



**All Ireland
Traveller Health Study
Our Geels**

Discussion & Recommendations



All Ireland Traveller Health Study

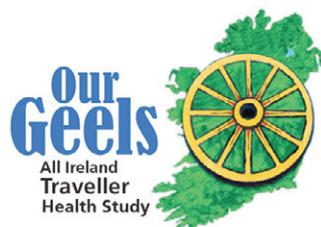
Discussion & Recommendations Part C of Technical Report 3

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For the All Ireland Traveller Health Study team

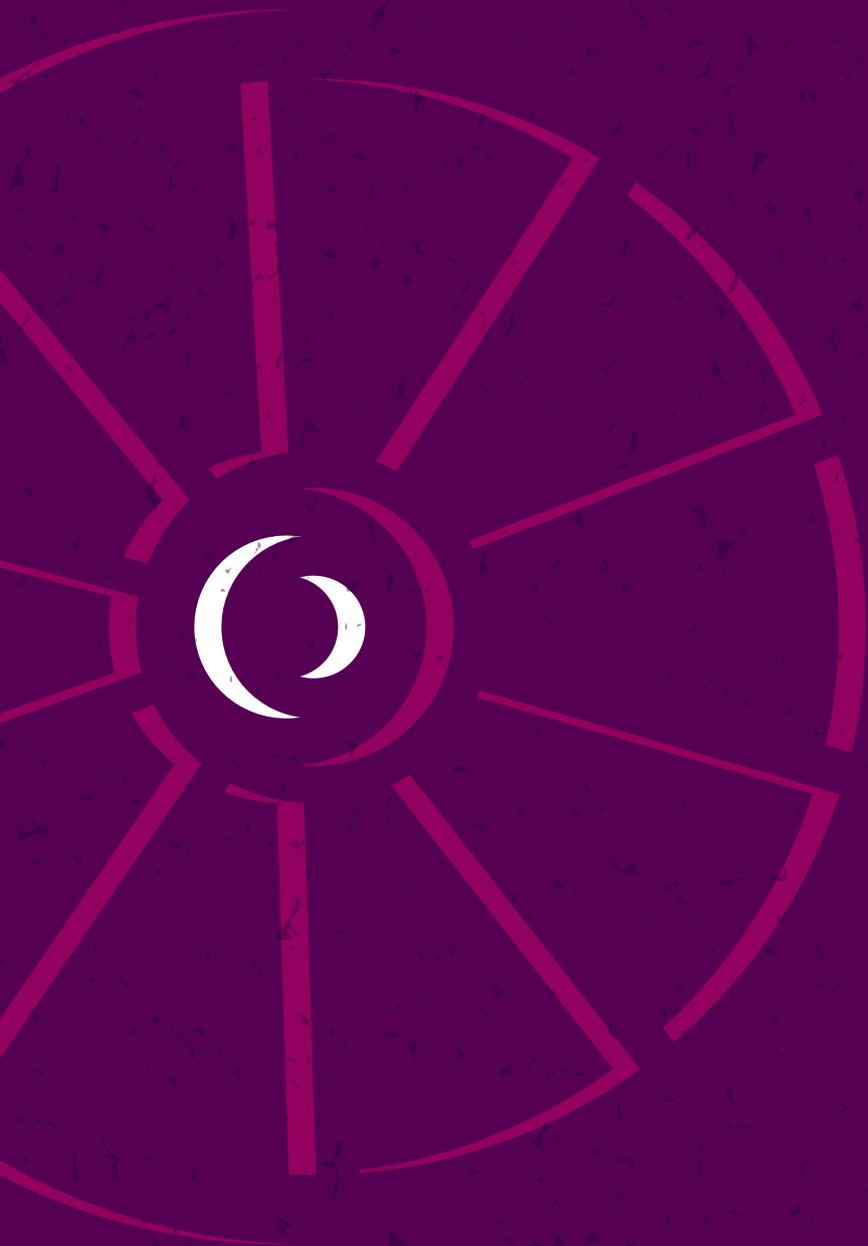


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DISCUSSION OF FINDINGS OF ALL 3 TECHNICAL REPORTS



Introduction

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 World Health Organisation (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 2 (Bunreacht na hÉireann, 1937). Though as a community Travellers have sufficient numbers to justify the minimum requirement of a TD representative, they do not satisfy 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 than 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 a unique 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 a unique 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.



