireland, whether measured across social groups or in pockets or areas of disadvantage. Health is strongly socially patterned in Ireland as elsewhere and health policy requires cross-sectoral initiatives led by, but not confined to, the formal health sector (Middleton, 2001).

Approach

As with models of health inequalities and disadvantage generally, the burden of health problems experienced by Travellers is arguably strongly attributable to social conditions and educational and cultural opportunity and engagement (Quirke, 2006). The study approach also acknowledges the considerable influence that psychosocial factors potentially of specific relevance to Travellers, such as discrimination, can have on health outcomes (Krieger *et al.*, 2005). Health policies overly dominated by disease-focused and reductionist solutions that operate at the level of the individual without a wider appreciation of social determinants are unlikely to be successful (Bradley and Corwyn, 2002; Marmot *et al.*, 2008). The key health issues for Travellers identified during the consultation process were as follows:

- Environment and poor living conditions.
- Issues related to equality of access to, participation in, and outcome of service provision.
- Right of Travellers to appropriate access to services based on culture and way of life.
- Lifestyle issues.
- Lack of culturally appropriate provision.
- Lack of data on Traveller health and health needs.
- Lack of recognition of Traveller culture and identity.
- Individual and institutional level racism.
- Social exclusion.

Figure 1: Social Determinants Approach



Source: Dahlgren and Whitehead, 1991

Irish Travellers

Irish Travellers are a small indigenous minority group that has been part of Irish society for centuries. They have a value system, language, customs and traditions, which make them an identifiable group both to themselves and to others. Their distinctive lifestyle and culture, based on a nomadic tradition, sets them apart from the general population.

The Equal Status Act (Government of Ireland, 2002) defined the Traveller Community as follows: *'Traveller community means the community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions, including historically, a nomadic way of life on the island of Ireland.'*

This is the same definition as the Race Relations Order in Northern Ireland (UK Parliament, 1997).

Traveller separateness, partly by choice, enables them to retain their identity as an ethnic group, often in the face of opposition and pressure to conform to general societal norms (Ní Shuinear, 1994). Their experience of low social status and exclusion, which can prevent them from participating as equals in society, is often aggravated by hostility and misconceptions of people towards them (Helleiner, 2000). Yet there are many positive aspects to Traveller life, not generally appreciated by the wider population. Some of these characteristics are in keeping with the so-called social capital literature, which advocates the positive health benefits of social supports and networks, family ties and kinship, community participation and cross-generational respect, all hallmarks of traditional Traveller communities (Gmelch and Gmelch, 1976).

The challenge in devising a research instrument for this study was to capture the complex whole that is the modern Traveller community, both the positive and negative aspects, and to compare and contrast that experience with the general population.

Traveller Population

According to the 2006 census (Central Statistics Office, 2007a) there were just over 22,000 Travellers living in the Republic of Ireland (Central Statistics Office, 2007b) and 1,770 in Northern Ireland (Northern Ireland Statistics and Research Agency (2002) cites 2001 Census figures for NI). It is accepted that this is a count of ascertained Travellers only (Kobayashi, 2005). It does exemplify an important demographic characteristic of the Traveller population however: the low number of Travellers in the middle and older age groups, compared with the general Irish population pyramid (Figures 2 and 3).

Figure 2: 2006 Population Pyramid by Age and Sex (Central Statistics Office, 2007a)

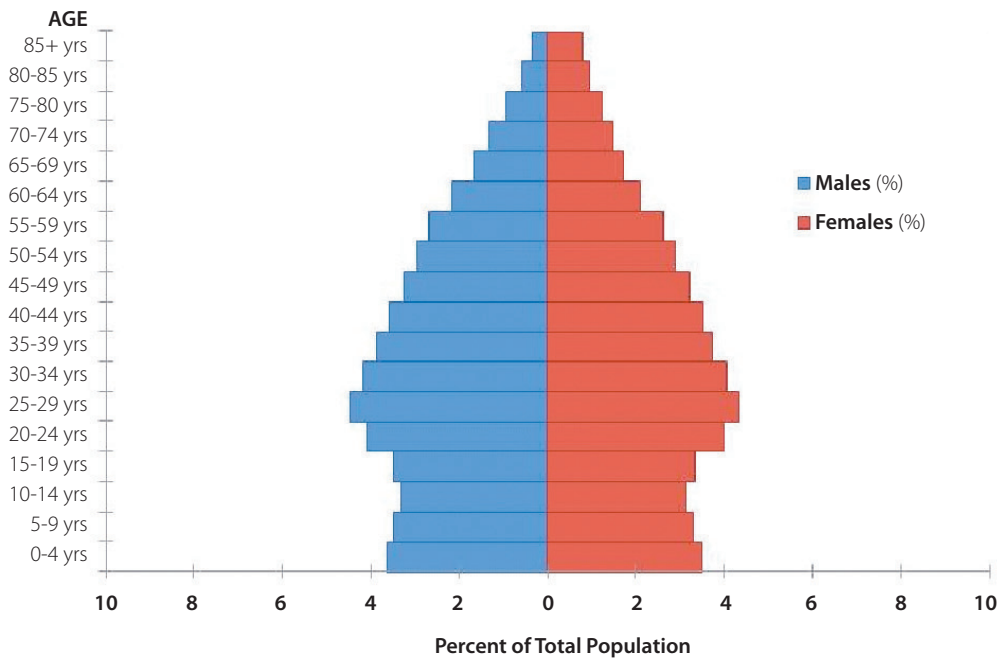
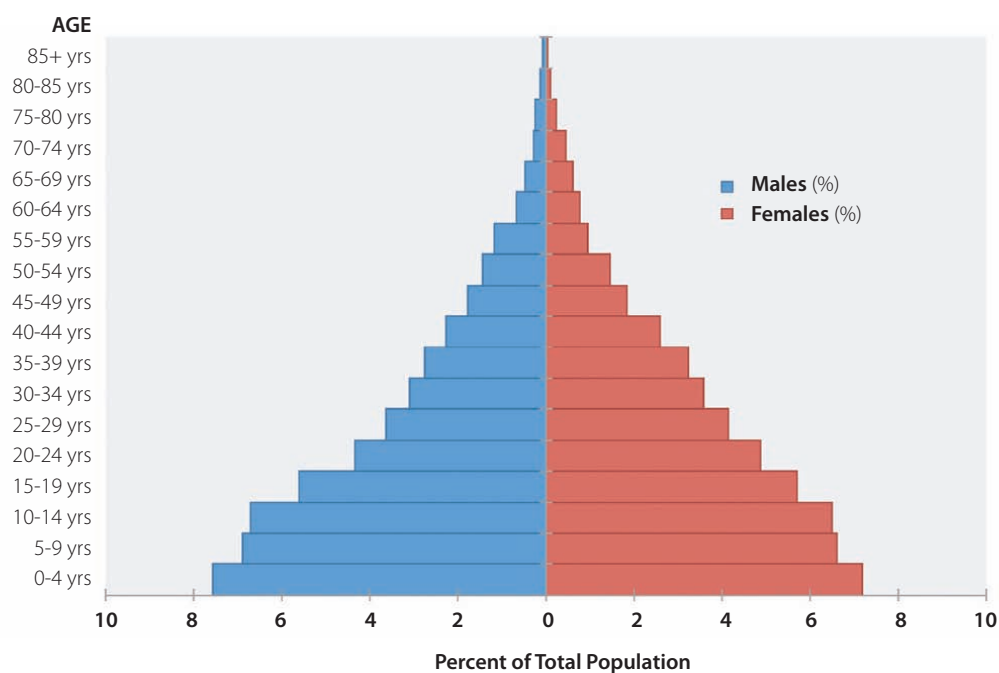


Figure 3: 2006 Traveller Population Pyramid by Age and Sex (Central Statistics Office, 2007b)



These population pyramids illustrate a very different profile for the Traveller population than the general Irish population. Whilst the general population pyramid is increasingly typical of Westernised developed countries, with relatively large numbers of middle-aged people and increasing numbers of old people, the Traveller population is more reminiscent of a pyramid of a developing country, characterised by high fertility and premature mortality. The 2006 Census also published a detailed profile of non-Irish national persons living in Ireland (Central Statistics Office, 2007c). In contrast with Travellers, these pyramids emphasised patterns classically associated with immigration, with large numbers of young people, particularly males. One challenge in the All Ireland Traveller Health Study was to undertake as accurate a census as possible with the highest level of ascertainment to update the information available from 1987 and to conduct also a vital statistics exercise that gave as accurate as possible a picture of prevailing fertility and mortality patterns.

Review of the policy contexts framing the All Ireland Traveller Health Study

The following section describes some important policy statements regarding Traveller health and well being, by the domains of accommodation and living conditions, education and literacy, income adequacy, cultural and ethnic identity, and lifestyle and health choices. A number of studies relating to the Traveller group are also commented upon, as well as policy statements that relate to overall Traveller status and wellbeing.

Accommodation and Living Conditions Provision of Traveller-Specific Accommodation

With the publication of the Task Force on the Traveller community, a number of policy developments have been undertaken in the area of Traveller accommodation since 1995, such as the establishment of Local and National Traveller Accommodation Consultative Committees (NTACC) and the Traveller Accommodation Unit in the Department of the Environment (National Traveller Accommodation Consultative Committee, 2008).

The issue of Traveller accommodation has long been contentious (MacLoughlin, 1995). The Traveller accommodation crisis has been highlighted repeatedly in Government and other reports over the years. Five-year local Traveller accommodation programmes were developed in response to the Housing (Traveller Accommodation) Act (1998), but many Local Authorities failed to adopt or implement these programmes (Coates *et al.*, 2008). The Act provides for consultation mechanisms with Travellers and Traveller organisations at national and local levels and provides local authorities with increased powers of eviction from unauthorised Traveller encampments. It established the NTACC on a statutory basis. The main reason given for non-implementation of these plans is objections by local residents to the development of Traveller sites in their area (Department of Justice, Equality and Law Reform, 2005).

As stated above, NTACC was established under the Housing (Traveller Accommodation) Act, 1998. The principal function of the Committee is to advise the Minister in relation to matters concerning accommodation for Travellers.

All Ireland Traveller Health Study

In 2004 NTACC conducted a review of the operation of the Housing (Traveller Accommodation) Act, 1998 which stated that NTACC provides a useful structure for consultation and debate on Traveller accommodation and related issues, and that the opportunity for Government Departmental officials, local authority members and officials, Traveller representatives, and other experts in Traveller issues to discuss and advise the Minister on matters regarding Traveller accommodation was significant.

NTACC has no specific powers to influence implementation of Traveller Accommodation Plans as it acts in an advisory only capacity to the Minister. The reconvened NTACC is currently examining the issue of Traveller participation in Local Traveller Accommodation Consultative Committees. It should be noted that during the review of the 1998 Act the proposal for a specific Traveller Accommodation Agency was put forward by Traveller organisations to address the weaknesses in the effectiveness of the NTACC. However, this proposal has not been adopted.

The Local Traveller Accommodation Consultative Committees (LTACC) were established under Sections 21 and 22 of the Housing (Traveller Accommodation) Act 1998. The local authorities appoint these local committees to advise on the provision and management of accommodation for Travellers. The Local Traveller Accommodation Consultative Committees are made up of members of the appointing local authority, officials of the local authority, representatives of local Travellers and Traveller bodies and one member from each relevant housing authority within the administrative county council, where the Local Traveller Accommodation Consultative Committee has been appointed by the council of a county.

The European Commission against Racism and Intolerance (2001) stated in its second report on Ireland: *'One of the main barriers to improvement of the situation as regards accommodation is reported to be the unwillingness of local authorities to provide accommodation and resistance and hostility among local communities to planned developments, often resulting in injunctions and court cases. In this respect, it has been commented that the fact that no sanctions are provided for in the Housing (Traveller Accommodation) Act against authorities who do not take measures to provide accommodation for Travellers may weaken its effectiveness.'*

In the 2008 the NTACC annual report estimated that 38% of Travellers were living in standard housing; 18% in private rented accommodation, 5% in private housing, 4% in shared housing, 6% in housing of their own resources, 8% in group housing, 1% in social housing, 13% in halting sites, and 7% on unauthorised sites (National Traveller Accommodation Consultative Committee, 2008)

In 1999 the New Policy on Accommodation for Travellers was produced (Office of the First Minister and the Deputy First Minister, 1999). In it the Department of the Environment proposed one strategic agency to deal with Traveller accommodation and agreed that that agency should be the Northern Ireland Housing Executive. The Department recommends responsibility for transient halting sites remains with the relevant District Councils. The target for accommodation in the Promoting Social Inclusion (PSI) 2002 policy is to develop appropriate permanent accommodation that meets the special needs of Travellers (Office of the First Minister and the Deputy First Minister, 2002).

In Northern Ireland 42% of Travellers live in social housing, 21% live on serviced sites, 9% live in privately rented housing, 6% live in privately owned housing, and 5% live in grouped accommodation. A further 5% live in cooperated sites, 5% in transit sites and 7% on unauthorised sites (Northern Ireland Housing Executive, 2008).

Education and Literacy

Traveller organisations have for many years expressed concerns regarding Traveller education in terms of equality of outcomes, data collection, and lack of interculturalism in the curriculum. The 1995 Task Force Report on the Travelling Community made 167 recommendations in the field of Traveller education - more than half of the total number of recommendations in the report (Report of the Task Force on the Travelling Community, 1995). This reflected the massive need for change in the provisions that existed.

Traveller educational status has been recorded repeatedly as considerably lower than that of their general peers, to an extent unmatched by any other community in Irish society. The 2006 census (Central Statistics Office, 2007c) revealed that 63.2% of Traveller children under the age of 15 had left school, compared to 13.3% nationally. Participation of Travellers in higher education was 0.8% (8 in 1,000). This compares to 30.2% (302 in a 1,000) of the national population. There are many possible explanations for this continued inequity. Advocates argue that it is difficult for Travellers to see the positive outcomes in staying on in mainstream education as many Travellers experience discrimination in trying to obtain employment (Danaher *et al.*, 2009).

There is a transgenerational issue, well established in the economics of education literature (Heckman, 1974; Harmon and Walker 1995). When parents have poor literacy, they then are not able to read or interpret the child's educational material or such literature as health instructions for taking medication. School policy must meet the challenges of attendance at school and assessment of children's skills and abilities with allocation to the appropriate class situation. All too often in the past separate or even segregated teaching of Traveller children occurred and assumptions about intellectual capability were coloured by the child's membership of the Traveller community. To address such factors the 'Report and Recommendations for a Traveller Education Strategy' was published in 2006, and proposed a 5-year strategy to examine Traveller Education including education in preschool and the early years, primary, post-primary, further and adult education and third-level education. The primary goal of the strategy is to achieve equality for Travellers in education, in terms of access, participation and outcomes (Department of Education, 2006).

The 'Report and Recommendations for a Traveller Education Strategy'

- examines existing provisions and supports for Travellers in education at all levels from preschool to higher education
- identifies objectives for Traveller education, sets out plans of action, with suggested time scales
- makes recommendations in relation to optimising or reallocating existing resources
- sets out expected outcomes
- addresses all aspects of Traveller education taking a holistic lifelong learning perspective from preschool provision to adult and continuing education.

The general recommendations of the report include a focus on the need to meaningfully engage with parents of Traveller children, in particular through Community development and relationship building with educational providers. Inclusionary education strategies within preschool, primary and post-primary educational settings were viewed as essential in allowing Traveller children to fully enjoy their right to education. Further, recommendations included an emphasis on equality, inter-agency support and adequate funding of specialised assistance programmes. Within third-level education, the Strategy emphasised the need for alternative entry routes, support and mentoring of those Travellers entering third-level education.

In Northern Ireland, data from Connolly and Keenan (2002) suggest that

- 18% of Traveller children access preschool or nursery compared to 58% of the general population.
- 59% of Travellers aged between 16 and 24 years leave school with no qualifications, compared to 17% of this age group in the general NI population.
- 92% of Travellers have no GCSEs or higher qualifications.

Income Adequacy

The Department of Environment Northern Ireland Census 2001, counted 1,710 Travellers in Northern Ireland. Features of multiple disadvantages experienced by Travellers included long-term unemployment - only 11% are in paid employment whilst 70% who are economically active have had no paid work in the last 10 years. In Northern Ireland 89% were unemployed compared to 4% for the general population (Department of the Environment, 2001). In the 2006 census in the Republic of Ireland (Central Statistics Office, 2007c) the unemployment rate for Travellers was 75% compared to 9% for the general population.

Research into the economic activities of Traveller culture identifies an emphasis on income generation rather than wage employment. However with increasing regulation and enforcement in work areas associated with Travellers (e.g. recycling, waste disposal, horse trading) opportunities for self-employment have become more difficult to find. Barriers to Travellers accessing the labour market include educational standard, lack of role models and discrimination. The majority of Travellers are unemployed and are dependent on social welfare payments. This often results in families living in poverty trying to cope with the increasing costs of basic services, as well as the struggle to feed and clothe large families (Report of the Task Force on the Travelling Community, 1995).

The Report of the Task Force on the Travelling Community stated that it was important that the full range of employment and training options are open to Travellers and that institutional or discriminatory obstacles are removed. The links between Traveller cultural identity and traditional employment types were recognised. In order to fully exploit these links, a need has been identified to take account of traditional structural characteristics of Traveller economic activity in implementing culturally reinforcing employment policies. This involves a community development model that establishes a 'logic of empowerment' which aims 'to help remove shame of self or the will to hide one's differences when they are compared to the 'norm' or majority'.

The Committee to Monitor the Implementation of the Recommendations of the Task Force on the Travelling Community found shortcomings in implementation and disparities *'between the objectives of the Task Force and the opportunities offered by a range of State sectors'*. The main recommendations of the Task Force Report addressed the effective organisation of trading activities, the development of recycling and waste management strategies, the development of strategies to increase participation by Travellers in mainstream employment and training/ employment schemes. FÁS accepted the Task Force Report and Travellers are now included on a range of programmes.

There are various local initiatives and models of good practice that have been developed but have not been mainstreamed. The THU in the Eastern region commissioned work and published a report on developing a 'toolkit' for employment of Travellers. The report, entitled 'Toolkit and Guidelines for the Employment of Travellers in the Health Service Executive' (Traveller Health Unit, 2007), gives an overview of some of the barriers and enablers to training and employment for Travellers.

Factors identified that result in a low level of participation in the labour market by Travellers:

- A lack of recognition of Traveller culture.
- A lack of outreach or specific efforts to recruit Travellers, and poor tailoring of recruitment documentation to meet the needs of Travellers.
- A lack of additional support for Travellers, for example, childcare supports.
- A lack of progression options as a result of participating on (particularly) labour market programmes.
- Loss, or fear of loss, of welfare and secondary benefits.

Enablers to training and employment

Labour market research on participation of Travellers also identifies good practice for overcoming barriers and low participation rates. They must be considered at all stages of the recruitment process, from planning to delivery, and they include:

- Adopting an inter-agency approach, including engagement with Traveller representative organisations.
- Availability of additional supports to Travellers throughout the recruitment process.
- The availability of dedicated staff to build relationships and support Travellers: mentoring and high support is seen as particularly important.
- An outreach approach, and engagement with local Traveller organisations in attracting Travellers to programmes.
- Flexibility and innovation in delivery of programmes.
- Finally, the importance of Travellers who have participated on programmes and in the workplace as role models is seen as very important, both in the workplace and also amongst the Traveller community as a whole.

The public policy context has acknowledged the need for Traveller inclusion in the labour market, and has specifically identified this need in respect of the public sector, highlighting a leadership role that the sector has to play in this regard. Positive action measures are consistent with Employment Equality

and Equal Status legislation, and Travellers are specifically mentioned as one of the groups for whom positive action can be undertaken. Key policy and national agreements also have a consistent emphasis on lifelong learning in the workplace in particular for low skilled and low paid workers.

Recognition of Traveller Cultural and Ethnic Identity

Travellers are officially recognised as a minority ethnic group in the both Northern Ireland and Great Britain (UK Parliament Race Relations Order, 1997). Travellers are considered as a minority ethnic group by many specialised and expert equality and anti racism organisations, by many academics, and by all of the main Traveller representative groups in Ireland, North and South (Equality Authority, 2006; Human Rights Commission, 2004; McDonagh, 2002). Whilst the Irish Government does not assign this specific status, Travellers are however recognised as having distinct grounds for protection under Ireland's anti-discrimination laws (Employment Equality Act, 1998 and the Equal Status Act, 2002). For example, the National Traveller Health Strategy (DOHC, 2002) recognises Travellers as *'a distinct minority with their own culture and beliefs and most importantly that they have a right to have their culture recognised in the planning and the provision of services'*.

The United Nations Committee on the Elimination of Racial Discrimination (United Nations Committee on the Elimination of Racial Discrimination, CERD, 2005) concluded:

'Recalling its General Recommendation VIII on the principle of self-identification, the Committee expresses concern at the State party's position with regard to the recognition of Travellers as an ethnic group. The Committee is of the view that the recognition of Travellers as an ethnic group has important implications under the Convention (Articles 1 and 5).'

The Irish National Committee for the 1997 European Year Against Racism highlighted that *'one of the more visible forms of racism is that experienced by the Traveller community, based on their distinct culture and identity which is rooted in a tradition of nomadism'*.

The Task Force placed particular emphasis on this issue by devoting a chapter to discrimination and in the health chapter, they acknowledged that the context of constant discrimination that the lives of Travellers are exposed to has a health impact and has relevance for health provision (Report of the Task Force on the Travelling Community, 1995).

Lifestyle and Health Choices

It is well recognised that there is a social gradient to health behaviour and this can in itself present an inequity if health promotion policies do not take this into account (Ridde *et al.*, 2007; Kelleher, 2007; Lynch *et al.*, 1997). Repeated health surveys illustrate that adverse lifestyle, including smoking, alcohol consumption and unhealthy diet are strongly socially patterned (Kelleher *et al.*, 2003; Morgan *et al.*, 2007) and the challenge is to understand what motivates those health choices and how supportive positive changes can be made. Knowledge, skills and education are all important determinants, but so are factors such as amenities, income adequacy and ease of choice. *'Making the healthier choice the easier choice'* is a fundamental aspect of Health Promotion Strategy in Republic of Ireland (Department of Health, 2000). In areas such as diet, cultural practice and traditions are important, as well as access

to affordable, adequate food (Hodgins *et al.*, 2006). Lifestyle can also be a signal as well as a symptom of ill-health. In the context of Travellers it is necessary to understand traditions, practice and cultural norms when investigating lifestyle behaviours. The influence on disadvantaged groups of availability of drugs and other recreational substances and the compounding complexity of exposure of Travellers to adverse social scenarios in disadvantaged situations such as prisons all have to be taken into account (Hannon *et al.*, 2007; Fountain, 2006).

Brief History of Traveller Health Surveys in the Past

The 1963 Commission on Itinerancy Report

The Commission on Itinerancy Report (Commission on Itinerancy, 1963) was the first formal initiative to address Traveller health. The terms of reference of the Commission as set out were:

'To enquire into the problem arising from the presence in the country of itinerants in considerable numbers; to examine the economic, educational, health and social problems inherent in their way of life.'

The starting point for the Commission therefore was that 'itinerancy' was a problem, and it was part of mainstream thinking at the time that solutions included rehabilitation, settlement and assimilation into the general population. The Commission's Report comments on the social and ethical behaviour of Travellers and their tendency to keep aloof from the majority population. There was no explicit acknowledgement or examination of issues such as discrimination towards Travellers.

In chapter VII of its report the Commission examined various aspects of the health of Travellers, such as medical requirements, adult, infant and child health, family size, conditions at birth, hygiene, food supply, clothing and age structure and life expectancy. Two health issues that gave them particular and appropriate concern were the high infant mortality rate (IMR) and the low life expectancy of the Travelling community in comparison to the national average.

The Report of the Travelling People Review Body (1983)

The Report of the Travelling People Review Body (Travelling People Review Body, 1983) was asked to examine *'the needs of Travellers who wish to continue a nomadic way of life'* and *'how barriers of mistrust between the settled and Travelling communities can be broken down and mutual respect for each others' way of life increased'*. It was thought that *'the extent to which they (Travellers) will integrate into the settled community will depend on individual decisions by them and not on decisions made by Travellers as a whole or any grouping of them.'*

The review body also considered the issues of Traveller health and as with the earlier report, noted that life expectancy for Travellers appeared to be considerably shorter than for the population as a whole. It was noted that Traveller families were larger than the national average and that the age profile was exceptionally young. It recommended *'the regular and systematic collection of data on the health status of Irish Travellers.'*

The Travellers Health Status Study 1986 & 1987

The publication of the 'Travellers Health Status Study - Census of Travelling People 1986' (Barry and Daly, 1988) and 'The Travellers Health Status Study - Vital Statistics of the Travelling People 1987' (Barry *et al.*, 1989) gave rise to considerable concern about the health status of the Traveller community. The main findings reported at that time were:

- Traveller fertility rate. The fertility rate of Travellers in 1987 was 34.9 per 1,000 - more than double the national average and the highest in the European Union.
- Health of the Traveller mother and baby. Travellers had more than double the national rate of stillbirths, and the IMR was three times higher than the national rate.
- Traveller mortality. Traveller men lived on average 10 years less than settled men, and Traveller women lived on average 12 years less than their settled peers. Travellers were only then reaching the life expectancy that settled people had reached in the 1940s, and Travellers of all ages had very high mortality rates compared to the general Irish population.
- Traveller Health. Travellers had higher rates of morbidity than the general Irish population. The Report of the Task Force on the Travelling Community (1995) presents a comprehensive range of strategies to address the situation of the Travelling community. Such as the following general recommendations:
 - That the distinct culture and identity of the Traveller community be recognised and taken into account
 - Provision of increased resources to Traveller organisations
 - Promoted a partnership approach to working with Travellers

The 1995 Task Force Report

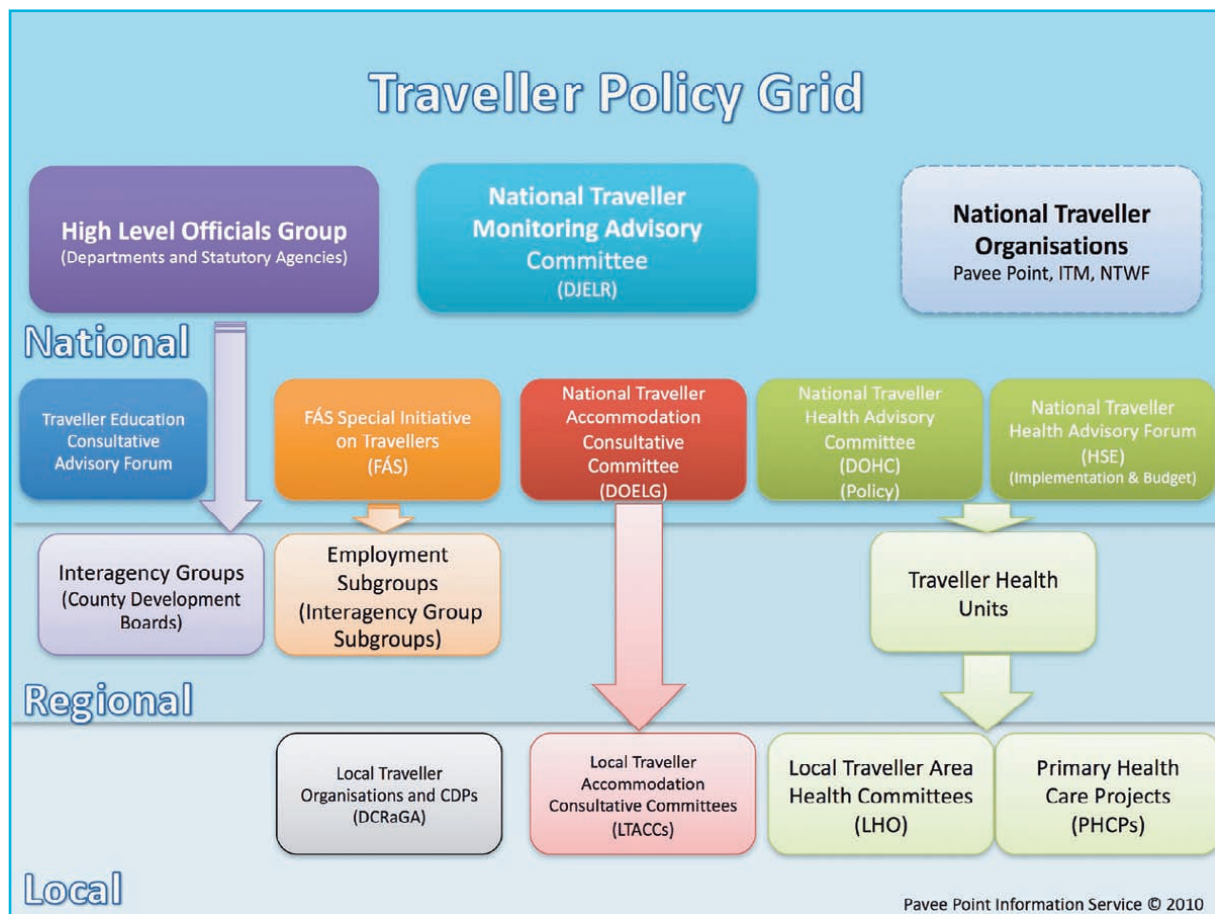
As background information for the 1995 Task Force Report, a study on the uptake and utilisation of health services was performed (O'Donovan *et al.*, 1995). This study examined interviews with 200 Travellers in Dublin and Galway and Service Providers in all Health Board Areas in order to establish the main issues in relation to Traveller access to the health services. The questionnaire was designed in collaboration with Travellers, Traveller support groups and medical personnel. Questionnaire administration posed logistical challenges in this study, due to both respondents' literacy and access to families, facilitated by assistance of Peer Researcher support. The questionnaire examined family size and composition, accommodation status, as well as a range of questions related to personal and family health status, lifestyle, health beliefs, access to GMS services, use of preventative medicine and child health services, hospital services, women's health, health education and their views on the existing health services.

This study identified specific obstacles, including illiteracy, which leads to difficulties completing forms for the renewal of medical cards; lack of provision for tracing and transferring the health records of Travellers who are mobile, which makes referrals and continuity of care more difficult; and prejudice on the part of the general public and service providers, resulting in Travellers being refused access (O'Donovan, *et al.*, 1995). It reported that Travellers had generally a low expectation of health services, and that Travellers had high utilisation rates of a small number of services (specifically Accident and

Emergency Services (A & E) paediatric services and obstetric services) but low usage rates of many other services, particularly preventative services. Difficulties were experienced by all health boards in the utilisation and delivery of A & E services; including perceptions of inappropriate use of these services, non-attendance at follow-up appointments and difficulties arising because Traveller patients are sometimes accompanied by large family groups. These findings informed important policy recommendations in the Task Force Report (Report of the Task Force on the Travelling Community, 1995), including the recommendation for self-held patient records that might overcome challenges of data transfer. The 1995 Task Force placed particular emphasis on the impact which discrimination has on Traveller health and its relevance to health provision, identifying this discrimination as happening both at the individual and interpersonal level and at the institutional level.

The 1995 Report of the Task Force on the Travelling Community identified the provision of health services and in particular, questions associated with access to and utilisation of these services, as being of major concern to the Traveller community. The main elements of these strategies in health include the introduction of a number of measures to improve the health status of the Traveller community and to remove the obstacles to Traveller access to health services. They also acknowledged the relationship between health and accommodation and the need to facilitate the participation of Travellers in the planning of health services through the establishment of the National Traveller Health Advisory Committee and the establishment of regional THUs. Figure 4 describes the committees and structures established and/or revised subsequent to the publication of the 1995 Task Force Report (Report of the Task Force on the Travelling Community, 1995).

Figure 4: Framework of the Traveller and Service Provider partnership committees and structures. These structures have been established and/or revised to implement the recommendations from the 1995 Task Force report



New Targeting Social Need 1999

In 1998 the New TSN (Targeting Social Need) and PSI working groups were established in Northern Ireland. The New TSN can be seen as an initiative which *'tends to compliment the equality provisions outlined under the Northern Ireland Act 1998'* (UK Parliament, 1998). One aspect of this policy is to promote social inclusion including adopting *'a strategic approach to the needs of minority ethnic people'*. A steering group of senior civil servants has been set up to oversee the implementation of the New TSN across government departments. A New TSN Unit within Office of the First Minister and Deputy First Minister (OFMDFM) advises departments on how best to implement the New TSN and working groups have been set up for each aspect of the policy (Office of the First Minister and the Deputy First Minister, 1999).

The factors which cause social need and exclusion do not always fit comfortably within the areas of responsibility of individual Departments. Through the PSI (2002) element of the New TSN, Departments work together - and with partners outside Government - to tackle factors which contribute to social exclusion and to improve the life circumstances of groups at risk of social exclusion. As part of PSI, work is already ongoing to prevent and tackle social exclusion among Travellers.

The following are some findings (specific to the Traveller community) in the New TSN:

- There is clear evidence of deprivation and poor health among Travellers.
- Long-term unemployment is a problem, with only 1 in 10 Travellers in paid employment.
- There is a high illiteracy level among Travellers and 92% have no GCSEs or equivalent.
- Travellers have generally poor living conditions – they are 8 times more likely than the general population to live in crowded accommodation.
- Child mortality up to age 10 has been found to be 10 times that of the population as a whole.
- On average, Travellers die about 15 years earlier than the general population. Only 1 in 10 of the Traveller population is over 40 years of age and only 1 in 100 is over 65.
- Further work needs to be carried out on developing good indicators for health inequalities; for instance, better ways of measuring the gap in health status between minority ethnic groups, e.g. Travellers, and the rest of the population (1999 New TSN and PSI working groups).

Investing for Health 2002

The Northern Ireland public health strategy 'Investing for Health' was published in 2002 (Department of Health, Social Services and Public Safety, 2002). The strategy contains a framework for action that is based on a multi-sectoral partnership working amongst Departments, public bodies, local communities, voluntary bodies, district councils and social partners.

The key aims of the strategy are to improve life expectancy across the population and to reduce health inequalities. The strategy has a particular focus on the most disadvantaged in Northern Ireland.

'Health is an outcome that results from a whole range of influences in everyday life. Inequalities in these determinants are responsible for inequalities in health.'

'Investing for Health' goes on to say that '*differences in social and educational opportunities*' are strongly implicated in the occurrence of these inequalities (Department of Health, Social Services and Public Safety, 2002).

Perceptions of Health and Health Services by the Traveller community in the Greater Belfast Area (2005)

This study involved finding out perceptions of the Irish Traveller community of their health needs, their perception and experience of health services in general and the Royal Hospitals in particular.

Most Travellers believe they suffer poor health and attribute this to three main factors: lack of appropriate accommodation, discrimination and racism they experience and poor health behaviours. Most Travellers believe that improvements in their health status will come with opportunities to participate in employment and social activity, coupled with a programme of Traveller specific accommodation and a reduction in the discrimination and prejudice they face. Travellers recognise that improved access to health services over recent years has created some positive change in their lives today. The first piece of research commissioned by a statutory agency on the condition of Traveller health in Northern Ireland took place in 1993 and covered the Eastern Health and Social Services area (Ginnety, 1993). This employed an ethnographical approach that sought to discover the views people hold about their social world and attempted to elicit the naturally occurring health knowledge that is used by Travellers themselves. A total of 55 Travellers participated in indepth interviews. The report concluded that poor environmental conditions and poor access to existing health and social services were major influences on Traveller health. It also highlighted the need to involve Travellers in decision-making.

Since 1987, no national studies have been conducted on Traveller health in ROI, but research carried out in recent years suggests that the health status of Travellers may not have improved. This review does not seek to cover these various studies, many of which have methodological limitations, including small numbers, difficulty in identifying Travellers and lack of generalisability of findings. Some indicative examples only are included.

The Irish Sudden Infant Death Association (ISIDA) found in their Annual Report of 1999 that the rate of Sudden Infant Death Syndrome (SIDS) among Travellers was 12 times greater than the rate among the settled population (Irish Sudden Infant Death Association, 1999).

In 2000, a study on Travellers attending the Adelaide and Meath Hospital in Tallaght in south-west Dublin (Traveller Health Unit in the Eastern Region, 2000), found that while over a third of the hospital's general population patients were in the over 65 year age group, compared with 11% of general population aged over 65 years (Central Statistics Office, 2003b), just 2% of Traveller patients were aged over 65 years, compared with 3% of Traveller patients aged over 65 years (Central Statistics Office, 2003b).

Travellers Health: A National Strategy 2002 - 2005

This strategy is very significant in that it represents a change in national policy towards Travellers. It firstly recognises Travellers as a distinct minority group in Irish society with a health status far below the general population and having specific health needs.

'Travellers are particularly disadvantaged in terms of health status and access to health services. Generally speaking, they suffer poor health on a level which compares so unfavourably with the settled community that it would probably be unacceptable to any section thereof' (Department of Health and Children, 2002).

The strategy contains 122 actions that were to be implemented over a 4-year period, from 2002 to 2005. To date, some of the key recommendations that have been implemented are the establishment of the national and regional Traveller Health Structures, which have facilitated the development of Traveller Health initiatives at local level. It recognises the role that primary healthcare projects have had in addressing Traveller health issues and it recommends their replication throughout the country.

'Primary healthcare for Traveller Projects will be developed in conjunction with Traveller organisations in all Health Board areas where there is a significant Traveller population by the end of 2005' (Department of Health and Children, 2002).

Since 2002, 40 PHCTPs have been established around the country and they have trained more than 300 Traveller women as TCHWs (see Technical Report 1 for further details).

National Drugs Strategy (NDS) (interim) 2009-2016

The National Drugs Strategy acknowledges the concerns over the growing problem drug use. Data is not available to indicate the number of Travellers who present for treatment as heretofore Travellers have not been recorded as a distinct group under the National Drug Treatment Service (NDTRS) (Department of Community, Rural and Gaeltacht Affairs, 2009).

However, in research commissioned by the National Advisory Committee on Drugs (NACD), Fountain (2006) found that the prevalence pattern broadly mirrors that of the general population, with cannabis, sedatives and tranquillisers most commonly used, followed by cocaine, ecstasy and lastly, heroin.

The issues experienced by Travellers in relation to drugs are entwined with issues of inequality and marginalisation. This means that Travellers are more likely to be exposed to the risk factors that lead to problem drug use. It also implies that response mechanisms to address the associated problems need to factor in these issues. There are heightened concerns within the Traveller community about the growth in problem drug use. This is also acknowledged by the HSE as a key and growing concern. The NDS also acknowledged that Travellers face specific problems that stem from a *'lack of awareness of the existence and nature of drug services, lack of formal education, stigma and embarrassment, and lack of culturally appropriate provision'* (Fountain, 2006).

The NACD report found that, while there are some good models of service provision, Travellers experience specific problems relating to access to services arising from a lack of awareness of the existence and nature of drug services, lack of formal education, stigma and embarrassment and lack of culturally appropriate services (Fountain, 2006).

The High Level Group on Traveller Issues (a.k.a. The High Level Officials Group) 2003

Previously the Task Force Report on the Travelling Community (Report of the Task Force on the Travelling Community, 1995) was one of the main forums for Traveller participation. The High Level Group on Traveller Issues is a cross-departmental group established under the aegis of the Cabinet Sub-Committee on Social Inclusion. The aim of the High Level Group on Traveller Issues is to find ways of securing better outcomes for Travellers and greater supervision across government departments for Traveller specific measures. The High Level Group on Traveller Issues is chaired by an Assistant Secretary to the Department of Justice and comprises members of the Senior Official's Group on Social Inclusion and other senior public servants with key responsibility for the delivery of Traveller specific services.

The High Level Group on Traveller Issues has issued one report in 2006 (Department of Justice and Law Reform, 2006), which includes a recommendation that a coordinated inter-agency approach to the delivery of services and supports for Travellers might be a key way of enhancing service delivery. The report further identifies as a priority issue effective consultation between Travellers, Traveller organisations and statutory bodies to support the development of an inter-agency approach and to improve communication at national, regional and local level.

National Traveller Monitoring and Advisory Committee 2007

In 2007 the Committee to Monitor and Coordinate the Implementation of the Recommendations of the Task Force on the Travelling Community (1995) was reconstituted as the National Traveller Monitoring and Advisory Committee.

The function of the National Traveller Monitoring and Advisory Committee is complementary to the High Level Group on Traveller Issues and provides a forum where the views of a wide cross-section of stakeholders can be expressed. It represents an important mechanism for securing Traveller participation with Travellers and Traveller organisations. At the launch of this Committee Minister for State at the Department of Justice, Equality and Law Reform with Special Responsibility for Equality Issues, Frank Fahey T.D. stated that it would have '*a cross-cutting role*' and would address issues other than those being addressed in existing Departmental Committees.

Other Important Policy Developments Pertaining to Travellers

The National Action Plan on Social Inclusion (NAP inclusion) 2007-2016

A key EU policy development is the National Action Plan against Poverty and Social Exclusion, which provides a common social inclusion framework within which member states are required to develop and report on strategies and associated targets aimed at reducing social and health inequalities, and the poverty and exclusion resulting from this.

The strategic approach of this document towards combating poverty and associated social exclusion embodies a recognition of the complex, multifaceted nature of poverty and emphasises the need for a coordinated cross-sectoral response to this.

The NAP inclusion is part of an EU-wide process designed to assist Member States in achieving the EU goal of making a decisive impact on poverty by 2010 and beyond. Of particular use is the fact that it provides consistent and robust indicators for the measurement of poverty.

The Report on consultation for the National Action Plan against Poverty and Social Exclusion 2006-2008 clearly identified minority ethnic groups and Travellers among the most vulnerable groups and proposes various concrete steps to address their situation. Issues identified include housing, education, languages support, employment, improved data collection and policy 'poverty proofing'.

The 2007-2016 plan states that access to quality health services is a prerequisite for participation in the social and economic life of society and cites the importance of the National Intercultural Health Strategy (Health Service Executive, 2008) in addressing the unique health and support needs of minority groups, such as Travellers, refugees and migrants.

The Intercultural Health Strategy, 2007-2012

The primary objective of the strategy is to provide a framework through which service users and providers are supported in addressing the unique care and support needs of people from diverse cultural and ethnic backgrounds. Within a health landscape, this implies that the health service acknowledges the distinct health and support needs of minority ethnic groups and, through a range of mechanisms, translates this into responsive, flexible ways of facilitating equal and optimal access to and utilisation of health services, with positive health outcomes. An integrated approach will be developed for conducting health impact assessments. Aspects of equality and diversity will be developed and conducted in the longer term within a health impact assessment framework. This will be effected within the context of work currently under way within the Population Health Directorate concerning the development of a strategic framework for health impact assessments.

Northern Ireland

Similar challenges for Travellers in terms of premature mortality have been noted in NI as in ROI. According to 'Investing for Health' (Department of Health, Social Services and Public Safety, 2002), Travellers die about 15 years earlier than the general population in NI. Only 1 in 10 of the Traveller Population is over 40 years of age and 1 in 100 is over 65. Child mortality up to age 10 has been found to be 10 times that of the population as a whole.

The Royal Hospitals Group in Belfast commissioned research (McMahon, 2005) into a health assessment and needs of Travellers in Belfast. The DHSSPS also supports a community health project with An Munia Tober in Belfast. In 1999 a new 'Targeting Social Needs' policy initiative in Northern Ireland contained a specific theme of PSI, and a PSI Working Group on Travellers was created. In 2000 an initial PSI report was published (Office of the First Minister and the Deputy First Minister, 2000). The Executive in Northern Ireland produced a response to the PSI Working Group on Health in 2002 (Office of the First Minister and the Deputy First Minister, 2002), which contained a number of recommendations aimed at improving the health and wellbeing of Travellers.

Measures of Overcoming Barriers to Health Promotion and Healthcare for Minority Populations: International Experience

There is a strong international literature on the health needs of minority groups ranging for example from the Inuits of Canada (Young, 2003; Health Council of Canada, 2005), the Aboriginals and Māoris of Australia and New Zealand (Carson *et al.*, 2007; Davis *et al.*, 2006; Anderson *et al.*, 2006; Pincock, 2008) Blacks, Hispanics and Native Americans in the United States (Rhoades, 2003; Roubideaux, 2005; Kaufman *et al.*, 1998) and South America, immigrant Asian and West Indian populations in the United Kingdom (Davey-Smith *et al.*, 2000; Smaje and Le Grand, 1997), and Roma and Gypsy populations in Europe (Parry *et al.*, 2007; Cemlyn, 2009; Vokó *et al.*, 2009; Hajioff and McKee, 2000). Indeed the Irish in Britain and the US have been documented extensively also (Clucas, 2009; Kelleher *et al.*, 2006; Scally, 2004; Garrett, 2002; Abbotts *et al.*, 1997). This literature concerns itself with several aspects of catering equitably for distinctive groups and individuals across society. At the level of provision of services, barriers may be encountered such as language and norms of behaviour. Healthcare providers may fail to appreciate nuances of understanding that lead to an inadequate treatment experience. Access may be impeded by resources, eligibility and means of payment. Cultural aspects such as family and social support and the differing needs of men and women are all considerations. Practicalities in infrastructural delivery, including mobile populations and distance from care, are all important. Krieger (2003) emphasises the need to distinguish factors associated with race and culture from those of economic disadvantage, to ensure an adequate understanding of policy and practice. Services must find a fine line between ensuring all are treated equitably and fairly on the one hand and imposing on the other hand a 'one size fits all' model that consciously or unconsciously has the effect of hindering participation or adequate care for a vulnerable individual (National Economic and Social Forum, 1996; Quirke, 2001). This literature clearly has resonances for the assessment of health services from a Traveller perspective using increasingly well recognised quality assessment procedures of norms of care such as those of the Picker Institute in the United Kingdom, employed in 2007 in the first general consumer satisfaction survey undertaken by the Republic of Ireland's HSE (Boilson *et al.*, 2007).

Technical Steering Group and Related Governance Structure

A study on this scale required major engagement with stakeholders together with support and oversight of the research team. The Department of Health and Children (DOHC) appointed a Technical Steering Group (TSG) to monitor the research project.

Technical Steering Group (TSG)

The TSG group comprised of Dr Philip Crowley, Deputy Chief Medical Officer, Chair, DOHC; Ms Heather Robinson, Department of Health, Social Services and Public Safety (latterly Mr David Reilly (DHSSPS)); Dr Evelyn Mahon, Trinity College Dublin; Ms Olive McGovern, Social Inclusion Unit, DOHC (until 2008, thereafter Mr Tim McCarthy); Ms Leonie O'Neill, National Planning Specialist, Social Inclusion Unit, Health Service Executive (HSE); Ms Ronnie Fay, Pavee Point and Ms Rosaleen McDonagh, Irish Traveller Movement.

The TSG met with the UCD study team on a quarterly basis and reported to the DOHC having the following terms of reference:

- To monitor the research through each stage of development and ensure contractual commitments were met.
- To provide practical advice during the various stages of research, including liaison with statutory agencies, workforces and Traveller groups.
- To report to the DOHC on progress of the research with respect to tracking milestones and progress.
- To review the final draft of report to be submitted to the DOHC for approval.

The TSG met on a total of 14 occasions, the last of which was held on 28th June, 2010 and received 13 progress reports from the UCD-led study team. In addition there was significant one-to-one engagement with members of the study team and group electronic communication. The TSG provided valuable support, in accordance with its terms of reference, at all stages of evolution of the study up to, and including, the final drafting stages of the three Technical Reports and Summary of Findings documents that constituted together the final output of the study. All the stakeholders represented on the TSG provided practical access to their respective networks, many of whom contributed generously of their time on a voluntary basis. We highlight specifically these contributions at different points in the three Technical Reports.

Traveller Stakeholder Group: Northern Ireland

A Northern Ireland (NI) Traveller Stakeholder Group was established. This group comprised of Ms Heather Robinson and latterly Mr David Reilly (DHSSPS); Dr Elizabeth Mitchell (DHSSPS), Mr Kieron Moore (DHSSPS), Ms Mary Scarlett (DHSSPS), Ms Angela McLernon (DHSSPS), Mr Derek Hanway (An Munia Tober), Ms Dolores Atkinson (Study Project Development worker), Ms Mary Duggan (NHSCT), Ms Lisa Moore (Craigavon Traveller Support Centre), Ms Lynne Curran (DSSSPS), Ms Roberta Weir (DHSSPS) and Dr Jill Turner (UCD).

The purpose of the Stakeholder Group was to facilitate approaches for information, support and access as necessary to action NI parts of the study. Heather Robinson was appointed as the chair of the group and she advised that the Stakeholder Group being convened by the DHSSPS would be time-limited to the lifetime of the survey. The Stakeholder group met monthly and explored some of the following issues: funding mechanisms for Peer Researchers, proofing the questionnaire for use in NI, mapping and scoping, support in relation to Traveller families, general practitioner (GP) and health visitors (HV).

Groups and Networks – Republic of Ireland

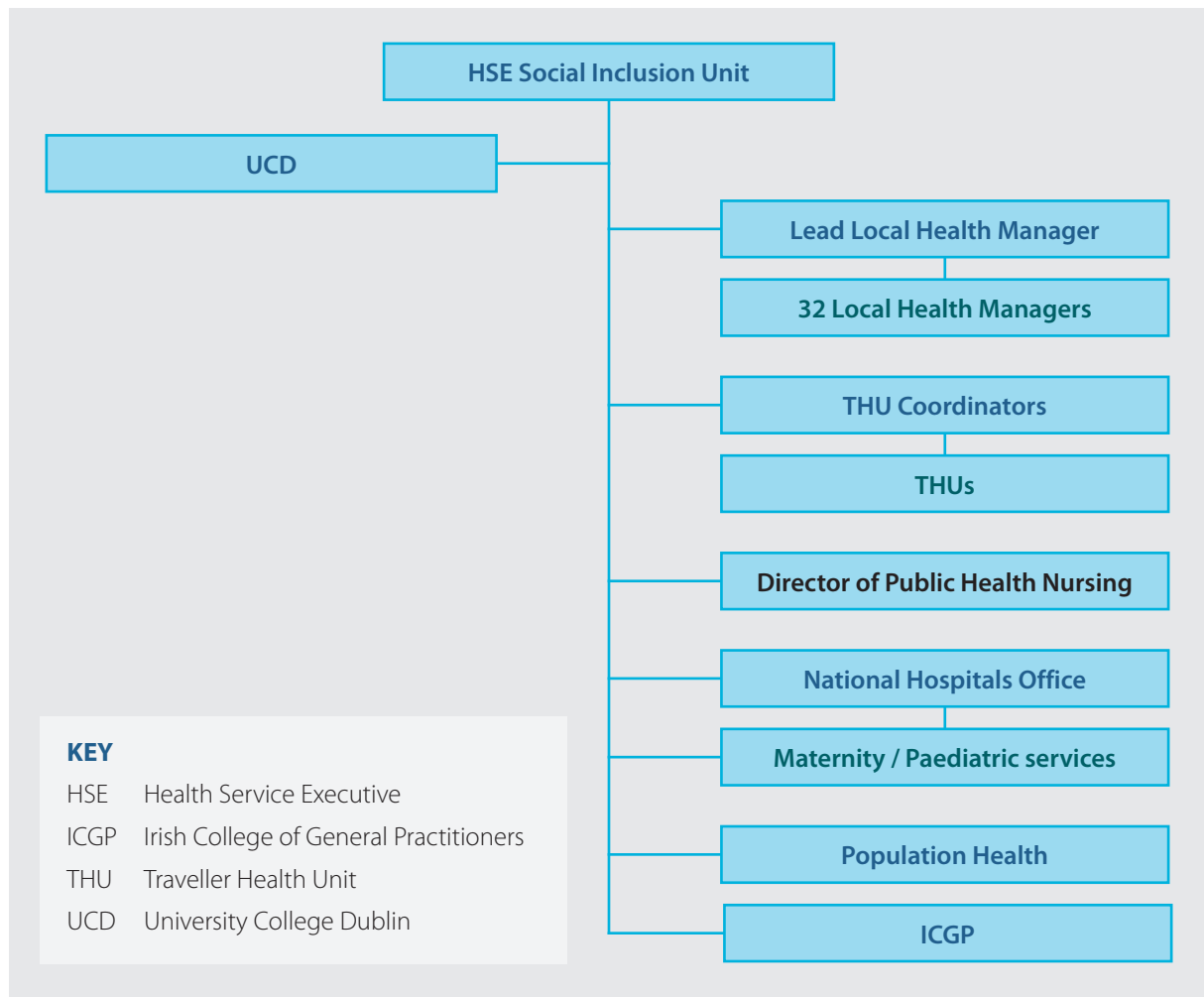
Groups and Networks were established by the HSE and the Traveller networks in the Republic of Ireland to support communication and study information dissemination during the study.

Traveller Liaison Committee – Health Service Executive

This committee was established in 2008 to give UCD direct access to the HSE staff around the country. The membership involved the Regional Social Inclusion Specialists and the THU coordinators along with the Chair of the Director of the Public Health Nurses group and other key HSE staff as appropriate (see Table 1). The role of this committee was to advise on the smooth running of the interface between the UCD study group and the HSE staff. Figure 5 describes the HSE structure established for the AITHS study. The Director and Assistant Director of the study team and other team members as appropriate were invited to attend the meetings of this committee to communicate, inform, brief and update on the study.

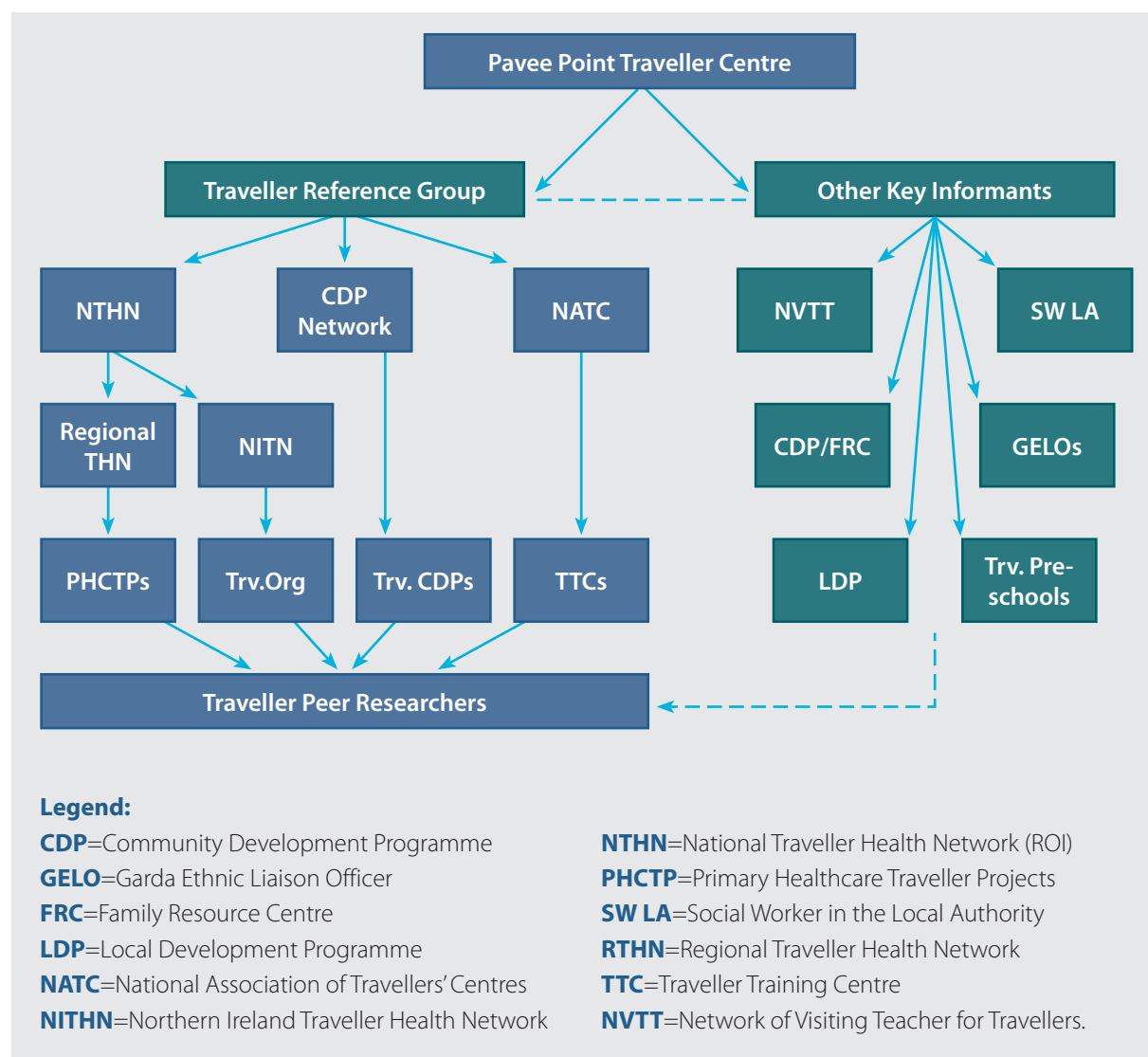
Table 1: Traveller Liaison Committee - Health Service Executive

Member Name	Professional role	Institution
Alice O'Flynn (Chair)	Assistant National Director	Social Inclusion
Leonie O'Neill	National Planning Specialist	Social Inclusion
Tony Quilty	Social Inclusion (SI) Specialist	HSE West
Concepta De Brún	SI Specialist	Dublin Mid-Leinster
Ronnie Fay	THU Coordinator	HSE East
Fergal Fox	THU Coordinator	Midlands
Martin Collum	THU Coordinator	HSE-NE
Mary Syron	THU Coordinator	HSE West
Mary Kennedy	THU Coordinator	HSE Mid West
Deirdre O'Reilly	THU Coordinator	HSE South
Liam Keane	SI Specialist	HSE South
Maire O'Leary	SI Manager	Donegal LHO
Rebecca Loughry	SI Specialist	HSE SOUTH
Marianne Healy	Director PHN	Dublin NW LHO
Eileen Gilsean	Designated PHN for Travellers	Co Meath
Bill Ebbitt	Population Health	HSE East

Figure 5: Health Service Executive structure for AITHS study**The Traveller Study Reference Group**

The Traveller Study Reference Group was established by Pavee Point to bring together the Travellers/ Traveller Organisations to facilitate communication and engagement with Travellers and Traveller groups. The membership of this reference group is outlined in the flowchart in Figure 6. Pavee Point resource the National Traveller Health network and the Traveller Community Development Programme network, and obtained a commitment from the National Association of Traveller Centres (NATC) to work towards ensuring maximum participation of all national Traveller networks in the study. Pavee Point also has formal and informal links to groups such as the Garda Ethnic Liaison Officers, the network of visiting teachers for Travellers, the preschools for Travellers, local family resource centres and area based partnership companies. These vocational groups and organisations were contacted to support nationwide population coverage of the AITHS, and to provide information about the study to Travellers who used their service. They were also targeted with ongoing information and training on the study.

Figure 6: Traveller Study Reference Group



Existing Traveller Structures that Played a Critical Role in the Study

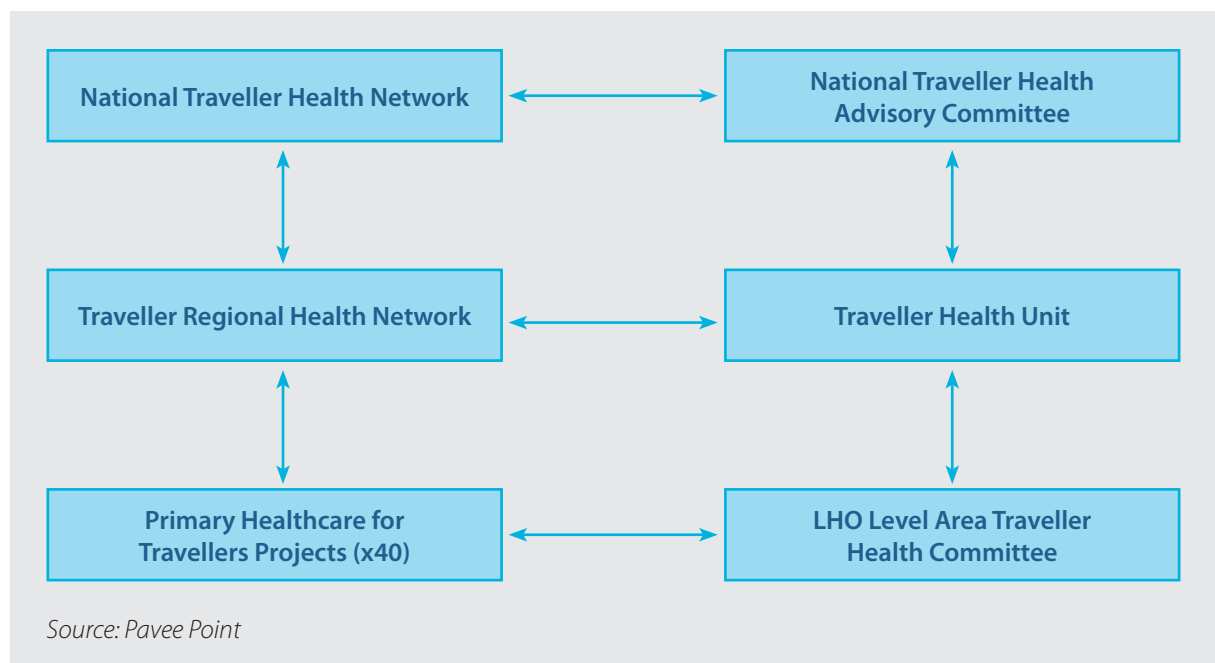
Traveller Community Development Projects

The approximately 20 Traveller Community Development Projects, located around the country facilitated access by the study team to additional Traveller Peer Researchers and coordinators as required. This need was particularly acute in areas where there was no existing Primary Healthcare for Traveller Projects (PHCTP).

Traveller Training Centres

There are 40 Traveller Training Centres (TTCs) in ROI, who operate under the network of the National Association of Travellers' Centres (NATC). The NATC provided access both to facilitate questionnaire completion and to potential Peer Researchers and coordinators. Again, this latter function was most important in areas where there was no Traveller infrastructure or PHCTP to liaise with the study team. A range of national, regional and local Traveller health structures has been developed since 1995. These structures played a critical role in the study. A schematic diagram in Figure 7 outlines these structures.

Figure 7: Traveller Health Structures



National Traveller Health Advisory Committee

Many of the structures in place to manage Traveller health issues have their origin in the Report of the Task Force on the Traveller Community (1995). The Task Force recommended the establishment of a Traveller Health Advisory Committee and Traveller Health Units (THU) in each health board (now HSE area). In 1998, a Travellers Health Advisory Committee (THAC) was set up. The committee is representative of the DOHC, the HSE and the National Traveller organisations, i.e. Pavee Point, Irish Traveller Movement and the Traveller Women's Forum.

The terms of reference for THAC included drawing up a national policy for a health strategy to improve the health status of the Traveller community. The document, *Traveller Health: A National Strategy 2002 – 2005* (Department of Health and Children, 2002) sets out a response to the inequities identified in Traveller health status. Also in 1998 a specific 'Traveller health budget' was allocated to each of the health boards to develop Traveller health initiatives and to establish regional THUs. THUs now operate in each HSE area and work in partnership with local Traveller organisations.

This group was responsible for the development of the Traveller Health Strategy and one of the key recommendations in the strategy was this All Ireland Traveller Health Study. The THAC oversaw the tendering process and played a monitoring role in relation to the implementation of the study.

Traveller Health Units

The terms of reference of the THUs are as follows:

- To monitor the delivery of health services to Travellers and to set regional targets against which performance may be measured.
- To ensure that Traveller health is given due prominence on the agenda of the HSE.
- To ensure coordination and liaison between the HSE and other statutory and voluntary bodies, in relation to the health situation of Travellers.
- To collect data on Traveller health and utilisation of health services.
- To ensure the appropriate training of health service providers in terms of their understanding of and relationship with Travellers.
- To support the development of Traveller-specific services, either directly by the HSE or indirectly through funding appropriate voluntary organisations.

National Traveller Health Network

The Pavee Point health team established the National Traveller Health Network (NTHN) in 1997 and have coordinated its activities since then as a forum for training, representation, feedback and information exchange for Traveller groups involved in Traveller health. The NTHN is an essential forum through which Traveller organisations share their learning experiences, discuss common issues that affect them and familiarise themselves with new developments in relation to Traveller health. The national Traveller organisations also use it as a mechanism to develop a mandate, receive support and provide feedback and information from the National Traveller Health Advisory Committee.

At regional level, co-terminus with the existing THU regions, there are Regional Traveller Health Networks.

Regional Traveller Health Networks

These networks were initially developed as a structure to support Traveller organisations working in health and are used to elect representatives on to the THU and ensure they have a mandate and a feedback mechanism to local Traveller groups. The National and Regional Traveller Networks coordinate, host and resource NTHN meetings. The NTHN also uses these committees to pass on information on national policy developments and get feedback on local initiatives and challenges. These networks have been strengthened and resourced by the THUs since 2004 to facilitate the decentralisation of the training and the capacity building by Pavee Point to regional level.

Pavee Point also resource the national and regional Traveller health networks as a forum for training, representation, feedback and information exchange for Travellers and Traveller organisations. The roles of these regional and national networks were expanded (as outlined below) to act as a key link between Traveller, Traveller organisations and the study team at UCD.

National and Regional Traveller Networks and the All Ireland Traveller Health Study

These networks have acted as vital liaison points in the inclusion of Travellers as key stakeholders in the implementation of the AITHS. In this regard, they participated in such roles as

- ensuring that Travellers and Traveller organisations understood the rationale and implications of the study
- ensuring that Travellers and Traveller organisations had a sense of 'ownership' of the study
- the ongoing development of the capacity of Travellers to engage with the study
- the identification of key informants in each region to support the study
- the support of the mapping and count in the geographical areas with Traveller populations
- the identification of, and the development of a contact system for, hard-to-reach Traveller groups such as those resident in institutions, or those who were homeless
- the development of a local preliminary scoping census of Travellers in each region to facilitate further development of the sampling framework for the study.

Local Health Offices

Local Health Offices (LHOs) act as entry points for communities to access health and social services, and the Traveller Primary Healthcare Projects act in partnership with the HSE through these offices. Each LHO area with a significant Traveller population has a Traveller Area Health Committee.

The HSE played a pivotal role in the study through using these structures and mechanisms and advised the LHO Managers to support the study and facilitate release and access to staff and projects as appropriate. HSE staff made the support of the AITHS a priority, particularly for those staff working directly with the Traveller community. The Primary Healthcare for Travellers Projects (PHCTPs) had a key role to play in the data collection for the Traveller needs assessment, and Traveller primary healthcare workers acted as 'Peer Researchers' in the study. The Public Health Nursing Service also had a key role in the collection of data on births and in the follow up relating to further data collection for the birth cohort study.

The Primary Healthcare for Travellers Project

The Primary Healthcare for Travellers Project plays a key role in the delivery of health services to Travellers. The PHCTP was initiated in 1994 as a joint partnership initiative between the former Eastern Health Board and Pavee Point.

The Report of the Task Force on the Traveller Community (1995) and the National Travellers Health Strategy (Department of Health and Children, 2002) strongly endorsed the work of the PHCTP and recommended its replication. The National Travellers Health Strategy set many targets which are dependent on the development of an effective and inclusive local Traveller health infrastructure and recommended that the PHCTP are the 'cornerstone' of the strategy and should be developed as an effective mechanism to facilitate the implementation of its actions. Many Travellers participate in the PHCTP. Depending on the density of population there may be more than 1 primary healthcare steering group in a Local Health Office (LHO) area.

Peer Researchers

Each PHCTP unit runs a training programme to develop the capacity of Travellers to become Community Health Workers or Traveller Community Health Workers (TCHW). They identify and develop an understanding of the factors influencing their health, and act both as advocates for Travellers and liaison workers for the health service. The initial projects conducted local needs assessments by and for Travellers, and used the findings to develop joint projects and initiatives with local health services.

The TCHWs were clearly identified in the study as Peer Researchers, and their location in 40 PHCTPs around the country was key to the AITHS. The UCD study team worked closely with Pavee Point, the National Traveller organisation, which has been involved in the training and capacity building of Traveller organisations and the Peer Researchers, and which also resources the NTHN.

Table 2 details locations of PHCTP projects in each of the 8 THUs, which are co-terminus with the former health board boundaries. The study team operated the research through these local and regional levels, linking into the THU structure in ROI and via the Traveller organisations and the Investing for Health Managers in NI.

FÁS (Foras Aiseanna Saothair, the Irish National Training and Employment Authority in ROI), facilitated the release of trainee health workers in existing projects for the duration of the census in order that they might act as Peer Researchers and in many cases extended existing training programmes for up to 8 weeks to incorporate the data collection period.

Table 2: Primary Healthcare Projects: broken down by THU regions

Eastern Region	
Ref	Project
1	St. Margaret's Traveller Action Group (Ballymun)
2	Blanchardstown Traveller Support Group
3	Pavee Point (Dublin 1)
4	STAG (Southside Traveller Action Group, Sandyford)
5	Kildare Traveller Network (Newbridge)
6	Co-operation Fingal (Balbriggan)
7	Wicklow (Newcastle)
8	TravAct (Coolock)
9	Tallaght Travellers PHCP
10	Clondalkin Travellers Development Group
11	Exchange House (Dublin 1)
12	Athy Travellers Club
13	Ballyfermot Traveller Action Project
Midlands Region	
Ref	Project
14	Longford Traveller Development Group
15	Tullamore Primary Healthcare Project
16	Laois Traveller Action Group
17	Athlone
Mid-Western Region	
Ref	Project
18	Limerick Travellers Development Group
19	Clare Care PHCP
20	Roscrea 2000
21	Thurles
22	Nenagh Community Network
North-Eastern Region	
Ref	Project
23	Louth PHCP (Dundalk)
24	Drogheda PHCP
25	Meath Primary Healthcare Project (Navan)
North-Western Region	
Ref	Project
26	South Donegal Support Group (Killybegs)
27	Donegal Traveller's Project (Letterkenny)
28	Sligo Travellers Support Group (Sligo Town)
29	Leitrim Travellers Project
30	Tubbercurry PHCP
Southern Region	
Ref	Project
31	Le Cheile Family Resource Centre (Mallow)
32	Traveller Visibility Group (Cork)
33	Kerry Travellers Support Group
34	West Cork Traveller Association (Clonakilty)
South-Eastern Region	
Ref	Project
35	Co Wexford PHCP
36	Carlow / Kilkenny PHCP
37	Bunclody Traveller Women's Project
38	Waterford Travellers PHCP
39	Clonmel Travellers PHCP
40	New Ross PHCP
41	Cashel Primary Healthcare
Western Region	
Ref	Project
42	Galway Travellers Support Group (City)
43	Galway Travellers Support Group (County)
44	Tuam Travellers Edu./ Dev. Group
45	Roscommon Traveller Development Group
46	Mayo Travellers Support Group (Castlebar)
47	Mayo Travellers Support Group (Westport)

Northern Ireland

In NI, the study group worked through a number of Traveller network groups. These included: the Healthcare for Travellers Project in An Munia Tober; the members organisations of the Regional Traveller Network NI; Traveller Toybox projects, and the Health Action Zones.

Traveller Organisations in Northern Ireland

A regional study coordinator was appointed by the Department of Health, Social Service and Public Safety in Northern Ireland (DHSSPSNI) to support the development of a Traveller Health Network which incorporated all the potential study coordinators from different areas in the North and acted as trainers for the Traveller Peer Researchers.

Existing Traveller Health Infrastructure in Northern Ireland

In 2005 the Race Equality Strategy (NI) was launched (Office of the First Minister and the Deputy First Minister, 2005). Within this Strategy and subsequent Action Plans (Office of the First Minister and the Deputy First Minister, 2006) there was specific reference to Travellers and their health. The DHSSPS have also funded a community-based health project in Belfast since 1999.

The development of Health Action Zones in some areas of Northern Ireland has created an inter-agency focus for action on Traveller health. In other areas there are close collaborative and cooperative working practices between local Traveller Organisations, community development organisations, and local health and social services.

Study Methodology

Instrument Development and Piloting

Traveller Census and Quantitative Study

The objective of the census was to provide population estimates broken down by sex, age, region, nature of accommodation, access to facilities and services. Every Traveller family enumerated in the mapping and scoping exercise on the island of Ireland was invited to participate in the census part of this study.

For the purposes of this study, a family unit was determined from an adaptation of the Central Statistics Office (CSO) definition (Central Statistics Office, 2007a):

- a husband and wife or a cohabiting couple; or
- a husband and wife or a cohabiting couple together with one or more usually resident never-married children (of any age); or
- one parent together with one or more usually resident never-married children (of any age)
- one person living alone
- only people who normally live with the family will be included in a family unit

The study team expanded the CSO definition to include an additional category where Travellers could determine who were members of their family unit to incorporate the inclusion of, for example, a foster child or niece who may be living with them as a member of their family.

The objective of the health status and health services utilisation studies was to obtain information on health status and factors affecting it and to obtain information on service utilisation and factors affecting it.

The study team devised different instruments for this survey, a census section, health status for adults, health status for children and health services utilisation for adults. The team also developed proxy questionnaires for the health status and health utilisation for adults.

Questionnaire Design

The final questionnaire used was determined after wide consultation to ensure that the questions were appropriate and acceptable to the Traveller population. It included questions taken from previous studies with Travellers (O'Donovan *et al.*, 1995) and national surveys, e.g. Lifeways, and also covered areas such identified in the scoping document. These included

- employment status
- level of education
- social support
- general health status
- specific experience of racism and discrimination
- behavioural risk factors (smoking, alcohol consumption, drug taking, dietary intake and eating patterns, exercise)

- cultural factors (breastfeeding rates, early marriages, large family size, concepts of health and health beliefs)
- access to and use of health services (including GP consultation rates/hospital attendance rates)
- use of prescribed medicines
- use of cures
- use of dental services/aural services
- use of speech therapy services
- use of gynaecology/maternity services (including family planning)
- standard/type of accommodation and social environment
- community involvement
- sports and leisure activities.

Sampling Strategy

The census contained 3 principal sections:

Section A: Family census, was completed on behalf of all respondent households by the principal informant, who was usually the mother. This included basic information on the age, sex, marital status etc. for all family members.

Section B: Children's health status and utilisation for a selected child aged 5, 9 or 14 years, and proxy questions, which were completed by the mother as appropriate.

It was decided to obtain detailed information on all Traveller children aged 5, 9 or 14, with a set of common questions, together with age-appropriate questions. If there was more than 1 child of these ages, or twins/triplets, a random choice of 1 child was made. Children of other ages were not surveyed.

Section C: Where there were no children of these exact ages in the family, an adult was surveyed on a random basis, and randomly either the health status or health utilisation questionnaire was administered. Where there was only one adult (aged 15+) he/she was chosen.

As far as possible the individual himself or herself answered the questions; alternatively a subset of the questions was answered on the individual's behalf by the principal informant.

In terms of the respondent burden for the census the following gives greater detail of the questionnaire sections that were administered. Each family unit completed Section A. Then, depending on the individual chosen for the more detailed information, the following held:

For a child aged exactly 5 years, 9 years or 15 years at last birthday:

Section B1 of the questionnaire was filled in for a child at each of these ages, and information obtained using Section B2 (age 5), Section B3 (age 9) or Section B4 (age 14).

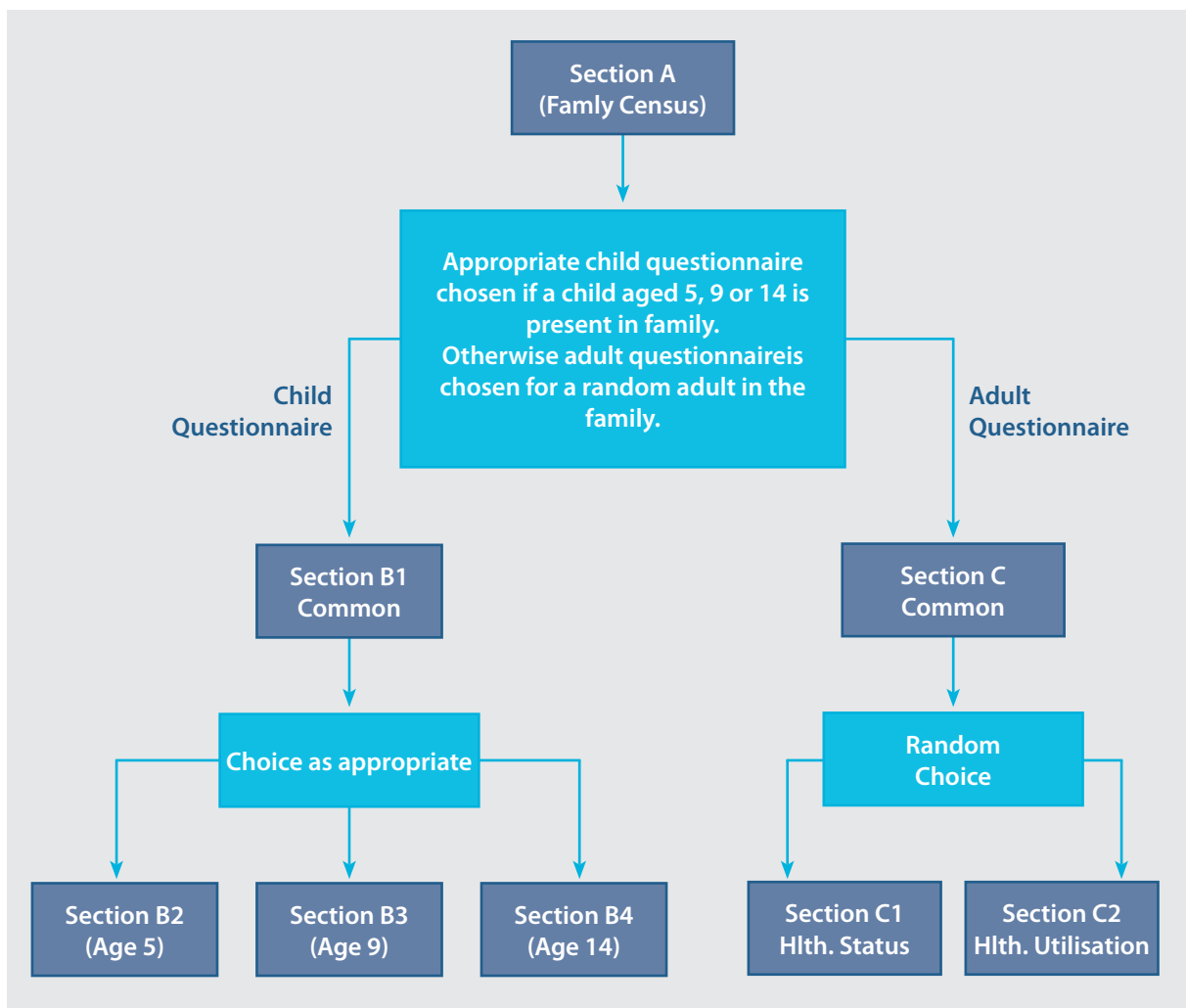
For an adult:

On a random basis either Section C1 on health status or Section C2 on health services utilisation was administered.

Thus in a family unit there were 5 possible questionnaire combinations (Figure 8):

1. Section A and Sections B1 and B2
2. Section A and Sections B1 and B3
3. Section A and Sections B1 and B4
4. Section A and Section C1
5. Section A and Section C2

Figure 8: Questionnaire administration



Peer Researchers, Coordinators and Fieldwork Training

Pavee Point identified that 40+ Primary Healthcare for Traveller Projects, which included approx 320 TCHWs and 40 project coordinators who had received training in basic research methods, would be available to the Study as enumerators. All enumerators were trained to a standardised level. This had many advantages over using enumerators from outside the Traveller community (e.g. Local Authority Social Workers or Housing Welfare Officers), both in terms of their acceptability to Travellers, and also their local knowledge of where Travellers lived in the region.

The training for the study was delivered by the UCD team as a Trainer's Training Course to coordinators and assistant coordinators of the projects, who in turn provided that training to the TCHWs in their teams. The PHCTP coordinators coordinated the work of their PHCTP teams locally and also acted as the key link and resource to the study team. In areas where there were no PHCTPs the regional networks covered the area with CHWs who had contact in these areas. Where this was not possible and while conducting the census in the regions they made contact with key informants, i.e. other Traveller organisations or projects, visiting teachers, PHNs and Traveller Training Centres.

The initial coordinators targeted were the existing coordinators in the Primary Healthcare for Traveller Projects; these projects normally have two coordinators in place, one representing the HSE perspective (PHN or RGN) and one representing the Traveller organisation perspective (Community Development Worker). At the beginning of the study there were 40 of these projects in the country and approximately an additional 6 Projects in development as PHCTPs. Due to a lack of resources for Traveller health, some were supported by the local THU to facilitate their participation in the study.

We wish to acknowledge the assistance of a range of stakeholders (detailed in full at the beginning of the report) who have made a significant contribution to the research study and include the Department of Health and Children and the Department of Health, Social Service and Public Safety Northern Ireland; the HSE; the Traveller Networks in both the ROI and NI; FÁS; Public Health Nurses and Health Visitors.

Analysis Strategy for the contextualisation of the AITHS Census and Health survey data

A comparison section follows the presentation of the census and health survey main report, where comparable population-level data is abstracted and presented in tandem with the AITHS findings, in order to provide context and richness to the understanding of the Traveller condition.

Choice of Comparative Data

The items used for data collection in the AITHS were derived primarily from a number of existing survey instruments that had been used for data collection in Ireland. The results of these surveys were therefore used as appropriate comparators for the AITHS results. Items were derived from such survey instruments as used by the SLAN (Survey of Lifestyle, Attitudes and Nutrition) 2002 and 2007 surveys (Kelleher *et al.*, 2002; Morgan *et al.*, 2008, the National Longitudinal Study of Childhood/Growing

up in Ireland study (NLSC/GUI) (Williams *et al.*, 2009), the Lifeways Cross-Generational cohort study (O'Mahony *et al.*, 2007), the Health Behaviour in School-aged Children (HBSC) study (Nic Gabhann *et al.*, 2006), Krieger *et al.* (2005), KIDSCREEN (KIDSCREEN/DISABKIDS questionnaire, 2010), INSIGHT '07 (2007), and the Continuous Household Survey in NI (2008-2009). The aim of this section is to consider the key variables noted in the AITHS and compare the Traveller social, economic and health position with that of the general Irish population, and where possible, specifically with the position of the Irish population of social class (SC) 5 or 6 (from the classification used by the Irish CSO, where SC 5 or 6 means that the present or last occupation of the person is in either the semi-skilled or non-skilled occupational categories) or medical card users. It is acknowledged that the Traveller community is not homogeneous, and that as a distinct minority community it has characteristics that set it apart from the general Irish public in significant respects. Nonetheless because social inequality is one possible contributory feature to the health status of its population it is appropriate to control or adjust for that possibility insofar as possible.

Description of the Data Sources Accessed

Lifeways is a cross-generational cohort study of 1,000 Irish families funded by the Health Research Board, in which data was collected from family members including mothers, fathers, grandparents and children (O'Mahony *et al.*, 2007). Two subsets of the Lifeways population were used to obtain the data for this comparison. Firstly, a dataset was created using baseline survey data from all adults in the study (mothers, fathers and grandparents, n=2,158 persons). Of this adult dataset, 510 persons had a medical card, and were therefore included in the analyses. For the second dataset, data were taken from the 5-year follow up child examination from Lifeways, affording direct comparison to 5-year-old Traveller children. These questions focused on the index child, with whom the mother was pregnant at the Lifeways cohort inception. There were follow up data on 68% of children, of whom 199 had mothers who had reported having a medical card at baseline. Despite the fact that Lifeways recruitment focused on pregnant women, subsequent studies have shown that the Lifeways cohort can be used as a representative sample of the general Irish population (Niedhammer *et al.*, 2009).

INSIGHT '07 is a study of consumer satisfaction with health and social care services. Data were collected by means of a survey of a nationally representative sample of Irish adults identified through the 2002 census, with supplemental sampling of the over 50 age group. The final sample was 3,517 respondents, of whom 1,282 had medical cards. SLAN 2002 is a population-based survey of Irish adults. These data have been received through the Irish Social Science Data Archive (ISSDA). SLAN 2002 gathered data on 5,992 participants, 1,645 of whom held medical cards. For this analysis, the data relating to persons who held medical cards were retained. SLAN 2007 is a population based survey of adults aged 18 and over, living in private accommodation, identified through the GeoDirectory. The SLAN 2007 raw data relating to medical card holders (n=3,445) has been made available to us through Dr Karen Morgan of RCSI. Results from SLAN 2007 were also gathered from the published reports, and in this case, comparisons with the AITHS group were made with published results relating to SC 5 and 6. Of the SLAN studies, SLAN 2007 comparisons were preferentially included as the most current data, although comparisons with SLAN 2002 were included if the equivalent data item was not available in SLAN 2007.

The HBSC study 2006 is an EU linked survey of school-going children in Ireland, coordinated through NUI Galway. Data was collected on 9-year-olds, 10-11-year-olds, 12-14-year-olds and 15-17 year-olds. Collaboration was agreed with Dr Saoirse Nic Gabhann of NUI Galway, and the HBSC team undertook to supply the data needed to make complete comparisons. Data was gathered from the child as first respondent, and reference to this is made in the text of this paper where appropriate. Comparisons were made with the subset of children in SC 5-6 (n=333 9-year-olds, and n=907 12-14-year-olds).

The NLSC/GUI study has contributed some of the most recent data on child health indicators for comparison with AITHS. NLSC/GUI is a large, prospective cohort study which to date has gathered baseline data on two subgroups: 9-month old infants and 9-year-old children. For this study, the data relating to the 9-year-olds (n=8,570) were compared with the 9-year-olds in AITHS, with specific comparisons being made with the NLSC/GUI children in SC 5-6, or to those in the lowest quintile of family income. Data were collected both from the parents, and from the children themselves (in the case of the 9-year-olds). Where relevant in this paper, it is clarified whether the data were by child or parent-report. Data tables have kindly been provided by Professor James Williams of the Economic and Social research Institute (ESRI), and other data has been gathered from the NLSC main report (Williams *et al.*, 2009).

The Continuous Household Survey is a yearly survey carried out by the Northern Ireland Statistics and Research Agency (NISRA). It samples 1% of the NI households, and gathers information on a number of household factors: population, housing, employment, health and education. Data is available by household income and by employment skill set of the household. In this document, where specific comparisons are made between the NI data and the AITHS data, the default comparison is between the AITHS data and the general Continuous Household Survey data. In cases where the comparisons are made with the NI data relating to semi skilled or unskilled workers only (comparable with the CSO SC 5-6 grouping), this is specified.

Analysis Strategy

All publications of the most significant recent population surveys (Kelleher *et al.*, 2003; Morgan *et al.*, 2007; Williams *et al.*, 2009; O'Mahony *et al.*, 2007; INSIGHT '07 (2008), Nic Gabhann *et al.*, 2007; Kelly *et al.*, 2009; Krieger *et al.*, 2005) were accessed and data were abstracted. To access data specific to either the medical card holders or the SC 5-6 groups of the general population, raw data was also required from a number of studies. Raw data files were accessed for the Lifeways study, INSIGHT'07 and the SLAN 2002 and 2007 studies. In the case of the latter 3 studies, the data was received through the ISSDA. Investigators from the HBSC, NLSC/GUI and SLAN 2007 studies kindly made either raw data or study-specific tables available for comparison, and we acknowledge their assistance. Further data relating to the general population in Northern Ireland were obtained from both the NI Continuous Household Survey (2008-2009) and the 2005 Infant Feeding Survey (Bolling *et al.*, 2007). We specifically refer to the work of Professor Nancy Krieger in Harvard School of Public Health in Boston because she is a world authority on the relative contribution of race, ethnicity and minority community affiliation to

health, an under-researched but relevant topic for Traveller health. Frequencies are presented as valid percentages in all cases. All data are presented as descriptive statistics. Where possible, tabulations were performed by sex and by age group, in keeping with the presentation of the AITHS data. Because of the sample size and the large number of variables for consideration, no formal statistical testing of hypotheses was undertaken as part of this comparative description.

Estimated Traveller Population

The Travellers count was based on the number of Traveller families enumerated at the census multiplied by the average family size. Further details on the rationale for the process and demographics are included in Technical Report 2. In ROI census, project coordinators returned field reports of anonymised family codes with a comment on each code, indicating the status of the family, whether interviewed or not interviewed (because they moved, refused or were unavailable). In addition, on completion of the census fieldwork, each project completed a telephone interview confirming the numbers of families enumerated, response rate and number of files uploaded. The field report, the interview and the uploaded files were used to corroborate the total family count in each project. To avoid double counting, during the 6-week census period those who had moved out of the island of Ireland were not enumerated as part of the study population and those who moved within the Island were enumerated in the area to which they moved. The number who moved away was subtracted from the count in each project area, and project area counts were then aggregated to reach the final Traveller count.

In the NI census, the total number of families enumerated was reported by the central field coordinator in NI.

In ROI and NI, average family size was obtained from the question: 'How many Traveller family members (including yourself) normally live with you?'

Table 3: Estimated Traveller Population

	ROI	NI	Total
Number of Traveller families enumerated	9,056	1,562	10,618
Number of Traveller families interviewed	7,042	1,450	8,492
Response rates (%)	78%	93%	80%
Average family size	4.0	2.5	3.8
Estimated Traveller population	36,224	3,905	40,129

Figure 9: Republic of Ireland Survey Response

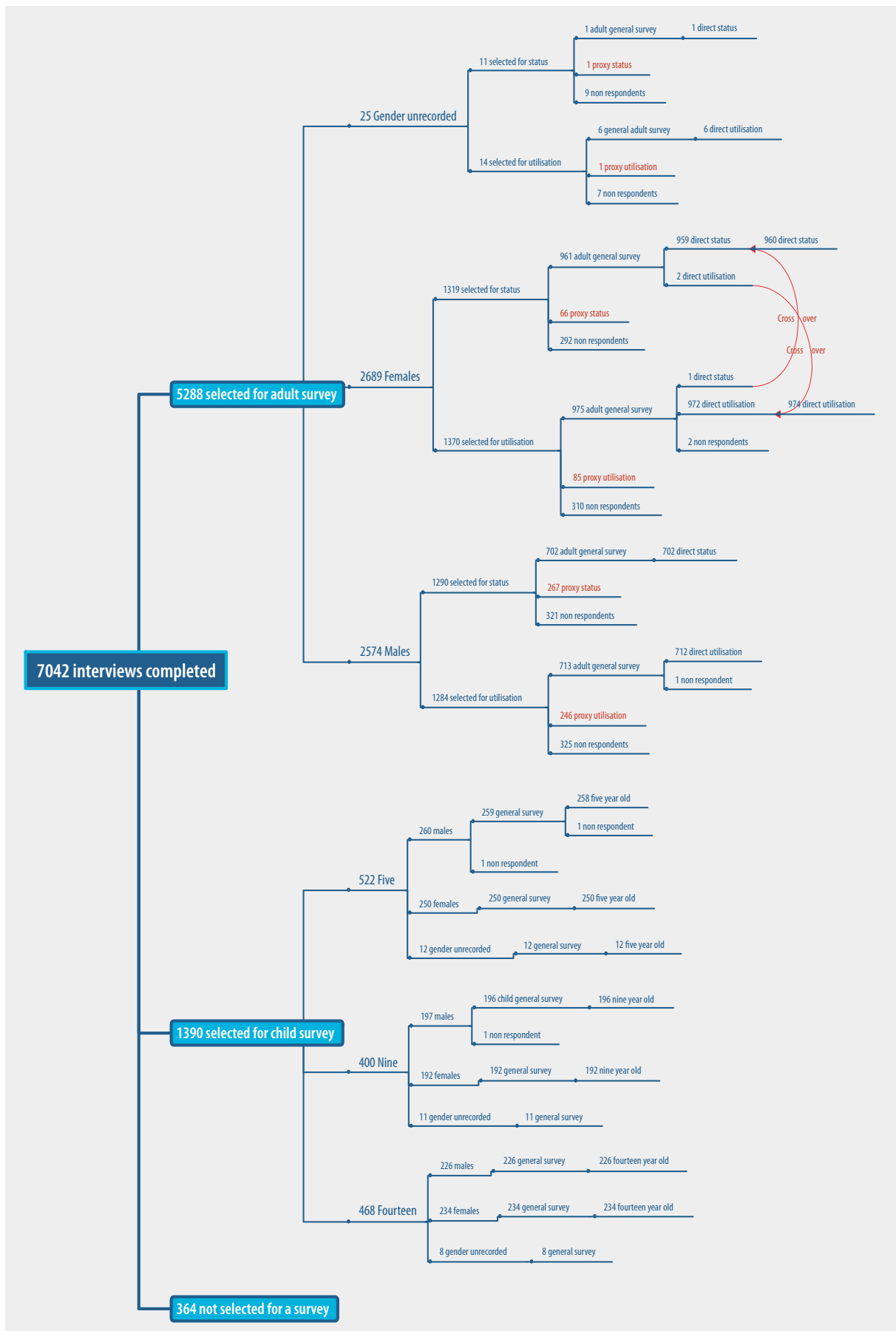
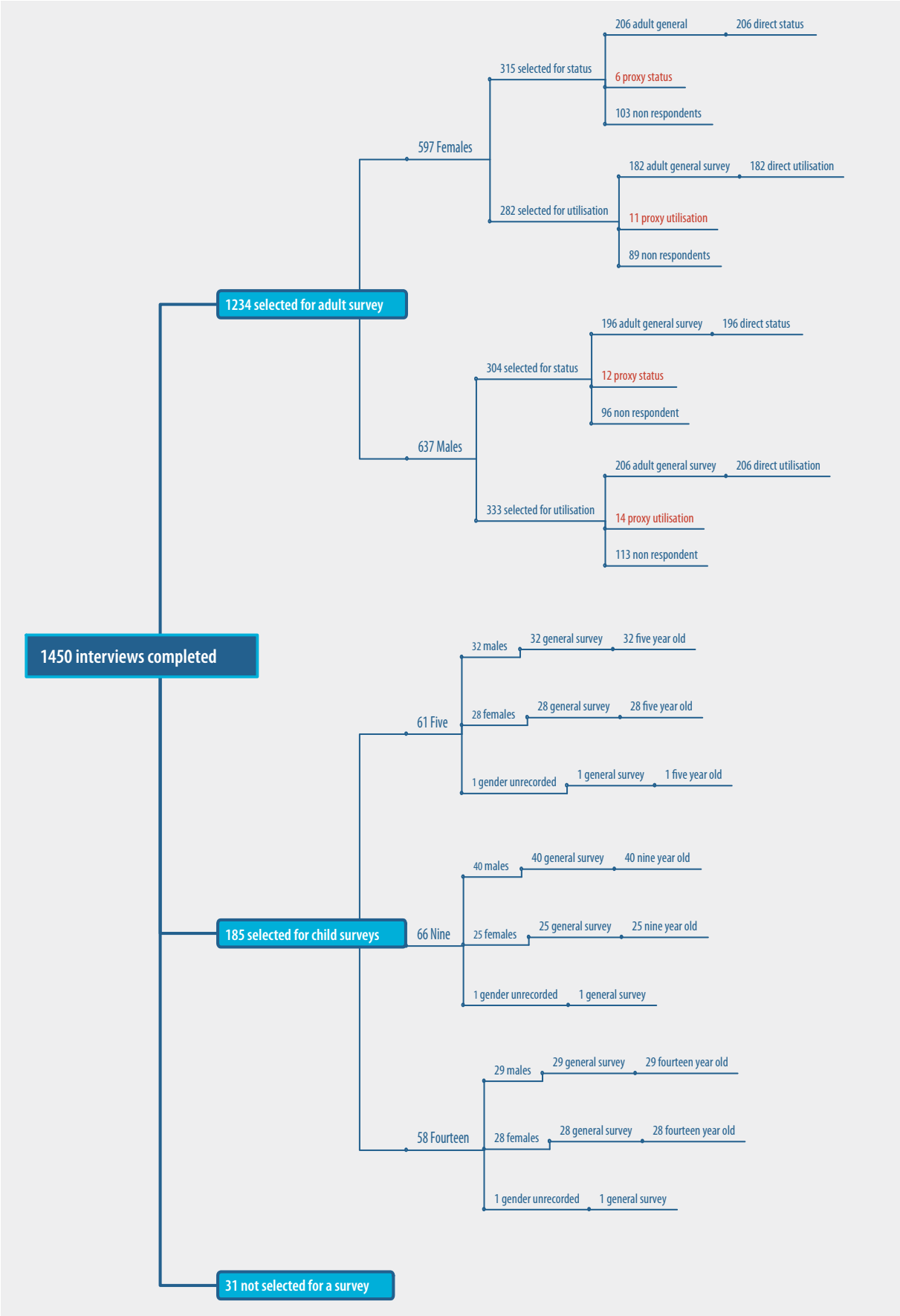


Figure 10: Northern Ireland Survey Response



Context of Findings: Comparable Datasets

The AITHS has provided a unique and comprehensive overview of the demographic, social, economic and health position of the Travelling community in Ireland, both in the Republic of Ireland (ROI) and Northern Ireland (NI). However, to adequately frame this picture in context, a comparative narrative is needed.

Social and Living Conditions of Traveller Families

General Summary

The majority of respondents, 75.9% in ROI and 94.3% in NI, lived in family units of 5 or less. Respondents most frequently lived in a house (73.3% ROI, 55.4% NI), followed by trailer/mobile home or caravan (18.2% ROI, 23.8% NI). In ROI housing was most frequently provided by a local authority (57.1%), whereas in NI accommodation was provided by the housing executive (50.9%). Most homes comprised 2 to 4 rooms (78.8% ROI and 82.9% NI). Most of the houses and flats had central heating (92.9% ROI and 95.8% NI). Most accommodation had both hot and cold water, (94.4% ROI and 85.6% NI), an individual bath or shower (63.7% ROI and 78.5% NI), and flush toilet (91.6% ROI and 84.4% NI).

Rubbish collection was weekly in 61.6% of ROI families but fortnightly for most NI households (70.9%). Most also received post delivered to their home (96.9% ROI and 90.7% NI), which arrived regularly in 97.5% of households in both jurisdictions. In ROI 23.3% of families and 18.0% families in NI had no transport. A majority in both jurisdictions (56.8% ROI and 62.3% NI) said they last moved for personal choice, the next most frequent reason being better facilities (39.7% ROI and 26.1% NI).

Considerable numbers of families who lived in Group Housing or sites reported a lack of footpaths, public lighting fire hydrants and safe play areas, the latter being unavailable for 77.5% of ROI and 79.9% of NI respondents. A quarter of families (24.4% ROI and 24.8% NI) considered where they lived to be unhealthy or very unhealthy and again appreciable numbers (26.4% ROI and 29.0% NI) considered their place of residence unsafe.

Difficulty in reading and filling out forms was reported by 28.8% of ROI families and 35.3% of those in NI but 95.5% of ROI and 89.8% of NI family respondents could calculate change from a Euro or pound note as relevant. In the past year 78.5% of ROI and 62.6% of NI families had not travelled at all, and of those who did, this occurred most frequently in the summer period in both jurisdictions, peaking in June and July.

In ROI 42.0% and in NI 46.0% of families reported that they often or very often felt discriminated against. Religion or faith was ranked as very important by 83% in ROI and 78.6% in NI, with high ratings of importance given to Traveller culture, identity and community membership also. Nomadism

was ranked fifth in both jurisdictions, rated as very important by 53.9% of ROI families and 39.3% of NI families. The overwhelming majority are Roman Catholics: 98.0% in ROI and 96.7% in NI. Most respondents either had a general medical services card, 94.1% in ROI, or were registered with a GP 94.9% in NI. Of those in ROI without a card, ineligibility was the main reason (49.6%), whereas in NI, the most frequent reason was having recently moved (47.8%).

Commentary

The AITHS census provides unique information pertaining to the living conditions of the Traveller community. Comparable data from the general population is available from the 2006 Irish Census (Central Statistics Office, 2007a). Analyses according to type of accommodation have been included in the body of the report.

81.1% of Travellers in ROI and 87.4% of Travellers in NI, who lived in a house or flat, had 4 or fewer rooms in their home, compared with 25.1% of all private permanent households in the 2006 Census. In total, 12.8% of Travellers in ROI and 2.6% of Travellers in NI, who lived in a house or flat, reported owning their own home, compared with 70.3% (359/510) of the Lifeways study's medical card holders. The majority of Traveller families have basic household amenities such as flush toilets, running water and postal and rubbish services. Nevertheless, in a 21st century developed economy, there remain Traveller families without such amenities, in disproportionately greater proportions than the general population.

Access to motor vehicles is similar in the Traveller and general comparable populations, with more Travellers having access to cars and vans than a population sample of persons at relative socioeconomic disadvantage, e.g. Lifeways medical card holders (Table 4). In data from the SLAN 2002 medical card holders, 64.9% of persons use a car to go shopping.

Table 4: Family access to a car or van, in AITHS and Lifeways

	ROI Travellers (n=6,992)	NI Travellers (n=1,438)	Lifeways medical card holders (n=510)
Access to a car and/or van	76.7%	82.0%	68.0%
Use a car to go shopping	70.2%	69.9%	63.1%

Self-report of literacy varies markedly between the Traveller and general population groups (Table 5), with more Travellers expressing difficulty with day-to-day literacy issues. Comprehension of the written instructions provided with prescription medicines, providing a measure of practical and functional literacy, is poor in the Traveller group. This would constitute a significant health concern.

Table 5: Self-reported literacy ability in the AITHS and Lifeways Studies

	Travellers (ROI) (n=6,938)	Travellers (NI) (n=1,431)	Lifeways medical card holders (n=498)
Can usually read and fill out forms	71.2%	64.7%	92.4%
Of those who can read and fill out forms, can do them but with difficulty	13.9%	23.2%	7.0%
Can calculate change from €/£5 or €/£10 note	95.5%	89.8%	99.0%
Of those who can calculate change, can do it but with difficulty	6.1%	14.5%	4.9%
Of those who take prescription medications, have difficulty reading the instructions	49.6%	62.6%	9.4%*

*Data derived from the SLAN 2002 medical card holders, since this variable was not present in Lifeways

Religion may be more important to the Travellers than to the general comparable population. Religion is 'important' or 'very important' to 89.4% of ROI Travellers and 85.3% of NI Travellers, compared with 68.6% of Lifeways medical card holders. Among the medical card holders in SLAN 2002, 93.3% of participants who provided a valid response indicated that they belonged to a religion. Whilst there was no direct measure of importance of religion in SLAN, 35.8% of respondents indicated that they regularly attended church or parish activities, or that they were involved in charitable or voluntary organisations.

Child Health (All Children)

General Summary

Information was collected on 1,380 children in ROI: 521 5-year-olds, 399 9-year-olds and 460 14-year-olds. In NI, a total of 183 child health interviews were conducted with the adult respondents, with 61 responses for 5-year-olds, 65 for 9-year-olds and 57 for 14-year-olds.

The majority (64.6% ROI and 55.7% NI) of both male and female children were reported as weighing between 3 and 4 kg at birth. Older children in a family tended to have been relatively lighter at birth than the subsequent offspring. Most children (56.9% ROI and 65.9% NI) were born at full term (i.e. between 37 and 41 weeks of gestation), a pattern similar according to age and sex in both jurisdictions. The breastfeeding rate for children overall was 5.6% in ROI and 7.1% in NI.

In ROI and NI, 90.3% and 97.3% of children respectively were reported as having no ongoing health problem. For those children who had a health problem, the number one reported condition was asthma, which accounted for 71.9% of reports of chronic conditions in childhood in ROI. There were much lower rates reported for other conditions, including inborn errors of metabolism. Patterns were similar for both male and female children, with asthma the most frequently reported adverse chronic health condition in each age group. Chest infection was the most commonly cited recent acute condition. Around a quarter of children (22.9% ROI and 26.0% NI) were reported to have ever had an accident, boys more frequently than girls in ROI but not in NI and older children more frequently than younger ones. The most frequently reported type of injury in both ROI and NI was a fall.

41% of Traveller children in ROI and 47.6% in NI had visited a hospital Accident and Emergency Department (A & E) in the previous 12 months, and 36.5% of children in ROI and 43.9% in NI had done so on 1 to 3 occasions. Again the gender and age group variation was small.

10% of children in ROI and 7.8% in NI had stayed at least 1 night in hospital in the last year, with little variability according to age group or sex. The most frequent length of stay was 1 to 3 nights, as indicated by 66.7% of those hospitalised. Younger children had the shortest length of stay. The most frequent indications for admission were infectious conditions, including fever or viral conditions, asthma and other non-surgical conditions.

Both in ROI (58.4%) and in NI (58.5%), a majority of mothers reported adding regular salt to their child's food while cooking. In ROI 26.8% and in NI 43.7% reported that their children ate five or greater portions of fruit and vegetables daily.

Commentary

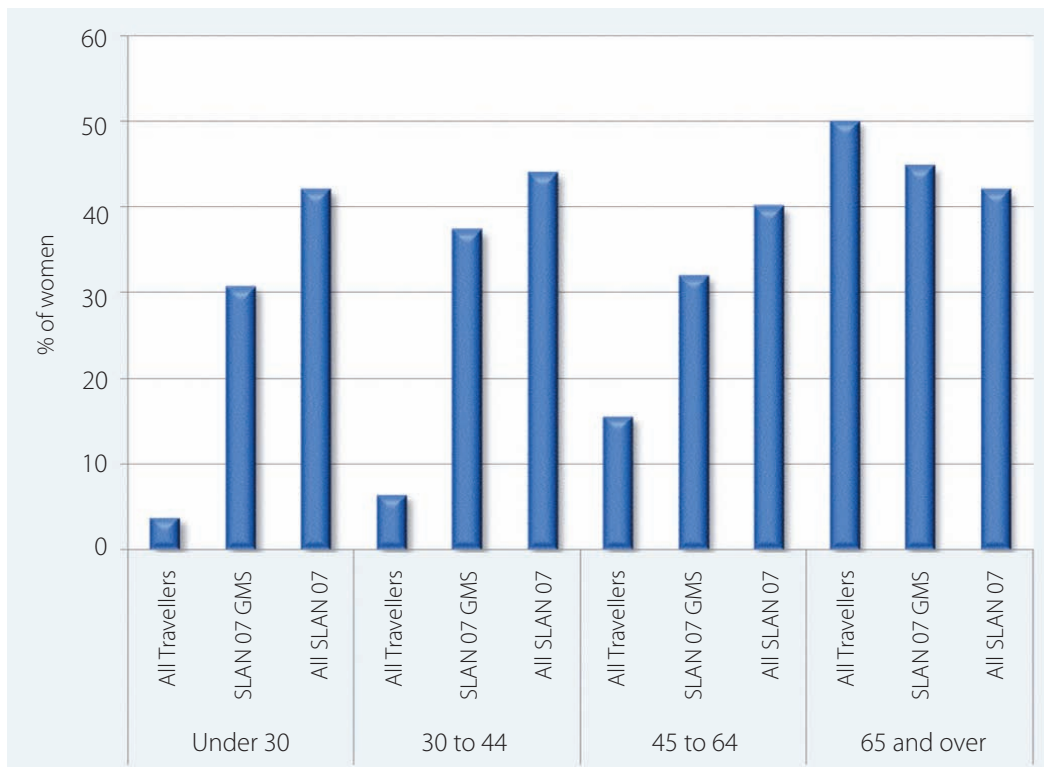
The AITHS surveyed specific age groups of children (5, 9 and 14-year-olds) because comparable Irish data on these ages were available. The following comparisons are drawn from three sources of data on Irish children: for the 5-year-olds: the 5-year-old children of the medical card holders in Lifeways; for the 9-year-olds: the Middle Childhood Study of children aged 9-10 from the HBSC 2006 study (Kelly *et al.*, 2008) and the 9-year-old survey from the NLSC/GUI (focusing on the children in social class 5 and 6 where possible); and for the 14-year-olds: the HBSC 2006 data on 12-14-year-olds. Infant birth weight as described in the AITHS and Lifeways studies is shown in Table 6. In the 2007 Irish Perinatal statistics (ESRI, 2009), 68.7% of newborn infants weighed between 3 and 4 kg. ROI Travellers had a higher prevalence of low birth weight infants than did the general population.

Table 6: Birth weight of the survey child

Infant weight	Traveller (ROI) (n=1,223)	Traveller (NI) (n=157)	Lifeways medical card (n=188)	ESRI 2007 national perinatal statistics (n=69,318)
<2500g	6.1%	4.5%	2.1%	3.7%
≥ 4000g	15.3%	14.0%	17.0%	16.7%

Breastfeeding rates amongst the AITHS groups are very low. Breastfeeding is notably low in younger Traveller women. This is in comparison with the under-30s medical card holders in SLAN 2007, who have breastfeeding rates only somewhat lower than the other ages in that social class group. From the NLSC, 29.5% of the 9-year-old study children were ever breastfed in the survey of mothers in SC 5-6 group (1,831/6,202 respondents). From the 2005 NI Infant feeding survey (Bolling, 2006), 63% of NI mothers from the general population initiated breastfeeding in 2005. Figure 11 shows the breastfeeding rates in women in the AITHS and SLAN studies who have had at least 1 child, by age of the woman at the time of interview. It is notable that older Traveller women had substantially higher rates of breastfeeding.

Figure 11: Number of women who report having breastfed any child, of the women who have had a child, in the AITHS and SLAN studies



In total, 90.3% of ROI and 97.3% of NI Travellers reported that their child did not have an ongoing chronic health problem, illness or disability. From the 2008-2009 NI Continuous Household survey, 94% of children in the general NI population and 90.9% of the NI children of semi-skilled or unskilled workers also reported no long-term illness. Asthma was the commonest reported chronic health condition in Traveller children, and this finding is similar to recent data from the general Irish population. A recent report (Manning *et al.*, 2007) indicates that 21.6% of 13 to 14-year-old children in the general ROI population reported ever having asthma.

Parents in the AITHS were asked to rate their child's current health (Table 7). There are more 'Excellent' ratings in the AITHS groups than in the comparative datasets, although the different methods of data ascertainment in the HBSC study must be borne in mind. In the HBSC, data were collected from the children themselves, not their parents or guardians, as in the AITHS.

Table 7: Rating of the child's current health, in the AITHS, Lifeways and HBSC, by age

	5-year-olds			9-year-olds			14-year-olds		
	Travellers			Travellers			Travellers		
Rating of health	ROI (n=520)	NI (n=61)	Lifeways (n=177)	ROI (n=386)	NI (n=65)	HBSC 9-year-olds in SC 5-6 (n=333)	ROI (n=459)	NI (n=55)	HBSC 12-14-year-olds in SC 5-6 (n=907)
Excellent	45.4%	42.6%	28.8%	55.4%	46.2%	40.2%	52.9%	54.5%	34.4%
Very good and/or good	48.4%*	49.2%*	67.8%*	39.4%†	43.1%†	54.1%†	40.1%†	40.0%†	54.5%†
Fair or poor	6.2%	8.2%	3.4%	5.1%	10.8%	4.8%	7.0%	5.5%	11.1%

*Composite of "Very Good" and "Good" answers

†"Good" answer only, as there was no "Very Good" option in HBSC

In total, 22.9% of ROI Traveller children and 26.0% of NI children have ever had an accident that required hospital treatment. 26.5% of ROI and 23.8% of NI Traveller 9-year-olds have ever had such an accident, in comparison with 30.9% of 9-year-old NLSC/GUI children in SC 5-6. 42.7% of HBSC children in all social classes reported an accident which 'required treatment from a doctor or nurse' in the last 12 months.

Regarding specific injuries, 16.7% of ROI and 16.7% of NI 5 year old Traveller children were reported to have ever had a burn or a scald, in comparison with no reported burns or scalds in the last 12 months in 199 5-year-old Lifeways children whose mother holds a medical card. 2.2% of ROI and no NI 5-year-old Traveller children were reported to have ever had an accidental poisoning, in comparison with 0.5% (9/199) Lifeways 5-year-old children, whose mothers hold medical cards, who had an accidental poisoning in the last 12 months¹.

The 5-year-old AITHS children from ROI are more likely to have stayed overnight in hospital, with 9.5% of ROI and 3.3% of NI 5-year-olds having been an inpatient for one or more days in the previous 12 months, in comparison with 2.3% of the Lifeways 5-year-olds whose mothers hold medical cards. In the last 12 months, 6.0% of ROI AITHS children and 10.6% NI AITHS children were reported to have not received medical care for a problem that needed attention, compared with 2.8% of NLSC/GUI 9-year-old children in SC 5-6. In the NLSC/GUI, 9.1% of the parents of this 2.8% indicated that this was because they could not pay for the care, compared with 19.1% of ROI Travellers and 28.6% of NI Travellers

¹ It should be noted however that there are a number of limitations in these comparisons of accident incidence. Firstly, the items collected vary with regard to time scale. For the HBSC and Lifeways studies, data were collected on accidents in the last 12 months, and in the AITHS and NLSC/GUI, data were collected on whether the child had ever had an accident. Second, the AITHS and NLSC/GUI items related to hospital treatment, whereas the HBSC item related to doctor or nurse treatment. Third, as already stated, the methodologies vary somewhat between the studies, in that AITHS, Lifeways and selected NLSC data were collected from parent or guardian report, whereas the HBSC was collected by child report.

who indicated that their children did not receive care because of this reason. This disproportionate healthcare threat to Traveller children is notable. Given the high number of medical card holders in the Traveller community, this is an unexpected finding, but it may reflect the number of Travellers whose medical cards are not current or are in the process of being applied for.

With regard to specific medical problems, Table 8 shows the relative frequencies of sight, hearing and speech problems within the 5-year-olds in the AITHS and the Lifeways medical card holder families, while Table 9 shows these frequencies in the 9-year-old AITHS children and the 9-year-old SC 5 or 6 children in the NLSC/GUI². The Traveller groups report higher rates of such problems than are the comparable populations.

Table 8: Ever had or has a specific health problem, in the 5-year-old group

Health concern	ROI Travellers (n=507)	NI Travellers (n=60)	Lifeways medical card holders (n=199)
Eye problem	15.5%	23.3%	5.4%
Hearing problem	12.4%	11.9%	4.3%
Speech problem	15.1%	18.6%	9.8%

Table 9: Ever had or has a specific health problem, in the 9-year-old group

Health concern	ROI Travellers (n=388)	NI Travellers (n=64)	NLSC SC 5-6 (n=1,114)
Eye problem	17.6%	28.2%	17.1%
Hearing problem	12.9%	22.3%	8.3%
Speech problem	13.5%	18.8%	7.5%

² The different prevalences of problems noted may be partly explained by the different data items collected. In AITHS, the parents were asked whether the child ever had or currently has an eye, hearing or speech problem; in NLSC/GUI, the parents were asked if the child ever had a sight or hearing or speech problem which needed correction, and whether the child had a speech problem; and in Lifeways, the parents were asked whether the Lifeways child had these issues as 'ongoing problems'. The definition of the eye, hearing or speech problem in question was left to the parent or guardian's own interpretation in all 3 studies.

5-year-old Child Health

General Summary

A majority (74.6% in ROI and 80.3% in NI) of mothers rated their 5 year-old's health as either excellent or very good, and the pattern did not differ for males and females. Almost all (96.1% in ROI and 93.4% in NI) reported receiving needles or vaccinations, peaking at 12-15 months.

Most also reported their children washed their teeth at least daily (94.8% in ROI and 93.4% in NI), again comparable among sexes. Only around a third of children in ROI (36.4%) had seen a dentist in the last 12 months, compared to 78.7% in NI.

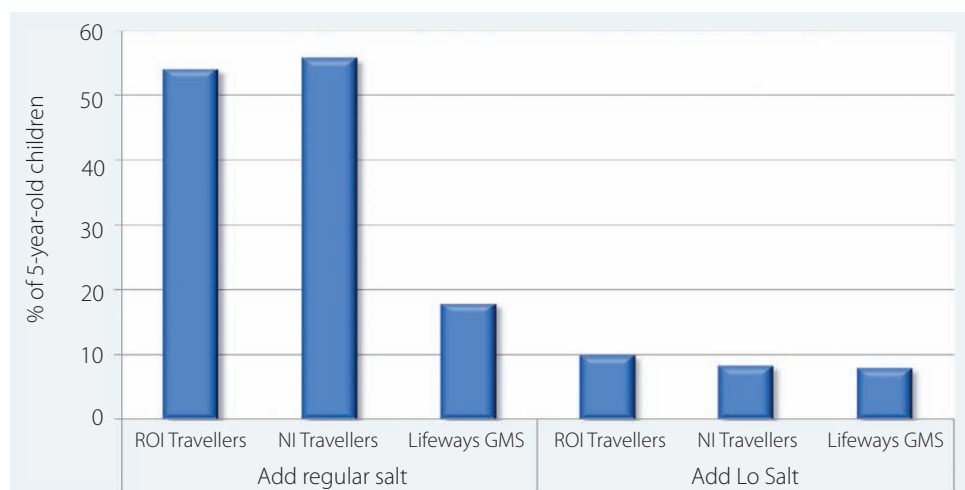
9 out of 10 children of both sexes had already started primary school in both ROI and NI. Similarly, 9 out of 10 children had their first meal of the day between 7 and 9 a.m. (90.9% ROI and 91.7% NI). Most children were reported as in the normal weight range (93.2% ROI and 82.0% NI). A majority of children were reported as eating most things (57.8% ROI and 66.7% NI, whilst a fifth in ROI (20.5%) and a tenth in NI (11.7%) were described as fussy eaters.

Commentary

Comparable data were available on 199 Lifeways 5-year olds whose mothers held medical cards. Similar numbers of Lifeways 5-year-olds surveyed had started primary school (87.2% vs. 90.1% of ROI and 90.2% of NI Traveller 5-year-olds). Compared with 7.6% of Lifeways parents, 4.5% of ROI Travellers and 6.6% of NI Travellers thought that their 5-year-old was underweight. In contrast, 2.3% of ROI Travellers and 11.7% of NI Travellers thought that their child was overweight, compared with 8.2% of Lifeways parents.

Regarding diet, most Traveller children and Lifeways children were deemed to eat a reasonable variety of foods, with 20.5% of 5-year-old ROI Traveller children, 11.7% of 5-year-old NI Traveller children and 20.7% of 5-year-old Lifeways children described as 'picky eaters'. Parents add salt to their child's food in the Traveller group more frequently than in the Lifeways group (Figure 12).

Figure 12: Usually add salt to child's food while cooking, in the AITHS and Lifeways 5-year-old group



9-year-old Child Health

General Summary

A majority of mothers (94.8% in ROI and 89.3% in NI) reported the health of their 9-year-old children as excellent or very good.

Most (81.4% in ROI and 78.2% in NI) brushed their teeth at least daily. In ROI 60.9% and in NI 76.9% of children had been seen by a dentist in the last 12 months. Just 2.4% in ROI and 3.1% in NI were reported as smokers. In ROI 84.9% of children were reported as always wearing a seatbelt, compared to 65.6% in NI.

Around one fifth of 9-year-olds (22.9% ROI and 18.5% NI) had access to a computer, most of these, both male and female, used it a little of the time only. There was wide variability in number of days children were active for at least an hour daily; just under half (48.6%) were active 7 days in ROI, and 25.4% in NI. In ROI 24.6% were reported to have a mobile phone and in NI 52.3%. Almost all watched TV (including videos and DVD) regularly, the majority spending between 1 to 5 hours per day on weekdays and at weekends also.

Most children (92.5% in ROI and 84.6% in NI) had their first daily meal between 7 and 9 a.m. and most reported daily breakfast during school week (79.9% ROI and 64.9% NI) with higher rates at weekends. Whilst fruit (34.6% ROI and 36.9% NI), and vegetables (29.0% ROI and 24.6% NI) were reported as being eaten more than daily by respondents, diet fizzy drinks (45.9% ROI and 39.3% NI) and fish (27.9% ROI and 43.5% NI) were never consumed by appreciable numbers. Sweets, crisps and chips were consumed on several occasions weekly.

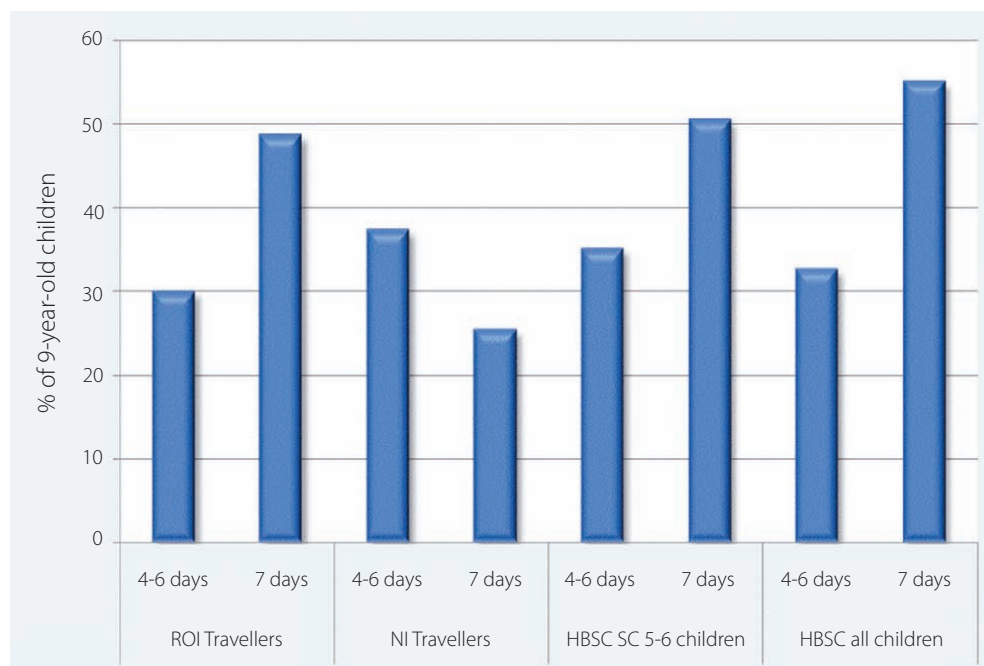
Many parents thought their children were always fit and well (65.2% ROI and 71.9% NI), and not at all sad (49.1% ROI and 51.6% NI) or lonely (64.8% ROI and 62.5% NI). Most felt they got on well at school (63.7% ROI and 62.9% NI). There were few appreciable differences according to gender. Whilst the majority of parents did not think their child had been picked upon in the last year, appreciable numbers (22.5% ROI and 22.2% NI) said that they had been. A majority (58.4% ROI and 61.9% NI) felt it was always safe for children where they lived and a majority (76.3% ROI and 96.7%) reported their children had a network of up to 10 friends. Over 95% of families in both jurisdictions reported they had eaten together, visited relations, sat and watched TV or chatted in the last week.

Commentary

In total, 69% of the 9-year-old children in SC 5-6 in the NLSC/GUI study were judged by their parents to be very healthy, and 29% were judged to be healthy, but with a few minor problems. 89.8% and 91% of 9-year-old children in SC 5-6 in the HBSC study and the lowest income group in the NLSC/GUI study respectively brush their teeth daily or more than daily, compared with 81.4% of ROI and 78.2% of NI Traveller 9-year-olds. Similarly few children in this age group have tried smoking tobacco in the HBSC SC 5-6 9-year-olds (3.0%).

Use of a seatbelt varies. From the HBSC SC 5-6 9-year-olds, 86.8% always use a seatbelt when they sit in a car, compared with 84.9% of ROI but only 65.6% of NI 9-year-old Travellers. Physical activity is shown in Figure 13. The NI children appear to be less active than ROI and HBSC children, though the numbers in NI are small. From the NLSC/GUI 9-year-olds, of all children surveyed, only 3% were not physically active for at least one hour on one day of the week, compared with a similar proportion in ROI Travellers (3.4%). Again, substantially more NI AITHS 9-year-olds were not physically active (6.8%).

Figure 13: Percentage of 9-year-old children who are physically active for a least an hour a day, by number of days of activity per week



Fewer 9-year-old children in the HBSC SC 5-6 group report eating fruit and vegetables, than do parents of 9-year-olds in the AITHS; only 22.8% of HBSC SC 5-6 9-year-olds report eating fruit more than once a day, and fewer again (15.9%) report eating vegetables more than once a day. 34.3% of ROI Traveller 9-year-olds and 7.7% of NI Traveller 9-year-olds eat sweets once or more a day, compared with 25.5% of HBSC 9-year-olds in SC 5-6, 23.3% of ROI Traveller 9-year-olds and 12.4% of NI Traveller 9-year-olds drink sugary, fizzy drinks once or more a day, compared with 17.1% of HBSC 9-year-olds in SC 5-6. 5% of 9-year-olds in the NLSC/GUI lowest income group did not have breakfast regularly, compared with 10.3% of ROI and 19.3% of NI 9-year-olds, who had a weekday breakfast 2 or fewer days a week.

Of the NLSC/GUI 9-year-olds, 89% had a computer in their home. This compares with 22.9% of ROI and 18.5% of NI Traveller children.

Regarding the issue of bullying, 40% of NLSC 9-year-olds self-reported that they had been bullied or picked on in the last year. However, by maternal report in NLSC/GUI, prevalence of bullying in the last year was 23.4%, comparable with parental report of bullying in 22.5% of ROI and 22.2% of NI Traveller 9-year-olds. In the HBSC study of 9-year-old children in SC 5-6, 50.5% of the children reported that they had experienced bullying at school in the last few months. In contrast, 22.5% of ROI Traveller 9-year-olds and 22.2% of NI 9-year-olds had been picked on by an adult or a child in the last 12 months, by parental report.

Less than 1% of children in the ROI and no children in the NI AITHS 9-year-olds are reported to have less than one close friend, compared with 8% of NLSC 9-year olds (Table 10). These findings may be consistent with the strong emphasis given to community in the Traveller culture. 95% of NLSC/GUI 9-year-olds agreed that they felt safe in the area where they live. Parental report regarding the AITHS 9-year-olds described that 93.6% of NI but only 85.2% of ROI children feel safe most of the time or always.

Table 10: Number of close friends in the AITHS and NLSC/GUI 9-year-olds

Number of close friends, by parental report	ROI Traveller 9-year-olds (n=384)	NI Traveller 9-year-olds (n=60)	NLSC/GUI 9-year-olds (n=8,570)
0-1	0.8%	0.0%	8%
2-3	14.3%	31.7%	41%
4 or more	84.9%	68.3%	51%

14-year-old Child Health

General Summary

In ROI 93.0% and in NI 94.5% of parents rated their child's health as excellent or good.

The majority (88.4% in ROI and 87.5% NI) brushed their teeth once or more than once daily. In ROI 59.4% and in NI 71.4% of children had seen a dentist in the last 12 months. Rates of ever smoking tobacco were 6.3% in ROI and 9.1% in NI. Overall, the vast majority, nine-tenths, of children were reported not to drink alcohol. Boys were somewhat more likely than girls to have tried various alcoholic beverages, particularly beer, with 8.3% of boys in ROI consuming it rarely and 3.2% more frequently than that. In ROI 82.3% and in NI 64.8% reported that they always used a seatbelt.

Physical activity for at least an hour daily, every day, was reported by 39.6% of ROI and 15.7% of NI 14-year-olds. As with the younger respondents, boys were more likely to report higher activity levels. A majority in both jurisdictions of both boys and girls watched television (including videos and DVDs) for between 1 and 5 hours daily. In ROI 39.6% and in NI 31.1% reported no regular daily access to a computer.

The majority (89.0% in ROI and 68.4% in NI) had their first daily meal between 7 and 9 a.m., whilst 72.7% in ROI and 83.7% in NI had breakfast 5 days a week, higher at weekends. There was a wide spectrum in consumption patterns of various foods and beverages, ranging from never to more than once daily. In ROI 27.8% of children consumed fruit and 28.8% vegetables more than once daily, whilst 16.4% had sugary drinks and 21.4% had sweets more than once daily. Fish were never consumed by 24.6% of children. Crisps and chips were consumed regularly across the week. The patterns between males and females were not notably different. In NI, most children consumed fruit (56.3%) and vegetables (60.0%) at least daily and 26% sweets. Fish consumption was again rare, with 29.1% never eating it.

School attendance was 89.2% overall in ROI and 72.3% in NI. Higher numbers in NI were attending training centres (17.5% compared with 6.2% in ROI) and comparable for males and females.

In relation to measures of social support and networks, patterns were generally positive with some differences between boys and girls. For instance 61.7% of males in ROI were reported as always fit and well and 60.4% were always full of energy compared to 54.1% and 53.1% of girls on respective measures. Conversely more girls (54.6%) were reported as always getting on well at school than boys (46.2%).

Most parents (83.9% in ROI and 83.0% in NI) indicated that their child had not been picked upon at all in the last year, but an appreciable minority indicated this had occurred, slightly less so in the case of boys (13.9% and 7.7%) than girls (18.3% and 25.9%). A majority of respondents (60.9% in ROI and 60.0% in NI) considered their child always feels safe in the area where they live.

Respondents indicated strong networks for their child, 76.9% of whom stated they had up to 10 or more close friends, a similar situation for both boys and girls. A majority of 14-year-olds communicated with their friends by phone or text, 50.8% in ROI and 63.0% in NI reporting they did so daily.

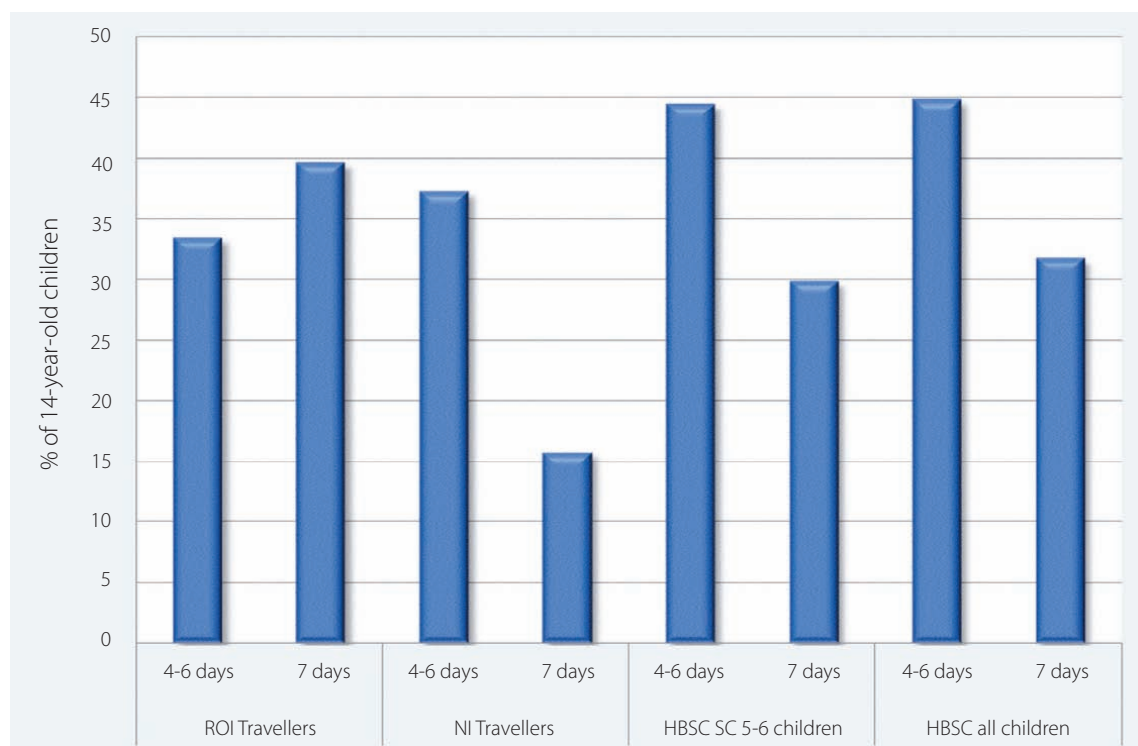
Commentary

Fewer HBSC SC 5-6 12-14-year-old children rated their health as 'excellent', in comparison with the parental report of the health of the 14-year-old Traveller children (34.4% vs 52.9% in ROI and 54.5% of NI Travellers).

91.1% percent of 12 to 14-year-old children in SC 5-6 in the HBSC study brush their teeth daily or more than daily, compared with 88.4% of ROI and 87.5% of NI Traveller 14-year-olds. Only small numbers of Traveller children have tried tobacco in this age group, compared with 29.1% of HBSC 12 to 14-year-old children in SC 5-6. At age 14, by parental report, 92.6% of ROI Travellers and 91.1% of NI Travellers never drink alcohol, compared with 76.7% of HBSC 12 to 14-year-olds in SC 5-6. However, it should be once again noted that HBSC data is gathered by child report.

Of the HBSC SC 5-6 12 to 14-year-olds, 78.8% always use a seatbelt when they sit in a car, compared with 82.3% of ROI and only 64.8% of NI 14-year-old Travellers. Physical activity is shown in Figure 14. Once again, as in the 9 year old group, the NI children are less active than the ROI and HBSC children, although the absolute number of respondents in this NI group are small.

Figure 14: Percentage of 14-year-old children who are physically active for a least an hour a day, by number of days of activity a week



On weekdays, more Travellers regularly have breakfast than HBSC children. 72.7% of ROI and 83.7% of NI Traveller 14-year-olds have breakfast every morning, compared with 68.8% of HBSC social class 5-6 12-14-year-olds. Self-report of fruit and vegetable consumption is lower in the HBSC sample than in the parent-reported AITHS. 44.0% of ROI Traveller 14-year-olds and 61.1% of NI Traveller 14-year-olds eat 4 or more portions of fruit and vegetables a day, compared with HBSC 12 to 14-year-olds in SC 5-6, only 19.0% of whom report eating fruit more than once a day, and 16.3% of whom report eating vegetables more than once a day.

At least daily consumption of sweets is reported in 32.1% of ROI Traveller 14-year-olds and 26.0% of NI Traveller 14-year-olds, compared with 37.5% of HBSC 12 to 14-year-olds in SC 5-6. Consumption of 'soft' drinks is similar between the groups; 27.9% of ROI Traveller 9-year-olds and 21.8% of NI Traveller 14-year-olds drink sugary, fizzy drinks once or more a day, compared with 26.5% of HBSC 12 to 14-year-olds in SC 5-6.

There are differences in methodology in reported child health between studies. The by-proxy reporting of child's health behaviour may over-estimate child's behaviour when reported by parents (van Roy *et al.*, 2010). Furthermore, Theunissen *et al.* (1998) state that by-proxy reporting may be over estimated at child-parent level, but is valid at group level. As stated in footnotes through the text, these caveats related to differing study methodology must be considered when evaluating the comparative data relating to the Child Health sub study.

Adult Health Status

General Summary

In ROI, 3,358 general adult interviews were conducted, 1,415 with men and 1,936 with women. A majority of adults indicated their health was either excellent (22.6%) or very good (27.8%). Males and females overall had a similar pattern but there was an inverse age-related gradient, with older adults less likely to rate their health as excellent or good and more likely to rate it as fair or poor.

In NI, 790 health interviews were conducted with adults, 402 with men and 388 with women. 50.4% of NI adults rated their health as either excellent or very good (14.9% and 33.8% respectively), with women more likely to rate their health as excellent (17.1%) than men (12.8%). Again there was an inverse relationship with age: the older the respondent the more likely to rate their health as fair or poor.

In ROI there were high rates of registration with a GP, 96.9% overall, with women slightly more likely to be so than men and there was a positive age gradient, the older the respondent, the more likely to be registered. Most respondents also had an up-to-date medical card (92.6%) overall, rising to 99% of those aged 65 years and older. In NI again, 93.9% were currently registered with a GP, rising to 100% of those aged 65 years and older. Access to services as measured by general practice availability north and south is therefore comprehensive. This was perhaps surprising, given the importance of this issue in the past, due to records transfer and registration problems. (O'Donovan, *et al.*, 1995). An appreciable minority of respondents in ROI (17.8%) indicated their daily activity or work was limited by long-term illness, more so in men (19.9%) than women (16.2%) and again, strongly age-related, rising to 40.7% of those 65 years and older. In NI 15.1% indicated their daily activity was limited by long-term illness or disability, also with an inverse age gradient, rising to 32.0% in the 45-64 year age group.

A number of different morbidities were reported. The commonest health complaint reported as being diagnosed by a GP in ROI was a back condition (30.4%). Reported diagnosis of angina was 4.3% overall, similar in both men and women, and positively related to age. Amongst those aged 65 years and older, rates were highest of heart attack (11.1%), angina (24.2%) and stroke (3.3%).

Most respondents of both sexes and in both jurisdictions had not been screened for cardiovascular risk factors in the last 12 months, though risk factor detection was age related and was undertaken predominantly by the GP in both ROI and NI. Of those tested a third of respondents in ROI (35.2%) had been diagnosed with high blood pressure in the last 12 months and a quarter (25.9%) had been diagnosed with high cholesterol. In NI 44.3% were diagnosed with high blood pressure and 36.8% with high cholesterol. This pattern too was positively age-related in both jurisdictions.

A third of respondents in ROI (31.3%) and 39.9% in NI were on some form of prescribed medication, rising in a graduated manner to 77.9% of those aged 65 years and older in ROI. In NI this rise was even steeper, applying to 82.1% of those aged 45 years and older.

Commentary

Travellers rate their general health in a more positive manner than populations such as SLAN 2002 and Lifeways, but in a similarly positive way to the SC 5-6 group from SLAN 2007 (Table 11). Of note however, is the high proportion of Traveller persons in the oldest age group who rate their health as fair or poor, in comparison with the other data sources. Overall, 18.9% of ROI and 13.9% of NI Travellers rate their health as fair or poor, similar to the 17% of all respondents in the available NI data (The Continuous Household survey, 2008-2009) who rated their health as 'not good' (versus 'Fairly Good' and 'Good').

Table 11: Self-rating of health

	Travellers (ROI) (n=3,344)	Travellers (NI) (n=787)	SLAN 2002 medical card holders (n=1,610)	SLAN 2007 medical card holders (n=3,439)	Lifeways medical card holders (n=510)	INSIGHT '07 medical card holders (n=1,277)
Under 30 years:						
Rate health as excellent or very good (%)	63.0%	61.2%	52.3%	61.6%	50.4%	72.5%
Rate health as fair or poor (%)	9.5%	6.5%	15.2%	10.0%	4.2%	6.9%
30-44 years:						
Rate health as excellent or very good (%)	61.4%	37.4%	47.1%	52.6%	55.8%	56.4%
Rate health as fair or poor (%)	16.7%	14.0%	18.0%	16.1%	15.6%	15.0%
45-64 years:						
Rate health as excellent or very good (%)	30.2%	31.0%	24.5%	32.7%	35.8%	32.9%
Rate health as fair or poor (%)	35.6%	33.6%	34.2%	36.1%	19.0%	32.9%
65 and older:						
Rate health as excellent or very good (%)	19.9%	20.0%	26.2%	30.7%	37.4%	29.1%
Rate health as fair or poor (%)	49.2%	66.7%	36.4%	34.3%	21.5%	35.0%

AITHS participants were asked whether their daily activity or work was limited by a long-term illness or disability. A similar item was collected in the SLAN and NI Continuous Household surveys, and comparative results are presented in Table 12. It can be seen that similar reporting frequencies are noted in the under-64 age groups, with some differences seen in the over-64 age group. From INSIGHT '07, 18.3% of all participants with medical cards reported a long-term illness that limited their daily activity.

Table 12: Percentage of respondents in the AITHS, SLAN 2007 and the NI Continuous Household Survey 2008-2009 who reported a limiting long-term illness

	Travellers (ROI) (n=1,622)	Travellers (NI) (n=390)	SLAN 2007 GMS participants (n=3,718)	NI Continuous Household Survey 2008-2009 (n=4,008)
Under 44 years	11.8%	12.4%	13.5%	12%
45-64 years	32.8%	32.0%	30.8%	27%
65 and older	40.7%	28.6%	27.3%	41%
Total	17.8%	15.1%	23.6%	24%

When it comes to more specific measures of general health, such as an estimate of days during which ill-health had an impact, the Traveller group appear to be in poorer health than the comparable populations (Table 13), although it is interesting to note that the SLAN 2002 medical card population have a higher rate of limitation by a long-term illness or disability.

	Male					Female				
	Travellers (ROI) (n=631)	Travellers (NI) (n=187)	SLAN 2002 medical card holders (n=656)	INSIGHT '07 medical card holders (n=538)	SLAN 2007 medical card holders (n=1,287)	Travellers (ROI) (n=834)	Travellers (NI) (n=190)	SLAN 2002 medical card holders (n=954)	INSIGHT '07 medical card holders (n=748)	SLAN 2007 medical card holders (n=2,158)
In the last 30 days...										
Physical health was not good for one or more days	62.0%	50.8%	35.6%	34.4%	-	60.6%	53.2%	30.5%	41.4%	-
Mental health was not good for one or more days	59.4%	58.6%	21.8%	13.5%	-	62.7%	55.1%	23.4%	19.9%	-
Poor physical or mental health restricted normal activities for one or more days	56.5%	48.7%	24.5%	29.2%	21.1%	56.2%	46.6%	23.3%	30.1%	19.6%
Daily work or activity was limited by long term illness or disability	19.9%	13.1%	36.6%*	24.2%	29.7%	16.2%	17.1%	24.6%**	19.2%	23.0%

*13.4% of general SLAN 2002 population

**12.1% of general SLAN 2002 population

Table 13: Impact of ill-health on last 30 days

Of the 1,260 INSIGHT '07 participants who were medical card holders, 97.5% of women and 95.5% of men were registered with a GP; whereas of all INSIGHT '07 participants (n=3,410), 87.9% of men and 92.8% of women were registered with a GP. Overall, Travellers are accessing health screening for cholesterol and high blood pressure at least as much as the SLAN 2007 GMS population (Table 14).

Table 14: Screening for high blood pressure and high cholesterol in the last 12 months

	Travellers (ROI) (n=1,928)	Travellers (NI) (n=394)	SLAN 2007 medical card holders (n=3,440)
Under 30 years:			
Screened for high blood pressure (%)	32.5%	28.6%	31.2%
Screened for high cholesterol (%)	20.7%	25.1%	15.0%
30-44 years:			
Screened for high blood pressure (%)	41.8%	57.6%	36.9%
Screened for high cholesterol (%)	33.3%	50.0%	24.0%
45-64 years:			
Screened for high blood pressure (%)	68.6%	71.4%	62.7%
Screened for high cholesterol (%)	61.6%	64.8%	52.9%
65 and older:			
Screened for high blood pressure (%)	85.1%	85.7%	74.3%
Screened for high cholesterol (%)	76.2%	100.0%	62.3%

Use of prescription medications is roughly similar in the Traveller and the other comparable populations. In the 45-64 year age group, 59.3% of ROI Travellers and 82.1% of NI Travellers are taking regular prescription medications, compared with 56.9% of Lifeways medical card holders and 65.0% of SLAN 2002 medical card holders.

Regarding the incidence of specific illnesses, the Traveller group appear to have a greater burden of chronic diseases than the general population (Table 15), with conditions such as back conditions, diabetes, and heart attack increased by a factor of 2 in the Traveller group, and respiratory conditions such as asthma and chronic bronchitis increased by a factor of 2-4, in comparison with the general SLAN population. However, when the Traveller population is compared with the medical card holders within SLAN 2007, the differences become less prominent.

Specifically considering cardiovascular risk factors, the excess burden of cardiovascular morbidity noted is also reflected in an excess of cardiovascular risk factors seen in the Traveller group, as compared with the SLAN 2002 medical card holders. For those Travellers who had their blood pressure and/or cholesterol checked in the last year, the number with a high level detected was overall higher than the number within SLAN 2002 and 2007 who reported having a high reading checked (Table 16). However, with respect to the unscreened Traveller population, clearly the true prevalence of these conditions is not known.

Table 15: Doctor-diagnosed illnesses, within the last 12 months, by comparative group

Illness	Travellers (ROI) (n=1,624)	Travellers (NI) (n=382)	SLAN 2007 general population (n=10,364)	SLAN 2007 SC 5-6 (n=3,445)
Back condition	30.4%	25.2%	16%	22.1%
Asthma	12.5%	25.7%	6%	8.9%
Chronic bronchitis*	12.0%	9.4%	3%	5.9%
Cancer	1.0%	0.3%	1%	2.8%
Arthritis**	13.8%	13.2%	11% [†]	28.1% [†]
Diabetes	6.1%	6.1%	3%	6.5%
Angina	4.3%	2.1%	2%	5.6%
Heart attack	2.3%	2.1%	<1%	2.3%
Stroke	1.1%	1.1%	<1%	2.2%

*Defined as Bronchitis or emphysema in AITHS and Chronic bronchitis in SLAN 2007

**Defined as arthritis in AITHS, and separate items for rheumatoid and osteoarthritis in SLAN 2007

[†]Combination of the reported incidences of rheumatoid and osteoarthritis

Table 16: Self-report of high blood pressure and high cholesterol in the AITHS respondents, and the SLAN 2002 and 2007 medical card holders ³

Illness	ROI and NI Travellers who reported having blood pressure or cholesterol screening	All ROI and NI Travellers who answered the adult health questionnaire	SLAN 2002 medical card holders	SLAN 2007 medical card holders
Self-report of high blood pressure	n=647	n=1,904	n=1,637	n=2,838
Under 30 years	17.9%	3.6%	5.3%	5.2%
30-44 years	31.3%	10.4%	9.7%	9.2%
45-64 years	49.3%	26.3%	24.0%	35.1%
Over 65	54.1%	38.5%	31.0%	36.0%
Total	36.5%	12.4%	23.3%	28.3%
Self-report of high cholesterol	n=669	n=1,869	n=1,637	n=2,657
Under 30 years	11.6%	2.4%	1.3%	1.9%
30-44 years	21.4%	7.7%	7.3%	13.0%
45-64 years	39.8%	22.6%	19.6%	30.3%
Over 65	46.1%	34.0%	15.0%	26.3%
Total	28.0%	10.0%	13.4%	22.8%

³ The data items from which these measurements are derived vary between the studies. For the AITHS, the numbers presented are the persons who reported having undergone screening in the last 12 months and who received a diagnosis of high blood pressure or high cholesterol, and these numbers are then presented as a percentage of all AITHS respondents in that age group. For SLAN 2002, the numbers presented represent the persons who reported doctor diagnosed high blood pressure or cholesterol at any time. For SLAN 2007, the numbers presented represent the persons who reported doctor diagnosed high blood pressure or cholesterol in the last 12 months.

Smoking, Alcohol and Illicit Drugs

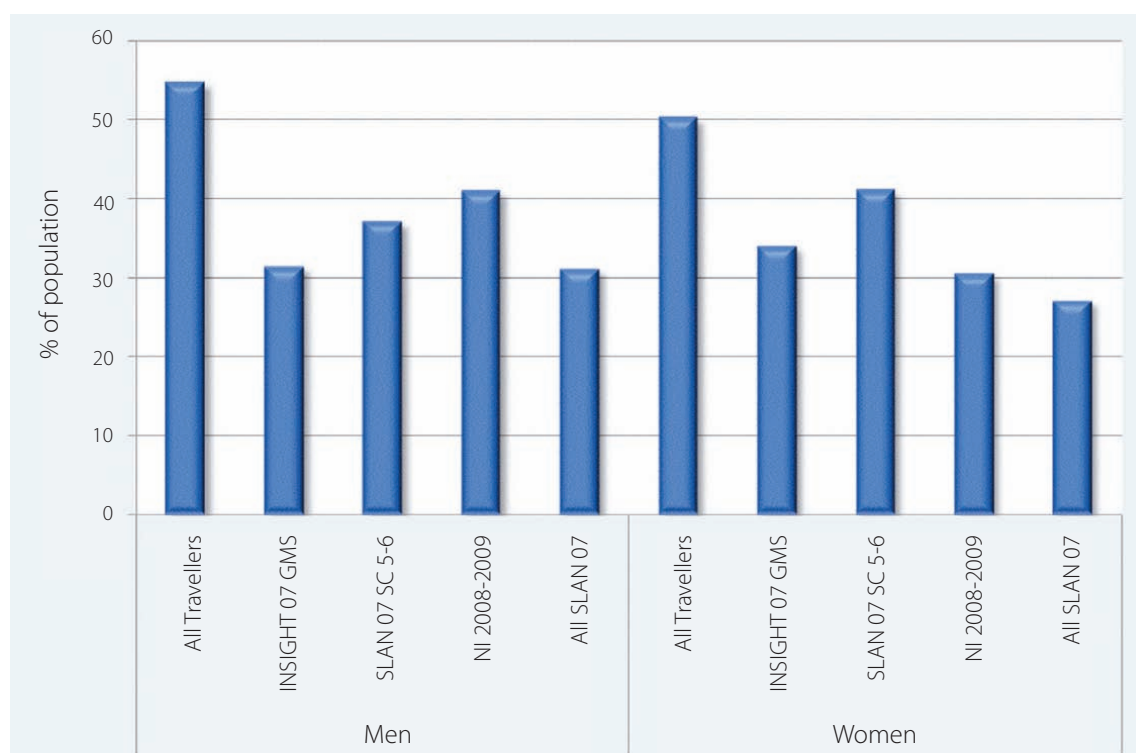
General Summary

Overall, 52.5% in ROI and 50.8% in NI were current smokers; 43.5% in ROI and 38.4% in NI were regular smokers, a further 9% in ROI and 12.4% in NI were occasional smokers and rates in men and women were comparable in ROI but somewhat lower in women (47.8%) than men (53.9%) in NI. Regarding alcohol consumption, 38.1 % of respondents in ROI and 39.3% in NI indicated they never drank, with rates of non-drinking being considerably higher in women than men. The lowest rate of never-drinkers (30.9% in ROI and 32.1% in NI) was in the 30 to 44-year-old age group. A majority of respondents (66.3% in ROI and 64.6% in NI) considered illicit drugs to be a problem in their community and this was a consistent pattern for both men and women and across age groups.

Commentary

There is a high prevalence of current tobacco smoking within the AITHS. This compares with current smoking in 37% of adults in social class 5 to 6 in SLAN 2007, 32.5% in the INSIGHT 2007 medical card holders, and 34% of all semi-skilled and unskilled workers in the 2008-2009 NI Continuous Household survey. Figure 15 shows the prevalence of current smoking by sex in the AITHS and comparable populations. Data from all SLAN 2007 participants is also included as a comparator with the wider population.

Figure 15: Current tobacco smoking in the AITHS, INSIGHT '07, NI Continuous Household survey 2008-2009 semi-skilled and unskilled workers and SLAN 2007 studies



The reported frequency of alcohol consumption in the AITHS is comparable to that of the medical card holders in SLAN 2007, and both groups have lower frequencies of consumption than do the general SLAN 2007 population. However, of those who do drink alcohol, the AITHS participants drink more alcoholic drinks than do SLAN 2007 medical card holders. 66.1% of male and 42.3% of female ROI Travellers and 65.6% of male and 39.3% of female NI Travellers drink six or more alcoholic drinks on days when they are drinking alcohol, compared with 35.8% of male and 17.0% of female SLAN 2007 GMS medical card holders (Table 17). From the 2008-2009 NI Continuous Household survey, 74% of all respondents drink alcohol, with 82% of 25-44-year-olds and 77% of 45 to 65-year-olds reporting alcohol consumption.

Table 17: Self-reported frequency of alcohol consumption in the SLAN 2007 and AITHS groups

	Travellers (ROI) (n=1,639)	Travellers (NI) (n=399)	SLAN 2007 medical card holders (n=3,428)	SLAN 2007 all participants (n=3,718)
Under 30 years:				
Never drink alcohol (%)	40.9%	45.4%	16.2%	11%
Drink >2 times per week (%)	9.3%	16.1%	26.7%	38%
30-44 years:				
Never drink alcohol (%)	30.9%	32.1%	19.6%	14%
Drink >2 times per week (%)	16.3%	29.1%	28.0%	38%
45-64 years:				
Never drink alcohol (%)	39.9%	35.8%	30.7%	21%
Drink >2 times per week (%)	17.6%	32.1%	30.3%	41%
65 and older:				
Never drink alcohol (%)	46.2%	28.6%	43.5%	41%
Drink >2 times per week (%)	14.3%	28.6%	25.1%	28%
Total				
Never drink alcohol (%)	38.1%	39.3%	32.7%	19%
Drink >2 times per week (%)	13.4%	22.8%	27.1%	38%

Safety

General Summary

Some 12% of respondents in ROI, and 8.1% in NI, reported one or more injuries serious enough to interfere with daily activities in the last 2 years. This finding was strongly age-related, rising to a 25.3% of the over-65 age group in ROI. Whilst the majority were accidental (65.7% in ROI and 78.1% in NI), there were an appreciable number of reported non-accidental injuries, particularly among women in ROI (38.8%) and in the middle-age groups. The most frequently cited location for an accident was in the home (42.9% in ROI and 51.6% in NI) and the pattern differed somewhat by sex and according to age group. Most were treated in accident and emergency service (40.6% in ROI and 34.4% in NI), followed by the GP (28.9% in ROI and 31.3% in NI), a similar pattern according to sex and age group.

A majority of respondents (88% in ROI but 63.5% in NI) overall and according to sex and age groups reported regular use of a seat belt while driving in a car or van.

Commentary

The Traveller groups appeared to have overall fewer injuries than the SLAN 2002 medical card holders group (Table 18). Notable is the high frequency of non-accidental injury in the Traveller groups, especially in ROI. Using a different questionnaire item, 7.6% of men and 6.7% of women of the SLAN 2007 medical card holders reported an injury in the last 1 year which necessitated a medical consultation (11% and 7% respectively in the general SLAN 2007 population: data not included in the table because of the variation in data items). Compared with 88% in ROI and 63.5% in NI, 84.6% of SLAN 2002 medical card holders reported that they always wear seatbelts whilst in the front of the car.

Table 18: Accidents in the last 2 years, in AITHS and SLAN

	Travellers (ROI)		Travellers (NI)		SLAN 2002 medical card holders	
	Male (n=692)	Female (n=943)	Male (n=191)	Female (n=203)	Male (n=626)	Female (n=921)
Suffered an accident in the last 2 years which interfered with daily activities	13.2%	11.1%	8.4%	7.9%	14.3%	16.5%
Most recent injury was non-accidental	29.3%	38.8%	25.0%	18.8%	5.6%	13.4%

General Exercise and Household Physical Activity

General Summary

Most AITHS respondents reported that they undertook physical activity fewer than 3 times per week, with reported rates of strenuous activity fewer than 3 times per week of 76.6% in ROI and 76.3% in NI, of moderate activity of 60.1% in ROI and 75.1% in NI and of mild activity of 55.6% in ROI and 67.4% in NI. Men were more active than women.

A majority of respondents (70.2% in ROI and 69.9% in NI) reported using a car to go shopping. Rates were comparable between men and women, but were inversely related to age, with older respondents less likely to use a car and more likely to go on foot.

A quarter of respondents (25.5% in ROI and 26.3% in NI) reported spending less than an hour per week watching television or playing computer games but most men and women and all age groups in both jurisdictions reported appreciable time doing so.

Commentary

The AITHS participants report overall more leisure time physical activity than do the medical card holders in SLAN 2002 and 2007, and the general population in SLAN 2002 (Table 19). In the SLAN 2002 general population, 72.3% of men and 76.4% of women use the car to go shopping, comparable with reported use in AITHS of 70.2% in ROI (70.6% in men and 69.9% in women), and 69.9% in NI (74.5% in men and 65.5% in women). Marginally lower car usage was described in the SLAN 2002 medical card holders: 64.2% in men and 65.3% in women.

Similar to the figures quoted in the AITHS, 30.8% of the SLAN 2002 general population and 22.8% of the SLAN 2002 medical holder population report watching less than 1 hour per week of television.

Table 19: Leisure-time physical activity by intensity of activity, for frequency of activity of 3 or more times per week in AITHS and selected SLAN studies

	Travellers (ROI)		Travellers (NI)		SLAN 2002 medical card holders		SLAN 2002 general population		SLAN 2007 medical card holders	
	Male (n=577)	Female (n=769)	Male (n=179)	Female (n=186)	Male (n=669)	Female (n=970)	Male (n=2,429)	Female (n=3,502)	Male (n=1,240)	Female (n=2,088)
Strenuous exercise	30.6%	17.6%	29.3%	17.8%	5.8%	3.2%	15.2%	6.6%	7.3%	4.2%
Moderate exercise	41.9%	38.4%	26.1%	23.8%	16.9%	23.1%	25.9%	37.3%	21.6%	20.8%
Mild exercise *	46.8%	42.7%	32.4%	32.8%	29.3%	30.5%	21.5%*	21.6%*	46.4%	45.7%

* 'Mild exercise most days'

Diet

General Summary

Just under half of respondents in ROI reported at least daily fruit or vegetable consumption (45.3%), less frequently so by men (39.4%) compared with women (49.7%), with little variation by age. In NI, 31.7% reported eating daily fruit and vegetables, again less frequently for men (27.1%) than women (35.9%) and again with minimal age variation.

Four in 10 Traveller respondents in ROI (40.3%) and 31.3% in NI reported eating fried food less than once per week, with just 11.8% in ROI and 12.9% in NI reporting daily consumption. Men were more likely to consume fried food frequently than women. This pattern was also inversely age related: 17.1% in ROI and 15.1% in NI of those under 30 years consumed fried food daily, compared with 1.1% of the oldest respondents

In ROI butter was the most popular spread (56.2%) and was consumed at least most days by both men (56.9%) and women (55.8%). This was no strong age trend. In NI consumption was more evenly spread between butter, low fat or vegetable oil spreads. In ROI a majority of respondents either usually (11.7%) or always (38%) added salt to food at table, men more so than women, and younger respondents more than older people. In NI, 19.3% usually and 20.5% always added salt to food at table, men more so than women and with little variation by age.

AITHS respondents hardly ever ate out, particularly in restaurants (62.0% in ROI and 67.5% in NI), and women ate out less frequently than men. There is a strong inverse pattern, with older respondents less likely to ever eat out, and rates of fast food and home delivery consumption were higher in the younger age group in both jurisdictions.

Most respondents saw no problem with trying to eat more healthily (65.4% in ROI and 52.4% in NI), and by far the most frequently cited barrier was price (29.3% in ROI and 36.8% in NI), followed by family preferences (16.2% ROI and 20.6% NI). Patterns were similar for men and women and according to age group.

Commentary

Compared with data from the SLAN 2007 report suggesting that 65% of adults in all social classes reported eating at least 5 portions of fruit and vegetables per day in the general population (Harrington *et al.*, 2008), only 45.3% of Travellers in ROI and 31.7% of Travellers in NI report eating daily fruit and vegetables. When viewed in the context of the comparable populations, Travellers reported more frequent consumption of fried food (Figure 16). With respect to use of butter, low fat spread and table salt, patterns of consumption by Travellers closely resemble those of the SLAN 2002 population (Figure 17), with lower consumption of those fats in the NI Travellers.

Figure 16: Fried food consumption. Respondents noting consumption of fried or 'fast' foods 4 or more times per week

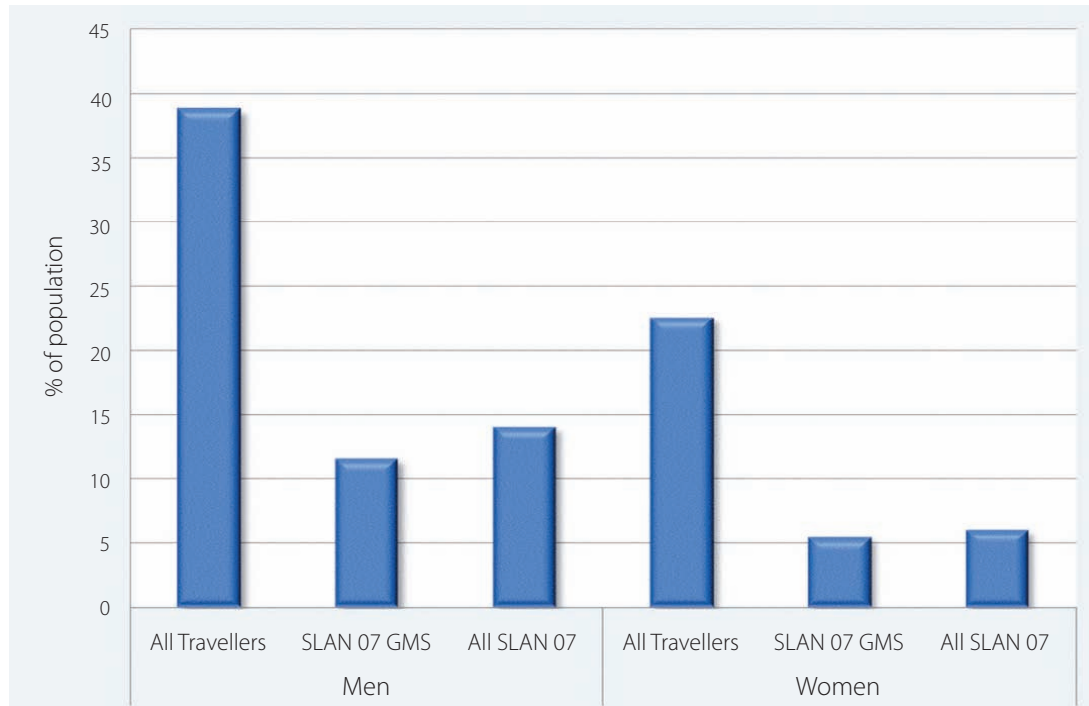
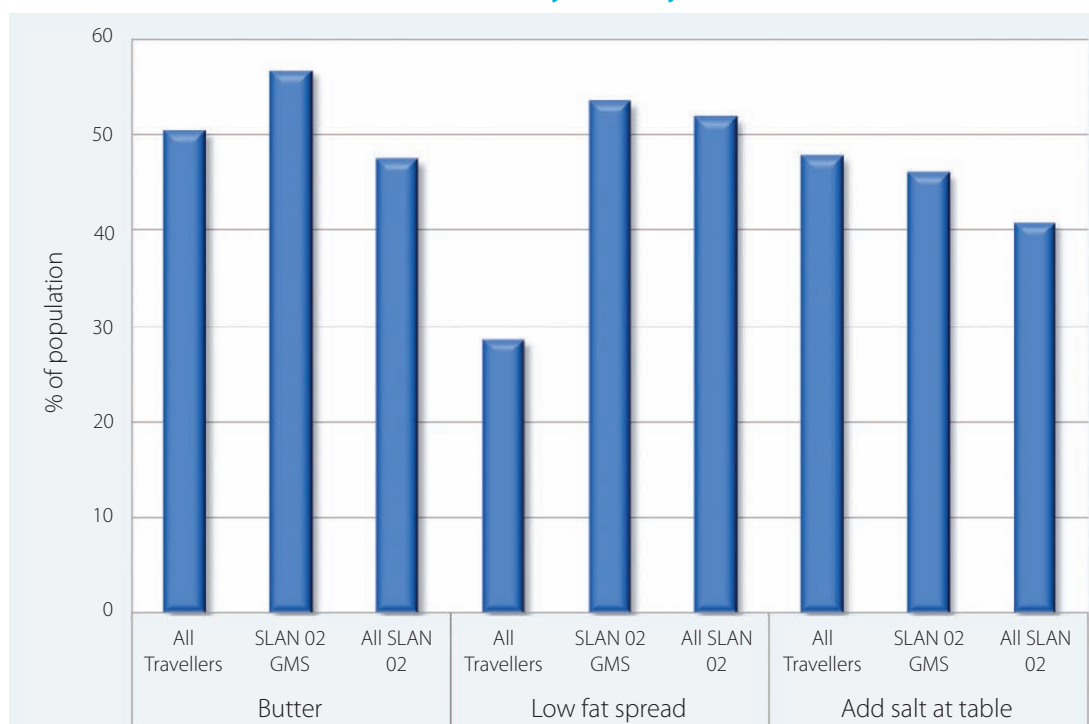


Figure 17: Consumption of butter and low fat spread 'every or most days,' and addition of salt to food at the table 'usually or always,' in AITHS and SLAN 2002



Social Capital and Social Support

General Summary

ROI respondents gave a broad range of responses to the statement that generally speaking, most people can be trusted: a quarter strongly disagreed (25.8%) and a tenth strongly agreed (10.2%), with the remainder somewhere mid-way. There were no notable differences by sex and the oldest age group was somewhat more in agreement than others with the statement. In NI the most frequent category (42.6%) was the neutral one of neither agreeing nor disagreeing, and younger people were more likely to agree than older respondents.

The number one grouping providing respondents with a lot of support in ROI were parents (53.3%), followed by spouse or partner (50.4%), with support from other sources lower. In NI, parents also ranked first (46.1%), again in an age-related pattern. However spouse or partner ranked fourth (27.0%) after other sources such as other relatives, children and friends. Partner was not applicable in respondent's situation for 61.0% in NI compared with 29.6% in ROI.

Commentary

To assess feelings of trust in individuals in the Traveller and other groups, participants were asked if they agreed with the statement, 'Generally speaking, most people can be trusted'. It is clear that in comparison with the SLAN 2002 medical card holders, the Traveller groups felt much less trustful (Table 20), with over a quarter of ROI Travellers strongly disagreeing with this statement.

Table 20: Agreement with the statement 'Generally speaking, most people can be trusted'

	Travellers (ROI)		Travellers (NI)		SLAN 2002 medical card holders		SLAN 2002 All participants	
	Male (n=694)	Female (n=945)	Male (n=191)	Female (n=201)	Male (n=620)	Female (n=902)	Male (n=2,355)	Female (n=3,395)
Strongly agree or agree	23.5%	24.7%	24.1%	29.9%	70.0%	67.7%	67.3%	67.1%
Strongly disagree	28.0%	24.2%	6.8%	8.5%	2.4%	2.6%	2.8%	2.3%

Rating of social supports in the AITHS and SLAN 2002 respondents is shown in Table 21. The percentages shown represent the valid percentage of all those who had access to that kind of support, i.e. if a respondent indicated that they did not have children, or that a supportive relationship with the clergy was not applicable to them, they were removed for the purposes of calculating the percentage. The Travellers can be seen to rate the support they receive from their parents more highly than do the general SLAN 2002 population.

Table 21: Number who agreed that the following groups of friends and family gave them 'a lot of support', in the AITHS and SLAN 2002 studies

Source of support	Travellers (ROI) (n=1,559)	Travellers (NI) (n=367)	SLAN 2002 medical card holders (n=1,639)	SLAN 2002 general population (n=5,974)
Spouse/Partner	71.6%	69.2%	78.3%	81.6%
Parent(s)	69.6%	59.3%	55.4%	38.3%
Child(ren)	65.9%	55.0%	61.7%	52.9%
Other close relatives	40.7%	34.2%	39.0%	30.2%
Friends	36.0%	31.5%	37.2%	34.0%
Clergy	40.9%	20.2%	-	-

Furthermore, in comparison with a low income mixed race group aged between 25 and 64 from the US where similar questions were asked (Krieger *et al.*, 2005), experiences of ethnic discrimination seem more common among the Traveller group (Table 22)⁴.

Table 22: Experience of discrimination in Travellers in the AITHS, compared with a survey of Black, Latino and White working class adults in Boston, USA

Ever experienced discrimination, once or more than once:	Travellers (ROI) (n=1,604)	Travellers (NI) (n=398)	Black Americans (n=156)	Latino Americans (n=299)	White Americans (n=205)
At school	62.1%	67.0%	20.5%	8.7%	9.8%
Getting work	55.1%	63.9%	27.6%	19.6%	14.2%
At work	43.9%	52.8%	19.2%	14.4%	11.7%
Getting accommodation	56.5%	75.6%	25.6%	10.5%	10.2%
Getting healthcare	39.6%	54.0%	17.3%	14.0%	5.8%
Being served in a shop or pub/ restaurant	60.7%	72.3%	41.0%	19.6%	10.2%
Getting insurance or a loan	39.3%	60.2%	25.6%	16.2%	7.8%
On the street or in a public setting	49.7%	70.1%	38.0%	24.0%	15.1%
From the guards or police, or in the courts	52.3%	64.7%	21.8%	17.5%	6.3%

⁴ We include this comparison because the data items capturing experience of discrimination used in AITHS were derived from the instrument used by Krieger *et al.* (2005) and therefore the measurements can be seen as directly comparable, although there is a proviso that unlike the other comparisons in this document, in this case the comparator group is clearly not from the general Irish population.

Health Issues Specific to Women

General Summary

In the case of ever married Traveller women only, information on family planning was elicited. Overall 40.8% in ROI and 50.4% in NI had ever been on the contraceptive pill and this showed a strong age pattern, with the group most likely ever to be on the pill those in the 30 to 44 year age group (53.6% in ROI and 51.9% in NI).

Those not taking folic acid or multivitamins in the last year were 44.8% in ROI and 40.7% in NI, and this was strongly inversely age related. Over a third of those under 30 in ROI (32.8%) reported almost daily intake compared to 23.0% in NI.

Over a quarter of respondents in ROI reported having undergone breast screening with a mammogram (29.5%) and almost a quarter reported cervical cancer screening (23.9%) in the last year (from estimates from the relevant target age groups for such screening). In NI, the small sample size for this item means that the findings may not be reliable.

A large majority (82.9% in ROI and 76.4% in NI), indicated that a woman having problems with the change of life would seek help from the GP (85.9% in ROI and 73.1% in NI), a point agreed upon by respondents of all ages. TCHWs featured as a source of support in a fifth of respondents' responses and other health professionals were cited by 32.5% of ROI and 54.8% of NI respondents.

Commentary

More women in SLAN 2002 reported having been on the oral contraceptive pill (77.2% of 30-44 year-olds in the medical card group, and 72.8% of all 30 to 44-year-old SLAN 2002 participants), than in the AITHS population. Of the women in SLAN 2007 who were medical card holders, 11.6% had cervical screening and 13.3% had a mammogram in the previous year. From the Northern Ireland Screening Programme (2006), 72.2% of women in the 25 to 64-year-old age group had accessed cervical screening within the preceding 5 years (and within 5 years of a satisfactory test). Rates of breast screening in the Traveller women were similar or greater than those in the corresponding age groups in the SLAN 2007 Medical Card Holder group. Rates of cervical screening were considerably higher (Table 23). The sample size is small in the NI group (n=13) and therefore this group is not commented upon.

Table 23: Screened or tested in the last year for breast or cervical cancer, in women by specific age groups and all ages

	Breast screening (Mammogram)		Cervical screening (Smear test)	
	Travellers (ROI) (n=143)	SLAN 2007 GMS (n=2,025)	Travellers (ROI) (n=141)	SLAN 2007 GMS (n=2,010)
50-59-year-olds	28.4%	28.6%	22.7%	14.2%
60+ year-olds	23.6%	15.2%	22.2%	7.3%
Total (all ages)	25.2%	13.3%	22.7%	11.6%

Health Service Utilisation

Patterns of Health Service Utilisation

General Summary

Sources of Information and Ease of Access

Traveller respondents accessed information about health from a range of sources. The most frequently cited source was the GP (91.1% ROI and 89.0% NI), followed by family or friends (31.8% ROI and 35.8% NI), TCHW (29.4% ROI and 8.4% NI), PHN (28.0% in ROI) or health visitor in NI (6.3%), Primary Care Projects (25.0% in ROI and 4.3% in NI) and Health Organisations (3.3 % in ROI and 5.0% in NI).

Most people felt their opportunities to access services were about the same as everyone else. For instance 72.3% in ROI and 73.5% in NI thought their access to the Accident and Emergency Department (A & E) was the same, with 14.9% in ROI and 17.9% in NI rating their access as worse, and 12.8% in ROI and 8.6% in NI as better, than everyone else. Respondents were asked to rate various difficulties in accessing health services. The barriers identified included the waiting list (cited by 62.7% of respondents in ROI and 46.8% in NI), embarrassment (47.8% in ROI and 50.0% in NI) and lack of information (37.3% in ROI and 28.6% in NI).

Services Used in Last 12 Months

In the last 12 months in ROI a quarter of respondents had been a hospital inpatient either once (15.4%) or more than once (10.6%) and similar numbers had attended as a day-patient once (12.8%) or more than once (9.9%). A third (32.8%) had been to hospital as an outpatient and a third (29.7%) had been to A & E. Three-quarters (75.6%) had visited their GP at least once. Utilisation of other services was less frequent. Women availed of services more frequently than men and there was a positive age gradient.

In NI 10.8% had been an inpatient once and a further 4.9% more than once, and similar numbers had attended as a day-patient once (10.4%) or more than once (2.6%). A quarter (25.2%) had been to hospital as an outpatient and a third (33.3%) had been to A & E. Two-thirds (64.7%) had visited their GP at least once. Utilisation of other services was less frequent. Women again availed of services more frequently than men and there was a positive age gradient.

In ROI 41.0% had complete trust in health professionals treating them, compared to 34.6% in NI; women had more trust than men but there was no consistent age pattern. Just under half of respondents in ROI (46.6%) completely felt they were given enough time to discuss their problem with healthcare professionals, compared to 32.3% in NI.

In ROI 70.0% felt they had been given about the right amount of information and in NI, 61.8%; there was no clear age or gender pattern. In ROI 57.6% and in NI 38.8% felt they had always been treated with respect and dignity throughout the consulting experience. There was some variation also in whether respondents judged they had been given enough privacy; in ROI 63% indicated this was always the case, compared to 39.3% in NI.

There was a wide range of response by respondents in how they rated the quality of care received while in hospital. In ROI it was rated as excellent (17.4%) or very good (26.5%), with the remainder rating it less well. In NI, it was rated excellent by just 5.0% and very good by 28.8%. A majority (85.9% in ROI and 78.2% in NI) would recommend the service to someone else.

When asked if they ever wished to make a complaint about some aspect of the health service, 25.6% in ROI and 36.4% in NI said yes and of these, 38.8% in ROI and 55.4% in NI indicated they knew how to go about it. Whilst numbers were small, more people were satisfied or somewhat satisfied with the outcome in NI (72%) than ROI (37.7%).

Commentary

Table 24 shows the different sources of health information in the AITHS and the INSIGHT '07 studies. The GP is the primary source of information for the majority of persons. Notable is the fact that the INSIGHT '07 participants were at least 4 times more likely to access health information over the internet than were the Traveller groups. Furthermore, helplines appear to contribute very little to health information in either group.

Table 24: Accessing health information, in AITHS and INSIGHT '07

	Travellers (ROI) (n=1,668)	Travellers (NI) (n=383)	INSIGHT '07 medical card holders (n=1,293)	INSIGHT '07 all participants (n=3,517)
General practitioner	91.1%	89.0%	88.6%	83.3%
Family or friends	31.8%	35.8%	21.4%	26.6%
TCHW	29.4%	8.4%	-	-
Traveller organisations	14.3%	7.3%	-	-
PHN or Health Visitor	28.0%	6.3%	-	-
Primary care projects	25.0%	4.2%	-	-
Health organisations	3.3%	5.0%	3.5%	5.7%
Internet/world wide web	2.5%	1.8%	9.8%	16.5%
Media	13.7%	3.7%	15.0%	17.5%
Helplines	0.8%	4.4%	0.7%	1.0%

Most Traveller respondents felt their opportunities to access services were about the same as everyone else. From the comparable data: of the medical card holders in INSIGHT '07 who provided a valid answer, 75.4% thought their access to A & E services was the same as everyone else, as did 75.6% of all INSIGHT '07 participants. For access to mental health services, 80.0% of medical card holders in INSIGHT '07 thought that their access was the same as everyone else's, as did 78.3% of all INSIGHT '07 participants.

Usage of GP services was similar in the AITHS and INSIGHT '07 populations, although usage of hospital services and in particular usage of A & E is considerably higher amongst the Travellers (Table 25).

Table 25: Services used in the last 12 months, in AITHS and INSIGHT '07

	Travellers (ROI)		Travellers (NI)		INSIGHT '07 Medical card holders		INSIGHT '07 general population	
	Male (n=932)	Female (n=1,029)	Male (n=216)	Female (n=189)	Male (n=542)	Female (n=751)	Male (n=1,700)	Female (n=1,817)
Hospital inpatient								
Once	15.6%	15.0%	8.2%	13.8%	10.0%	11.4%	6.7%	10.1%
More than once	9.5%	11.5%	7.2%	2.2%	7.6%	6.0%	3.5%	4.1%
Hospital day patient								
Once	13.5%	11.9%	9.6%	11.3%	8.6%	8.5%	5.8%	6.7%
More than once	8.2%	11.5%	3.3%	1.7%	6.5%	4.6%	3.0%	3.1%
Hospital outpatient								
Once	15.7%	14.9%	10.0%	18.7%	8.2%	9.6%	8.7%	7.3%
More than once	16.0%	18.6%	10.0%	12.6%	15.0%	13.4%	9.2%	7.5%
A & E								
Once	19.0%	14.3%	18.9%	23.9%	5.3%	9.9%	9.1%	7.7%
More than once	13.3%	12.8%	11.8%	12.5%	4.1%	4.5%	2.8%	3.1%
General practitioner								
Once	18.1%	12.9%	15.3%	17.5%	14.0%	12.7%	20.1%	16.3%
More than once	53.1%	66.6%	41.7%	56.1%	59.4%	63.1%	40.5%	55.0%

Comparisons were made between the experiences of healthcare services (hospital as an inpatient or outpatient, A & E and GP services) in the AITHS survey, and the available data items in INSIGHT '07 relating to experiences of hospital inpatient and outpatient services, and of GP services (Table 26). Clearly, measures of satisfaction with the quality of health service care are appreciably higher in the INSIGHT '07 group than in the Traveller group. It would appear that Traveller respondents either perceive or actually do experience a poorer quality of healthcare service than do the general Irish public.

Table 26: Experience of service

Experience of service*	ROI Travellers (n=1,324)	NI Travellers (n=263)	INSIGHT '07 All respondents (n=2,758)	INSIGHT '07 medical card holders (n=1,292)
Completely trusted health professional treating you	41.0%	34.6%	82.7%	81.8%
Had enough time to discuss your health problem	46.6%	32.3%	78.4%	76.2%
Was treated with respect and dignity by the healthcare team	57.6%	38.8%	87.7%	88.0%
Given enough privacy when discussing condition	63.0%	39.3%	91.0%	91.3%
Received the right amount of information	70.0%	61.8%	82.2%	82.0%

* Proportions are of those respondents who agreed completely with the statement

In keeping with this finding of differing experiences of measures of quality of service, the comparative picture relating to the overall experience of inpatient hospital care also shows an overall lower satisfaction with care in the Traveller group. Regarding inpatient experiences, 344 INSIGHT '07 participants (170 of whom were medical card holders) responded to an item enquiring as to the overall quality of their experience. 26.1% and 38.6% rated their inpatient experience as 'excellent' or 'very good', respectively (27.5% and 40.1% in the medical card holders). This compares with 17.4% and 26.5% of ROI Travellers, and 5.0% and 28.8% of NI Travellers. 86.2% of all INSIGHT '07 participants who answered questions relating to an inpatient experience (88.5% of the medical card holders) would recommend the hospital to a friend, compared with a similar proportion of ROI Travellers (85.9%), but a slightly lower proportion of NI Travellers (78.2%).

Of all the participants in the INSIGHT '07 survey, 19.1% said that they had ever wished to make a complaint about some aspect of the health service, compared with 25.6% of ROI Travellers and 36.4% of NI Travellers. Only 39.4% of INSIGHT '07 respondents who wished to make a complaint said they would know how to go about it; however this compares with a similar proportion in ROI Traveller group (38.8%). A larger proportion of respondents in the NI Traveller group felt they knew how to make a complaint (55.4%). Of those persons in INSIGHT '07 who ever made a complaint, 68.7% were satisfied or somewhat satisfied with the outcome. Of those who did make a complaint in the AITHS group, the outcome was satisfactory or somewhat satisfactory in 72.2% of the NI Traveller group and in only 37.6% of ROI Traveller group.

It is clear from these results that the Travellers surveyed accessed healthcare structures more often than did the INSIGHT '07 participants. However, overall, the INSIGHT '07 participants rated their experience with hospital appointments and inpatient experiences in a more positive manner than did the Traveller group. Whilst the Travellers rated the overall quality of their care slightly lower than did the INSIGHT '07 participants, their ratings of the specific aspects of care relating to their dealings with health services staff are substantially lower.

Overall Summary of the Comparative Section

This comparative discussion has drawn data from multiple sources, to create a picture of Traveller health and social status in contemporary Ireland. The primary comparator groups were those of similar socioeconomic standing in the general Irish population, although comparisons were also drawn with the samples of all the general population where this proved informative.

With regard to health status of Travellers, we have shown that this population subgroup subjectively rates their health in a positive manner, but in fact have substantially higher rates of ill-health affecting them on a day-to-day basis than is demonstrated in the comparator populations. They have a higher burden of chronic diseases, and higher measures of risk factors such as smoking, high blood pressure, cholesterol, and dietary consumption of fried foods. Fewer Travellers drink alcohol than do the general population, but those who do drink, drink more frequently. They have similar rates of injury than the comparator populations, but have higher rates of non-accidental injury. Breastfeeding rates are extremely low.

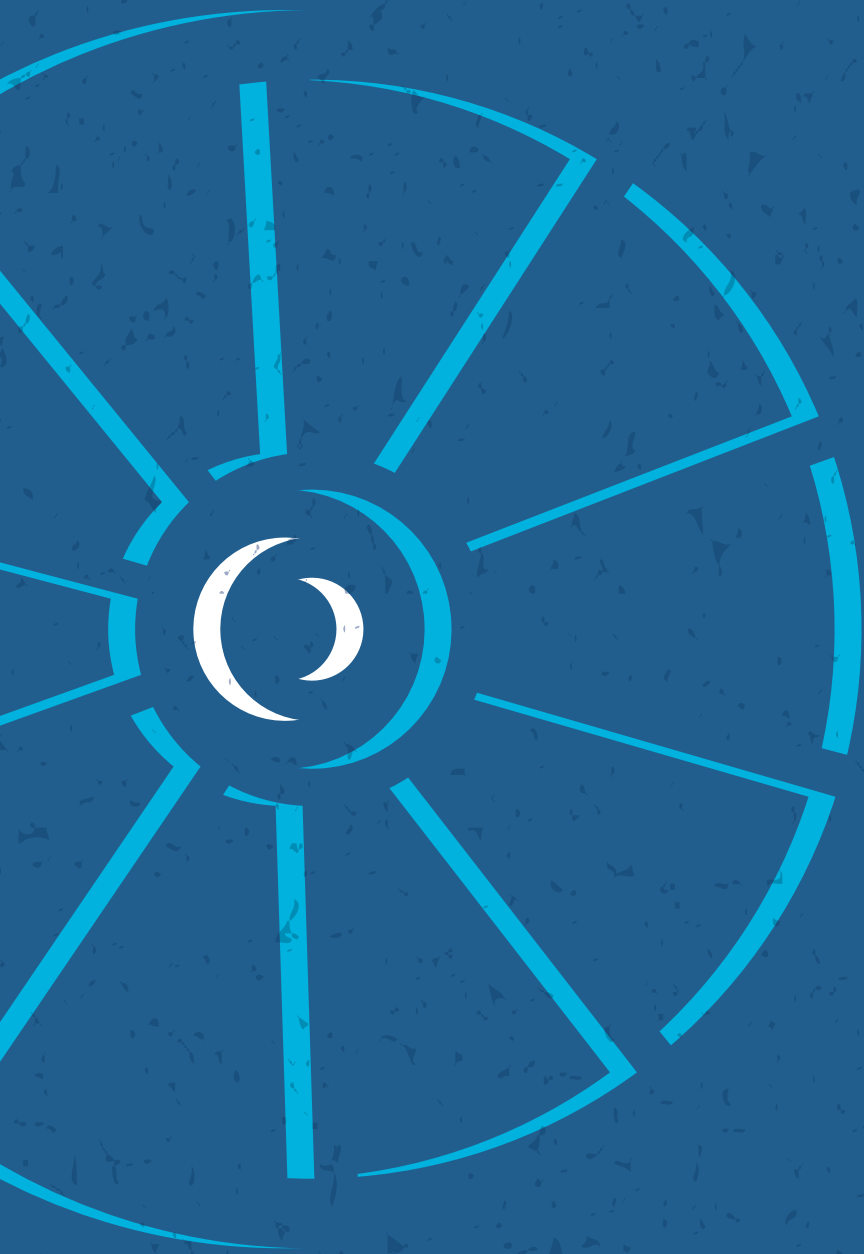
Again, Travellers rate the general health of their children in a very positive light. However, when data is examined on specific health concerns, it can be seen that Traveller children have higher reported prevalence of hearing, eyesight and speech problems. Traveller children clearly benefit from the established Traveller community: they have multiple close friends. By parental report, experimentation with alcohol and tobacco is also rare in the Traveller 14-year-olds, and Traveller children are physically active in their day-to-day life. However, in comparison with other children, few have home access to computers.

Travellers report similar sources of support, with regard to social support from friends and family, as do the comparator population. However, the comparison between the Travellers and the general population with respect to measures of trust is striking. The frequency of reporting of experiences of discrimination is also high.

Travellers report that they access health services with a greater frequency than do other comparator populations. They also access preventive medicine services, such as voluntary screening programmes. Furthermore, their experiences of health services are consistently less positive than are the experiences of the comparator population in INSIGHT '07. It is also notable that more Travellers reported not accessing care for their children because of a concern about paying for services than did the comparator population, notwithstanding the fact that they have medical cards.

In summary, this comparative exercise has shown that the Travelling community has a higher burden of ill-health than does the general population. Whilst Travellers would appear to access hospital services more frequently than do others, their experience of the services are not as positive.

The Vital Statistics and Mortality Study



Introduction

This section examines the demography and vital statistics of the Traveller population in Ireland. The demography section concentrates on the determination of the total count of Travellers and on their age/sex distribution. The results are based on data collected in the census survey of Travellers carried out on the nominal census dates of 14th October, 2008 in the Republic of Ireland (ROI) and 16th February, 2009 in Northern Ireland (NI). The Vital Statistics section examines mortality in the Traveller population based on an enumeration of deaths in ROI and NI that occurred in the 12-month period prior to ROI census survey.

The number of deaths in NI was too small for separate analysis and most mortality estimations therefore use ROI mortality data only. This allowed comparison with national statistics in ROI and with the previous Traveller census, which took place in 1987. If all-island calculations had been made, the small number of deaths in NI would not affect the overall thrust of the analysis but would limit comparability.

Comparisons are made with the general Irish population and with results from the previous Traveller census in 1987. Note that all comparisons are made with the entire population. This is legitimate because Travellers form only a small proportion of that population. For convenience we refer to the mortality data as relating to the year 2008 though technically mortality statistics in ROI relate to the 12-month period from 15th October, 2007.

Methodology

Demography & Vital Statistics

The total Traveller population count was based on the number of Traveller families enumerated at the census, multiplied by the average family size estimated by analysis of census interview data. Age- and sex-specific numbers were derived by applying the age-sex distribution from census interview data to the total population count.

During the census the project field coordinators in ROI and NI returned field reports of anonymised family codes with a comment on each code, marking the status of the family to the best of their knowledge. Information from the field report was correlated with information from a final interview to confirm (1) the total family count in each project, (2) the number of families interviewed, (3) the number of those who were not interviewed because they moved. Since those who moved out of the island of Ireland were not to be enumerated as part of the study population and because those who moved within the island would be enumerated in the area to which they moved, the number who moved was subtracted from the count in each project, and project counts were aggregated to reach the final Traveller count.

9,056 families were enumerated in ROI. More than 9,300 electronic-initiated interview files were initially received from the field in a single database. The database included files for a number of interview outcomes: consented interviews, refusals, unavailable families or moved families, in addition to invalid empty files and duplicates. All invalid files were removed. Duplicates and non-consented interviews (refusals, moved and unavailable families) were also removed. This left a total of 7,042 consented family interview records, giving a response rate of 78%.

The same process was followed in NI, where 1,562 Traveller Families were enumerated. Over 2,000 files were initially received and following the removal of all invalid, duplicate, refused, moved and unavailable files we were left with a total of 1,450 consented Traveller families giving an exceptional response rate of 93%.

Each of these family-level records included census data (age, gender, education, occupation, marital status and institutionalisation) on more than 1 family member. Individual level records of census data were created from the family-level records for further analysis of average family size and the age and sex breakdown of the Traveller population on the island.

Information about average family size was derived from the census. For the purposes of this study, a family unit was defined as

- a husband and wife, or a couple, who live together
- a husband and wife, or a couple, who live together with one or more never-married (single) children (of any age)
- one parent who lives with one or more never-married (single) children (of any age)
- one person living alone

This definition of family unit was based on the definition used in Volume 5 of the National Census, Ethnic or Cultural Background (Central Statistics Office, 2007c).

The Mortality Study

The mortality study was based on a retrospective identification of all Irish Traveller deaths that occurred on the island of Ireland during a 1-year period between 15th October, 2007 and 14th October, 2008.

Retrospective enumeration of mortality is a recommended methodology where there are difficulties with exact registration records and was used by the United States census office for all census data collection from 1850 to 1930 (Kelleher *et al.*, 2006). In our study, Traveller deaths were identified by Traveller families, and this approach addressed the problem of wrongly identifying deceased persons as members of the Traveller community and at the same time minimised the number of Traveller deaths that would be missed.

For the census, 450 Traveller Peer Researchers and 90 study coordinators, who were working in Primary Healthcare for Traveller projects and Traveller organisations on the island of Ireland, were trained as local data collectors using the laptop computers. During the census, Traveller enumerators (Peer Researchers) identified and visited 10,618 Traveller families and offered them the opportunity to participate in the census. Public Health Nurses (PHNs) in ROI and Health Visitors (HVs) in NI were also asked to report all deaths among Irish Travellers that they were aware of which had occurred within the study time frame on the island of Ireland.

We checked and transferred the information on to a spreadsheet, and if necessary followed up with the study coordinators or PHNs for clarification.

Findings

Demography

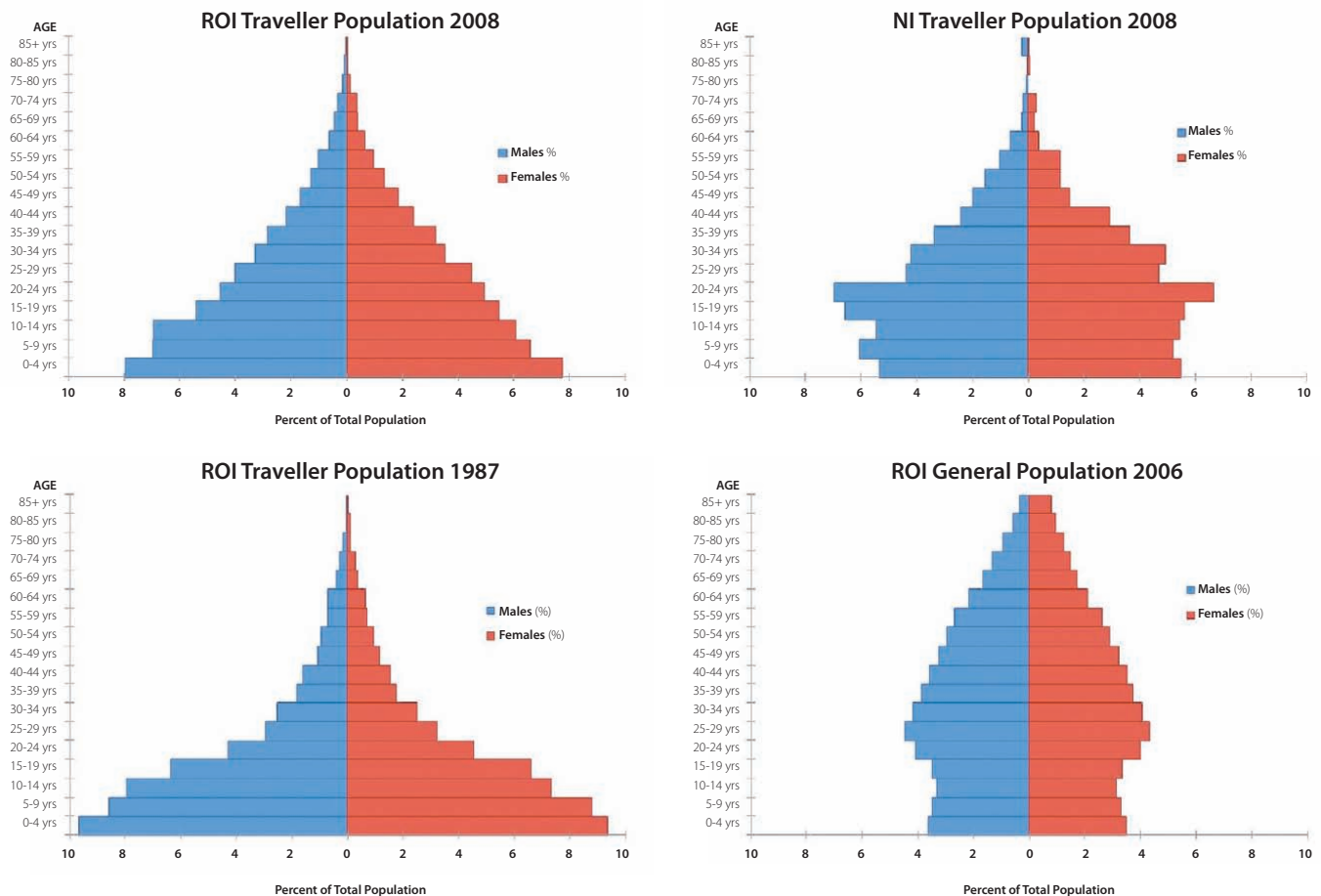
A census of the Traveller community in Ireland was undertaken in 2008 (early 2009 in NI). In total there were 40,129 Travellers living on the island of Ireland (IOI): 36,224 (90.3%) in ROI and 3,905 (9.7%) in NI (Table 27).

Table 27: Estimation of Traveller population (2008)

	ROI	NI	IOI
No. of Traveller families enumerated	9,056	1,562	10,618
Average family size	4.0	2.5	3.8
Estimated Traveller Population	36,224	3,905	40,129

Travellers have a very distinctive population profile. In ROI their population pyramid is very similar to that in developing countries, with a wide base that narrows steeply. This is indicative of a high birth rate and a young population. As Travellers get older, the population pyramid becomes narrower at the top. This is the consequence of high mortality rates at a younger age.

Figure 18: Population pyramids for Travellers (a) in ROI 2008, (b) in NI 2009, (c) in ROI 1987 and for (d) the ROI general population 2006



In NI the Traveller pyramid suggests an inward migration of Travellers to NI from ROI. The peak in numbers aged 15-24 is not otherwise consistent with the numbers observed in younger age groups.

When compared with 1987, Travellers in ROI now are living at slightly older ages and the proportion of those in the youngest ages has decreased. More middle-aged Travellers are now apparent.

The contrast between the Traveller community and the general population by age groups is summarised in Table 28 below. The following highlight the current differences between ROI Travellers and the general population:

- 63% of Travellers under 25 compared with 35% nationally
- 42% of Travellers under 15 compared with 21% nationally
- 3% of Travellers 65 years or over compared to 13% nationally

Table 28: Age distribution of Traveller and general populations

Age group	General population 2006*	Travellers 2008	Travellers 1987
0-4 Years	7%	16%	19%
5-14 years	14%	26%	33%
15-24 years	14%	21%	22%
25-39 years	22%	21%	14%
40-64 years	30%	13%	10%
65 years +	13%	3%	2%

* From the CSO, 2006 national census figures. (Central Statistics Office, 2007b)

Mortality

In ROI there were 188 deaths among Travellers in 2008 and 11 in NI. Mortality analysis concentrated on ROI data to allow for comparative analyses. There were 124 (66.0%) deaths in males and 64 (34.0%) in females. No matter what way one examines the mortality data, the picture painted is a bleak one for Travellers. Compared to the general population, Travellers experience considerably higher mortality at all ages in both males and females (Table 29). The problem stretches across the entire age spectrum.

Table 29: Age-specific Mortality Rates per 1,000 in Traveller and general populations 2008*

Age group (Years)	Male Traveller Population	Male General Population	Female Traveller Population	Female General Population
Less than 1	16.33	5.24	9.78	4.23
1-4	0.00	0.21	0.00	0.15
5-14	0.40	0.19	0.22	0.07
15-24	2.23	0.83	1.06	0.22
25-34	6.07	0.92	2.41	0.36
35-44	9.36	1.46	1.48	0.92
45-54	16.75	3.28	4.26	2.41
55-64	23.59	8.75	20.51	5.54
65-74	69.43	24.40	42.57	13.67
75-84	184.62	69.20	124.08	46.35
85+	808.82	192.32	606.61	158.58
Total	6.62	6.79	3.40	6.50

* Excluding 6 Traveller deaths with unknown age

Infant Mortality

Infant mortality has classically been considered a good indicator of a population's level of health and development. The infant mortality rate (IMR) is defined as the number of deaths under the age of 1 year in babies who were born alive per 1,000 live births. There were 12 Traveller infant deaths reported to us in ROI for 2008 (actually in the calendar year prior to the census) and we estimated that in that period there were 849 births. This gives a Traveller infant mortality rate of 12/849 or 14.1 per 1,000 live births. Table 30 gives the IMRs for the general population in 2008 (Central Statistics Office, 2009c) and the corresponding figures from the 1987 Traveller study.

Table 30: Infant Mortality Rates (per 1,000 live births)

	1987	2008
Traveller infant mortality(ROI) per 1,000 live births (95% CI)	18.1 (8.7-33.2)	14.1 (7.3-24.7)
General population infant mortality per 1,000 live births (ROI)	7.4	3.9
Ratio	2.4	3.6
Excess mortality per 1,000 live births	10.7	10.5

Looking at the gap between the Traveller and general population in terms of a relative difference the situation has deteriorated since 1987. Traveller infants today are 3.6 times more likely to die than infants in the general population. In 1987 when rates were much higher in both groups, Traveller infants were 2.4 times more likely to die than infants in the general population.

General Mortality

What is an SMR?

In this section we compare Traveller mortality with that of the general population. Obviously we need to account somehow for the fact that Travellers are much younger than the general population and for that reason alone would be expected to have a lower mortality than their settled peers. The way we tackle this is to give a 'standardised' result. Essentially we take the group of Travellers we are interested in – perhaps the whole population, or perhaps just males or females. We ask ourselves: 'How many deaths would we expect in this group, if they remained the same age, but had the mortality experience of the general population instead of their own?' If we have enough information we can do this easily. We get the number of deaths we would expect in the group and we compare that to the actual deaths observed. So the comparison becomes that between what we actually see and what we might expect to see if the Travellers were as 'healthy' as the general population.

There are two ways we can compare the observed and expected deaths. We can put one over the other and see how much greater (in a multiplying sense) Traveller mortality is compared to the general population. Suppose we had 150 observed deaths in Travellers and we calculated that we would only expect 50. This would mean that Traveller mortality was three times (150 divided by 50) greater than in the general population. We usually express this by multiplying by 100 to get in this case $3 \times 100 = 300$. This is what we call the standardised mortality ratio (SMR).

$$SMR = \frac{\text{Observed Deaths}}{\text{Expected Deaths}} \times 100$$

The SMR tells us how much worse or better any particular group is compared to the general population. For all our calculations here the general (also called standard) population has been taken to be the 2008 population in ROI. Of course the SMR for ROI itself in 2008 is 100 (the observed deaths are the same as expected deaths) and if an SMR was less than 100 it would suggest that the group had a lower mortality than the general population.

Allied to the concept of the SMR is to compare the observed and expected deaths by subtracting one from the other. This gives us the excess deaths. In the example above the Travellers would have experienced 100 excess deaths, got by subtracting the expected 50 deaths from the observed 150 deaths. The excess deaths give a better idea of the impact of a particular comparison – especially when we calculate excess deaths for particular causes of death.

For instance observing 4 deaths where we expect 2 gives an SMR of 200, but only 2 excess deaths. We might not worry too much about 2 extra deaths in the community. On the other hand 70 observed deaths where we expected 50 gives an SMR of 140 ($70/50 \times 100$) much less than the SMR of 200. However this time there are 20 excess deaths which might be quite worrying. Both the SMR and the excess deaths must be considered when comparing mortalities.

Table 31 shows the Standardised Mortality Ratios (SMRs) for Travellers and the general population. Allowing for the age differences between the Traveller and general populations, overall Traveller mortality is 3.5 times higher. Traveller males have 3.7 times the mortality of males in the general population; for females the mortality is 3.1 times higher.

Table 31: Standardised Mortality Ratios for Travellers (2008) (age and sex standardised)

	Observed deaths in Travellers	Expected deaths*	General population SMR (2008)	Traveller SMR (2008)	95% CI for SMR	Excess deaths
Males	124	33.3	100	372	(310-444)	90.7
Females	64	20.7	100	309	(238-395)	43.3
Total	188	54.0	100	348	(300-401)	134.0

* Based on the male, female or total general population rates as appropriate

The following table (Table 32) and Figures 19-21 examine Traveller mortality now compared to the situation in 1987.

Table 32: SMRs for Travellers 1987 to 2008

Gender		1987		2008	
		SMR	95% CI	SMR	95% CI
Male	General population	161	(159 -163)	100	-
	Travellers	351	(257-468)	372	(310-444)
Female	General population	150	(147-152)	100	-
	Travellers	472	(334-648)	309	(238-395)
Total	General population	155	(153-157)	100	-
	Travellers	397	(316-491)	348	(300-401)

Figure 19: SMRs for Male Travellers 1987 to 2008

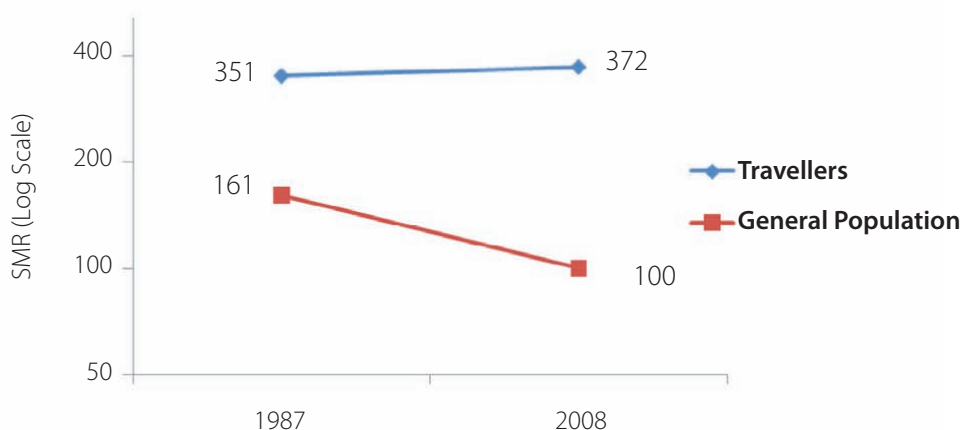


Figure 20: SMRs for Female Travellers 1987 to 2008

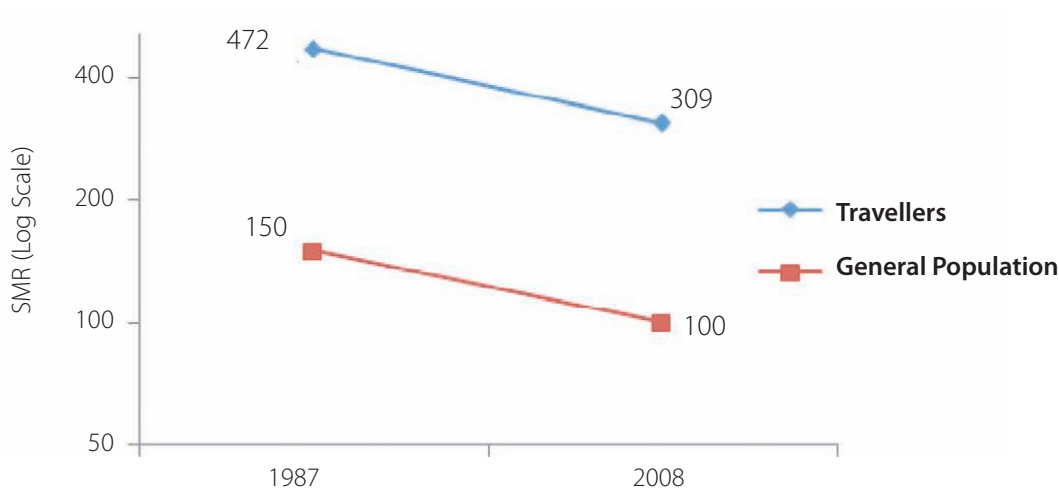
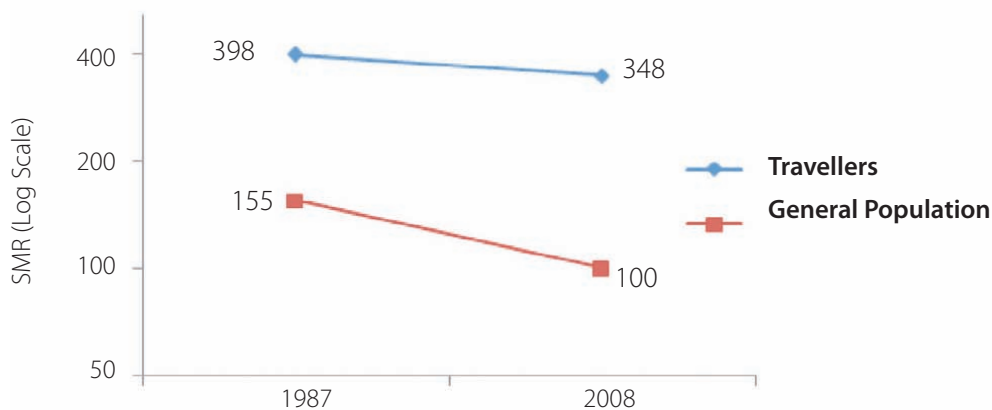


Figure 21: SMRs for All Travellers 1987 to 2008



These paint a stark picture of Traveller mortality and what has happened over the past 20 years. The main findings are given below:

- Compared to 1987, male Travellers in 2008 have shown no improvement and indeed have a slightly higher mortality (SMR of 372 versus 351).
- This is in the context of there being a major improvement in mortality in the general male population (SMR of 100 in 2008 versus 161 in 1987).
- As a consequence, the gap between the Traveller and general populations has widened for males in the past 20 years. Traveller males had a 2.2 times (SMR of 351 divided by 161) higher mortality in 1987 while the figure in 2008 is 3.7 times higher.
- For female Travellers there has been a 35% reduction in mortality since 1987 (SMR of 309 compared to 472).
- This improvement is very slightly larger than the 33% reduction seen in the general female population (SMR of 150 compared to 100), though of course Traveller female mortality remains much higher than in the general population

- The mortality gap between Travellers and the general population has essentially not changed in females. Female mortality was and is about 3 times higher than in the general population.
- Taking Travellers as a whole, combining males and females, Traveller mortality has fallen over the past 20 years but at a slower rate than in the general population. The mortality gap between Travellers and the general population has widened.

Causes of Death

Causes of death are based on 126 deaths that we confirmed in the General Register Office (GRO) scaled up to the total of 188 deaths (separately in males and females). This explains the fractional numbers of 'observed' deaths in some of the tables. Figures 22-24 show the distribution of causes of death in the GRO-confirmed cases and Tables 33 and 34 give the relevant SMRs based on the scaled-up estimates.

It can be seen that Traveller mortality in both males and females increased for all causes. In terms of SMRs respiratory conditions show the greatest increase in Travellers in both males and females. The next highest category is deaths from external causes (e.g. accidents, poisonings, suicides etc.) in males, which is 5.5 times higher than in the general population. In males heart disease is next in ranking, while in females heart disease has the second-highest SMR.

Looking at excess deaths however we get a slightly different picture. There were 33.3 excess deaths in males due to external causes in 2008; this is 36.7% of the total male excess deaths (90.7). There were 41 male deaths (scaled up) from external causes in 2008 where only 7.5 would have been expected. In terms of impact on male, and indeed total, mortality, external causes have a major influence.

Apart from external causes in males the greatest areas of excess mortality in both males and females are in heart disease and respiratory conditions. Though the SMRs for cancers in both males and females are below the all-cause SMR, excess deaths from cancer are around the same level as those for respiratory disease.

Figure 22: Causes of GRO-confirmed Traveller deaths: males and females; ROI (n = 126)

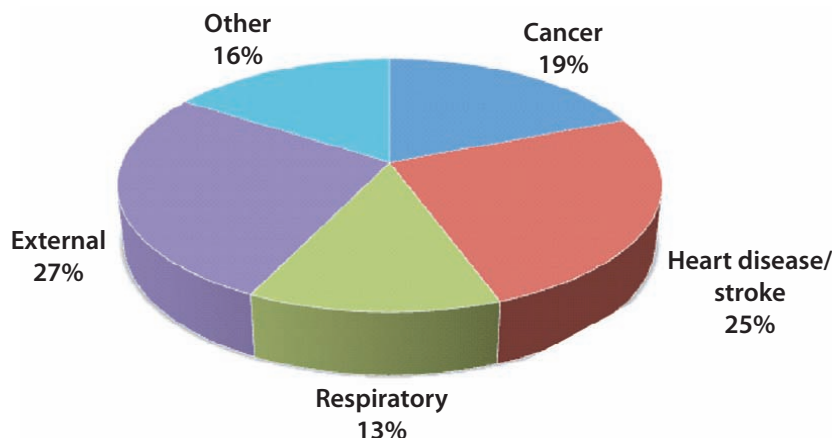
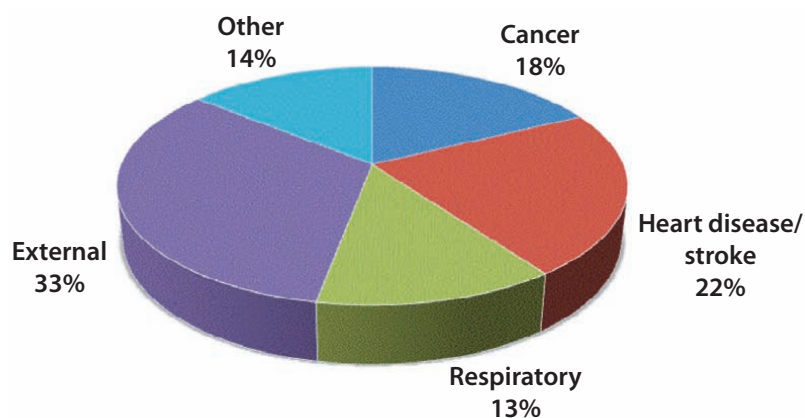
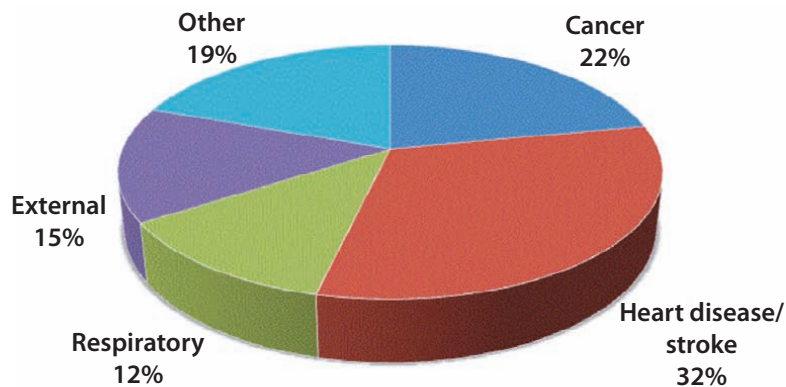


Table 33: Cause-specific mortality in male Travellers (2008) – GRO- assigned causes, scaled up

Males	Observed deaths	Expected deaths	SMR	95% CI	Excess deaths in male Travellers
Cancer	21.9	9.0	242	(135-399)	12.9
Heart disease and Stroke	27.7	8.2	337	(203-536)	19.5
Respiratory	16.0	2.2	746	(373-1,335)	13.8
External causes	40.8	7.5	548	(364-792)	33.3
All other causes	17.5	6.4	271	(140-474)	11.1
All male deaths	124.0	33.3	372	(297-460)	90.7

Figure 23: Causes of GRO-confirmed Traveller deaths: males; ROI (n = 85)

Table 34: Cause-specific mortality in female Travellers (2008) – GRO-assigned causes, scaled up

Females	Observed deaths	Expected deaths	SMR	95% CI	Excess deaths in female Travellers
Cancer	14.0	8.0	176	(80-334)	6.0
Heart disease and Stroke	20.3	4.1	489	(261-837)	16.2
Respiratory	7.8	1.5	536	(174-1,252)	6.3
External causes	9.4	2.4	393	(144-855)	7.0
All other causes	12.5	4.7	263	(113-517)	7.8
All female deaths	64.0	20.7	309	(221-419)	43.3

Figure 24: Causes of GRO-confirmed Traveller deaths: females; ROI (n = 41)

External Causes of Death and Suicide

External causes of death include deaths through suicide and through alcohol and drug poisoning/overdoses. Because external causes contributed to over a third of the excess deaths in males, and because suicide among Travellers has been shown to be a major problem, we examine vital statistics related to suicide in more detail in this sub-section.

Confining analysis to the GRO-classified causes of death, Table 35 shows the distribution of the mode of death in external causes. There is always a worry that alcohol or drug overdoses (comprising nearly half the male external-cause deaths) could be actually suicides though of course it is impossible to know. In the 12 GRO-confirmed suicides, 10 were by hanging and there was one drowning and one overdose.

Table 35: Mode of death among external causes of death in 126 GRO-confirmed deaths

Mode of death	Male			Female		
	n	% of all	% of 28 external	n	% of all	% of 6 external
Non-external cause	57	(67.1%)	-	35	(85.4%)	-
Hanging	9	(10.6%)	(32.1%)	1	(2.4%)	(16.7%)
Drowning	2	(2.4%)	(7.1%)	0	(0.0%)	(0.0%)
Overdose (alcohol/ drugs)	13	(15.3%)	(46.4%)	2	(4.9%)	(33.3%)
Other external causes	4	(4.7%)	(14.3%)	3	(7.3%)	(50.0%)
Total Deaths	85	(100.0%)	-	41	(100.0%)	-

Scaling up the 12 GRO-classified suicides to the total of 188 deaths, Table 36 shows how the suicide rates in Travellers compare with the general population.

Table 36: SMRs and excess deaths from suicide in Travellers – scaled up (2008)

	Observed suicides	Expected suicides	SMR	95% CI	Excess suicides in Travellers
Males	14.6	2.2	660	(316-1,214)	12.4
Females	3.1	0.6	489	(59-1,764)	2.5

The suicide rate in male Travellers is a statistically significant 6.6 times higher than in the general population. The female suicide rate is also higher but the difference did not reach statistical significance.

Life Expectancy

The following table (Table 37) gives life expectancies for Travellers in 2008 and 1987 and for comparative purposes the corresponding figures for the Irish population.

Table 37: Life expectancies 1987 and 2008

Year	Gender	Age	Life expectancy (years)		Traveller deficit (Years)
			Travellers	General population	
2008	Males	0	61.7	76.8	15.1
		15	48.1	62.3	14.2
		45	23.7	33.8	10.1
		65	10.6	16.6	6.0
	Females	0	70.1	81.6	11.5
		15	55.9	67.0	11.1
		45	28.0	37.7	9.7
		65	12.3	19.8	7.5
1987	Males	0	61.7	71.6	9.9
		15	48.9	57.4	8.5
		45	21.3	28.8	7.5
		65	10.1	13.1	3.0
	Females	0	65.3	77.2	11.9
		15	52.1	62.9	10.8
		45	25.1	33.6	8.5
		65	10.4	16.4	6.0

Unlike the SMR, which does not utilise information on ages at death, life expectancy does - and provides a very complete picture. The results mirror those of the SMR analysis.

- Traveller male life expectancy now at 61.7 years is identical to what it was in 1987. There are marginal increases in life expectancies at later ages.
- This life expectancy in Traveller males is at a similar level to that of the general population in 1945-1947 when it was 60.5 years (Central Statistics Office, 2009b).
- Because life expectancy in the general population has increased, male Traveller deficit at birth has increased since 1987 by 5.2 years. A male Traveller now can expect to die 15.1 years before his general population counterpart.
- Traveller female life expectancy at birth has increased by 4.8 years from 65.3 years to 70.1 years. This is slightly greater than the increase in the general female population of 4.4 years.
- Traveller females now have a level of life expectancy experienced by the general population in 1960 to 1962 when it was 71.9 years (Central Statistics Office, 2009a).
- The mortality gap between Traveller and non-Traveller females has narrowed only slightly (by 0.4 years).

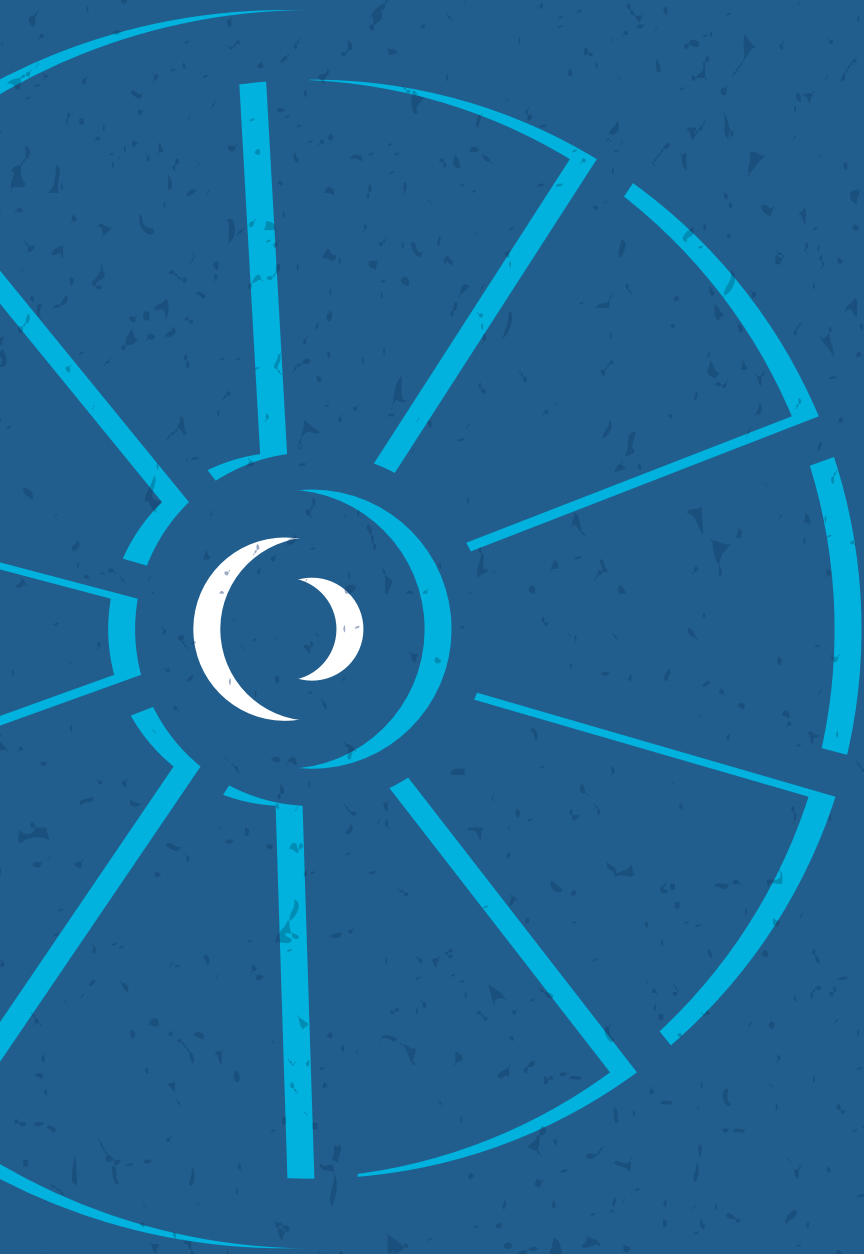
Discussion

At all ages and for all causes of death, Travellers experience a higher mortality than the general population. The problem is endemic and complex and will not be solved in the short term without considering the wider contextual issues. The picture we have painted points to the need for a holistic, integrated, long-term approach to improving the lives of Travellers and reducing their deaths, which involves the community at each stage of this development. The fact that an identifiable disadvantaged group in our society is living with the mortality experience of previous generations 50-70 years ago cannot be ignored. That fact that the gap between Traveller mortality and that in the general population has widened in the past 20 years shows that comprehensive approaches to address this situation are required and are indeed vital.

Table 38: Comparison of Traveller mortality in ROI with that of the general population

		Traveller population 2008	General population value or expected value.
Proportion of population aged < 25 years		63%	35%
Proportion of population aged 65+ years		2%	11%
Infant mortality rate (per 1,000 live births)		14.1	3.9
Number of Traveller deaths		188	54
Excess deaths		134	0
All-cause SMR	(Males)	372	100
	(Females)	309	100
Life expectancy at birth	(Males)	61.7 yrs	76.8 yrs
	(Females)	70.1 yrs	81.6 yrs
Change in life expectancy since 1987	(Males)	0 yrs	+5.2 yrs
	(Females)	+4.8 yrs	+4.4 yrs
External cause SMR	(Males)	548	100
	(Females)	393	100
Respiratory disease SMR	(Males)	746	100
	(Females)	536	100
Heart disease and Stroke SMR	(Males)	337	100
	(Females)	489	100
Suicide SMR	(Males)	660	100
	(Females)	489	100

The Birth Cohort Study



Introduction

The Birth Cohort Study is a longitudinal study of Traveller babies on the island of Ireland (IOI). The study is ongoing and will end on 13th October, 2010. The purpose of the birth cohort study is to enumerate the number of births to Irish Travellers in 1 calendar year and follow up the babies for a year in order to capture important indicators of health. These include infant mortality, feeding methods, immunisation uptake, developmental performances, health services utilisation and health needs of Traveller babies. Data from the study is used to calculate other important indicators including crude birth rate and fertility rates. Full data collection will only be completed after the study timeline ends on 13th October, 2010. A complementary report will be produced at a later date.

Study Methodology

The birth cohort study is a study of Traveller babies born between 14th October, 2008 and 13th October, 2009, with babies followed up for 1 year (Figure 25).

The recruitment of participants was a 2-phase process:

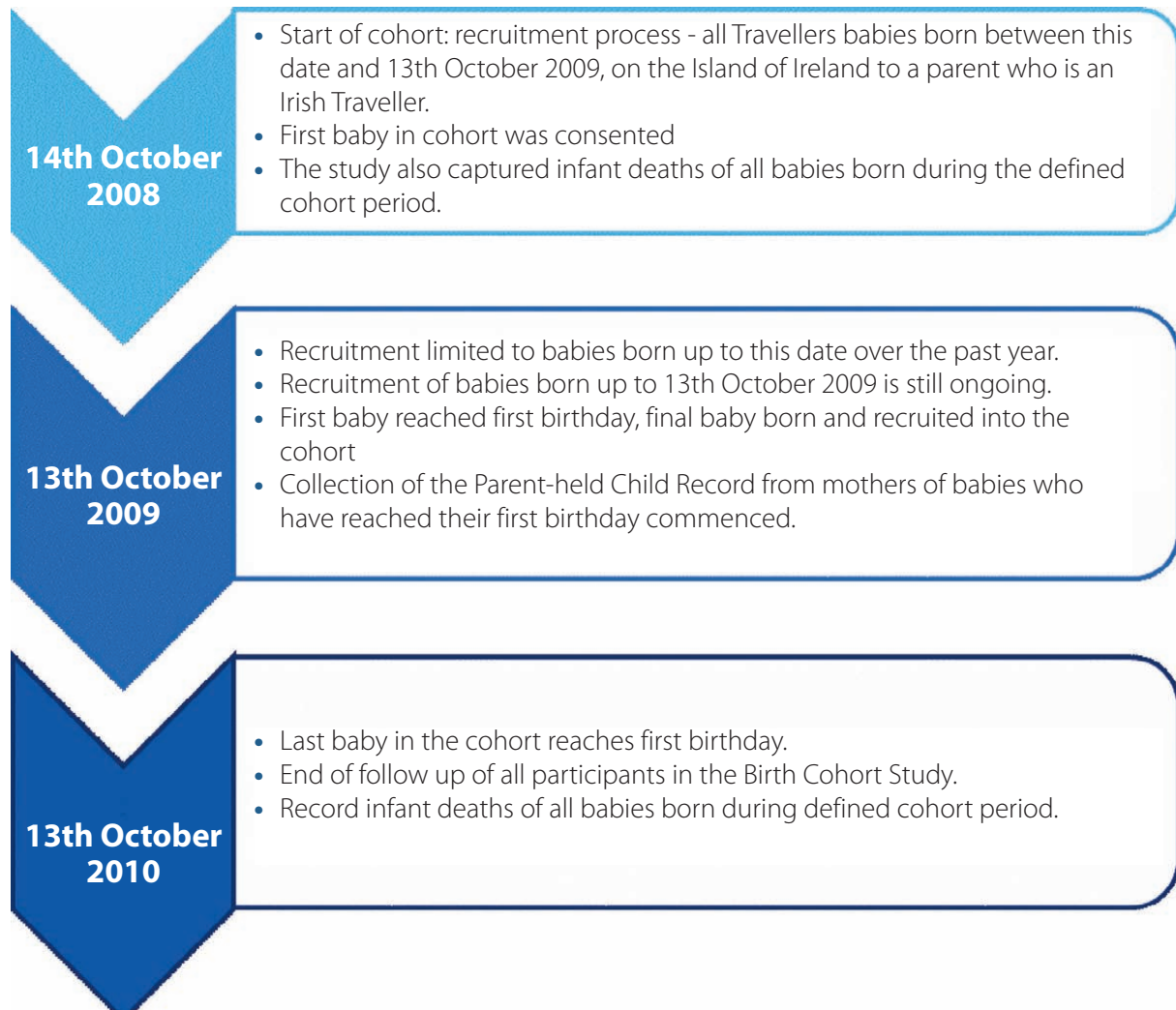
Phase 1: During the AITHS census, the Peer Researchers identified potential participants and encouraged participation, followed by official consent by PHNs. In NI, this was further supported by the HVs' notifications.

Phase 2: Direct promotion and official invitation by the PHNs and HVs during postnatal visits.

The study promotion, consenting and data collection is being performed by the Public Health Nurses in ROI and the study coordinator for NI. These roles were supported indirectly by Traveller project coordinators, Health Visitors and TCHWs.

Data for the study comes from 3 major sources - the consent form, a Parent-held Child Record (developed specifically for the study) and linkage data from maternity hospitals.

Figure 25: Timeline of the Birth Cohort Study



Population Birth Estimates

The initial estimated number of births for the birth cohort study was based on 2 sets of existing data and later, data from the AITHS census 2008.

Estimate 1 was based on the Irish Census 2006 (Central Statistics Office, 2007) while estimate 2 was based on the 1986 Traveller study (Barry *et al.*, 1988) and the 2005 Vital Statistics Report (Department of Health and Children, 2006). In addition, the AITHS 2008 provided the latest up-to-date census data on the Traveller population and was fully utilised to ensure that the birth cohort study captured the real number of Traveller births (Table 39).

The final 'corrected' estimate was 1,000 to 1,400 births for the island of Ireland.

Table 39: Estimated number of Traveller births using different data sources

Sources	Estimated births
Irish Census 2006	1,324
1986 Travellers' Health Status Study & 2005 Vital Statistics Report	1,240
2008 AITHS Census- range for number of Traveller children IOI (total under 1-year-old to 3-year -old)	862-1,400
2008 AITHS Census- estimated number of pregnant women with potential live births in IOI	1,272-1,669

Preliminary Findings: the Birth Cohort Profile (June 2010)

980 live births were identified by the PHNs and HVs for the island of Ireland. Of these, 502 (51.2%) consented to take part in the study. There were 465 (47.4%) refusals. As of June 2010 there were 13 (1.3%) mothers who still had 'to be approached' in NI. These figures will be included in the complementary report that will be produced after the study end date of 13th October 2010.

For ROI, there were 913 live births with 468 (51.2%) consented while in Northern Ireland, there were 67 live births identified with 34 (50.7%) consented, 20 (29.9%) refusals and 13 (19.4%) to be approached for consent. It should be noted that the consenting process is ongoing until the end of cohort on 13th October, 2010.

The maternal age profile of Traveller mothers has not changed since 1987 (Figure 26). The highest age group of mothers is still in the 20-24 age group with an average age of 25.9 years. This is comparable to other ethnic minorities, for example, Australian Aboriginals and New Zealand Māori. However, since 1987 there has been a shift in the average maternal age of the general Irish population, with an average age of 31 years old (Figure 27).

Figure 26: Distribution of maternal age by 5-year age groups for ROI Travellers and general population during 1987 and 2008

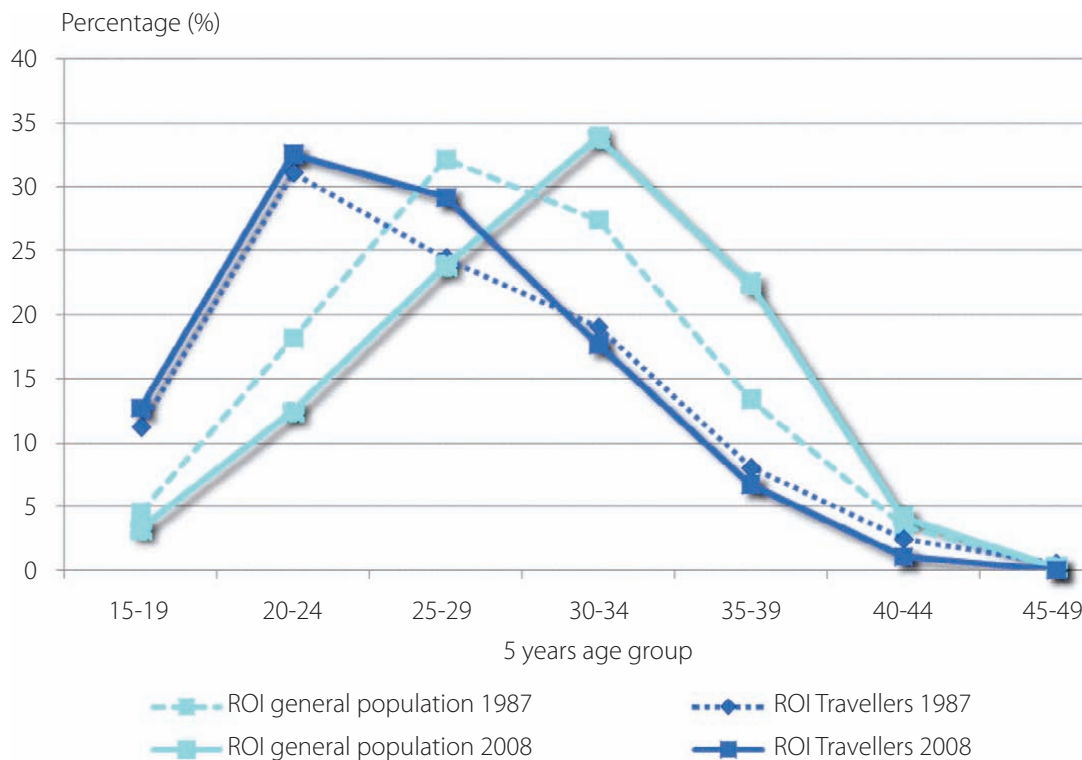


Figure 27: Average maternal age of IOI compared to other minority groups and in comparison to the general population of the country



Health Services Use: Maternity Hospitals

Only 30.6% of total Traveller births occur in the 3 Dublin maternity hospitals, as opposed to 35.9% of the general population. 69.4% of Traveller births occur in other maternity units outside Dublin. For NI, 70% of Traveller births occur in the Belfast and Craigavon maternity units.

Crude Birth Rate and Fertility Indicators

The crude birth rates of Travellers in ROI and NI has fallen. This was 25.1 per 1,000 population in ROI and 17.9 in NI (Figure 28). There is a variation in crude birth rate among the THUs with Mid-Western, Western and South Eastern THUs having the higher crude birth rate when compared to the IOI average (Figure 29).

Figure 28: Crude birth rate of Travellers and general population in ROI and NI in 2008; Crude birth rate of ROI Travellers and general population in 1987

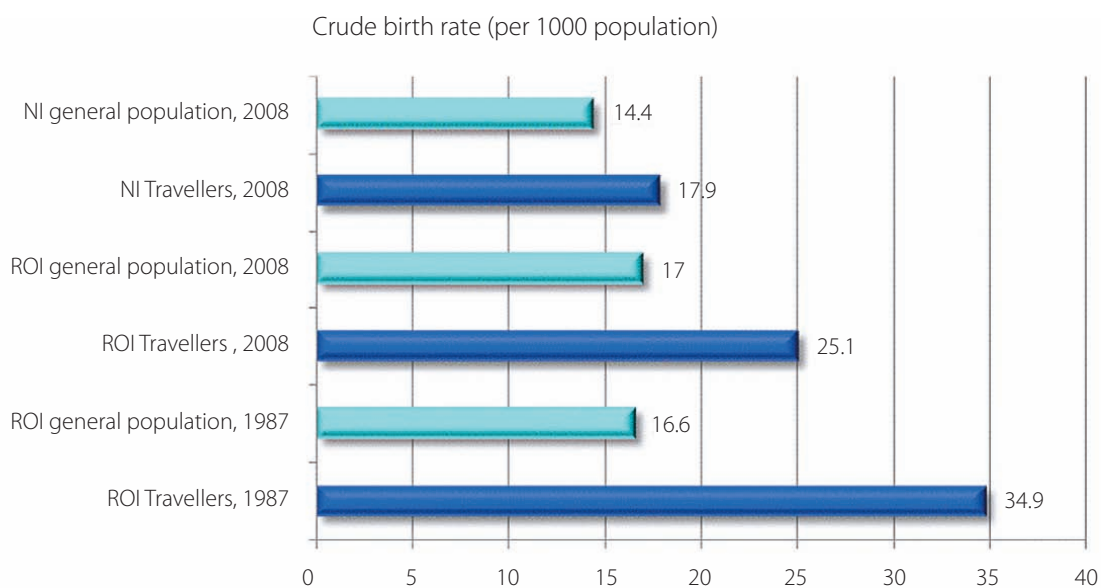
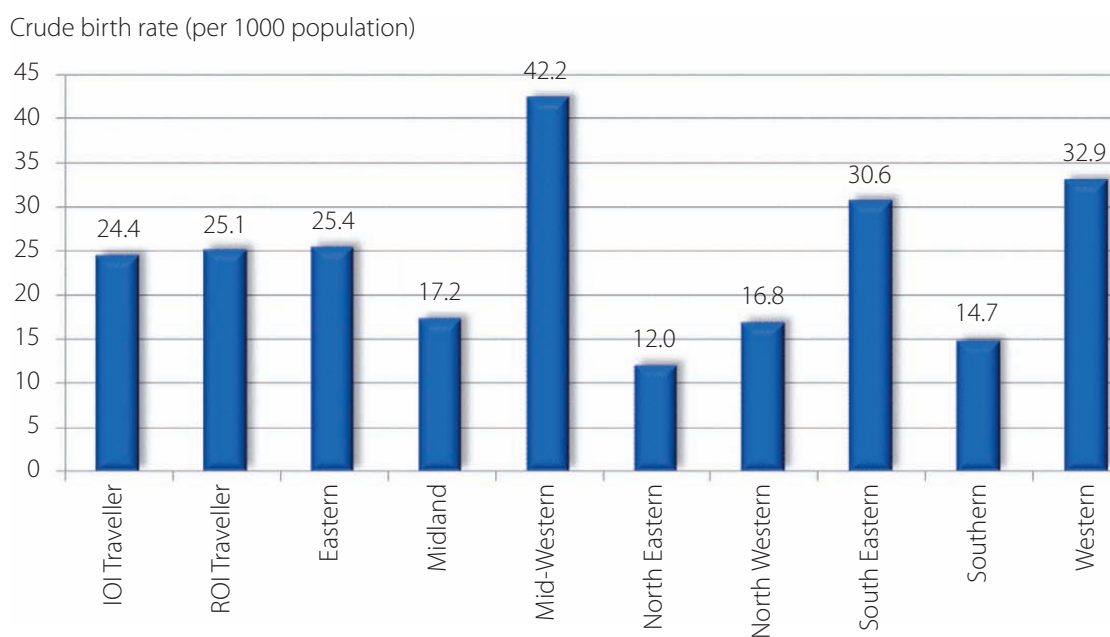


Figure 29: Crude birth rate (per 1,000 population) by Traveller Health Unit and in comparison with island of Ireland and ROI Traveller average



The total fertility rate has also fallen to 2.7 per 1,000 in the 15 to 49-year-old female age group. This is above the general population total fertility rate of 2.1 for both ROI and NI (Figure 30). This rate is below New Zealand's Māori but one of the highest in Europe (Figure 31).

Figure 30: Total fertility rate of IOI Travellers, general population Republic of Ireland and Northern Ireland; other comparative ethnic groups and their respective countries

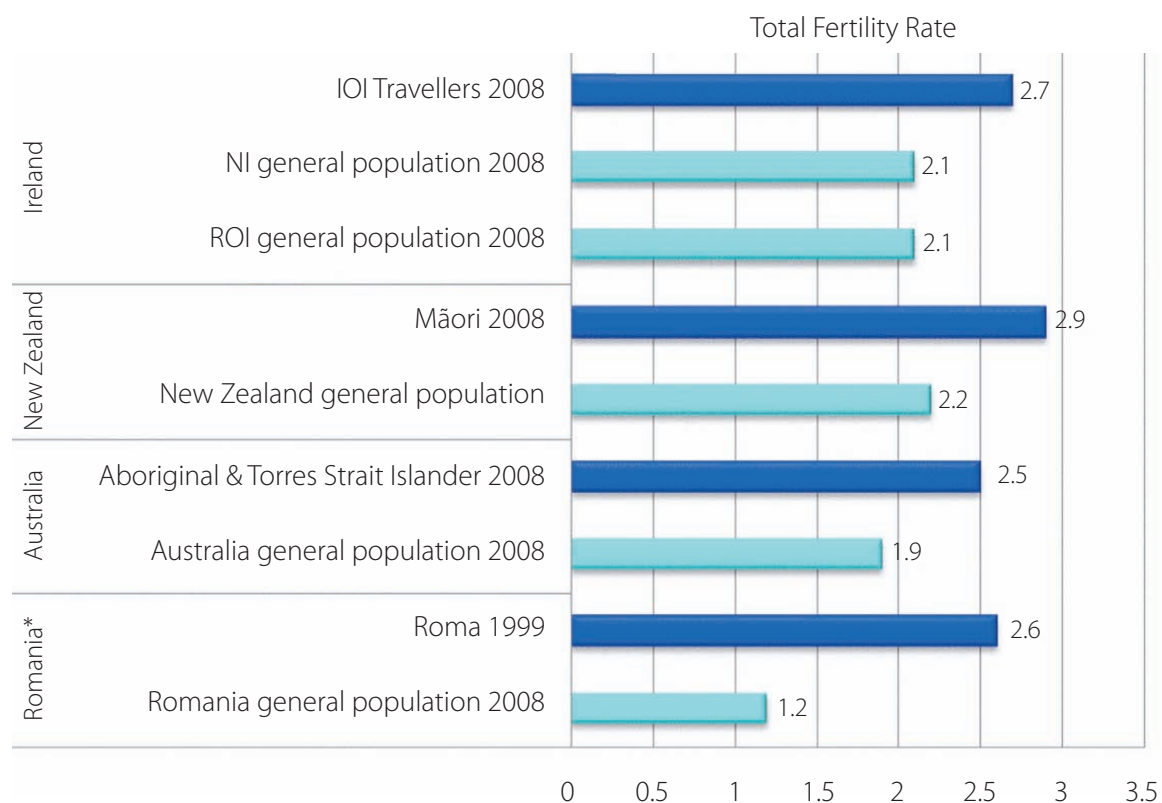
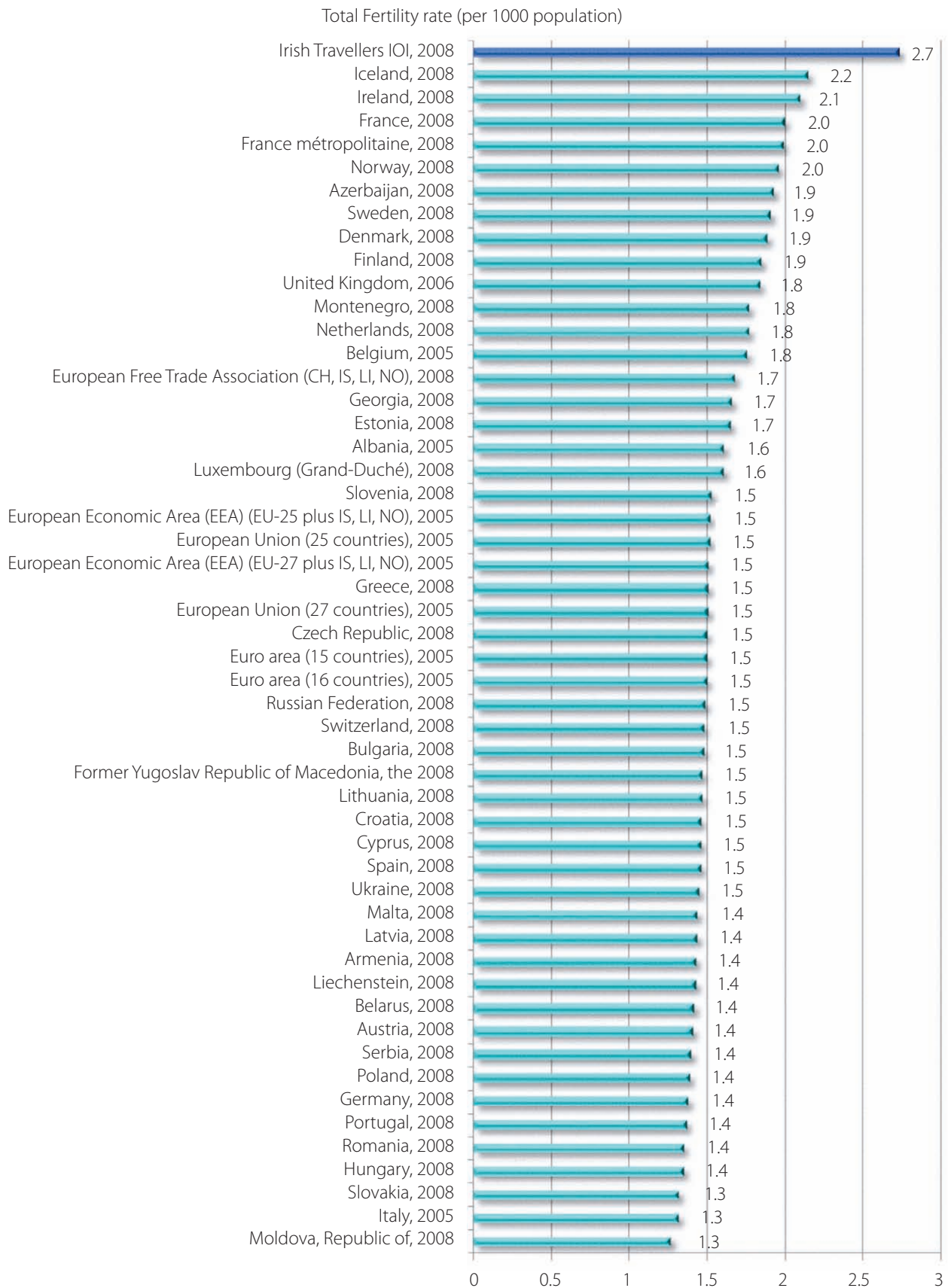


Figure 31: Total fertility rate (per 1,000 population): Europe



Source: EUROSTAT (2010)

Available at: <http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&language=en&pcode=tps00112&plugin=1>

Discussion

The average age of Traveller mothers has not changed compared to 1987. Traveller mothers are younger compared to the general Irish population. This picture is similar to other minority groups in Australia and New Zealand.

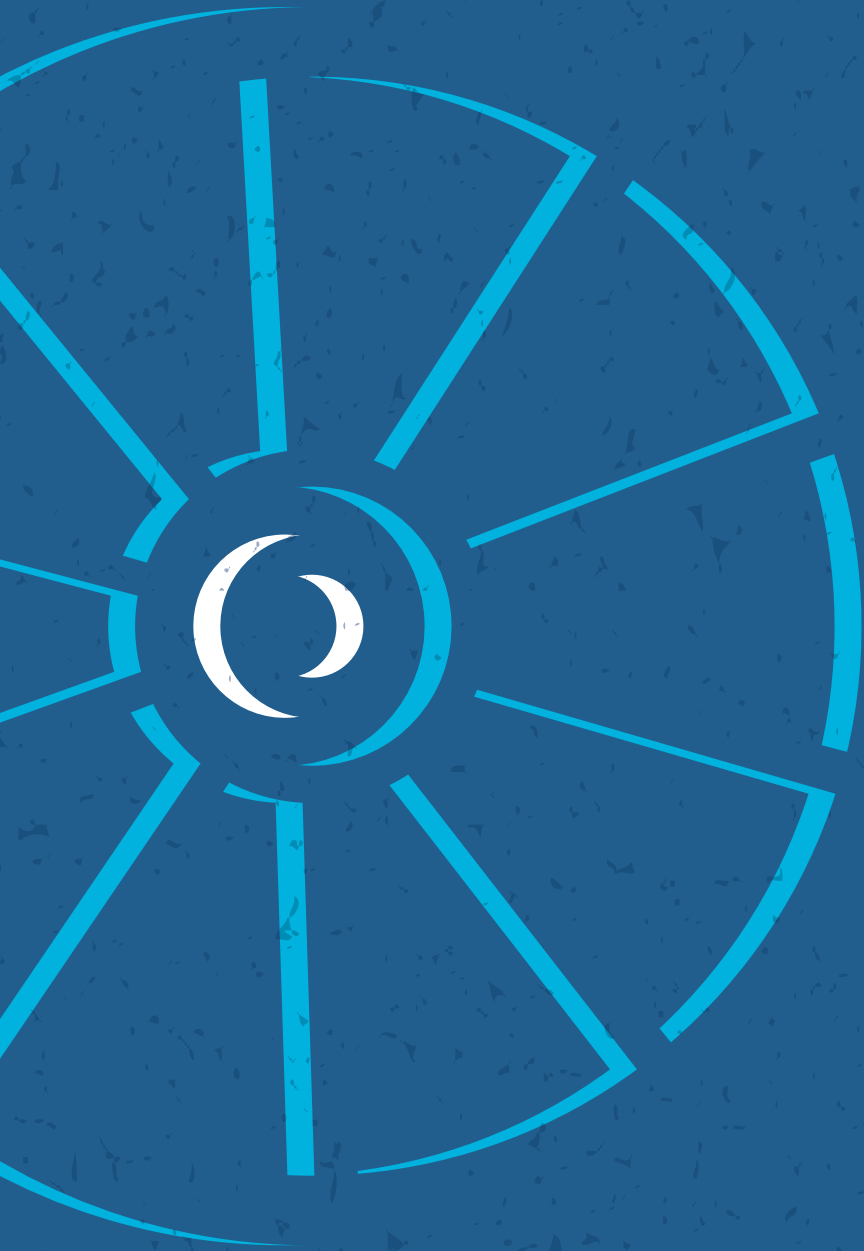
There were less Traveller births (30.6%) occurring out of the 3 major Dublin maternity hospitals compared to the national births average (35.9%). This means that 69.4% of Traveller births occur outside the three major Dublin maternity Hospitals. This may be related to the lower births to the Travellers in the Dublin area. Further breakdown of the recorded births also show a difference in distribution of births by each maternity hospitals compared to the general population. Certain hospitals have more Traveller births, which may be related to the consent uptake and the catchment areas of the hospitals.

The crude birth rate has shown a fall compared to 1987. It however, remains one of the highest in Europe. The crude birth rate of NI Travellers is lower than the island of Ireland average. There is a difference in distribution of births across all THUs. The Mid-Western, Western and South Eastern THUs have higher crude birth rates compared to the island of Ireland average.

The total fertility rate for Travellers in IOI is 2.7. This is higher for Travellers in ROI, which is 2.9. The total fertility rate for the general population ROI and NI is 2.1. The Mid-Western's THU has the highest total fertility rate at 4.3, followed by the Western THU at 3.3. The IOI Traveller's total fertility rate is higher compared to the Australian Aboriginals but lower than New Zealand's Māori. This figure is the highest when compared to European countries average.

There has been a fall in the crude birth rate and fertility rate compared to the 1987 figure. This may have been contributed to the overall change in culture as will later be discussed in the consultative study, improvement in general, sexual health knowledge of Traveller women and increased use of contraception by the Travellers.

Travellers in Institutions



Introduction

The Republic of Ireland (ROI) National Census of 2002 and 2006 (Central Statistics Office, 2004 and 2007) and the 2008 AITHS census of Irish Traveller families suggest that very small numbers of Travellers are resident in institutions. Extending the study to Travellers resident in institutions posed a challenge due to the low numbers of Travellers and the large numbers of institutions, and follow-up in hospitals, homeless shelters, refuges and care institutions was not possible. The 2006 ROI census identified Travellers in various communal establishments. The largest number of Travellers in these communal establishments were located in prisons (144) (Central Statistics Office, 2007 c, p58) and there is a relatively small number of prisons in ROI (14). Because of the available information about ROI Irish Traveller prison population (Central Statistics Office, 2004; 2007c and Kennedy *et al.*, 2005), and because prisoners often self-identify by asking to be accommodated near to other members of the community, this part of the study focused on a census, and the health status, of Travellers resident in adult prisons in ROI. The number of institutional residents likely to be Irish Travellers was too low to permit follow-up in institutions in NI (Northern Ireland Statistics and Research Agency, 2002).

Study methodology

Irish Prison Service: Traveller Prisoner Census

Governors in the 14 ROI prisons were asked to provide the number of Traveller prisoners in their prison on 3 specific dates during the time of the AITHS community census (14th October, 28th October and 11th November 2008), based on Irish Travellers who self-identified, such as by requesting to be accommodated adjacent to other members of the Traveller community. The IPS also provided data on the total number of prisoners in custody on the 3 dates.

Irish Prison Service: Traveller Health Status Study

Following consultation, UCD and the IPS Healthcare Directorate agreed a protocol for extending the health status study into prisons. The IPS disseminated promotional information targeting Traveller prisoners (information flyers and posters), and facilitated access to Traveller prisoners to 2 UCD researchers who were trained health professionals, in order to gain Traveller prisoners' consent to collect specified data from their prison medical record. Following a pilot process in a single prison, an additional 3 male prisons with large populations were targeted, with the aim of recruiting a sample of 100 Traveller prisoners, to allow comparative analysis.

Traveller prisoners who expressed interest in participating were brought either singly or in groups of 2 or 3 to a dedicated room, where researchers informed them about the project, and provided an information sheet and a copy of the data-collection form, explaining the nature and purpose of the data being sought. Questions on the form comprised a subset of the health status questions asked in the community during the AITHS. Interested participants consented in writing. UCD researchers were then provided with access to relevant individual medical records to collect the data.

Three key stakeholders associated with prisoner health were interviewed as part of the qualitative study, and 6 prison nurses were invited to participate in a health service provider Computer-Assisted Telephone Interview (CATI). Outcomes from prisoner-associated qualitative and health service providers input are reported elsewhere.

Findings

IPS Census

While all prisons responded to the census request, 3 all-male prisons, with large prisoner populations, could not identify Traveller prisoners, and the final estimate of males was scaled up to take account of this. The average estimate of female Traveller prisoners was 21, which was in keeping with the Traveller families' AITHS census return (18); the average estimate of male Traveller prisoners was 299, twice that of the Traveller families' estimate (150).

Travellers accounted for 8.7% of the prison population according to the IPS, and 4.5% according to Traveller families. It is not possible to verify which source provides the true number of Travellers in prison, and subsequent analysis was carried out using both figures.

Based on the IPS estimate of Traveller prisoners, the risk of a Traveller being imprisoned was 11 times that of a non-Traveller (RR 11.0, 95% CI 9.8-12.3), and for Traveller women the risk was 22 times that of non-Traveller women (RR 22.0, 95% CI 13.8-35.1) (Table 38). When calculated using the Traveller-reported prisoner population, the risk of a Traveller being imprisoned was more than 5 times that of a non-Traveller (RR 5.5, 95% CI 4.7-6.4), and for Traveller women the risk was 18 times that of non-Traveller women (RR 18.3, 95% CI 11.1-30.1).

The relative risk of imprisonment was higher for female Travellers than for males in both analyses. In the general population men are 27 times more likely to be imprisoned than women (RR 27.5, 95% CI 23.06-32.76) (based on 2006 census), whereas Traveller men were 8 times more likely to be imprisoned than Traveller women (RR 8.6, 95% CI 5.2-14.01) (based on Traveller estimates of Travellers in prison).

Table 40: Risk of imprisonment

	IPS estimates of Travellers in custody			Traveller estimates of Travellers in custody		
	Risk per 10,000	RR	(95% CI)	Risk per 10,000	RR	(95% CI)
All		11.0	(9.8-12.3)		5.5	(4.7-6.4)
Travellers	89.1			46.6		
Non-Travellers	8.1			8.5		
Male		10.8	(9.6-12.2)		5.2	(4.4-6.1)
Travellers	169.9			84.5		
Non-Travellers	15.7			16.4		
Female		22.0	(13.8-35.1)		18.3	(11.1-30.1)
Travellers	11.5			9.8		
Non-Travellers	0.5			0.5		

IPS Health Status Study

Recruitment for the health status survey yielded 26 Traveller prisoners (36% of all Travellers estimated by the IPS to be in custody on consent day). While every Traveller that attended the information session consented to participate, it became evident as the process progressed that many Traveller prisoners were either unable or reluctant to attend. The reasons were varied, but it became clear that in order to achieve the target sample of 100 it would be necessary to extend the process into many more prisons, which was not feasible.

During data collection it was not possible to collect reliable and consistent data on all of the desired variables, in some cases because of the way the electronic system recorded medical history and in others because some data fields (e.g. smoking and drinking habits) were not completed in all records. Taking into account the poor response rate and incompleteness of the data for some important variables, the data collection process was discontinued.

Because the achieved sample ($n=26$) was small and not representative, the limited findings cannot be reliably compared with those from any other study. Notwithstanding that the sample was not representative of the total population of Traveller prisoners, it was noted that more than a quarter of the group (27%) was documented as having been treated for a chronic disease in the previous 12 months. More than half (58%) had addiction problems, 39% had mental health problems for which they were being treated and 81% were currently taking prescription medication. Because all prisoners are routinely seen by a nurse and a doctor on committal, 100% had engaged with the medical service in the previous 12 months; the median number of interactions including committal was 8 with a nurse, and 10 with a doctor. Among the 62% who had interacted with the psychiatric services, the median number of interactions in the past 12 months was 4.5.

Discussion

Absence of an ethnic identifier was a major barrier both to accessing and recruiting Traveller prisoners and to collecting data in institutions. Follow-up in prisons relied on prison personnel's knowledge of Traveller identity (census) and on active self-identification by Travellers (health status study). When trying to recruit Travellers to the health status study, it was necessary to rely on Traveller self-identification in response to promotional documentation and information disseminated by prison staff. Issues of trust and a history of suboptimal engagement with structured services are likely to have played a role for those that did not respond.

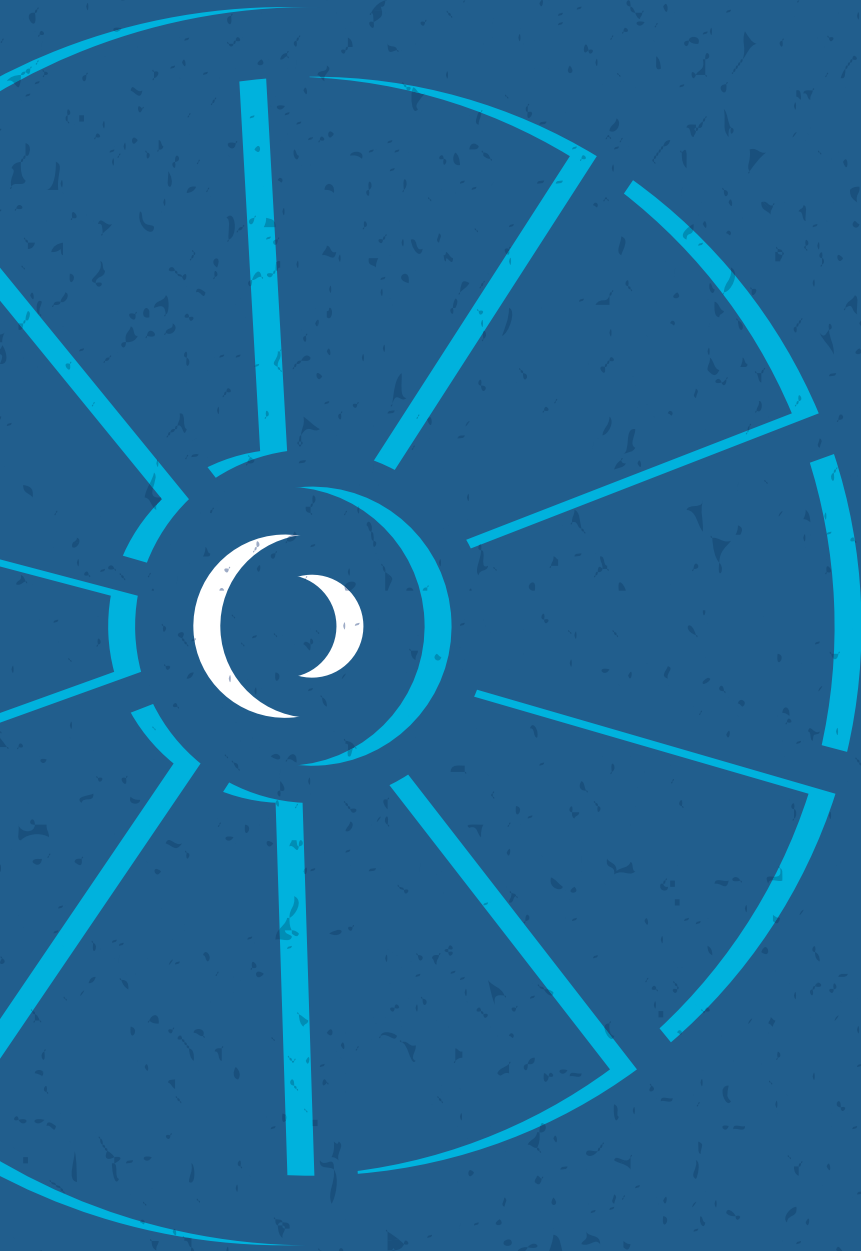
The reasons for the difference between the IPS and Traveller families' estimates of male Traveller prisoners are likely to reflect the fact that the IPS had to estimate the numbers and the sensitivity around any family volunteering information that a family member is in prison or that some Traveller prisoners had become dissociated from their family. However, whether using IPS (320) or Traveller estimates (168) of Travellers in custody, Travellers were over-represented in prisons in ROI at between 4.6% and 8.7% of all prisoners in custody, a multiple of the proportion of Irish Travellers in ROI population (0.5% in 2006 census; 0.9% in AITHS census 2008) and this is reflected in the high relative risk of imprisonment. Traveller men are at least 5 times more likely to be imprisoned than non-Travellers; Traveller women are at least 18 times more likely to be imprisoned than women in the general population. In particular Traveller women were over-represented. Using either method of estimating the numbers, the risk of imprisonment for Traveller men is lower than that for Traveller women.

Minority groups are often over-represented in prison. Reasons proposed for over-representation include socio-economic factors, alcohol and other drug misuse and mental health problems (National [Australian] Indigenous Drug and Alcohol Committee, 2009; Department of Corrections [New Zealand], 2008). It should be borne in mind that in this study more than 99% of Irish Travellers were not in prison.

Traveller prisoners receiving medical care prior to detention have access in prison to medical, nursing, psychiatric, pharmacy and dental services, and psychological and social supports; for any prisoner with a chaotic lifestyle, such as homeless prisoners or prisoners with addiction or serious mental health issues, detention in prison can provide an opportunity for compliance with treatment regimes that require, often multiple, follow-ups that may not be feasible for them in the community (such as vaccination against communicable diseases or access to dental and mental health services).

Travellers and prisoners are 2 minority groups whose health is a cause for concern. Traveller prisoners have double disadvantage and are a cohort worthy of further investigation. Currently, research on Traveller prisoner health can only be easily carried out if data collection is based on all prisoners, if ethnicity is established, and Traveller health is analysed as a sub-group, or if some means of Traveller self-identification is used; the latter might be too much to expect within a custodial setting. Including 'Irish Traveller' as a value in the existing ethnic identifier field in the prisons' IT system would facilitate Traveller health to be reported as part of routine high-level health status monitoring, and would also facilitate targeted recruitment of Travellers for future health research in this area.

The Qualitative Study



Introduction

In previous sections, we address the background to the AITHS and review as part of this the context for the study as a whole, which addresses the history of Traveller health policy over the last 4 decades, the importance of the wider health determinants influencing Traveller health and various exemplars of good practice for promoting Traveller health generally and providing appropriate healthcare.

The present section needs to be interpreted in the context of the other parts of the study. In seeking to understand how Travellers perceive their own health, the factors determining their health and the impact on their health of engagement with Service Providers, particularly in the health sector, we are situating this exploration as part of the wider project. We have already reported in the census survey what are the social circumstances of Travellers and what the prevalence is of various factors known to determine health, including living conditions, personal lifestyle and health status. In that section too we have presented frequency of engagement with the healthcare system and various factors well established as possibly influential on utilisation patterns.

This section is qualitative in its approach. The purpose is to listen and understand what the issues of relevance to the lives of Traveller are in their own estimation and to hear how these issues have a bearing on their health, as they themselves see it. This information is crucial to translating the findings of all sections of AITHS into evidence-based action and goes to the heart of motivation and engagement. This is also a rich opportunity to explore with Service Providers their perceptions of the issues and to link this to the view of Travellers in order to explore commonalities and possible future solutions.

Methodology

The qualitative component of the AITHS aimed to ascertain the perceptions and experiences of members of the Traveller community, Traveller advocates and Service Providers (via multiple qualitative research methodologies) in relation to Traveller health (including the broader social determinants) and services relevant to their health.

Theoretical Basis for the Traveller Qualitative Study

This study is aimed at providing an understanding of health status, health behaviour, health beliefs and health service provision among members of the Traveller community. As a methodological approach qualitative research aims to provide an emic⁵ understanding of the life world of those studies. That is, it seeks to discover locally understood social realities and to draw attention to processes, meanings and structural features.

Focus Groups

The aim of the focus groups was to include Travellers' voices, views, individual experiences and give insight while also identifying models of good practice (Barbour, 2008). Twenty-four focus groups were conducted (20 in ROI and 4 in NI, see Tables 41 and 42).

All of the focus groups were audiotaped and all except 2, which were transcribed verbatim with the confidentiality and anonymity of respondents guaranteed⁶. Each focus group was facilitated by a UCD researcher and a trained Traveller Peer Researcher.

Through further consultation with Traveller projects/equivalent groups in both ROI (via the NTHN and the National Traveller Reference Group) and NI (via the NI Stakeholder Group) this extended list of potential topic areas was distilled down.

The focus groups were either more open in style (generic) or (specific) around a particular topic area.

⁵ The emic perspective focuses on the intrinsic cultural distinctions that are meaningful to the members of a given society. Headland *et al.* (1990).

⁶ Two were inaudible to the transcriber because of background noise.

Table 41: Focus groups (ROI)

Focus Groups (ROI)	Tape/Notes
Women's Health	Tape
Men's Health	Tape
Older Women's Health	Tape
Young People	Tape
GPs, A & E, Medial Card and Dentists	Tape
Mental Health and Suicide	Tape
Addiction	Tape
Education	Tape
Work	Tape
Accommodation	Tape
Caring in the Community	Tape
Parental Perceptions of Child Health Services	Tape
Institutions	Cancelled

Table 42: Focus groups (NI)

Focus Groups (NI)	Tape/Notes
Accommodation	Tape
Mental Health and Suicide	Tape
Access to GP and Services	Tape
Generic	Tape

Recruitment

The focus group strategy included a purposeful sample specifically to look at maximum variation. Participation was on a voluntary basis with a minimum of 5 and a maximum of 12. The inclusion of Peer Researchers was central to the research approach and was vital in order to conduct the research successfully.

Method of Analysis

Data analysis was iterative running concurrently with the data-gathering process. Feedback from Travellers, Peer Researchers and stakeholders was included in the analysis. A manual thematic analysis was conducted by 3 members of the study team who independently analysed the data before coming together to discuss their findings. In addition, 4 inter-raters individually read sections of data from a range of focus groups for key emerging themes and met with the qualitative team to compare and contrast findings.

Semi-structured Interviews

Twenty-seven semi-structured interviews (SSI) were conducted in ROI and in NI with key discussants as listed in Table 43.

Table 43: Semi-structured interviews

SSI #	Interviewee	Tape/Notes
SSI01	Consultant 1	Tape
SSI02	Consultant 2	Notes
SSI03	Consultant 3	Notes
SSI04	Consultant 4	Notes
SSI05	Consultant 5	Notes
SSI06	Consultant 6	Notes
SSI07	Consultant 7	Notes
SSI08	Service provider 1	Tape
SSI09	Service provider 2	Tape
SSI11	Service provider 3	Tape
SSI12	Service provider 4	Tape
SSI20	Service provider 5	Tape
SSI21	Service provider 6	Notes
SSI22	Service provider 7	Tape
SSI13	Traveller advocate 1	Tape
SSI14	Traveller advocate 2	Tape
SSI15	Traveller advocate 3	Notes
SSI16	Traveller advocate 4	Tape
SSI17	Institutions 1	Tape
SSI18	Institutions 2	Tape
SSI19	Institutions 3	Notes
SSI23	Child services 1	Tape
SSI24	Child services 2	Notes
SSI25	Other 1	Tape
SSI10	Other 2	Tape
SSI26	Other 3	Tape
SSI27	Other 4	Tape

Travellers and Change in the 21st Century

Modernisation and the move toward city-centric industrial life in the west have arguably influenced Traveller culture, lifestyle and health in significant ways⁷. Travellers (symbolically and literally) have lived on the margins of mainstream society.

'...I think there is confusion around identity and confusion around trying to fit into the local community...Like there's a lot of reasons why they might not want to like, discrimination, racism, stigmatisation, there's a lot of issues that affects Travellers on a daily basis you know and the whole thing of identity crisis. Travellers have and are going through a major identity crisis at the moment' (Men 1).

Within the Irish context historical and literary reference at once romanticises and demonises Travellers. Travellers are often depicted in a one-dimensional and negative manner in a process classically referred to as a 'moral panic', that is in terms of a threat to the social order (see Cohen, 1973). These anxieties, often fanned by media representations have helped create perceptions of Travellers as 'folk devils'.

Ethnicity and Traveller Culture

A central issue in discussions surrounding Irish Travellers is that of identity and ethnicity. The qualitative data indicated that the concept of Traveller ethnicity remains a central issue to Irish Travellers in ROI and NI and one that they believe has consequences for them not only in terms of cultural survival but also in terms of health and life chances. They also recognise that definitions of Traveller identity have important policy implications (see also Coates *et al.*, 2008).

The oral tradition of Irish Travellers has meant that Traveller genealogies and factual histories remain problematic, blurred and contested. The notion for example, that they were dispossessed settled people (although with no basis in fact) fitted with the Irish nationalist project, but is interpreted by Travellers as disenfranchising them of their cultural heritage, that is, the right to travel (Pavee Point, 1992).

'...I would say that I was born into the Traveller Community so I would consider myself first and foremost to be a Traveller' (Men 2).

'...You shouldn't be proud to be Irish because you should be proud to be a Traveller...You shouldn't be proud to be Irish the way the Irish people have treated you and your family and your grandparents...and the way they discriminate and racism against ye you know' (Men 2).

⁷ Laslett's (1979) groundbreaking work mapping English society before the industrial revolution through to the twentieth century offers an historical glimpse into the social structure of a modernising western society undergoing major transformation and it documents the effects of change. No account of how such change has marginalised Travelling people has to our knowledge been documented in similar detail.

The ideal of the nomadic lifestyle remains a central pillar in terms of Traveller identity. Some travel regularly, others periodically, others have an ideal of Travelling rather than actual defining behaviour. Some had not travelled for a considerable time. But Irish Travellers who took part in the study agreed that they wanted to reserve the right to travel.

Identity and Homogeneity

The data suggest that while Irish Travellers identify as an ethnic group, they are not homogeneous. Traveller culture, as with all cultures, is diverse. The data showed broad and different experiences of the world while, for example, some Travellers are more isolated than others.

'...Even within the Travelling community, say the [X family] right, who rarely mix with others, even with other Travellers. They want to be in a site by themselves' (Men 2).

Travellers also occupy different positions on the economic spectrum. Travellers may be financially disadvantaged, but in rural areas for example, may be socially better off in terms of local acceptance and social capital^{8,9}. Difference is often nuanced.

Discrimination and Social Exclusion

When Travellers talk they tend to talk about themselves in juxtaposition to the 'settled community' - a 'them' and 'us' dialogue that might be described as a dichotomous worldview that of Travellers and non-Travellers. The focus group and interview data suggests that this is the result of regularly being exposed to distinctions being made about them from early childhood as different.

Discrimination emerged spontaneously as a commanding feature across the data. There was thematic prevalence and this was one of the first points of saturation spread across the Traveller and Provider data. While experiences varied, discrimination appeared to be constant and was reported in different contexts. Travellers perceive that they can't successfully navigate their lives because of discrimination. Service Provider data variously refers to Traveller lifestyle as chaotic, in crisis, frightened and suspicious.

'...There's a lot of reasons for that and one of them is because of the stigma and the discrimination that Travellers suffer...the choice is not there for them so they actually do integrate and integrate on the basis that they're hoping their children won't suffer the same that they have suffered as they were growing up' (Men 1).

'...the racism is not as blatant as it used to be. It's a bit more sophisticated now. Like at one stage there we seen signs on the doors of picture halls and pubs, 'no tinkers, no hawkers', right. So the signs were taken down and then when you actually went to the door they were saying, 'We don't serve your type here. We don't serve Travellers' (Accommodation 1).

⁸ Some Traveller families in the west of Ireland for example.

⁹ The idea of social capital may be sourced to Durkheim. These concepts however have been developed differently by Putnam (1995) and Bourdieu (1977, 1984).

'...Many people just don't understand what culture means and the difference between inter-cultural and multi-cultural approaches. But once they get it, they really get it and progress can be made'
(SSI: Traveller advocate).

Low self-esteem and discrimination was perceived as a main source of stress among men. Feelings of negative self-worth were reported as 'the biggest things' affecting the Traveller community.

'...We have lost our thick skin' (Men 1).

Discrimination, 'Telling', and 'Passing-Off'

Some mothers told of how their child would change their accent and dress code and deny their identity in order to fit in and avoid being bullied. There were numerous accounts from both adult focus groups and from young people that told of children and young adults 'passing off' at school/college/work in order to avoid being recognised as Travellers (see Garfinkel, 1967; Rogers, 1992).

The narrative illustrated that Travellers who had more frequent or even intermittent contact with non-Travellers reported better social relations, for example with publicans and hoteliers.

'...It depends on the area and where you live. It depends on the past experience of that locality with Travellers. It depends on the neighbours as well...You know there's a couple of ways of looking at it, you can actually take it on a prejudice level where you go in and for whatever reason the bar person wouldn't serve you, or would be completely ignoring you from the minute you walk up to the bar...You know you become a second-class customer in the space of a few minutes. Having said that, you can also prejudge people very quickly and that person could be busy, something could be on their mind and you could automatically think that that person isn't going to serve you' (Young People 1).

Young Travellers also hid their identity to get access to basic social facilities.

'...I have seen young girls glammed enough that they could walk on the red carpet in Hollywood and they are not let into the pictures' (Young People 1).

'...Traveller girls will dress down to get into a disco, but they don't take on settled person's ways'
(Young People 1).

One Traveller stated that, *'...if there is a problem with a Traveller then all Travellers are stigmatised...If something happens on the news you just say to yourself, I hope to God it's not a Traveller.'*

Socio-economic Position and Health Chances

A health determinants approach is fundamental to our understanding of Traveller health.

The All Ireland Institute of Public Health has produced a series of reports on health inequalities and their determinants across the island of Ireland, complementing a widely established international literature. More recently the work of the Health Research Board-funded unit for health status and health gain (Kelleher *et al.*, 2007) clearly establishes that significant health inequality exists in Ireland. A review of health inequalities in ROI and NI was recently compiled (See Farrell *et al.*, 2008).

Work and Unemployment

The change from agrarian society, through to the various phases of industrialisation and modernisation meant that Traveller's traditional employment became increasingly marginalised in a skilled and mechanised labour market.

'...Whereas now with the plastic and machinery Travellers are actually not needed. They are more feared now than they ever were. Like this woman said here, years ago you would see the settled people opening the doors for Travellers' (Work).

Historically, Travellers are thought to have played a significant role in the Irish rural economy. Fanning (2009) offers important narratives from Travellers detailing lifestyle and describing the range of Traveller occupations prior to the 1960s. Travellers traditionally worked as artisans and entrepreneur traders often in non-apprenticed trades. Travellers were self-employed independent units based predominantly around the extended family and kin (Fanning, 2009).

'...We did seasonal work, potatoes, the harvesting, the hay, the whole lot, even the turf and tin smithing, or whatever it was generally, rearing horses, breeding' (Men 2).

'...They're taking our culture away from Travellers which then leaves them to get involved with drugs. No pastimes, no employment' (Accommodation 1).

Often the broader determinants were discussed in the context of discussing employment, for example, education and discrimination.

'...I think to look at employment it has to look at all...wider than just employment. You know the education and all that has to fit into it. But also to acknowledge the work of the Traveller organisations. That there is role models within them organisations' (Work).

The focus group participants talked about hiding their identity when going for a job. Informal work if available could supplement a meagre income, but Traveller men reported that in addition to being discriminated against in the formal economy they are also excluded from the informal economy such as labouring, or gardening for example.

Gender and age appeared to be significant factors here in terms of recreational opportunities. Boys and men experience different opportunities and barriers than girls and women. Being a female Traveller means that opportunities are more restricted. Young boys were afforded more freedom than young girls.

'...Traveller men said they get dangerous amount of freedom after they leave school, which is different from the lack of freedom given to young women. There's a huge inequality of treatment there...and for young men that leads to high risk behaviour and that's going without any checks or balances and because these lads are not linking in with anybody, they are completely disengaged. They are disengaged from national school or secondary school at 14-15 and nobody sees them again, ever' (SSI: Service Provider).

Education

Education was identified in the data (by Travellers and Providers) as of key importance. It was viewed as a major barrier to improved lifestyle and health and in urgent need of redress by both Travellers themselves and Service Providers.

The negative effects were reported to begin in early childhood (as early as 3 years old) and to continue throughout the lives of Travellers. The data reported the importance of education or lack of education on wide ranging social, cultural psychological and economic factors. These affected self-esteem, and confidence of not just the child but the parents too.

'...the more confident the parent, the more confident the child' (SSI: Service Provider).

'...Slow learners, like I got put into a room with the teacher fixing jigsaws and I got put into the slowest class in school. Slow learners every one used to call it. And I got put into that like automatically without even doing a test. And just putting me down like' (Education 1).

'...In trailers like it is hard for a child to do their homework' (Education 1).

'...A lot of schools now has homework clubs where the children can wait and do their homework, that's good' (Education 1).

This is set against a backdrop of few role models, little history of Travellers staying in education or working outside the Traveller economy. Many of the young people indicated that there was very little point in staying on at school because there was no chance of gaining paid employment afterwards because of discrimination.

'...my second youngest said to him one day, 'You are not leaving school at sixteen' and he said back to him, 'you did your Leaving. You went to college. Where did it get you? You are at home on the dole' (Education 2).

Older Travellers offered accounts of being made to sit at the back of the class, being given a pen and segregated from the rest of the class.

'...Making you feel different and making the other children see you as different. Teachers were letting people know you were a Traveller' (Education 2).

'...You were a Traveller. You were nobody' (Education 2).

'...I know a young girl that when she went to school and never classed herself as a Traveller and went on and had a brilliant job and never came out and said she was a Traveller but the abuse that she had to listen to every day from her manager [about Travellers] that at the end of it she couldn't take it and she just left and he still didn't know she was a Traveller' (Education 2).

Bullying, name-calling and fights at school loomed large in most of the descriptions of school life, from both young people and their parents. When two separate groups of young people were asked during the participatory research what they would most like to change about being a Traveller (having also been invited to suggest what they most liked) they unanimously said, *'...being called names.'*

Adult education and the value of Traveller organisations, PHCTPs and training centres were recognised throughout the focus groups. They were seen as an alternate route through education when conventional routes were not seen as an option.

'...And I think once you are involved in an organisation or the likes of a training centre there is more doors open for adult Travellers to go on to further education if they want. But there is a lot of Travellers that would be...wouldn't be involved or know organisation in their areas that still would feel isolated' (Education 2).

'...Diversity is normal, and normality is diverse' (SSI: Service Provider).

'...education attainment level among the Irish population as a whole in say in the 40s compared to the 90s there is no comparison; and it took us from inception of the national school system from the 18th century...or 19th century it was. It took us a century and a half to get to here and now we are wondering why the Travellers can't do it about 5 times as fast?...but they have to do it 5 times as fast, they have to run while we walk, there is no choice in the world today' (SSI: Service Provider).

Accommodation

Good-quality, affordable, safe accommodation is essential to our wellbeing. In the census we present the different types of accommodation that Travellers occupy in both ROI and NI. The participants in the focus groups experienced, and spoke of, this spectrum. Some were living in houses and some in halting sites. Accommodation was cited as a key problem for Travellers and emerged as an important theme in many of the focus groups. However, provision and experience are not uniform between ROI and NI or between regional areas. Both users and providers recognise a need to improve both the level of accommodation provided and its quality.

'...Do you know, but it's 10 kids down there, there's a small baby and everything. Do you know if it rains, the muck is in the door. They're living in a muck pile' (Accommodation 1).

'...And these are people who have moved into standard housing that are being isolated and suffering from depression. Do you know what I mean, the council think they are doing a good job now? Put them in standard housing. They've been isolated from their extended family, do you know what I mean?' (Accommodation 1).

However, a lack of travel does not equate simplistically to a declining wish to travel for many, and is regularly invoked as a defining characteristic of being a Traveller and part of the Traveller identity as previously discussed. This links back to ideas of assimilation via living in houses rejected by Travellers.

'...I am a Traveller and the fact that me children have never lived in a house is one thing about them. Like even though they've never travelled a day in their life, they're still Travellers' (Accommodation 1).

A Traveller from ROI gave an example of what she considered a good site, which matched the NI experience.

'...A good site, it was only open at the time 6 months and it had houses on it and it had day units. The houses obviously, they had 4 bedrooms in them. But for those who wanted to still live in a caravan, they had a unit with toilets and kitchen facilities and what ever and they also had a bay. And that's what you call good accommodation' (Accommodation 1).

The data suggests that there are combinations of factors that cannot be reduced to any one institutional actor or agency but which nevertheless translate into a difficult context for improvement. There is a perceived need for discrimination to be tackled at institutional level on this particular issue.

A lack of homogeneity extends to finances, with some Travellers experiencing poverty and lack of choice. In cases of poverty Travellers suggested that if a loan scheme existed it would allow them to buy a trailer or group housing. To mention poverty does not by any means convey the depth of the data and the too numerous to quote hardships discussed involving evictions of some very vulnerable families in some parts of the island. Travellers are concerned also about living away from close family and among those who see them and react to them as deviant and alien.

Travellers also pursue rational choice. There was major concern about the consequences of moving into settled accommodation.

'...The support structure is there to the extent that if I'm living on a halting site and my mother is living in a house or she is living nearby. I'm always around, but I think the thing with Traveller families is as soon as you open your eyes in the morning you open the door it's like, do you want a cup of tea?' (Young People 2).

Environment and Health: Basic Services

There was concern about environmental issues. The physical environment concern frequently expressed was about the lack of basic facilities and amenities, including play areas. In terms of halting sites there was a variation in experience, some were regarded as good and some bad. Halting sites were often far from shops and amenities.

Major problems included lack of water, insufficient hot water and drainage, poor or no refuse collection, and problems with flooding and sewage. Damp and water ingress were reported to be a constant problem.

'...We have a hot water immersion but it doesn't last' (Young People 2).

Women in particular perceived health threats from the local environment. There was considerable worry about dangerous sites. Embankments, power lines and electric transformers, emerged as important points of health concern. Women talked about cases of infections in children. This was confirmed in the Service Provider interviews.

Civic engagement - Women's Experiences

Although experiences are individualised there continues to be a strong gender culture emphasising important differences between the lifestyles of men and women. Traveller culture is characterised by proud patriarchal dominance. Men were responsible for the family. Within Traveller culture it is the duty of the wife and children to be loyal to the father and women to obey men in the family¹⁰.

Traveller women historically tended to marry young. Modesty and the chaperoning of young girls until marriage were considered important. Deviation from these strict cultural codes (for boys and girls) was regarded as an affront to the family and wider community. Shame was to be avoided at all costs. Some Traveller women reported that more girls appear to be marrying at an older age (around 19) in ROI but younger in NI where marriage is legal at 16.

Both the rural and urban research with young people evidenced that it was the cultural norm for girls to help with domestic chores. This came to light when both boys and girls were asked to describe what constituted a normal Saturday morning for them. It was also played out via role play, as the girls swept the floor, washed the windows and peeled potatoes to show the types of domestic work they took responsibility for.

Women reported that in the past there was a much stronger sense of community, where they were able to keep in touch with families and extended families more. Contact and support from others outside the Traveller network was considered important and meant a great deal to many Traveller women.

¹⁰ Boys of 16 years of age, (sometimes younger) were considered as men among Travellers.

The experience of older women evidenced that the domestic sphere and family responsibilities continued to dominate many Traveller women's lives.

'...There's a lot of women in X, older women, over 50s and 'em they really don't look after their own health as much as they should – they're always kind of looking after their children and their husbands, they never care for their selves' (Older women).

Trust

Trust is considered an important component in health matters and the expanding literature on this currently reflects the importance of the relationship between trust and health (see Alaszewski, 2003; Mechanic, 1996; Barrett *et al.*, 2007).

Trust emerged from the focus groups as a major issue. Traveller women thought that outreach services facilitated Traveller trust. This was reported to enhance the uptake and use of services such as screening as borne out in ROI census data when Traveller healthcare workers were able to mediate between the services and individual Travellers in the community.

'...But I know the older women in X there's some of them that never had a smear test done in their lives and we have these women going around the sites doing the outreach and eh they explain to them how serious it is and eh to have them done and even the younger women as well never heard of smear tests. And the breast exam, it was the same with that – mammogram. Now thank God when they are going and doing their own thing, and making their own appointments and keeping their appointments. A lot has changed' (Older Women).

For those women who had the opportunity to train as Traveller Healthcare Workers, this has also afforded contact, support, trust, knowledge, payment, structure, social separation (from spouse, family and home), and promoted self-esteem and confidence.

'...Yes, before we started in the Primary Healthcare that you understand what rights is mostly now, but there's a lot of Travellers that doesn't – you will be left sitting in the queue and then there's people brought in before – you were only there beforehand' (Women).

Civic engagement – Men's Experiences

Many Traveller men talked of loss. This includes loss of structure and meaning to their lives. They reported hanging around, searching for a means to earn extra money, or trying to find things to do to relieve boredom.

'...When the money runs out you go home' (Men 2).

They were concerned with the need for and the loss of passing on traditional values and skills and were worried that the jobs were not there for younger men.

Bourdieu (1984) defines social capital as referring to valued social networks. Social capital may be measured in terms of the quantity and quality of social, economic and psychological support from family and kinship networks to help individuals and families overcome difficult situations or life events.

Cross-cutting ties with people generally, while important for everyday living, were often considered as being on a different basis of trust, since stereotyping, and perceived racism were regarded by Travellers to be constantly in the background.

Traveller men were highly pessimistic and fatalistic in outlook. Many men also agreed that they only felt truly comfortable around other Travellers.

*'...Yes you are a bit paranoid, you are looking around to see did anyone notice that you're being a bit paranoid and stuff like that and, and people don't realise that the stress that that bring on a person. Sometimes the Travelling man has to be macho, he goes outside and says 'Ah f*** it' he laughs it off and stuff like that' (Men 2).*

Traveller men also talked about involvement in acts of bravado that might be usefully described as 'Bantam Cock' Syndrome.

'...Say it straight out men, we have as many problems with the mental and physical health as women have. It is for the sake of bravado and the chest out like a bantam cock we won't talk about it, because men should talk about it. But the bottom line is our problems are there' (Men 2).

Secularisation

For many Travellers the (Catholic) Church remains important, although an increasing lack of respect was noted because of recent Church scandals in Ireland. Many Travellers however perceived religious belief as not being as important as in the past. The uptake and use of contraception particularly by women might be taken as a marker of this, for example,

'...Things have changed a lot, the way they use the service, contraception and stigma and asking for smears used to be secret and hidden but now is more open' (GP).

Women and Violence

Domestic violence is evidently of general concern to all communities both globally and when considered historically (Women's Health Council, 2009). In that sense it is not a new Traveller issue but a gender issue. Concern specific to the Traveller community was addressed by Traveller representatives. Pavee Point (the Irish Traveller organisation based in Dublin) for example, argues for the right for women to self-determination and ownership of their bodily integrity and the respect of Traveller culture.

'...There are barriers to access. Why don't some women use the services on offer? For example, if a rule says no men but a woman has a teenage son then she may not be able to use the place' (SSI: Traveller advocate, conducted in the scoping stage of the research).

Much of the feminist literature would support the view that male violence is a manifestation of the desire of men to exert power over women. Intervention strategies suggest an approach that teaches men how to control anger and improve interpersonal relationships by expressing feelings and removing frustrations and anger (Hamner and Itzin, 2000).

Sexual Orientation

The literature suggests that being lesbian, gay and/or bi-sexual (LGB) in any community is experienced differently according to the existing culture in that community and the surrounding society. It is also said to depend upon gender, age, and any disability present and ethnicity or minority group status. The Travelling community data supported this in various ways.

'...Some families are more liberal than others depending upon how traditional or liberal a particular family is' (SSI: Traveller advocate).

In order for gay men to fit into the community, for example,

'...A man might get married and then leave or divorce his partner but would have escaped the bachelor image and be accepted as 'straight' and be able to retain his position in the community' (SSI: Traveller advocate).

'...There is an expectation that men will procreate and carry on the family name. An awful lot of Travellers are hiding the fact (that they're gay)' (SSI: Traveller advocate).

There was a reported lack of much needed culturally relevant information for both 'straight' and LGB Travellers in the area of sexual health and sexual orientation generally.

'...But it is still a touchy subject' (SSI: Traveller advocate).

Addiction and Drugs

The health-related lifestyle issues of concern to Travellers were addiction, alcohol and drugs, rather than diet, physical activity and smoking.

Addiction and drug use were interpreted as mirroring the experiences of the general population and not something solely related to Travellers. While addictions straddle the social class spectrum, and may be seen as a general societal problem, the lower social classes and marginalised groups appear to be disproportionately affected because of the influences and stresses imposed by their relative socio-economic position (See Wilkinson, 2005; Haustein, 2006).

'...Alcohol and drug use which has increased... there is a greater pressure on services' (SSI: Consultant).

Travellers interviewed in NI reported that hard drugs were not a major problem in NI compared to the mainland UK and ROI although respondents knew of pockets in one or two small towns in NI¹¹.

It was understood that there had been a 'drug scene' in ROI for a considerable period and Travellers appeared to have a conceptual schema in relation to addiction. This ranged from habitual alcohol abuse through to habitual hard drug abuse. In several focus groups Travellers stated that hard drugs such as cocaine use has increased in ROI.

Alcohol was viewed as socially acceptable and was seen as an important social outlet for men. It was not seen as a drug and was not necessarily regarded as dangerous. Men tended to downplay problems of alcoholism.

'...Traveller women don't go to pubs but off-licenses to get drink. Men go out with men, but women stay on the site with children. The women hide it' (Addiction 1).

There was general concern about what was described as a trajectory of addiction. This pointed up the connection to actual and perceived exclusion of Travellers from public houses and other licensed premises.

'...It's back to discrimination... It is easier for Travellers to get drunk than it is to go to the pictures or a disco or to a local pub or anything like that. So I think they are very much isolated' (Addiction 1).

One Traveller said that many don't understand the symptoms of alcoholism.

'...They think they are only having a few drinks' (Men 2).

Addiction and drug abuse in the Travelling community is largely unspoken and hidden.

¹¹ Paramilitary organisations had for decades exerted control of drugs and drug dealing in NI. See for example, 22nd Report of the Independent Monitoring Commission 4th November, 2009.

'...Travellers know about extent of the problem but deny it. It's a shameful thing' (Addiction 2).

'...There is a lot of denial among the Travellers, even if they know a member of the family is using drugs. It's hidden you know, they see everyone else but they don't see their own' (Addiction 2).

Drug abuse in particular, was perceived as a major health threat to men in the future. Men expressed helplessness in the face of increasing illicit drug use and agreed that the problem was getting worse.

'Addiction I think that is going to have a major impact on Travellers in the next couple of years' (Men 1).

Traveller Experiences and Perceptions of Healthcare

The literature on the medical encounter between health professionals and lay people is replete with accounts of negative doctor/patient interaction and communication breakdown because of the expectations on the one hand, of a professional culture and on the other, lay interpretations of health (Kleinman, 1980; Helman, 1978; Department of Health (ROI), 1992; Salmon, 2000; Wood, 2000). The data supports general findings that socio-economic position was also deemed to influence this (McManus, 2001). A recent review of the research into doctor/patient communication found *'consistent evidence that race, ethnicity, and language have substantial influence on the quality of the doctor-patient relationship. Minority patients, especially those not proficient in English, are less likely to engender empathic response from physicians, establish rapport with physicians, receive sufficient information, and be encouraged to participate in medical decision making'* (Ferguson and Candib, 2002).

The doctor/patient experience was particularly fraught for Travellers and the use and uptake of GP services appeared to be patchy. This interface was often cited as being particularly problematic. Travellers often claimed that doctors often don't appear to listen to, or don't understand them. Many physicians were reported to adopt a physician-centred consultation sometimes with little or no attempt to adequately explain conditions or courses of treatment in a manner understood by Travellers.

'...There on Monday my father was in the local GP – went up because he wasn't well, and he went and got his prescription, within two days he had the antibiotics gone – because he couldn't read – he has a literacy problem. And the doctor never explained to him how to take them – never the chemist or the local GP, and also when they were saying a while ago, people goes to the doctor so many times that not actually explaining what's wrong with the person and lots of the times, you can't understand what they are explaining' (Women 1).

Sympathetic GPs tended to be well known to Travellers and some indicated that they travel further to be seen by these GPs.

The data indicated that Travellers found it difficult to articulate or explain themselves. Both men and women reported that they internalised communication breakdown as a personal problem associated with their inability to read, write or understand the doctor or chemist. The narrative indicated that men felt a sense of shame and embarrassment.

*'...We might not have the best education in the world. You go into a doctor and he is talking in bigger words and he is asking you questions in certain ways and he would say have your bowels moved and some people might know that that means did you s**t today. You get what I am saying? And they are not going to turn around and say I don't understand that because it makes you sound like a worser fool' (Men 2).*

Service Providers also talked about the benefits of respect and positive regard.

'...If you treat Travellers or anybody with respect and equality like everybody else and they know that's what is happening then there is never a problem' (SSI: Service Provider).

A Service Provider suggested that a model of best practice might be to provide written and verbal medical and discharge instructions to Travellers and caregivers could confirm that instructions were understood.

While the census data indicated that few reported having no medical card in ROI, it nevertheless remained an important issue for Travellers and was regarded as symbolic of relative powerlessness. Some Travellers said that they could not understand that *'in this day and age'* health data could not be stored centrally and accessed by different doctors in different locations.

The perceptions of many health service providers was that while this was clearly a problem for some it did not appear to be the rule.

'...There certainly would not be any more difficulty than anybody else to register with us' (SSI: Service Provider).

Having an up-to-date medical card was key to accessing a variety of health services, including dentists. Some Travellers reported problems with accessing medical cards. Lack of, or changing postal addresses was considered a major barrier.

'...With the dentists you have to have an up-to-date medical card if you are going to a private dentist, but we find with our own families as well, lots of the GPs are holding onto the medical cards, not giving the medical cards, so therefore they can't go to the private dentist because you have to show that card to get that treatment done' (Women 1).

Triangulated data from Traveller focus groups and Service Providers point to poor communication practices as a major barrier to successful health utilisation and provision.

'...The Primary Health Care Projects go out on site and the Travellers are more aware of them and that works... they trust them more now...They know what's happening to Travellers out there' (Women 1).

Preventative Health and Screening

Some Traveller men and women indicated that they were aware of lower life expectancy but tended towards immediacy and in dealing health issues mostly as they became acute. While there is evidence that women considered family planning, men and women generally tended not to consider health planning, surveillance and follow-ups. Those who did tended to be women.

'...They wouldn't go. I had 10 children and never went for a smear test or a breast check until I started overhearing the conversations here with (Person's Name) and the women here. If it wasn't for the primary healthcare teams around the country they wouldn't hear. We never knew about the menopause... There's parts of our bodies that I didn't know about' (Women 1).

Accident and Emergency and Hospitals

Travellers reported more positive experiences in the hospital. One exception was when visiting patients. Hospital rules frequently restrict the numbers of visitor to each patient. However, Travellers said that they felt more secure in groups, and family and cultural expectation required that they visit sick relatives. Travellers also expressed concern that foreign hospital staff often added a further communication barrier since they could not understand the Traveller accent.

The tendency was to avoid primary care services until health problems became acute or serious enough to necessitate the use of A & E services.

'...You see, a lot of the men, a lot of the older men won't go to a doctor because they don't think it is too macho... right, cause you see them coming out of the doctors, the people, people will think they, think they are weak or are sick and all that' (Men 2).

Mental Health

Travellers have traditionally relied on their family networks for social and economic support. Many fear the fracturing of these bonds as a consequence of being settled. A loss of social support structures combined with distrust, a sense of anomie, discrimination and low self-esteem is a potent combination likely to have implications for mental health and physical wellbeing. The loss or reduction of ties and support structures and emotional support, and the potential impact in terms of health status is well documented (Ginnety, 1993; Kawachi *et al.*, 1999; Balanda and Wilde, 2003; Walker, 2008). Greenan (2009) provides a useful summary of the literature.

Women reported feeling isolated and having periods of depression.

'...As a young person because you are emotionally embarrassed it's not all your identity but it's just when people are turning you down different types of things and are ashamed to be with you, you kind of feel embarrassed and you just kind of say to yourself why are they ashamed of me I am a person the same as everyone else, I have equal rights... The way that changes things is the way that people treat you down different and I just don't understand why. There is a lot of common suicides going on in Traveller community' (Young People).

Men talked openly about depression and mutual pretence in relation to denial of depression and this sparked emotive commentary in the focus groups.

'...We are all liars at this table, and I will tell you why. An awful lot of the men are hanging themselves, taking over doses, buying the rope the whole lot' (Men 2).

'...We have serious mental problems and we are not dealing with it, and for starters I have often got, Jesus serious depression in my house. I must say and I have had to go for a walk, women do the same thing. I am not depressed all the time, but I go for a walk' (Men 2).

The data showed that while mental health services were available they were often perceived as inadequate. Mind (2010) also notes similar health issues in relation to other ethnic minority groups, the health of the Irish in England for example (see Mind, www.mind.org.uk) and advocates good practice at a number of levels.

The Departments of Health in both ROI and NI have high-level groups looking at services for Travellers and much of the current strategy is looking at promotion and prevention rather than the specific focus on sickness. Current mental health strategy concentrates mostly on mental health promotion and prevention rather than specific focus on sickness.

Folk Medicine

The use of folk medicine and folk healing goes back to antiquity. We need to be cautious about romanticising Travellers and their use of folk medicine. The practice was and is more widespread than is usually imagined (Moore and McClean, 2010; Murphy and Kelleher, 1995).

'...I think it's like if there's kids up there and they have a skin rash and they actually brang it to the doctor and the doctor gave them creams over and over again and none of the creams actually worked. What is happening out in our area then, people, the older Travellers would tell the younger generation of a cure maybe down the country – it's where you go and buy the cream or get the cream off the person and you rub it onto the child for so many weeks and then it kind of heals up – it depends on what kind of sickness. Again there's cures out there for headaches, for bronchitis, whooping coughs and things because lots of times with the doctors, they don't be cured – lots of Travellers would have strong belief' (Women 1).

Service Providers and Policy Considerations

Civic Traveller Representation

Data from the Service Providers' semi-structured interviews recurrently identified a dearth of appropriate Traveller representation at various levels of governance and pointed towards a need for a Traveller 'champion'.

'...Getting a political champion for it (referring to Traveller health and social issues)...it is difficult but really important because it will give it a little bit of drive' (SSI: Service Provider).

These champions, in the views of respondents, should also hold a position with the authority to account for services of all inter-agency bodies.

'...In my view, you need to have policy that is coordinated at central governmental level, but you then need a middle layer where you have the delivery organisation to address these determinants of health, informing policy and equally being informed by what's happening in the ground. Most centrally with Travellers themselves and their support organisations' (SSI: Service Provider).

'...this is a cause worth championing, so if there was a champion or champion within the organisation...' (SSI: Service Provider).

Leadership should not only be seen from at the governmental level but also coming from the Travellers themselves. These leadership roles should be trained and supported during engagements.

'...we need leadership from the Travelling community itself...' (SSI: Service Provider).

'...the big issue around language, time of meetings, how comfortable people are. If you want Travellers involved, are you going to support them in advance of the meeting...follow up with people, and mentor... whole draft of issues like that, how do they get there, what type of arrangements are made...that would obviously change the dynamic of meetings...it is much harder for them, it is a totally different way of operating...' (SSI: Service Provider).

Many recommend Traveller engagement should be encouraged and implemented at all levels, local, regional and national.

'...there is a need for Traveller leadership at all level...' (SSI: Service Provider).

More community engagement was needed, according to respondents, for reciprocal reasons of mutual understanding. It is only through engagement that barriers can be broken down, needs and aspiration achieved (National Institute for Health and Clinical Excellence, 2008; Ochoa and Nash, 2009). This also leads to building of trust between the Traveller community and the Service Providers.

'...There are a lot of issues coming up which the national policy would have a clue about Traveller men, you know, obviously you can name accommodation, education, discrimination and the standard ones. You can read them, they are going to be named in there but the subtlety of what's on the ground in relation to how drug use (as an example) need to be responded to, how community need to be supported and talking about it...as a first step in addressing it, instead of going in all guns blazing. A sensitive, appropriate and culturally-specific response towards all these issues has to happen' (SSI: Service Provider).

At the more strategic level, service providers were also wary of sensitivities when interfacing with Travellers networks and advocates, which meant that key issues, although recognised, were not fully addressed.

'...One of the presentations was around some of the issues around the misuse of alcohol in the Traveller community. Now that would have been an elephant in the room previously because people would have felt 'that we are letting our community down if we talk about it to you know, people who weren't kind of part of our culture...when those kind of doors open and people feel confident enough and safe enough I suppose in a way – to actually begin to kind of talk about what is going on in their group or in their culture. That I think is a very good indication of again putting it up to the health services and thinking about – well what are you going to do – now that we are talking about it, to actually support what we need' (SSI: Service Provider).

There is also a need for reassessing community developments for Travellers. Community development strategies were mentioned across all departments as a method of both engaging Travellers and of promoting independence. However, this was perceived as patchy; there have been some excellent examples in some places while still poorly developed in most areas.

'...So, there are things that can be done in terms of re-focusing resources both monetary and human resources, to actually kind of, sort of, target what the priorities are and obviously the priorities are primary care teams and networks...And certainly the evaluations I have looked at in relation to the effectiveness of peer workers around outreaching and inreaching...I think there is pretty good evidence of their effectiveness' (SSI: Service Provider).

'...However, it is recognised that there are still massive work to be done but main barrier is related to engagement with Travellers' (SSI: Service Providers).

'...there is a need to do more community development. It has got better over the years but it has been a problem...There is problem with getting regular engagement' (SSI: Service Provider).

It is also recognised that community development and leadership skills take time to develop.

'...even though there is a commitment to community development...It takes time to get the other leadership and grassroots participation to build up to such a stage and such a stage that ability and capability to deal with such complex issues that you deal with...' (SSI: Service Provider).

Inter-Agency Fragmentation

Service Providers also reported that even though there was a good deal of inter-agency alliance, communication problems existed and represented a barrier to working effectively for Travellers. These include dedicated services like the THUs within the HSE working specifically with the Travellers. Lack of such dedicated units or personnel from various departments have been noted to make situation more complex and fragment services. Lack of coordination can also worsen an already complex situation.

'...So, although we are kind of talking specifically about health maybe – a lot of the work we do is either with the community and voluntary sector and the NGO sector – or it is with other government departments as well.' (SSI: Service Provider)

'...Sometimes the guards (reference to the Irish police force, the Gardaí) go in to arrest someone but leave the whole family in a mess. We have other responses, outreach person available to support drug user and family' (SSI: Service Provider).

'...so the (Service Provider) will know who to contact in (governmental agencies)...they know exactly who to contact, but they find it difficult to get anything addressed for the family or for the child' (SSI: Service Provider).

Any form of public health interventions, with regards to societal factors, is regarded as complex interventions by the public health literatures, thus requiring the cooperation of all agencies.

'...There are so many policies that in theory are cross-governance, one of the things that we know about organisation...is that, across Government working is not working very well...' (SSI: Service Provider).

'...what you have got is Government working with (service organisation) taking central policy responsibility but it is not clear to me what does that translates to in action with the delivery organisation, how the other government departments are held accountable for their bits or what that plan is...' (SSI: Service Provider).

'...With end delivery organisations we have pockets and examples of very good practice and at different times it has been very good, but it has not been coherently joined up over sufficiently long period of time and the commitment has waxed and waned over time...so you have a disjointed picture and that needs to be tackle in the future...' (SSI: Service Provider).

'...Yes, there has been progress but it is very irritating and disturbing to see how very little progress there has been...so hand on heart there has been progress but not enough, and not fast enough and not coordinated enough...' (SSI: Service Provider).

It was felt that perhaps central Government should become involved in policy coordination.

'...so maybe a steering group chaired by a Minister or Junior Minister which has...or one of the Junior Minister for Health assigned by the Minister for Health with a responsibility to deliver and he would then bring all the groups together for progress report to go back to government. It gets the proper matter coming through, full ministerial commitment, CEO and Board commitment, senior management commitment and a couple of state agencies...' (SSI: Service Provider).

Responses from the Service Providers indicated that they felt that inter-agency fragmentation and inaction caused frustration. Reference was made to a 'battle' in dealing with unresolved issues that might lead to burnout of Service Providers.

'...The policy is centrally driven...at the minute, if the policy is dumped into one department, everybody else seems to think 'oh well, it is over to them then' that simply isn't just good enough...and we know for complex issues like this, that they do require a range of input in order to make a sufficient difference...and the other critical thing working against us perhaps is, this is a long term issue.' (SSI: Service Provider).

(Speaking with regards to on going water pump issue on caravan site) *'...I came in in 2002 and this is 2010, so the environment situation is very, very slow to change and that I think burns Service Providers - any Service Provider – out...it is within their remit to advocate to those agencies and to those statutory bodies on behalf of their clients and they will do that, but inaction frustrates them'* (SSI: Service Provider).

Selection of appropriate personnel dedicated to Travellers can be challenging. This relates more generally to reluctance of service providers to work with disadvantaged groups. It was felt that working with Travellers required more energy and demands more dedication from the service providers. This is not so much seen as a burden to the service provider but the nature of the situation. In addition, due to the pressure of resources, Service Providers who work with Travellers might find themselves isolated from the rest of their own department. Leadership support and support from service providers from other agencies is crucial.

'...Not everyone is suitable for Traveller services, you need to choose the right person' (SSI: Service Provider).

'...and unless you have people who are committed to Traveller health and their health development, nothing's going to happen. You need the commitment; you need dedication, not somebody who is put into those positions' (SSI: Service Provider).

Some of the Service Providers also called for more creative use of existing budgets. Only the health services have a dedicated budget through its delivery body while other agencies with a cross-sectoral remit do not necessarily have such a specific budget.

Some thought that there was a lack of *'...appropriate engagement with Travellers'* (SSI: Service Provider) and that policy should be rights- and needs-based and not based on Government aims. This however has not been requested solely by the Travellers.

‘...So, I think that that rights-based approach if you want to put it like that... it is incredibly important – because it is about adults interacting with each other. And I think from the Traveller community point of view, one of the positive aspects I think about having the THUs and about actually interacting as a service for us, as a health service, with members of that community and talking to them and listening to them about what their experience is, is that they can actually shape then what the services are going to be. And that is very, very important’ (SSI: Service Provider).

‘...it needs to be positioned within the context of health and wellbeing and therefore advocating the rights of Travellers but also the responsibility of governments in other departments to respond to this need’ (SSI: Service Provider).

Inter-agency collaboration is more optimum at the higher level.

‘...Actually in terms of an integrated service directorate – actually makes it much easier to bring the different directorates together’ (SSI: Service Provider).

The issue of ethnic identifier, for example, was regarded as important for policy on Travellers to move forward. This has been brought up by most Service Providers as important for service planning and delivery.

‘...So, like it is something that we would be promoting very much... is that – embedding an ethnic identifier in terms of poor data sets, is a Government strategy’ (SSI: Service Provider).

‘...why are we having to do special survey? There should be something that which is captured routinely that we can use regularly to inform decision making...’ (SSI: Service Provider).

‘...unless we have got robust data, sure how can you plan services, it is ridiculous, it is ridiculous... It is very, VERY important’ (SSI: Service Provider).

However, there is concern by Service Providers that this needs more concerted effort.

Cultural Rights and Representation

While the right to enjoy cultural life belongs to every person, it is cultural minorities who may be particularly vulnerable in the enjoyment of this right, as they and their interests may not be adequately represented in democratic decision-making structures. At a broad level, in their relationship with the State and local government, as a minority, Travellers can be outvoted or marginalised by the wider community that at best does not share their priorities, and at worst may perceive their priorities as being opposed to those of Travellers.

‘...The political will needs to be there...’ (SSI: Service Provider).

'...You need strong advocacy - external and internal - and you need structures to enable people who are involved to have a voice...' (SSI: Service Provider).

'...political will, that's the big one I think...that's the thing that I believe that will help shift this on dramatically' (SSI: Service Provider).

'...I think that those changes in the government departments and who the new ministers are – ministers of State are, is quite a kind of positive message – so I think that high level group, is a very good kind of structure' (SSI: Service Provider).

'...if you want to get something of significance done...you give them the evidence, and if it keeps appearing on people's desk through various advocacy group, through questions on the Dail, through questions on the Oireachtas committee and through internal advocacy and external group...' (SSI: Service Provider).

The various international human rights laws and standards referred to in this report highlight the need to respect the right to enjoy cultural life at the early stages of policy-making and local decision-making in order to give rise to a more constructive relationship between the minority and majority communities. Effective minority participation facilitates fair processes and promotes decision-making that is sensitive to the needs of Travellers (United Nations Human Development Report, 2004).

'...but from a health service point of view, I suppose that what I feel is that because we based the strategy, our own inter-cultural strategy on some of the gold standards from other countries, then I think that is a good sort of grounding for us around what we are doing and how we deliver on it.' (SSI: Service Provider).

'...then you are bringing the political system into it...where it can be chaired by a government body or government minister...at the end of the day if there is systematic blockers...then it puts the onus back on the political system...it can act as a mechanism to question the present system as well' (SSI: Service Provider).

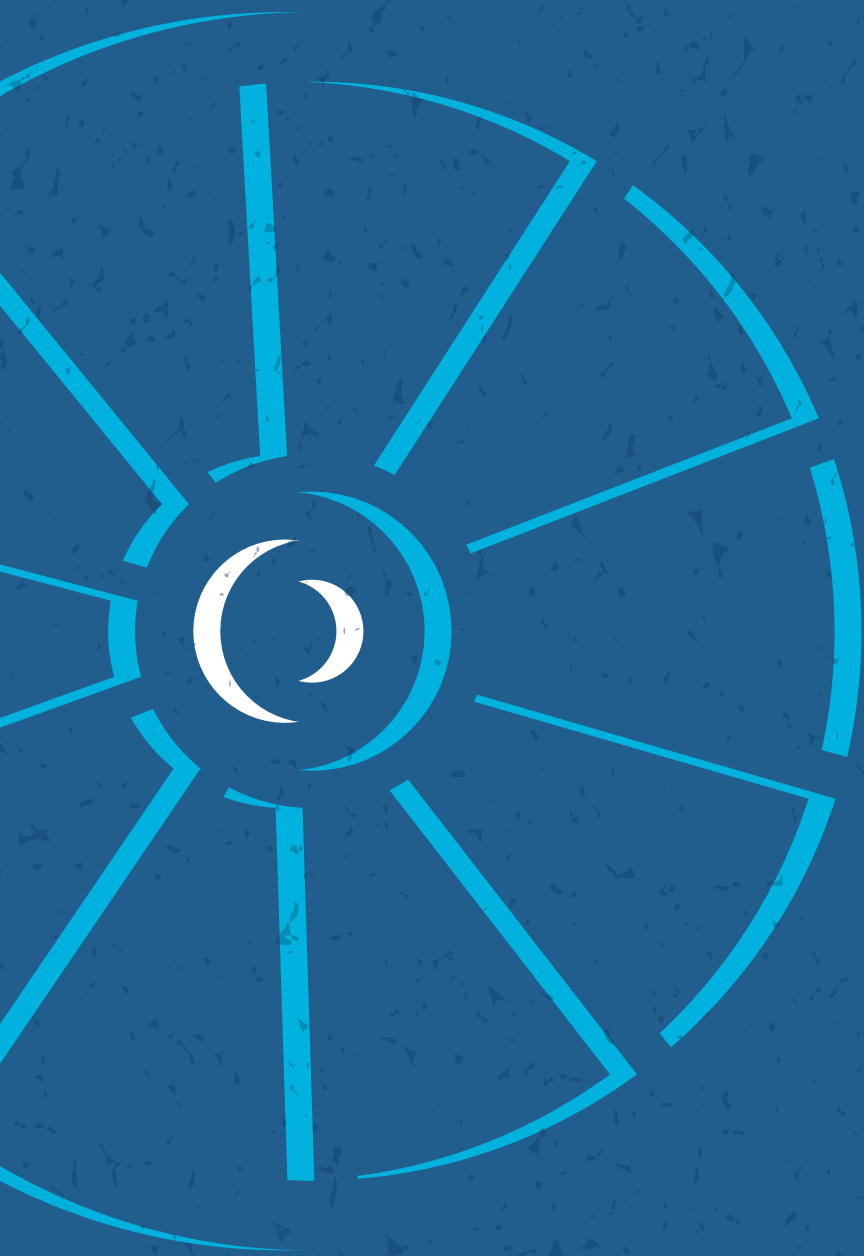
Political Representation of Travellers

The level of political representation amongst members of the Traveller community at both local and national level remains extremely low (O'Connell, 2006). A number of international treaty-monitoring bodies have expressed concern on this issue and have made recommendations in this regard. In particular, the United Nations Committee on the Elimination of Racial Discrimination has recommended that the authorities '*consider adopting affirmative action programmes to improve the political representation of Travellers, particularly at the level of Dáil Éireann and/or Seanad Éireann*' (Committee on the Elimination of Racial Discrimination, 2005 (paragraph 22))¹¹. There is a large body of international literature that discusses the optimum means of ensuring minorities are represented in the political process, with various mechanisms proposed, including reserved parliamentary seats. The purpose is to ensure that there is both representation and participation in public policy processes that impact on health and wellbeing.

In May 2008, the Council of Europe Commissioner for Human Rights noted that the level of participation of Travellers in elected bodies remains low at all levels. The Commissioner stated that he '*encourages further efforts to involve Travellers in political decision-making. Traveller communities should be adequately represented in local councils, and the possibility of reserving a specific seat for the Traveller community in the Irish parliament, perhaps in the Seanad, would merit serious consideration*' (Hammarberg, 2008).

¹¹ Dáil Éireann refers to the Irish parliament and Seanad Éireann refers to the Irish Senate

Health Service Provider Quantitative Study



Methodology

Setting/Sampling

This sub-study sought to undertake up to 500 health service provider interviews by Computer-Assisted Telephone Interview (CATI) in the Republic of Ireland and Northern Ireland. The methodology was purposeful and quota-based. Potential respondents were identified and recruited as follows to ensure that an acceptable quota of respondents by both professional groupings and regions was achieved.

Identification of Potential Respondents

Based on the scoping exercise conducted prior to the Traveller census when potential participants/families for the census were identified we estimated that 32% of Traveller families in the Republic of Ireland were in the HSE West region, 28% were in the HSE South area and 40% were in the HSE Dublin North East and Dublin Mid-Leinster areas combined (16% in DNE and 24% in DML).

The HSE provided the UCD team with a list of potential respondents broken down by both LHO area and professional groupings which was later amended and supplemented in consultation with members of the HSE Liaison Group in order to achieve a balance of respondents from each of the professional groupings across the 4 HSE Areas.

In NI the recruitment of potential respondents was also based on achieving a broad geographical distribution. In order to achieve this, and given the smaller sample size, the interviews to be completed in NI were divided among the 5 Social and Healthcare Trusts. A Principal Investigator (PI) in each Trust provided a list of potential respondents supported by the Stakeholder Group in Northern Ireland.

Recruitment

Service Providers who did not provide services to Travellers were automatically included in the sample as we had no *a priori* means of identifying those who do or do not provide services to Travellers.

Recruitment was a 2-stage process. Named respondents in both NI and ROI were identified as discussed above and were then contacted by letter from the UCD team explaining the purpose and procedures of the study and inviting participation. Respondents were invited to return the letter indicating whether they would or would not take part as well as indicating a time when it would be convenient for them to be interviewed. If there was no response to the letters of invitation we posted hardcopy questionnaires with the final reminder letters, asking respondents to complete in hard copy if preferable.

Interviewers

The interviews were undertaken by postgraduate students on the Master of Public Health and PhD programme from UCD, many of whom were health professionals themselves. In-house training and induction were provided by the study team on the instrument and the methodology. All the interviewers had to achieve a standard level of competency before being allowed to conduct live interviews.

Questionnaire

Following a literature review of previous Traveller studies and discussions with the TSG and the Principal Investigator Group, a draft questionnaire was drawn up and circulated to a number of health professionals including doctors, nurses, dentists and pharmacists.

Interviews

The data collection period commenced 22nd February, 2010 and was completed by 11th June, 2010.

Response

Ultimately 720 potential respondents were contacted as a minimum overall response rate of 50% and a minimum quota of 60% in each of the professional groupings and by region were sought.

53.4% (356 Health Service Providers) completed the survey. The overall response rate is 356 out of 666 eligible respondents (53.4%), or 356 out of 592 successfully contacted (60.1%).

Table 44: Achieved interviews

Professional Grouping	Northern Ireland			HSE West			HSE South			HSE DNE			HSE DML			TOTALS		
	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%
GP	30	8	27	42	24	57	36	23	64	21	17	81	31	17	55	160	89	56
Dentists	5	4	80	6	8	133	6	2	33	3	3	100	5	3	60	25	20	80
Other community services	15	*9	60	16	19	118	14	9	64	8	7	87	12	13	109	65	57	87
Public Health Nurses/Health Visitors	15	*11	73	16	18	112	14	15	107	8	9	112	12	13	109	65	66	101
Mental Health Services	5	4	80	8	4	50	7	5	71	4	4	100	6	5	83	30	22	73
Management/Policy	5	5	100	8	5	62	7	1	14	4	6	150	6	4	67	30	21	70
Hospital Staff	25	12	48	32	28	87	28	23	82	16	10	62	24	8	33	125	81	65
TOTAL	100	52	52	128	106	83	112	78	70	64	56	87	96	63	66	500	356	71

OQ denotes the number originally proposed as the maximum in each grouping.

AI denotes the number of achieved interviews

% denotes the percentage of the original quota achieved

* 5 of respondents in the community services grouping in the North were coded as Health Visitors for branching purposes.

Hospital staff interviewed included consultant doctors in key services such as A & E, Paediatrics, Obstetrics and Cardiology, nurses at various levels of responsibility and management staff.

A response of 'Refused' was recorded for 6 of the respondents in the data in relation to their professional grouping. These are included in the table above under the professional grouping given to the study team at the recruitment phase.

Results

Data is presented in the results section in sequence according to question. Sections B to F inclusive are broken down by region - (NI) Northern Ireland and (ROI) the Republic of Ireland - and by three categories 'GPs', 'Hospital Staff' and a third category 'Other Professional groupings'. Testing for significance was undertaken according to jurisdiction and professional category as appropriate.

Section A: Demographics

A very diverse group of professionals responded to the survey. GPs and nurses constituted the largest groups, as per the quota methodology.

Section B: Provision of Services to Travellers

Most respondents had some experience of provision of services to Travellers. Relatively few respondents reported rare contact and just 2.6% said they never provided services to Travellers.

Table 45: Provision of service to Travellers

	Never	Rarely	Sometimes	Often	Very Often	Refused	n
Total (n)	9	25	87	116	109	2	348
Overall (%)	2.6	7.2	25.0	33.3	31.3	0.6	
NI (%)	6.5	13.0	19.6	50.0	10.9	0.0	46
ROI (%)	2.0	6.3	25.8	30.8	34.4	0.7	302
Pearson's Chi-squared test $\chi^2 = 18.1349$, df = 5, p-value = 0.002782			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 18.1349$, df = N/A, p-value = 0.01099				
Total (n)	9	25	84	114	108	2	342
Overall (%)	2.6	7.3	24.6	33.3	31.6	0.6	
GP (%)	2.3	8.0	10.2	28.4	50.0	1.1	88
Hospital Staff (%)	6.6	7.9	26.3	36.8	21.1	1.3	76
Other (%)	1.1	6.7	30.9	34.3	27.0	0.0	178
Pearson's Chi-squared test $\chi^2 = 33.0959$, df = 10, p-value = 0.0002625			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 33.0959$, df = N/A, p-value = 0.0004998				

Section C: Access To and Use of Services

In this section respondents were asked a number of questions in comparison to non-Traveller patients in similar social circumstances. Overall, respondents considered Travellers less likely than other patients to access and use their services. There were significant differences between different service user groups, in how they categorised Travellers, and these patterns were not the same across all the questions asked. In particular Travellers were felt not to engage as effectively with preventive services, except antenatal services. Travellers were also more likely to receive prescriptions. Traveller men tended to present later than is desirable.

Overall, most respondents thought Travellers were either about as likely (43.6%) or less likely (35.0%) to understand how to use their service. There was a spectrum of opinion on whether Travellers understand how to access respondents' services. Just under half of respondents rated Travellers as about as likely to understand as others (43.8%) and just over a quarter (27.3%) as less likely. This did not differ across jurisdictions.

Travellers were considered less likely (51.0%) or much less likely (15.3%) than others to keep appointments. There was no significant difference according to jurisdiction in likelihood of Travellers keeping appointments compared with others. Respondents considered Travellers to be less likely (41.6%) or much less likely (10.7%) than other patients to be on time for appointments and there was no significant difference according to jurisdiction or professional grouping. Compliance with instructions about treatments was again rated as less likely or much less likely by appreciable numbers of respondents, 52.7% overall (42.6% NI and 54.4% ROI). GPs on this question assess Travellers as being less likely to comply with instructions than other groups.

Attendance for service follow-up was rated as less likely (47.7%) or much less likely (9.0%) by a majority of respondents (55.5% NI and 57.0% ROI) and was not significant according to jurisdiction. A majority (56.4%) of respondents thought Travellers less likely or much less likely to attend referral appointments from their service. There was no difference according to jurisdiction in respondents' assessment of the likelihood of Travellers attending referral appointments. GPs (65.5%) were significantly more likely than other groups to consider Travellers would not attend, and only just over one third of respondents felt Travellers and the general community had similar patterns of behaviour.

Travellers were considered by a very clear majority of respondents as being less likely (53.3%) or much less likely (22.4%) than others in similar circumstances to avail of preventive services. There was a spectrum of response to the question of Travellers making use of treatment for long-term illness, though with substantial numbers considering it less likely (39.4%) and with no significant pattern across jurisdictions.

Respondents thought it about as likely (42.6%) or more likely (6.5%) that Travellers would make use of antenatal services. There was no significant difference according to jurisdiction. Again, compared with the responses to other questions, Traveller women seemed to come close to meeting the expectation of Service Providers for this type of care, with 38.8% rating it about as likely and 6.3% more likely that Travellers would make use of postnatal services. This may suggest something about how Traveller women use antenatal care in contrast to other services.

Travellers were considered by a majority of respondents (57.3%) as either less likely or much less likely to make use of any screening services offered, with a highly significant pattern according to professional grouping, GPs rating it as least likely compared to the other groupings.

Likelihood in being prescribed medication marks a change in trend of response, a majority in both jurisdictions thinking it either about as likely (65.8% NI and 56.4% ROI) or more likely (18.4% NI and 19.1% ROI) than anyone else. There was however a highly significant difference according to professional grouping, a clear majority of hospital staff (73.9%) thinking this about as likely as anyone else.

There are striking differences between the 3 Traveller demographic groupings in the timing of their presentation of care, with men reported as especially likely to present late and children most likely to be early or on time. There is no significant difference in this pattern according to jurisdiction. GPs were significantly more likely to think children presented early or on time, whereas both hospital and other staff categories were significantly more likely to think women present late than GPs. Again, this may reflect the different ways in which services are used and the sequence of referrals.

Section D: Health Status

Respondents were asked to rate in importance factors having an impact on Traveller health. This of course, represents a purely external view of the determinants of Traveller health, but it is of interest to see what Service Providers think affects Traveller health. A clear majority, in both jurisdictions, considered all these wider determinants as of some importance.

A clear majority (78.3%) of respondents considered socio-economic factors as either important or very important to Traveller health. Socio-economic factors were considered as either important or very important in both jurisdictions (72.9% in NI and 79.2% in ROI). Whilst a large majority of all professional groupings similarly agreed, the Other grouping was clearly the most likely to consider such factors very important (60.7%).

Cultural factors similarly were clearly rated as important (83.5%) by respondents overall. Just 1 respondent in the entire survey thought culture not at all important. A clear majority of respondents in both jurisdictions (79.2% NI and 84.1% ROI) and across professional groupings thought culture important or very important, not significantly different in any category.

Environmental conditions were again rated as either important (32.9%) or very important (48.6%) by a large majority of respondents overall. A clear majority agreed in both jurisdictions (77.1% NI and 82.1% ROI). Similarly most respondents in each of the 3 professional groupings rated environmental conditions as important, though again there was a highly significant difference between the categories, with GPs least likely of the three groups to rate this factor as very important (29.5%) though a majority rated it as important (51.1%).

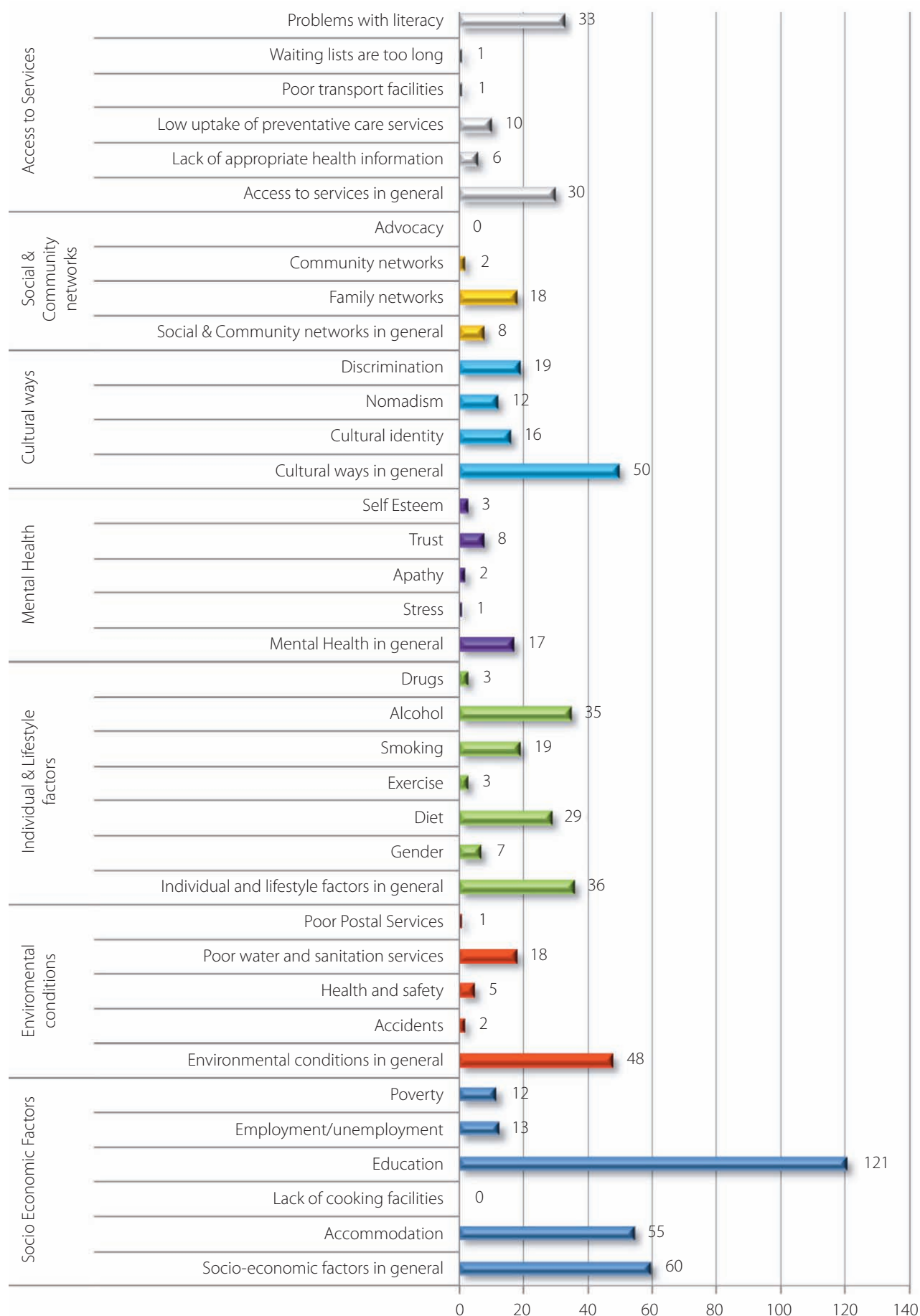
Social and community networks were also rated as important (41.8%) or very important (33.7%) by a large majority of respondents overall. Again also, as with the other determinants, the 3 health professional groupings rated their importance highly, but GPs were once more significantly least likely to rate networks as very important (15.9%) compared to the other two groups.

Individual lifestyle factors were rated as important (38.7%) or very important (41.0%) by a similarly large majority, again not significantly different according to jurisdiction, but with GPs more likely to rate lifestyle as important (51.1%) rather than very important (28.4%) compared to the other two professional categories.

Finally, in this section, respondents were asked to rate access to services in importance as a health determinant. This was rated also as important (39.0%) or very important (34.0%) by a majority of respondents, with no significant difference according to jurisdiction. A majority of all 3 professional groupings rated this as important or very important also, but again the GPs differed from the other two groups in being statistically least likely to rate this factor as very important (14.8%). The rating of the importance of this factor was a little lower than the others, possibly suggesting that service providers see access as somewhat less important than some of the other determinants.

Figure 32, below, gives the response to an open question in which respondents were asked to list the three factors they considered made the most impact on the health of the Traveller community. The question was put first unprompted and then if necessary prompted from a list of factors in categories. Accordingly respondents could make their own open suggestions or give their reaction to a preset list. Frequency of mention is presented in the figure. This shows that education was clearly in front of any other determinant as a cited factor, followed by socio-economic factors in general, accommodation adequacy and cultural factors. Notably lifestyle factors, including smoking, alcohol and drugs did not rate very high mention. Of other comments spontaneously made, violence, particularly against women was highlighted.

Figure 32: What things impact most on the health of the Traveller community?



Section E: Interface Between Travellers and Your Service

Overall, respondents reported significant difficulties for Travellers in using their services. There were marked difficulties with understanding instructions and understanding the nature and cause of their illness. Respondents felt that Travellers had less difficulty with asking questions and understanding the language used in the responses to these. It was not felt to be difficult to establish a relationship of trust with most of their Traveller clients.

Respondents gave a range of responses when asked how easy or difficult it was for Travellers to understand instructions about treatments. Opinion was divided, mainly being rated as neither easy nor difficult (37.9%) or as difficult (38.8%). There was no significant difference in response according to jurisdiction or professional grouping.

Asked if Travellers generally understood the nature and cause of their illness, a third (31.6%) thought it neither easy nor difficult but almost half (49.8%) thought it difficult for Travellers. Again there was no significant difference by jurisdiction or professional grouping and the tendency therefore was to rate this as difficult for Travellers.

There was again a range of opinion on whether Travellers understand factors concerning their health and wellbeing. A majority of respondents thought it either difficult (43.0%) or very difficult (6.6%) for Travellers. GPs were the professional grouping who thought this most problematic, rating it as either difficult (53.4%) or very difficult (5.7%).

There was also a range of opinion on whether Travellers understand the vocabulary health professionals use, reflecting perhaps the range and complexity of situations in which Travellers engage with services. It was seen as neither easy nor difficult by just over a third of respondents (34.1%) but with similar numbers either side of this estimate rating it as either easy (25.0%) or difficult (27.2%). There was a difference of borderline statistical significance among the Professional groups with GPs most likely to state that it was neither easy nor difficult (43.2% compared to 32.9% of hospital professionals and 30.5% of the other category).

Asked how easy it was for Travellers to carry out written instructions, for example with information leaflets or prescriptions, most respondents rated this as either difficult (47.2%) or very difficult (26.4%).

There was again a spectrum of opinion on whether it was easy for Travellers to ask about their condition, from very easy through to very difficult. A third thought it neither easy nor difficult (30.2%), flanked either side by those who thought it either easy (26.0%) or difficult (29.0%). There was no difference in pattern according to jurisdiction or professional grouping.

Asked more specifically how easy it was to ask questions about the consultation or treatment event, there was again a wide spectrum of response, with no difference according to jurisdiction or professional grouping. Relatively few respondents rated it as very difficult (3.6%) however.

Respondents were asked how easy or difficult it was to establish a relationship of trust with their Traveller patients. There was again a range of opinion but the majority found it either easy (30.6%), or neither easy nor difficult (28.3%).

Section F: Provision of Services to Travellers

Respondents were about equally divided, yes (49.0%) or no (46.7%), on whether information on how to use their service was translated into a format that can be easily understood by Travellers, with no difference according to jurisdiction. There was a significant difference in response according to professional grouping, in that hospital respondents were least likely to answer yes to this question (44.0%) and more likely to refuse (6.7%).

Again, asked if information on how to use their service was disseminated in a way that ensures Travellers receive it, such as information sessions, respondents were about equally divided, yes (49.6%) and no (45.3%) and there was no difference according to jurisdiction. Hospital staff again differed significantly in their response, being least likely to say yes (37.3%) and most likely not to know (9.3%).

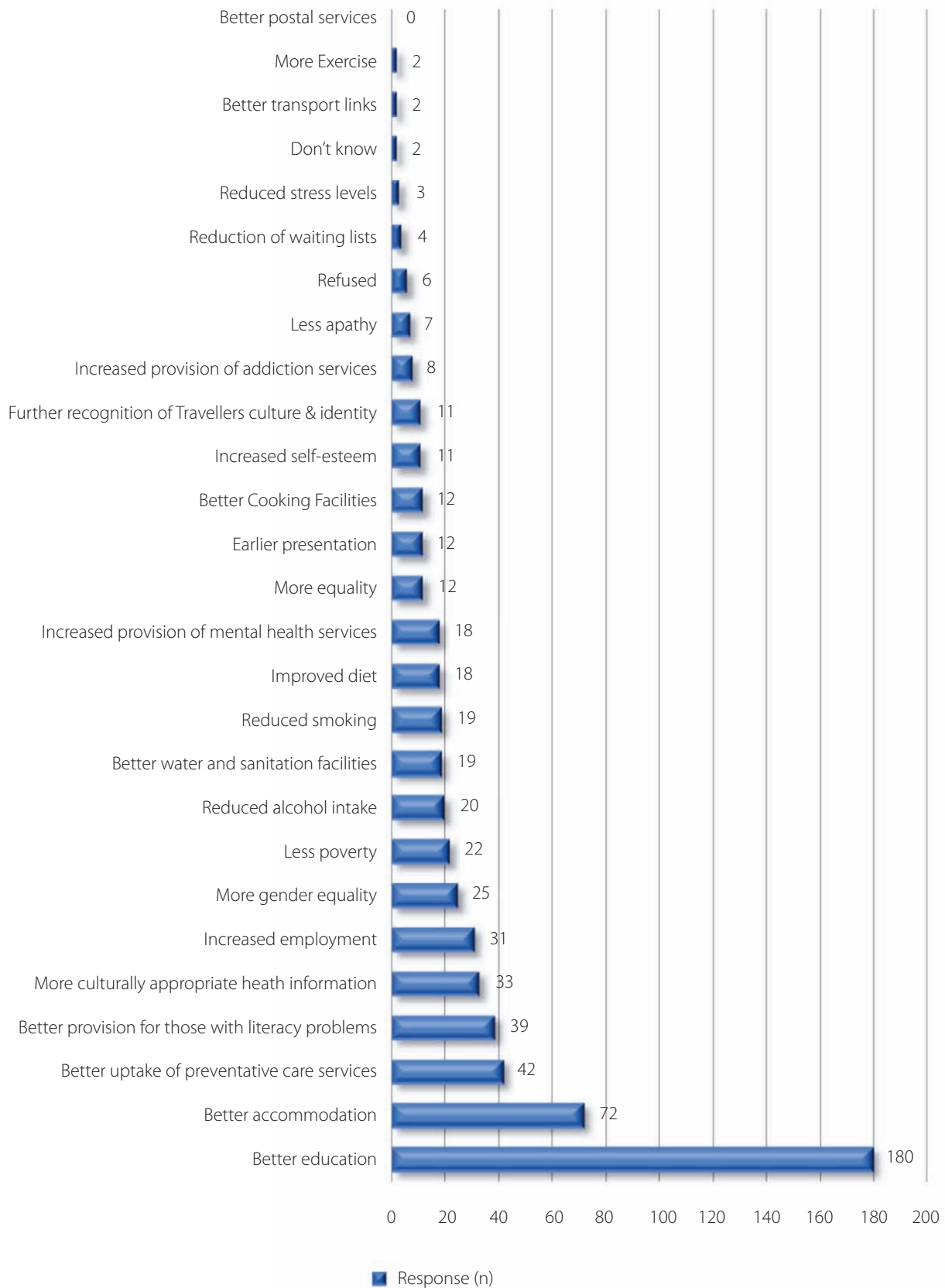
Respondents were asked whether in the course of their usual practice, there was engagement with Traveller advocates to help support service delivery. Half (50.0%) in NI and over half (59.3%) in ROI said yes. There was a highly significant difference according to professional grouping. The other professional category being much more likely (73.6%) to report such engagement than GPs (39.8%) or hospital staff (41.3%).

A majority of respondents (53.8%) agreed that an ethnic identifier is helpful. There was a highly significant difference according to jurisdiction. A clear majority in NI, where there is an ethnic identifier used by some providers, agreed it was (78.3%), whereas respondents in ROI were more divided, just half said yes (50.2%) and around a fifth (18.4%) did not know. There was also a significant difference according to professional grouping to this question, with GPs (30.7%) least likely and the other category most likely to agree (65.9%) and hospital staff in the middle (48.0%).

Respondents were asked how often they thought Travellers experience discrimination in their use of health services in general. While there was a wide range of responses to this question most respondents (66.7%) agreed either that it sometimes occurred (40.1%), or more often than that (26.6%).

Figure 33 again presents the response to an open-ended question on what 3 factors would most improve the health and wellbeing of the Traveller community, the format being both unprompted and then as necessary, prompted. Frequency of mention is presented in rank order. Again, better education was ranked by far the most highly, followed by better accommodation, better uptake of preventive services, better provision for those with literacy problems and more culturally appropriate services.

Figure 33: What things would most improve the health and wellbeing for the Traveller community?



Discussion

This Service Providers survey gives valuable insight into aspects of the current service delivery for Travellers and complements information gathered from other parts of the study. Respondents were selected in a purposeful manner but do represent a diversity of practice across all the main services and a spectrum of experience. We sampled in this way, as opposed, for example, to a bi-national random sample, because Traveller populations are concentrated in particular areas and many health professionals do not have much practical experience of care delivery to Travellers. Whilst as a consequence very few reported no Traveller engagement at all, and this was the principal reason given also for non-participation of those others we contacted, those interviewed extend from people with daily engagement with Travellers to those who see them less commonly.

There is agreement by Service Providers on many of the points Travellers themselves raised as problems, such as literacy, difficulty in following prescribed instructions, understanding of the consultation and the clinical implications of the encounter. These are well established points and are reinforced here. There are notably few differences according to jurisdiction suggesting a fairly typical reality, even though with the caveat that respondent numbers in Northern Ireland are relatively small.

There is quite a lot of supportive evidence that suggests Service Providers, particularly those actually dealing with Travellers, do understand some of the dilemmas and barriers Travellers face and are willing to engage with addressing these. Travellers and Traveller advocates appear to have achieved quite a level of recognition on a number of issues. For instance, the majority of Service Providers do show an understanding of the wider health determinants and clearly recognise the importance of socio-economic, environmental and cultural factors, as well as individual lifestyle and access issues. They also acknowledge discrimination as a possible factor in service delivery. Education was recognised as critically important by Service Providers, both as a contributory factor for ill-health and the principal means of improving it. These findings in this section of the survey are significant positive considerations to capitalise upon in implementing the findings of All Ireland Traveller Health Study as a whole.

Service Providers do agree too that communication and trust are factors of importance in working to provide services for Travellers. Again there is a need for a 2-way process here in triangulating these findings with the other parts of this survey. Trust, dignity and respect were important to Travellers in the census survey and the qualitative accounts amplify the importance of this. The professional, clinical ethos displayed by the service providers in this survey is important, as is quality of engagement. The scientific literature supports the need for cultural training in dealing with minority groupings and service providers seem very positively inclined to support that, on this evidence.

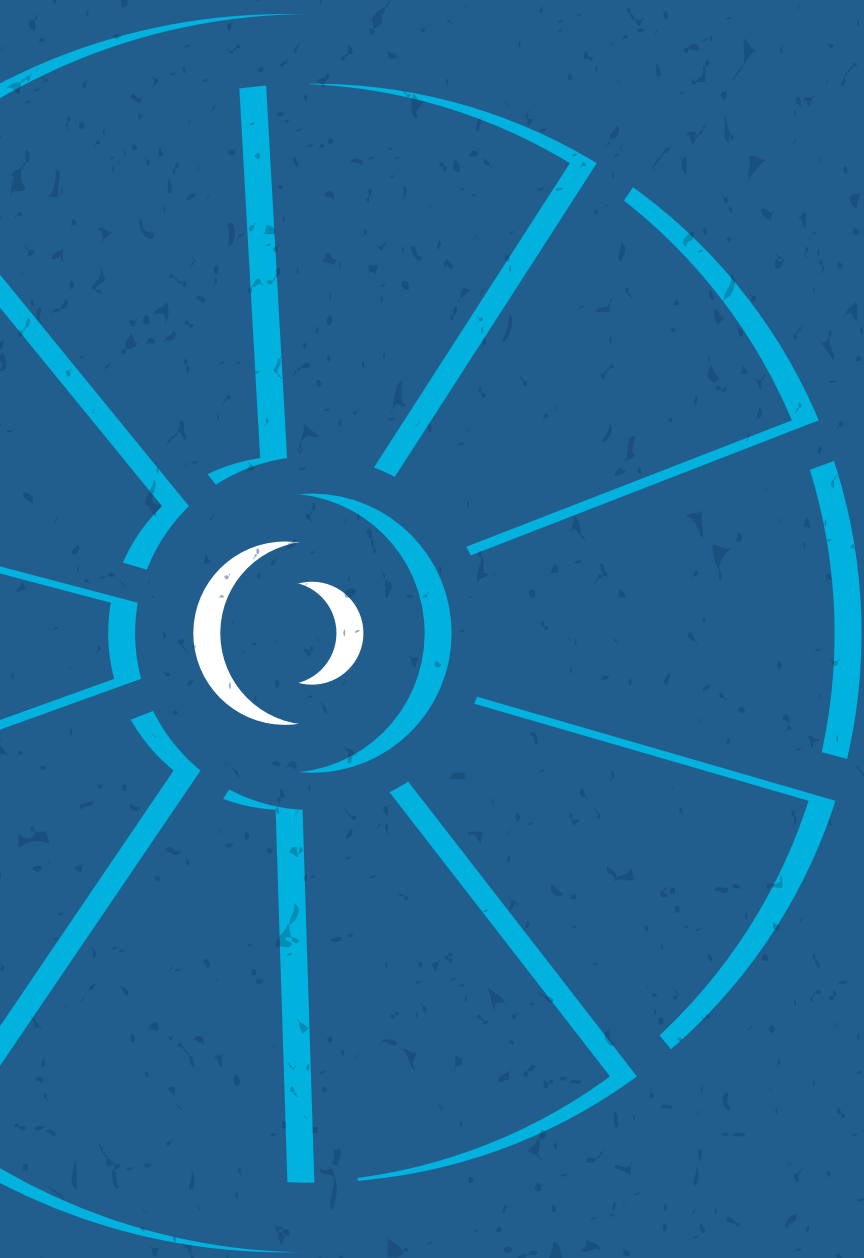
It is of interest that the ethnic identifier finds support in NI, where it is actually in place in some provider areas and that there is still ambivalence about this in ROI. This shows the need for consultation and engagement with service providers on the ground if this is to be actually implemented into the future.

There are some notable differences according to professional category that merit comment and further policy exploration. GPs were the hardest group to engage with this survey, particularly in Northern Ireland. This reflects the fact that they operate in a busy environment, are regularly asked to take part in surveys and many have no Traveller list. We did not have enough of the 'rarely or never' category to explore reasons for this in sufficient depth. However, given that the choice of doctor scheme still operates in ROI it is likely that the reasons given a decade ago in the Task Force Report (Report of the Task Force on the Travelling Community, 1995) are similar and still relevant today. The qualitative study corroborates that many of the barriers are practical and operational in nature. GPs were least likely to rate as very important the wider health determinants, least likely to have had engagement with Traveller advocates or awareness training. However, they were more likely to find engagement with Travellers easier than other groupings, reflecting the fact that they provide frontline services and offer care for minor as well as more serious conditions.

The hospital respondents differ in their response to the GPs, again reflecting the nature of care they offer. They are most likely to prescribe medication on a par with other patients, to have encounters that present difficult communication challenges and have little engagement with continuity of care or preventive service issues. The other professional category does contain a heterogeneous group of community or management providers, but they have the most appreciation of the issues Traveller advocates wish to see addressed and have had more engagement with those issues.

There are some important demographic concerns raised in this survey that link to findings in the other sections. We see that children are the first priority with Travellers, and women engage earlier than men. The presentation for antenatal and postnatal care continues to be important. Given the mortality findings in the vital statistics sections, particularly for men and in relation to respiratory and cardiovascular disease, it is important also to get earlier and more active engagement, especially in primary care, and to address the need for more engagement by Travellers in preventive services and follow-up, particularly for management of chronic disease, such as for respiratory and cardiovascular conditions. The poor health of male Travellers documented in our other reports, and the perception that they present particularly late for care, suggest need for urgent action to engage with this group of people.

Discussion of Findings of All 3 technical Reports



Discussion of Findings of All 3 Technical Reports

This was a complex and ambitious set of studies achieved with unprecedented cooperation and support of the Traveller community itself across the island of Ireland. In this concluding chapter we discuss the principal findings, drawing together the evidence base in all 3 Technical Reports from the census survey, the consultative studies and the associated retrospective mortality study and prospective birth cohort study. The views expressed herein are the independent assessment of the research team who undertook this commission.

While all stakeholders played a valued role we consider the input of Travellers themselves to have been remarkable. The mapping, scoping and training framework put in place to collect the core data was almost certainly indispensable to the novel methodology and in itself illustrates the capabilities and positive characteristics of a community that is not simply marginalised, but often discriminated against in wider society, compounding the material disadvantage that it suffers.

There are high expectations from the stakeholders about the study results, the government departments because of the resources invested as a measure of their commitment, the advocacy and representative groups because of a long struggle to achieve status for the Traveller community as a respected and distinct group in society and most importantly the respondents themselves, exemplified by an 80% participation rate in the anchor census survey for this project, which is by any standards an excellent rate for a survey of this depth and unprecedented for this group.

Capitalising on Positive Aspects of Traveller Life to Achieve Much Needed Change

Many positive aspects of Traveller culture and value systems should be better promoted. The strong sense of community, family support, religiosity, and valuing of Traveller culture and identity emerge from the data, complemented by both quantitative and qualitative findings and this should be capitalised upon. Another key factor is how valued children and young people are in the community. There is also a sense of proportion, fairness and optimism in the datasets, particularly the qualitative discussions and clearly there was a high degree of engagement. *This needs to be disseminated to the general public and harnessed as a means of achieving next steps.*

The research team associated with this project was committed from the outset to a study for, with and by, Travellers. We sought, as far as scientifically possible, to collect, describe and analyse the data to which we had privileged access in as accurate, systematic and contextually appropriate a manner as possible. We also saw our principal obligation to be as independent as possible so that our findings would be afforded the fair-minded respect our respondents wished for and deserved.

However, there is a constant judgement call in a project of this scale and sensitivity. Should we call the bad news in black and white? Should we emphasise the positives and complexities, in order to break down the pervasive stereotype that exists about Travellers? Should we keep it succinct to engage policy makers with the action points, or more nuanced to engage the peer review scientific community and give the project the credibility and longevity it deserves? Most importantly of all, how should we feed back the findings to Travellers themselves? If we try to please all of the people, all of the time, we please no one. The classical Aesop's fable of the group helping the donkey to cross the stream comes to mind. *Therefore the team takes the view that we must tell it as it is, in the depth and subtlety it requires.* The Travellers waited 20 long years for this study and its 3 Technical Reports contain a mine of information. This summary report gives the big messages and the genesis for all the nuances required as its findings start to impact on policy.

A Heterogeneous Community in the 21st Century

The demographic profile suggests a still very young population, but with some recent decline in fertility relative to the study in 1987. The pyramidal structure has altered somewhat since then, with relatively fewer children and more middle-aged adults, but it remains more akin to a developing country profile than to the developed country pattern of the general Irish population. Maternal and child health remains greatly important to this community. The qualitative data in particular highlight that the modern Traveller community is in a stage of fluctuation and change. Many challenges need to be met for both men and women at different life stages, based on this consultation. Traditions that have supported Traveller culture for centuries are still apparent and strong, even amongst younger people but, as with wider society, erosion is taking place and this is impacting on the sense of cohesion and community. Factors such as the intrusion of drug culture into the community are increasingly important and need to be tackled. There is evidence of change in traditions and of the relative empowerment of women. This shows in numerous ways, from the data collection process itself with Peer Researchers, through evidence of specialist women's health services in the census survey, the qualitative consultation and the Service Provider survey, all of which point to the engagement of women. However, men engaged with this project too, both as respondents to the survey and in the consultation groups. At initial planning stages it was uncertain whether information about men should be collected directly or by proxy but it became clear during piloting that men were in fact prepared to be directly interviewed and to participate in discussion. The compelling narrative in Technical Report 3a is self-explanatory and need not be reiterated in detail here.

How Valid are the Survey Findings?

A criticism of any survey based on self-report is that it is not reliable and may suffer from respondent recall and bias. In fact there are many encouraging signs of valid and accurate engagement with the methodology. Firstly, as noted above, there was a high response rate and completion of the various survey instruments. Secondly, there was a spectrum of response, reflecting variability across the community. A detailed, subtle profile emerged, of a population skewed towards the materially disadvantaged part of the social spectrum, but with mixed degrees of self-report on various aspects of their lives, and some very positive cultural features. Thirdly, there was strong evidence of triangulation, a scientific term meaning that the different data sources served to reinforce the findings.

To take some examples: respondents were frank on aspects of poor lifestyle such as smoking or alcohol consumption that might attract criticism from the more zealous end of the health promotion spectrum. The census data provide the prevalence rates in the community and the qualitative data explore reasons behind those prevalence rates. There were high rates of reported discrimination, but not by all of the people all of the time, which might have less credibility if universally reported. This speaks to these authors of the authenticity of the data as reported from the individual families involved. Furthermore, the Service Providers, both in Northern Ireland and Republic of Ireland, agreed that discrimination does occur at about the same rate as Travellers reported it. Conversely, some variables such as employment or low educational attainment do demonstrate a so-called ceiling effect, with almost universally high rates in both jurisdictions.

The qualitative transcripts speak not just of personal experience and engagement with the issues from the Traveller perspective, but also many instances of thoughtful reflection on what might motivate the general population to engage more positively with Travellers. A high degree of verbal flair and wit were regularly on display in the qualitative transcripts, as well as candour, characteristics the general Irish population would believe they share in common.

The ascertainment process of the deaths was painstaking; this was described by one Traveller wit as the pursuit of the 'definitely dead'. It is not likely that there was an over-inflation of numbers, indeed some under-ascertainment is possible given the logistical difficulties discussed in Technical Report 2 on death registration. Our mortality rates, if anything, are likely to be conservative. The cross-checking of cases suggests that the recall of diagnosis in some categories was reasonably accurate by family relatives.

Reasons for High Morbidity and Mortality

The health determinants approach suggests that disease specific endpoints need to be understood from a bio-psychosocial perspective that takes a comprehensive account of positive and negative influences (Whitehead, 1987; O'Shea and Kelleher, 2001; Wilkinson and Marmot, 2003; Mackenbach *et al.*, 2008). The findings from the census and vital statistics Technical Reports are very clear. Travellers experience higher mortality than the general population, have benefited very much less considerably from the downturn in mortality in the 2 decades since data were last examined in 1987 and as a consequence the mortality gap has widened. For men in particular the mortality pattern is bleak.

Age-specific mortality rates suggest excess rates at all ages for both Traveller men and women. We also know from the census count, which was as comprehensive as it is possible to be, that there are negligible numbers of Travellers over 50 years of age. This is not explained by migration, is not explained by integration into the general population, and not explained by denial of Traveller identity. The only realistic explanation is of premature death. The qualitative data also support this cultural reality. Many respondents at interview talked of the lack of role models as older adults and of middle aged women being the 'old hags' of the community, that is, both a rarity and old before their time or conversely 'treasures', akin to the value of antiques.

Cause-specific information suggests that amongst younger adults, traumatic causes, including accidents are an important factor, and more recently suicide is a key contributor. Suicide rates of both young men and women are high and in men many fold higher than contemporaries in the general population. In early to late middle-age, the main causes of death are respiratory and cardiovascular diseases. In the census survey, self-reported morbidity was higher than in the general population also for respiratory conditions including chronic bronchitis and for cardiovascular disease. In children, asthma was the most common ailment reported. Travellers certainly report high levels of typical lifestyle risk factors, seen commonly in materially disadvantaged groups, such as smoking, excessive salt and saturated fat intake and physical inactivity. However, they also report higher rates of diagnosed diabetes, and have high rates of risk factors such as hypertension and raised cholesterol; we discuss implications of this further below. The data suggest that a classical life-course explanation could be at play here. In such a model factors such as early childhood disadvantage are aggravated by adverse adult experiences, compounded by economic problems.

There is also an important psychosocial component (Berkman and Kawachi, 2000; Siegrist and Marmot, 2004; Wilkinson, 2005). Those who are less trusting report more CVD risk factors (McGorrian *et al.*, 2010) and it is well understood in the general literature that unhealthy lifestyle choices are not so much a wilful ignoring by people of a paternalistic health promotion message as a signal of a coping strategy in the face of difficult circumstances (Graham, 1987; McLeroy *et al.*, 1988; Lynch *et al.*, 1997). Our current understanding of cardiovascular disease is that it is a product of proximal adverse lifestyle leading to atheroma and clinical disease but influenced also by social patterning of those risk factors and by early adverse childhood circumstances (Yusuf *et al.*, 2004; Rosengren *et al.*, 2004; Barker, 1995). There is even likely to be a survivor effect at play, as those who survive childhood adversity are more likely to develop chronic disease as adults. Travellers fulfil all these criteria and it is very likely that this constellation of circumstances, coupled with a lack of access to preventive services particularly, makes for an explanation of risk.

Mental Health, Suicide and Social Disintegration

The WHO recently declared that mental ill-health is the new global epidemic (World Health Organisation, 2008) and Travellers, on the evidence of this study, are inordinately burdened by this issue. Premature mortality, especially among younger men, reflects the high rates of suicide and accident-related mortality. The qualitative consultation highlights thoughtful discussion on what it means to be a man in Traveller culture and how Travellers engage with each other and with wider society. The disintegration of traditional family structures, the decline of religious certainty and belief are adverse trends, though not as much as in the wider society. A further compounding issue is the traditional problem of finding employment, which is tied in with identity and personal self-esteem in the accounts of Travellers themselves.

The tight-knit community has positive effects, but also negative, in that there is literally little personal space for individuals and strong incentive to take part in group activities that can be damaging. Drinking patterns can aggravate mental health problems also, as binge drinking is associated with impulsivity and compounds clinical depression (World Health Organisation, 2008). Add to this a chronic problem with bridging to the general world around them and the corrosive daily relations with the general population Travellers themselves describe, and the mix is complete of poor self-esteem and self-efficacy in an unsupportive environment. There are a number of examples of fatalistic thinking in the narratives, particularly in trying to break the cycle of education and employability. There is ample evidence in these data of risk factors for mental ill-health, depression and suicide, whether from the quantitative census, the qualitative consultation or the mortality study.

Overcoming Educational Barriers

Education is well established as a key health determinant in the general scientific literature (Bambra *et al.*, 2010; Rosengren *et al.*, 2010) and emerges from all aspects of this study as a key need. It is not just that Travellers, as outlined in the introduction to Technical Report 1, do not achieve even a full primary school education in sufficient numbers, or that the relevance and appropriateness of that education deserves scrutiny. It lies deeper than that. There is a cross-generational deprivation at play. Parents cannot help with their children's school education. There are no older people with life experience to steer the community and to call on traditional skills and values. Younger people question their elders about the value of education when they see examples of community members who do not succeed in for instance gaining work as a result of having acquired some level of education. Relative to the general population they are falling constantly further behind.

Education is essential in numerous ways, to empower women to take control of their family and reproductive health to enable all Travellers, especially men, to achieve skills that will earn a living and to equip everyone to engage constructively in determining their role and contribution to society. The levels of education and conventional employment were so low in the census study that they could not function as discriminating variables in any of the analyses we undertook. The levels of attainment to third level training are literally anecdotal in a community of over 40,000 people. The analogy might be if a county town of similar population size had no personnel within its number to teach in schools, run healthcare and community facilities or provide any skill whatever above the level of manual labour. That is not to say manual labour is not valued, quite the contrary, without it no infrastructure would exist and it is essential to society. However functioning societies require heterogeneous skills.

It would appear that the unit of delivery of education is still not satisfactory. Travellers maintain and exert the right to Nomadism and that should not be in dispute in 2010. However, it is a misperception to say that this is the barrier to educational access as in practice based on the census data most Travellers are resident in a single location during conventional school term. Young people need support after hours to study as it is not easy at home. There is a fine line here in ensuring for instance parenting or after-school programmes that work effectively and simultaneously with schooling without imposing a model which is discriminatory in itself by separating out Traveller children from the rest.

There needs to be a means of persuading the parental generation of the need to break a vicious circle now, by supporting educational goals for their children. Children also need to engage and mix with others on an equal basis. There is a lot in fact that is good about Traveller culture for children. Children report large networks of family and friends and albeit based on information given by proxy, it is likely that younger Traveller children are relatively sheltered in lifestyle experimentation, precisely because they have still strong family networks.

Lifestyle, Empowerment and Health Status

Many Traveller advocates vigorously reject a paradigm that seeks to explain ill-health within the Traveller community in reductionist terms purely as a matter of adverse lifestyle or disadvantaged social circumstances (Minceirs Whiden, 2009). There are good reasons for this, with resonances for the wider literature on health promotion and on social inequalities. Firstly, this is seen as a classical form of 'victim-blaming' (McLeroy *et al.*, 1988). The person is responsible for their own poor health because, for instance, they continue to smoke, pursue a poor diet or drink to excess, a direct behaviourist interpretation (Levitt, 2000). To compound this paradigm is to say such individuals behave poorly because they are poor and if they would take steps to change this, such as obtaining somehow a viable income that was not state dependent, stay in education or otherwise conform to the wider social norm, then their problems would be resolved, (see Lynch *et al.*, 1997 for discussion of this issue).

It is well established in the health promotion literature also, as Blaxter and others have shown (Blaxter, 1987), that paradoxically the most disadvantaged are the last to agree with the proposition that they are disadvantaged, precisely because it renders them powerless if they agree that societal forces outside their control are patterning their situation. A reaction to this is to assert a cultural response, which is to say that the lack of recognition of the identity of Travellers explains the over-simplified view the general population holds towards Travellers, which is causing such corrosive negativity in their lives. If Travellers were afforded recognition, then, advocates would say, this leads onwards to a more empowered community. This position at its most assertive brooks no discussion at all about lifestyle.

Yet, all the recent evidence suggests the final common pathway to disease-specific outcomes is in fact mediated primarily through traditional risk factors. The INTERHEART global case control study of the causes of cardiovascular disease across 5 continents indicates little independent residual role for ethnicity, when all the conventional risk factors have been taken into account (Yusuf *et al.*, 2004; Rosengren *et al.*, 2004). It is the patterns of distribution of these risk factors that are culturally determined, and the role of certain psychosocial processes is highly culturally determined, both independent of, and mediated through, conventional risk factors (Marmot and Wilkinson, 2001; Davey-Smith *et al.*, 2000). Position on the social hierarchy and discretion to change are powerfully socially determined at community as well as individual level (Siegrist and Marmot, 2004).

What this means is that those most empowered are most likely to make life changes that promote their health. It is not that lifestyle is unimportant as a health determinant, but rather that it is the first thing to change if you are in control of your life and the last if you are not. *In this context knowledge about lifestyle is power, rather than an undermining of the dignity of one's social position.* Smoking presents an interesting paradox (Graham, 1987). As we already showed in Technical Report 1, prevalence rates are high and it is a major risk factor for both respiratory and cardiovascular disease, both too high amongst Travellers according to Technical Report 2a. Yet it did not feature as a prominent issue in either the qualitative consultation or the service providers' study in Technical Reports 3a and 3b nor indeed in another recent Traveller consultation in Northern Ireland (McMahon, 2005). Clearly, as numerous investigators have pointed out, smoking and other lifestyle factors are not internalised as health determinants, but seen as

a source of coping (Graham, 1987; Fitz-simon *et al.*, 2007; Hodgins *et al.*, 2006). The Travellers in this study smoke more heavily than those in social classes 5 and 6, but not greatly so. They have dietary patterns based on strong and respected traditions, which have their origins in rational patterns of the past when butter and salt for instance were scarce commodities.

Health promotion skills programmes must therefore be sensitive and culturally specific, for instance addressing the traditional value placed on salt and butter in the diet, the strict hygiene codes in Traveller kitchens and the limits of cooking equipment in homes. There is increasing worry about the impact of drugs on the young in the community and patterns of binge drinking by those who do drink alcohol, all of which require collective as well as individualist policy strategies. Now that we have provided the evidence base, there is an opportunity to engage Traveller advocates and TCHWs on sound and effective health promotion policies. To bring about these changes however, the big picture issues need to be addressed first. A recent robust systematic review of the health determinants policy literature suggests that some macro policy strategies, such as housing and accommodation are strongly evidence-based, others less so (Bambra *et al.*, 2010).

Racism, Discrimination and Disadvantage: Its Impact on Health and Wellbeing

In recent years the social capital literature has grown and it is now well established that aspects of immediate and wider community life can both promote and demote good health (Coleman 1988; Kawachi and Kennedy, 1997; Putnam, 1995; Kawachi *et al.*, 1999; Bourdieu, 1999; Berkman and Kawachi 2000; Kim *et al.*, 2006). All things being otherwise equal, a supportive community is a more positive place to be than an unsupportive community. Indicators associated with social capital include trust and participation, networks, personal support from significant others. The concept of Travellers as a community is integral to our understanding of their health status. Travellers self identify, share a culture and value systems, choose to socialise and congregate together, and value immediate and wider family networks. Bridging is an important concept in this literature, which entails 2-way communications with other groups, in this case between Travellers and the general community.

In more recent decades the traditional skills of barter and trade between Travellers and the general community have changed. A thing of the past is the nomadic tinsmith in rural life who performed a service in exchange for goods or food and who moved relatively freely in a society where most people were not particularly affluent anyway, but were largely self sufficient (Gmelch and Gmelch, 1976). The whole basis of modern Irish society has shifted, it has become more polarised and sharply divided on class lines (Kelleher, 2007; Balanda and Wilde, 2001 and 2003), and traditional skills have been replaced by mass production of goods and services on which everyone now relies and must find monetary means to purchase. Some Travellers have adapted well with antique dealing, horse trading, sports and music participation but the mass of the community has not. The lack of a skill or trade and lack of earnings have created a dependence on state welfare and contributed to a sense of frustration and futility, according to our findings.

Travellers at all points of interface report higher levels of discrimination than expected and lower levels of trust in others and in health service providers. *Even if this was a collective misperception and had no basis in objective fact, such a perception is likely to lower a sense of efficacy and self esteem and this is damaging to mental health and wellbeing* (Kawachi and Kennedy, 1997; Marmot and Wilkinson, 2001; Marmot *et al.*, 2008). Regrettably, it is all too likely that there is a very real basis to this perceived discrimination. The general population often, with honourable exceptions, has little time for Travellers. Stereotypical portrayals of Travellers who are inordinately likely to commit crimes and perform hostile acts against settled people are routine. It is important also of course to put the converse case, as there is room for optimism also. Many health service providers and policy makers are committed to Traveller health, and supported all aspects of these studies, in planning, staff engagement and as participants in the surveys and consultation process. This goodwill extends into the general community and must be harnessed now into action.

We show clearly in this study in Technical Report 2c that Travellers have higher incarceration rates than the general population, but also that the vast majority of Travellers are not in prison. Similar issues arise for other indigenous minority groups. A campaign in New Zealand for instance highlights specifically the more positive message that most Māori are not in fact in prison (Department of Corrections, 2008). Bridging is the key concept and it is a 2-way process. The general population needs to learn more about Travellers, to distinguish the prejudiced stereotype of some from the more subtle position of others that Travellers are for instance more likely to fall foul of the law, but that there are many reasons determining why that may be so, and one of these is a failure of institutional systems to understand Traveller engagement at different levels of society.

Many Traveller advocates see racism and discrimination as the root cause of ill-health in the Traveller community and this extends to a need to see ethnicity acknowledged unequivocally to Travellers as a starting point in the building of trust. The scientific literature suggests that the resolution of this equation is necessarily complex (Paradies, 2006; Schulz *et al.*, 2006; Berkman and Glass, 2000; Krieger, 2003). As Krieger points out, the robust data are not always available. In the US, where the Black/White/Hispanic labelling has existed for decades, it can be difficult to distinguish the relative effects of ethnicity and poverty. As she states, a study that examines only ethnicity is likely to miss poverty as the determining feature, whereas one that considers only poverty in material terms, misses the subtlety of the racial or ethnic experience (Krieger, 2003). We took care to include both types of variables in this study for this precise reason.

Berkman and Glass (2000) propose models that address how factors such as race and culture influence health pathways both upstream and downstream at macro-policy level, at meso level through networks and communities and at group or individual level through daily health choices and decisions. Such a framework might usefully inform future policy in implementing the findings of this study.

Taking self-rated health as an indicator, often cited in the literature (Paradies, 2006) in the Traveller dataset, all the domains associated with disadvantage play a role in its determination, including neo-material and psychosocial processes but also existing illness and lifestyle risk factors (Whelan *et al.*, 2010). Service Providers generally rated these wider health determinants as important or very important influences on Traveller health also in Technical Report 3b. The precise causal pathways leading to social and health inequalities are vigorously contested in the literature. The neo-material school contends that the modern post industrial, particularly urban experience leads to a constellation of economic disadvantages for the poor (Lynch *et al.*, 2000). The psychosocial school maintains that the experience of relative inequality, the social position afforded by an individual is crucial to the sense of self, of coherence and empowerment to engage (Marmot and Wilkinson, 2003). The truth is likely to be forged from a position somewhere in between, but at its heart lies the reality that skills provide the core means of engagement and education is the key to that engagement.

Travellers are a significant indigenous minority grouping and need definitive representation in the National legislative process. Traveller advocacy groups have and will undoubtedly continue to function in capacity building and empowerment. The strong verbal and oral reasoning tradition should be promoted as a means of social discourse. In recent years, a wave of articulate spokespersons have started to find their voice, this should be the vanguard of a new norm. There is a distinct cross-sectoral challenge here that is difficult to address at local or regional level.

As we outline in Technical Report 3a and b, it is not just Traveller advocate groups who recognise both the cross-sector policy challenge and the need for high-level policy engagement, service providers share this concern also. Without political representation, Travellers continue to be atomised and voiceless when it comes to policy decision-making. The solution to circumvent this challenge in the past has been committees, quangos and agencies. However, Travellers are disenfranchised in a very practical sense by their relatively small numbers and scattered location. They can never hope, in the conventional political system to make an impact that would determine policy for their community, just by sheer dint of numbers. There is a need to review Traveller representation in all aspects of the political process, at local, regional and national level, including the Houses of the Oireachtas in the Republic of Ireland. There is a precedent for this in the International literature, which addresses various means of ensuring indigenous minorities can exercise a voice (Organization for Security and Co-operation in Europe, 1999). We suggest that what would serve well in the Republic of Ireland for instance is proportional representation in the Dáil, as a single virtual rather than geographic constituency. The Constitution sets out the conditions for having TD representation in article 16, section s2 (Bunreacht na hÉireann, 1937). Though as a community the Travellers have sufficient numbers to justify the minimum requirement of a TD representative, they do not meet the constitutional requirement of a geographical three-seater constituency. There is in general increasing public interest in a constitutional review of representation (Rogers, 2010). Provision does exist for boundary reviews on a purely geographical basis, last conducted in 2007 (Constituency Commission, 2007), which might be a starting point for discussion. TDs based on popular Traveller vote would serve to accustom engagement with the democratic process. This would foster a mutual learning process on the art of the possible, in political terms. Again a unique ethnic or cultural identifier (see further below) would serve as the register for voting and democratise the Traveller community in a way that has been impossible for decades.

What Characteristics of Accommodation and Housing Matter?

We examined the question of accommodation in great detail in this report and various aspects of this issue are explored fully in the census survey in Technical Report 1, the qualitative consultation with both Travellers and Service Providers and the quantitative survey of Service Providers, as well as in the literature we reviewed. We refer readers to these sections for further detail. We found that most Travellers are living in houses, but there is a wide range of accommodation experience and the most destitute of Travellers are living in very poor conditions indeed. During the recruitment phase of the survey we were concerned that these were the families hardest to access and yet most in need of support. The evidence from this study suggests that it is appropriate amenities, rather than type of accommodation that are important factors. We present data according to type of accommodation in Technical Report 1. The qualitative consultation also demonstrates the impact accommodation has on all aspects of the lives of Travellers. This extends from exposure to physical hazards in the poorer quality accommodation to impact on mental health and wellbeing of living in stressful situations. The significant predictors of self-rated health for instance were availability of a flush toilet, considering one's place of residence to be healthy and the discretion to go on the road at least twice a year (Whelan *et al.*, 2010). The majority of Travellers live in houses by choice and it is the adequacy and location of that accommodation that is important, not its type. The qualitative consultation again demonstrates that being housed in an area isolated from family and friends can be very difficult for Travellers. Service Providers recognised, both in interviews and as part of the survey, that accommodation adequacy is a key health determinant. Of those in a trailer, halting site or caravan, it is amenities that matter. In Northern Ireland, family sizes are smaller, younger and more mobile and pregnant women were more likely to report themselves in unsafe or insalubrious circumstances.

The controversy over Traveller accommodation policy is longstanding and well rehearsed and it is not for this report to add to the prolix discussion. What we can say is that the better accommodated the Traveller family, the better the health status. Rather than protracting the ideological debate, the recommendation should be to ensure existing policy is comprehensively implemented so that there are for instance adequate amenities on halting sites, with the basic principle that the children particularly in such situations have rights to a secure childhood and that need should be the primary driver of policy. Marmot's recent reviews for both WHO and UK government on health inequalities stress the importance of early life intervention, based on a strong international research evidence base (WHO, 2004; Marmot *et al.*, 2010), which includes adequate accommodation and our findings are congruent with that.

Access to Care: Psychosocial as well as Infrastructural Barriers

When the study was originally conceived many believed that there were major barriers to healthcare access that would emerge in the survey. In fact, as with many aspects of this study, the reality was more complex. For instance the overwhelming majority of Travellers, on both sides of the border, declared in the census that they had access, either to GP registration or to general medical services. Travellers mostly believed themselves to have the same kind of access as others to various levels of service, including Emergency Room (ER or A & E) services. Utilisation of GPs was somewhat higher than the general population and considerably so of ER services, but children's accident rates were not unduly higher than the general population surveys. There were even signs that some of the promotion of specialist services had been effective, as rates of reported women's health screening were in fact higher than the general GMS population, presumably facilitated by primary care projects.

However, engagement may be suboptimal. Travellers were much less likely than the general population to trust health professionals and to feel respected in such encounters, based on the census data. In the qualitative datasets many miserable accounts were proffered about treatment received and a general sense of not being understood and catered for by the system. The clinical training most health professionals receive can be counterproductive in this situation. Such professionals pride themselves on not showing any differentiation based on race, colour or creed, but if the approach is too neutral then it lacks empathy and a failure to understand the context or predicament of patients means they can't engage effectively. This is the basis of a worldwide ethnic minorities literature, which we reviewed, and it needs vigorous examination here.

The Service Provider survey provides evidence from those most frequently used to working with Travellers that they are less likely to engage with services in key indicators such as outpatient appointments. Travellers were less likely to avail of preventive care. Service providers also report that Travellers have difficulty with literacy and medication prescription issues, as Travellers themselves reported. The Service Providers report too that men were more likely to present late for care, and children early. The data suggests that there is insufficient training for key frontline providers on cultural aspects of Traveller healthcare. Notably, the Northern Ireland Service Providers were more supportive of an ethnic identifier than those in Republic of Ireland. This is interesting as such an identifier exists already in Northern Ireland.

Taken together, the three sources of information, from the census, the qualitative consultation and the Service Providers' survey suggest that there is considerable and feasible room for improvement in the quality of the healthcare encounter.

A key concept in this context is health literacy, an extension of the health promotion concept of people being empowered to achieve positive health outcomes (Nutbeam, 2000). This recognises that core skills are necessary to maintain health and negotiate health care systems. Those with challenges including general literacy will experience difficulty in making change and in achieving successful health outcomes. The case of cardiovascular disease is one in point. In fact there is no systematic primary care detection system for cardiovascular risk factors in general and Travellers are no different from anyone else in this respect. However, relative to the risk they run they are not apparently having risk factors detected or treated. This phenomenon of unmet need was true in SLAN 1998 and in the Kilkenny Health Project, where a social gradient existed in detected CVD risk factors (Kelleher *et al.*, 2002; Shelley *et al.*, 1995) and more recently SLAN 2007 exhibited an inverse problem of under-ascertainment of smoking in more affluent GP patients (Brugha *et al.*, 2009). Given their high mortality, likely high incidence, and low appreciation of the risk factors in the community, it is appropriate to mount an opportunistic cardiovascular disease risk factor detection programme for Travellers.

The Case For and Against Unique Traveller Identifiers in Datasets

One issue that recurred in this study is the paucity of standard surveillance information. If all health service documentation contained a unique Traveller identifier then routine monitoring of trends would be facilitated and appropriate care provided. There is a general literature on unique identifier information for linking records and a more specific one on whether certain ethnic or minority groupings with distinct needs should have a means of identification in routine data systems. The registration process would have been much more straightforward if the equivalent of the census question on cultural and ethnic background, which includes a Traveller category, were available. It proved for instance impossible to collect really systematic information from prison databases despite cooperation of all parties. If general practice and hospital records held such information, in for instance GMS prescribing and HIPE information bases, then patterns of utilisation and treatment could be monitored. In the qualitative section, respondents were puzzled that transferable data were not available across healthcare systems. The principal investigator on this project recommended patient held records for Travellers to the original task force, but there has been no progress since. There is much to be said for having this information and methodology available and implementation of the identifier system piloted already is warranted. An ethnic and cultural background identifier, as used in 2006 census in Republic of Ireland for all health datasets is a key recommendation in the HSE National Intercultural Health Strategy (Health Service Executive, 2008).

What are the drawbacks to an ethnic or cultural identifier? First, there is the fear Travellers might have that they will somehow be discriminated against if they disclose a Traveller identity. This is a very real issue for Travellers, compounded by their fear of written information, which many for literacy reasons cannot read themselves to verify its accuracy. Service Providers at interview raised similar reservations in fact. The only way to combat this is to, on the one hand assure Travellers that the net result will be positive, and on the other to ensure that healthcare delivery staff are aware of the issues particular to Travellers. There also needs to be more 2-way dialogue between health professionals and Travellers on what code of practice is mutually acceptable in clinical settings, discussed further above in the section on access.

Who Needs to Do What to Put the Findings of this Study into Action?

There has been no shortage of policy production in the last 2 decades of relevance to Travellers. Nor is there a shortage of international literature and policies of direct relevance, what is required is translation of evidence into action. We do not seek to re-invent the wheel in this report, what we do is provide the evidence base that justifies expedition of the many existing recommendations made in recent policy documents. The Traveller community put its trust in this study and other stakeholders at all levels engaged with it to the credit of all parties; the results suggest an obligation on all stakeholders to translate the evidence of its findings into action. We have uncovered a life-or-death reality and it is as serious as that.

We highlight some key points below.

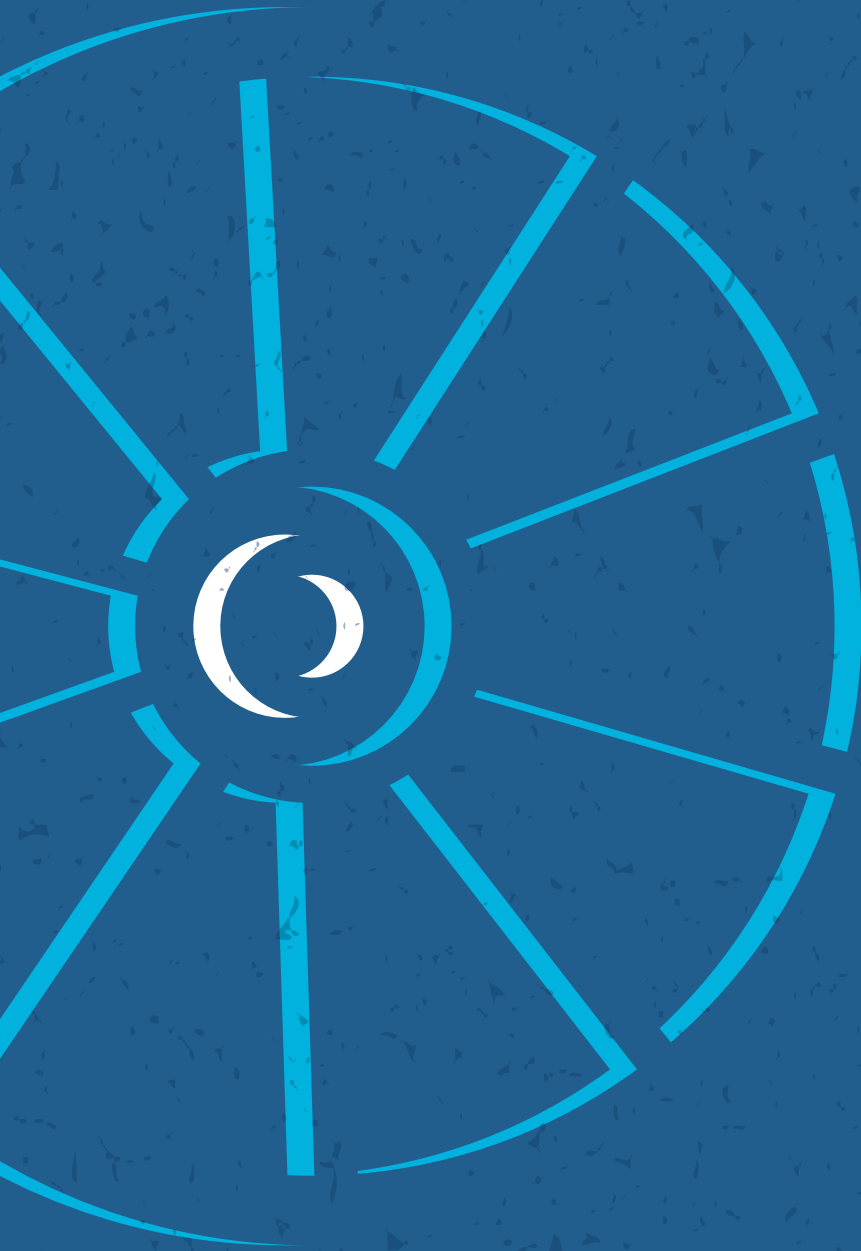
- **A strategic action plan should be set out, with a firm commitment to implementation, targets and timeframes.** We do not prescribe to the commissioners of this study how this is to be achieved but clearly it requires cross-sectoral engagement and a lead player or champion to deliver based on the findings of this report. We have shown that Travellers have distinct health needs and the challenge remains to close the gap between their health and that of the general population. This should be informed in part by the still valid recommendations of the Traveller Health Strategy (2002). At an operational level, initiatives and exemplars of good practice should be mainstreamed. Despite intensive investment in many areas of cross-sectoral intervention there has been little improvement in mortality and the gap has widened. This report is not intended as a critique of responsible agency activities, but the evidence base simply suggests a failure to improve the situation. For whatever reasons, Traveller public policy to date has not delivered and a clean sheet cross-sectoral strategy is required.
- **Adequacy of accommodation is essential to ensure health improvement for Travellers.** There should be no official halting site without basic amenities and a sufficient number of them to accommodate the travelling Travellers on the island. A charter negotiated between Travellers and the local authorities, overseen by the Minister for the Environment or its equivalent in both jurisdictions, could be drawn up and agreed on acceptable standards in relation to rubbish collection, keeping of animals and pets, and so on, to promote a neighbourly strategy for the future. We are simply restating what is already public policy in principle, be put into practice.
- The cornerstone remains education, whether in acquiring basic literacy, learning about one's culture and that of others, or acquiring life skills to get a job, negotiating the public service bureaucracy, achieving successful parenting or accessing health information. The debate on whether this should be mainstreamed or separate is longstanding and complex, but what seems clear is that delivery is not reaching the individual child to the benefit of that child in the conventional classroom setting. **The first-line objective is that every Traveller child should obtain the minimum equivalent of the Junior Certificate and that a similar percentage should go on through secondary school to professional or higher level education as the general population within 10 years.**
- **Strong attention should be given also to adult education,** for 3 reasons; firstly, the population is still very young, most people are under 30. Secondly, these are the parents and breadwinners of the immediate future. Thirdly education is the rate-limiting step to empowerment.

- A significant rate-limiting step is the establishment of mutual trust between Travellers and the rest of Irish society, on both sides of the border. **A national multi-level education campaign is required to help break down the stereotypes many people in the general population have about Travellers and produce a more rounded understanding.** The policy the media and other agencies have is contributing to this, implicitly or explicitly, in that many news stories are about a negative event and it is often mentioned after the fact that the incident is Traveller-related. The Traveller focus weeks and similar promotions organised by Traveller organisations regionally and nationally have led the way with novel approaches to communication but are not yet mainstreamed enough; this requires a concerted multi-level media strategy, centred on the evidence base this study provides. We recognise this will pose a planning challenge, but the very engagement in planning it will raise the awareness of the issues of relevance into the future.
- **As part of this campaign a National exhibition of Traveller crafts and traditions could be mounted, in the National Museum, as a mainstream event.** As we point out, capitalising on the positivities of Traveller culture provides important balance. The folklore archive at University College Dublin is for instance a rich repository of unseen material. Active art projects, and tourism development might indeed be a useful means of generating revenue, as Travellers, like other minorities have interesting traditions to share. Travellers do not lack positive role models, there are many well-known artists and sportspeople with a Traveller background, these should be engaged in supporting this process.
- What is an appropriate employment policy for Travellers? **The policy must be to treat the community like a small or medium enterprise and take a bottom-up strategy.** Traditional skills need to be re-created as their contemporary equivalent as well as more innovative strategies in line with the knowledge economy. Halfway or shelter schemes can even be counter-productive by perpetuating individuals in this limbo situation; the goal has to be a learned skill with employable potential. Cultural identity is key, not as a health determinant in itself but as a practical means of empowering and engagement.
- **The current undergraduate and graduate curricula for health and education professionals should explicitly include a module on Traveller health status and customs,** so that all are trained in the basics from first stages. There are some precedents for this, but it is not standard.
- **Hospitals with a significant Traveller catchment population should include a section on Travellers as part of routine staff inductions, general practices with a Traveller list should offer similar induction to staff and there should be a set of guidelines on how Traveller families are managed from frontline to discharge,** which are regularly reviewed. It is only when quality assured processes are put in place that an ethnic identifier system that Travellers can trust will be put in place.

There are 4 priority healthcare needs, based on the combined evidence from across the report, but most particularly the mortality data, which require an ethnic identifier to implement in practice.

- First, **all sectoral aspects of mother and child services merit top priority** to reduce infant mortality, support positive parenting outcomes and break the cycle of lifelong disadvantage that starts so early for Traveller families. Travellers value their children and Service Providers agree that children are their first priority. We produce data in all 3 technical reports that support this early life priority, from the mortality data, the census information on living conditions and from the utilisation of services sections, showing that Travellers would engage well with a concerted strategy focused on early life needs.
- Second, a gendered strategy needs to be adopted and **men's health issues need to be addressed specifically**, with an emphasis on empowerment and promotion of self-esteem for young Travellers of both sexes to improve mental health and wellbeing, but particularly drawing in the engagement of men. This requires a comprehensive cross-sectoral approach to facilitate work opportunity, break down the substance misuse problems and engage men in health service participation.
- Third, **there is a concerted need to address cause-specific issues for respiratory and cardiovascular disease**. This necessitates supportive and culturally appropriate strategies for all aspects of positive lifestyle as well as risk factor detection and management and the women peer leaders, particularly the TCHWs in the Primary Healthcare projects, are the agents for positive change here, since they have already been engaged in this process in various existing exemplars of good practice that require wider mainstreaming and adaptation.
- Fourth, many Travellers wanted services brought to them, but in reality, this kind of mobile service has been assayed in the past and failed. The utilisation of emergency services as a first line means that care will always be reactionary and hurried, rather than personalised, tailored and preventive, so an alternative focus is required. **Priority should be given to a new model of primary care delivery for Travellers dovetailed in the Republic of Ireland with the emergence of Primary, Continuing and Community care services, and in partnership with the Primary Healthcare for Travellers Project Networks**. By concentrating Traveller services into these new primary care units with a sufficient mass of staff with specialist training, a more proactive approach to services could be achieved. The mapping and scoping exercise gives us a clear geographical picture of where to start.

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