

**DESIGN OF THE
TRAVELLERS'
ALL-IRELAND HEALTH STUDY
-DETAILS-**

Submitted by
the Travellers' All-Ireland Health Study Group

Prepared by the Institute of Public Health in Ireland

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- Travellers and workers in Traveller organizations
- the lead Traveller organizations (Pavee Point Travellers' Centre and Traveller Movement (Northern Ireland))
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1. INTRODUCTION

Background

Irish Travellers are an indigenous ethnic minority who have been part of Irish society for centuries. They have a value system, language, customs and traditions that 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 settled people. Their experience of low social status, exclusion and prejudice gives rise to discrimination that affects all aspects of their lives.

Two key studies

Although there has been local research into Traveller health on the island, few studies allow for population level analysis. Many are either quite small, focus on local issues related to service provision, or have restricted representation.

Two studies - one in Northern Ireland and the other in the Republic of Ireland - have become the most commonly quoted research projects at the regional level.

The Travellers' Health Status Study 1987, commissioned by the Health Research Board in the Republic of Ireland, gave rise to considerable concern about the health status of the Traveller community. The study covered the whole of the Republic of Ireland, and focussed primarily on mortality, birth, and early childhood outcomes. It found that Travellers of all ages have very high mortality rates compared to the settled population: Traveller men living on average 10 years less than settled men, and Traveller women live on average 12 years less than settled women (Barry et al (1986, 1988, 1989)).

The first piece of research commissioned by a statutory agency on the condition of Traveller health in Northern Ireland was commissioned in 1993 and covered the Eastern Health and Social Services Board area (Ginnety (1993)). It offered a different approach to the Health Research Board's study in the Republic; putting Travellers health in the context of the historical/contemporary racism and discrimination they experienced. It highlighted the danger of imposing a value system in which natural remedies and cures were ignored (Ginnety (1993)).

While no studies as comprehensive as these two have been conducted since, recent research suggests that the gap between the health status of Travellers and settled people is not narrowing. The age pyramid for the Traveller community continues to include a lot fewer older people (CSO (2004)) and Sudden Infant Death is still much more common in the Traveller community than it is in the settled community (Irish Sudden Infant Death Association (1999)).

How this study came about

The National Anti Poverty Strategy in the Republic, recognizing the very much

poorer health of Travellers, includes explicit health status targets for Travellers (Working Group on National Anti-Poverty Strategy and Health (2001)).

“Travellers’ Health – A National Strategy 2002-2005”, the national Traveller health strategy in the Republic, includes a commitment to “*carry out a Traveller Needs Assessment and Health Status Study to update and extend the indicators used in the last survey of Travellers’ Health Status and to inform appropriate actions required in the area of Travellers’ health*”(DoHC (2002)). Such a study is a pre-requisite for the monitoring of progress towards achievement of these targets. A Traveller Ethics, Research and Information Working Group whose remit included the co-ordination and monitoring of the study during the Strategy’s term (2002-2005) was established.

In 1999 a New Targeting Social Needs policy initiative in Northern Ireland contained a specific theme of Promoting Social Inclusion (PSI), and a PSI Working Group on Travellers was created. In 2000 an initial PSI report was published with some 33 recommendations for action (OFM/DFM (2000)). The Executive in Northern Ireland then produced a response to the PSI Working Group on Travellers which contained a number of recommendations aimed at improving the health and well-being of Travellers. (OFM/DFM (2003)).

The two departments of health were very keen to undertake an All-Ireland study and saw it as a useful tool for developing future policy. In 2003 the Travellers’ All-Ireland Health Study Group was established to oversee the first All-Ireland study of Travellers’ health (see Appendix 4). With funding from the two departments of health, it asked the Institute of Public Health in Ireland to help design the study.

Consultations to design the study

The study group first conducted a written consultation, comprising a questionnaire sent to over 100 key stakeholders on the island, to identify the broad dimensions of the study. On the basis of the responses received, a discussion paper was distributed to over 350 individuals and organizations. The study group then conducted nine regional consultations involving Travellers/Traveller organizations and health and social service providers across the island. Approximately 400-500 people attended these regional consultations (see attached document for reports). A draft study design was then circulated, and discussed at an All-Ireland Feedback Event that was held in December 2003. The event was attended by over sixty people including representatives from the nine regions.

Contents of this document

This document covers five areas:

- the principles and aims of the study;
- the topics and subjects to be explored;
- how the study will be managed;
- how the information will be collected, analysed and interpreted; and
- other issues for the study.

It summarises the agreements reached at the All-Ireland Feedback Event.

2. PRINCIPLES AND AIMS

Study principles

During the consultations a number of principles that will guide all stages of the study were identified. The study will therefore be based on:

- 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 Travellers' health. These factors include education, accommodation, the experience of discrimination and racism, the health and social services, and lifestyles.
- Principles of equality, human rights and community development.
- Social inclusion, anti-racist, anti-sexist, anti-discriminatory and anti-poverty values.
- Respect for Traveller values, beliefs and perceptions as well as all other parts of Traveller culture including nomadism.
- Support (resources, training and other support) to ensure that Travellers and Traveller organizations can participate on their own terms in all stages of the study.
- Support to ensure participation of relevant health and social services providers in all 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.
- A view to ongoing international research with ethnic minorities.

A Code of Practice will be developed, and incorporated into the standardized research tools to be developed, and the research training and support to be provided. The All-Ireland Research Team and Regional Research Teams will implement this Code of Practice and will obtain approval from the Traveller Ethics, Research and Information Working Group in the Republic and appropriate committee in Northern Ireland.

Aims of the study

The aims of the study are listed in Table 1:

Table 1: Aims of the study

<i>To collect and analyze information</i>	on the number of Travellers, their health status and the factors that affect their health and health and social services needs.
<i>To use that information</i>	to influence the development of policy, resource allocation and health and social services delivery for Travellers.
<i>And to build research capacity</i>	by <ul style="list-style-type: none"> i) providing research training and experience to Travellers / Traveller organizations and others involved in the study; and ii) strengthening information systems to enable routine monitoring of Travellers' health status and health and social services needs.

These aims are considered to be complementary in the sense that all three will need to be achieved if the study is to be successful. It is critical that they be pursued in the context of a holistic model of health, a broad view of its determinants, and local/regional/national priorities. Some of these are listed in Appendix 1.

3. CONTENT OF THE STUDY

Four linked sub-studies

The four sub-studies are outlined in Table 2 below.

Table 2: Four linked sub-studies

<i>Sub-study 1: An exploration of health issues as perceived by Travellers</i>	This sub-study will explore health status and its determinants, access to and uptake of health and social services, and health and social services needs; as perceived by Travellers.
<i>Sub-study 2: Health and social services studies</i>	This sub-study will explore the same health issues; as perceived by service providers. Other parts of the sub-study will look at models of best practice for local Traveller services.
<i>Sub-study 3: Study of births and deaths</i>	This sub-study will look at deaths from various causes and include a study of all births to assess birth rates, birth and early childhood outcomes. A link with the proposed National Longitudinal Children's Study in the Republic of Ireland will be explored.
<i>Sub-study 4: Population estimates.</i>	An accurate estimate of size of the Traveller population is required for a number of the other sub-studies.

These sub-studies will reflect a holistic model of health, a broad view of its determinants and local/regional/national priorities.

Local, regional, North and South, and All-Ireland issues

The study will collect appropriate data to explore local, regional, North and South, and All-Ireland issues:

Table 3: Types of data to be collected

<i>Local data</i>	Some data will deal with specific issues that can only be addressed locally. Such data will not be combined with data collected in other localities.
<i>Regional data</i>	Other data will relate to the issues for the whole region that might be found, for example, in their (health and social) services plans. These data will contribute to regional findings and to inter-regional comparisons.
<i>North and South data</i>	These data relate to issues that might be found in the key policies, strategies and programmes of either Northern Ireland or the Republic (but not both) such as 'New Targeting Social Need' in Northern Ireland and 'Travellers' Health – A National Strategy 2002-2005' in the Republic. These data will contribute to findings for the corresponding jurisdiction.
<i>All-Ireland data</i>	Finally, some data will relate to All-Ireland issues that are common to the key policies, strategies and programmes in both Northern Ireland and the Republic.

The study regions in for this study are the health board areas in the Republic, and the whole of Northern Ireland.

Agreed minimum data sets (at the regional, North and South, and All-Ireland level) will be developed as a key component of efforts to mainstream the monitoring of Travellers health, and their health and social services needs.

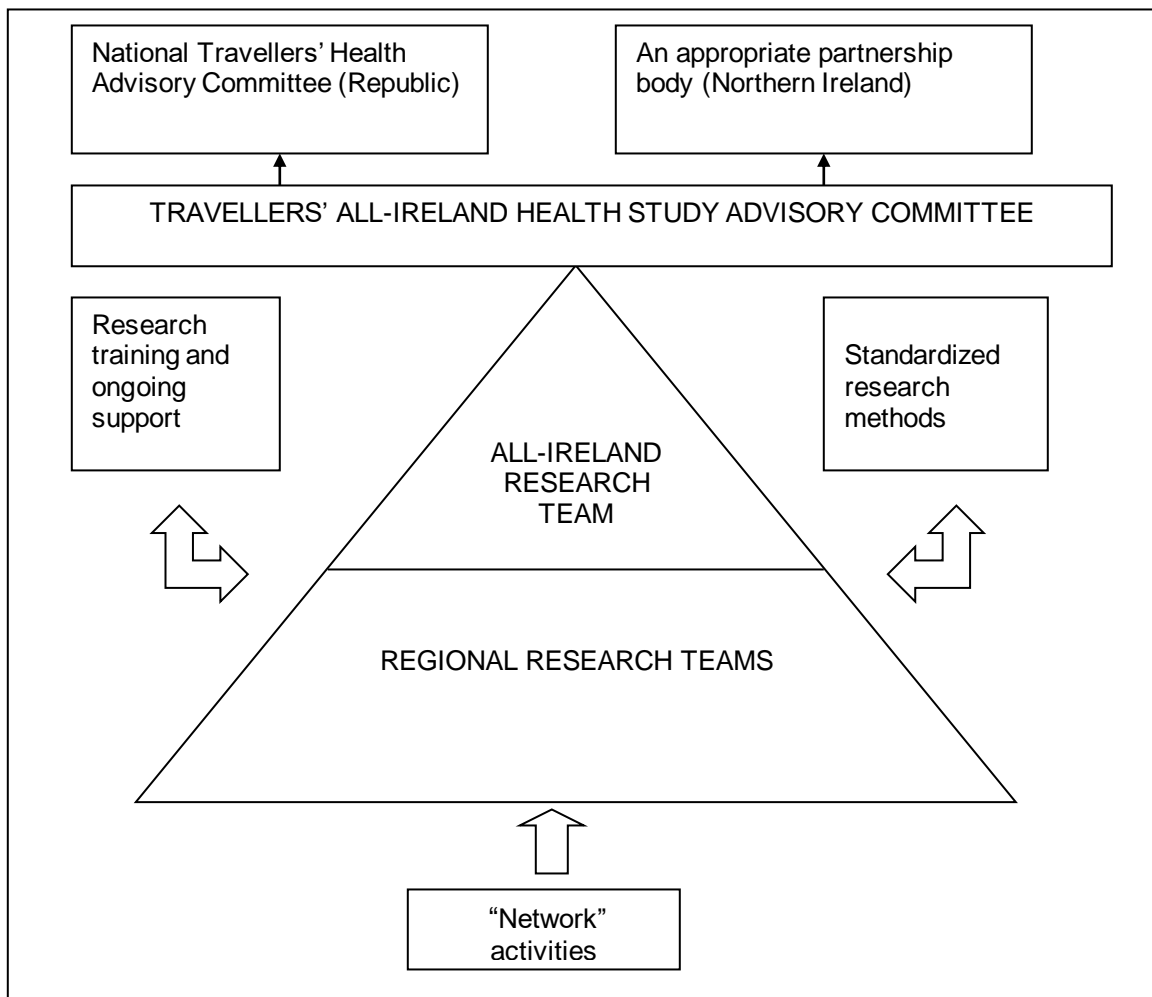
4. MANAGEMENT OF THE STUDY

A Travellers' All-Ireland Health Study Advisory Committee will oversee the establishment and conduct of the study, and will be accountable to relevant statutory bodies in the two jurisdictions to ensure that study findings are considered in policy development and service planning at the highest level (see Figure 1).

The day-to-day work will be undertaken by an All-Ireland Research team and nine Regional Research Teams (the whole of Northern Ireland and each of the health board areas in the Republic)¹.

It is vital that these teams work together operating as a “network”, rather than nine independent teams, in order to co-ordinate training and support, standardize research methods, share information and experiences, disseminate findings, and properly develop opportunities to enhance the study.

Figure 1: Management of the study



Travellers' All-Ireland Health Study Advisory Committee

In Phase 1 of the study, the Travellers All-Ireland Health Committee will undertake

¹ Health Services Reforms are being implemented in the Republic over the next few years; this study is described in terms of the existing health board areas.

community mapping of the Traveller population, resources and current level of services in the study regions. It will commence negotiations about the practical arrangements for the Regional Research Teams.

All-Ireland Research Team

The All-Ireland Research Team will be accountable to the Travellers' All-Ireland Health Study Advisory Committee, and will have responsibility for the day-to-day conduct of the study. In partnership with the Regional Research Teams, the All-Ireland Research Team will co-ordinate study design, data collection, data analysis and interpretation, and the reporting of findings.

The organizational structure of the All-Ireland Research Team is outlined in Table 4.

Table 4: Organization for both the All-Ireland and Regional Research Teams

MANAGEMENT:				
Traveller organizations	Services and other statutory agencies (eg education, housing, etc)	Public health representatives	Other researchers	
RESEARCH CO-ORDINATORS:				
Study Co-ordinator				
Sub-study 1 Co-ordinator	Sub-study 2 Co-ordinator	Sub-study 3 Co-ordinator	Sub-study 4 Co-ordinator	Training and Support Co-ordinator
DATA COLLECTORS/RESEARCHERS:				
Traveller peer-researchers Service researchers		Public health researchers Demographic researchers		

The All-Ireland Research Team will need to include representatives of national Traveller organizations, representatives from national service and other statutory agencies, public health representatives and other researchers. In particular, agencies from the education and housing sectors will need to be represented. The All-Ireland Research Team will include research co-ordinators for the whole study and for each of the sub-studies (see Table 4).

The All-Ireland Research Team could be housed in a number of different places; a national Traveller organization or an associated university are two possibilities.

Regional Research Teams

Regional Research Teams will manage the study in each of the nine study regions (the whole of Northern Ireland and the eight health board areas in the Republic).

The Regional Research Teams will have the same organizational structure as the All-Ireland Research Team. In particular they will include research co-ordinators for the whole study and each of the sub-studies in their region (see Table 4).

Local Traveller organizations will be the key point of contact with Travellers – they will identify Traveller peer-researchers and liaise with members of the Traveller community. Data will be collected by Traveller peer-researchers, public health researchers, services researchers and demographic researchers. The sub-studies are based on different types of data collected from different people; local knowledge has an important role in deciding who should collect that data.

There is considerable variation in the capacity of local organizations to participate in the study. For example, some of the regions in the Republic have specialist Primary Health Care for Travellers Projects that are based on Community Care Areas that have been established for quite a long time. Some Traveller Health Units in the Republic have research subgroups linked to university departments. The practical arrangements for the Regional Research Teams will need to take into account this variation. Only a broad outline of these arrangements can be given here.

It is proposed that the Travellers' All-Ireland Health Study Advisory Committee commence negotiations during Phase 1 of the study (see above); they would be finalized by the All-Ireland Research Team. It is vital that these negotiations cover the necessary clerical, secretarial and administrative support.

As far as possible, local people should be encouraged and supported to play leading roles not just in the management of the Regional Research Teams but also as research co-ordinators.

The Regional Research Teams could be housed in a number of different places: the Traveller Health Units in the Republic of Ireland, local Traveller organizations and associated universities are all possibilities.

5. STANDARDIZED RESEARCH METHODS

While the study must be sensitive to local and regional issues, it must also produce regional findings that can be combined to form a genuinely All-Ireland picture.

When data are collected in different localities by different people, the use of standardized research methods is critical to the building a genuinely All-Ireland study. Standardization will be achieved in three ways:

- use of a glossary of terms and definitions

- development of standardized research tools
- co-ordinated research training and ongoing support.

Glossary of terms and definitions

To support communication, a glossary of terms and definitions will be developed and maintained by the All-Ireland Research Team. While most terms and definitions are straightforward, others need careful consideration. Some of these are listed in Appendix 2; others will be added as the study develops.

Standardized research tools

In partnership with the Regional Research Teams, the All-Ireland Research Team will develop a standardized research tools to collect data. These tools will ensure that regional, North and South, and All-Ireland minimum data sets can be constructed from the locally collected data. The tools will cover the collection of qualitative and quantitative data and include topic guides or focus group schedules, questionnaires, interview procedures, etc.

To ensure that the local and regional contexts are systematically integrated into the study, guidelines for the analysis and interpretation of data, and reporting of findings will also be developed.

Research training and support

As well as developing standardized research tools, it is vital that these are used consistently across the island. To ensure this occurs appropriate research training and ongoing support will be provided to nominated Traveller peer-researchers, public health researchers, services researchers and demographic researchers.

The training will include:

- Appropriate Traveller culture awareness.
- Introductory training covering broad research issues
- Specialized training in the standardized research tools.

To ensure continuing input into data analysis and interpretation, and the reporting of findings, ongoing support will be provided to all researchers.

Pavee Point Travellers' Centre has a key role supporting the implementation of the National Traveller Health Strategy, funded by the Department of Health and Children, in the Republic. It is proposed that their remit be extended so that they can provide the research training and ongoing support for this study. In Northern Ireland this will be done in collaboration with an appropriate organization in that jurisdiction.

6. SUB-STUDY 1: HEALTH ISSUES AS PERCEIVED BY TRAVELLERS

Introduction

This sub-study will address health and its determinants in the widest sense:

- How health, illness and cure are understood in Traveller culture
- What Travellers in different circumstances feel affects and impact their health
- What Travellers in different circumstances identify as their health and social services needs
- How Travellers experience the quality and quantity of service provision in relation to all aspects of health
- The experiences Travellers have in relation to uptake of such services
- What Travellers see as the main barriers and examples of 'best practice' of Traveller engagement
- Any solutions Travellers identify in relation to difficulties in any of the above.
- Lifestyle behaviours (e.g. diet, exercise, substance use)

The study will include the perceptions of women, men, children, older Travellers, disabled Travellers, Travellers with different sexual orientations, adopted Travellers, Travellers in care, Travellers in prison, drug users, HIV/ Aids sufferers, nomadic Travellers, Traveller in 'settled housing estates' and Travellers not associated with a known local Traveller organization.

This sub-study will principally use qualitative methods. A small questionnaire survey will also be included.

Traveller- peer researchers

Most of the fieldwork will be carried out by Traveller peer-researchers. This approach maximizes the potential for identifying 'insider' or 'experience-near' descriptions of groups and individuals; increasing the depth, quality and validity of the data generated (Geertz, 1973).

The group of peer-researchers should comprise men and women, and people of different ages. In some cases it may be easier for respondents to talk about sensitive issues to non-Travellers or people they do not know. In these cases a trained member of the Regional Research Team will collect the data.

Qualitative study

Increasingly, participatory research methods have become recognized by funders, practitioners and communities as the most appropriate and rigorous approach to health needs assessments in a cross cultural context. They give a clear voice to the study population and put emphasis on action as well as theory (Minkler and Wallertein (2003), Balcazar et al (2003)).

The qualitative study will follow a step-by-step process, similar to the one used in the Primary Health Care for Travellers Projects in Republic of Ireland:

- Local planning of field work in close collaboration with Traveller and Traveller organizations
- Identification of peer-researchers
- Appropriate training of peer-researchers
- Conduct of interviews, focus groups and other data collection activities
- Collation and initial interpretation of data
- Feedback of findings to the communities who will prioritize the identified needs and, where appropriate, suggest changes to service provision

The main approach to data collection will be in-depth interviews with individuals and groups. Additional methods will be developed according to identified information needs. Appendix 3 describes a range of qualitative data collection methods that can be applied.

Triangulation of methods, independent data analysis, feedback sessions with interviewees, and peer reviews will be used to validate the data collected. As far as possible audio data will be taped or otherwise recorded (subject to permission), and transcribed so it can be imported into a database for analysis. This provides the opportunity to go back to the original source if needed. All visual data (e.g. art or video) will also be stored in its raw form as well as being transcribed.

Researchers in the Regional, and All-Ireland Research teams will meet at regular intervals to assess progress, to identify emerging themes, and to continually review sampling procedures. Qualitative data collection will continue until data saturation is reached (that is, until no new themes, issues or concerns emerge from the continuous data analysis). A sample size of 2,000 families (approximately one third of all Traveller families) is expected to be sufficient.

Questionnaire study

The objectives of the questionnaire study are to quantify perceived health and to explore lifestyles; a significant extension of the indicators included in the Traveller Health Status Study 1987.

The study will explore diet, physical activity, smoking, alcohol consumption, consumption of legal, illegal and prescribed drugs, sexual health, general health and mental health (see Appendix 1). Adapted standardized questionnaires will be used.

A representative sample of Travellers, selected from participants in the qualitative study, will be invited to complete an interviewer-administered questionnaire. A quota sampling procedure will be used; with some possible adjustment to ensure that regional samples are large enough to enable basic statistical analysis at the regional level.

Approximately one in two families - an estimated 1,000 interviews - will be involved.

7. SUB-STUDY 2: HEALTH AND SOCIAL SERVICES STUDIES

These will be based in local health and social services, and will explore health issues as perceived by service providers and models of best practice for Traveller health and social services.

Health issues as perceived by service providers

The understandings and experiences that service providers have of Travellers, their health and social needs, and use of services will be explored in this study. The study will focus on:

- The understanding providers (at all levels) have of health issues related to Travellers.
- What providers identify as the health and social services needs of Travellers
- How providers experience the quality and quantity of service provision to Travellers
- The experiences providers have in relation to uptake of such services
- What they see as main barriers and examples of 'best practice' of Traveller engagement
- Any solutions providers identify in relation to difficulties in any of the above areas.

The study will follow a step-by-step process, similar to the one used in the Primary Health Care for Travellers Projects in the Republic:

- Identifying key organisations and individuals at local level
- Local planning of field work in close collaboration with these organizations and individuals
- Conduct interviews, focus groups and other data collection activities
- Collation and initial interpretation of data
- Feed back of findings to the participants, who will prioritize identified needs and suggest changes.

Fieldwork will be conducted by Traveller peer-researchers and service researchers, as is appropriate.

As with other aspects of the Travellers' All-Ireland Health Study, standardized research tools for data collection, data validation, data analysis and interpretation, and reporting of findings will be developed by the All-Ireland Research Team in collaboration with the Regional Research Teams.

A representative sample of providers of front line services such as GPs, health visitors, social workers, occupational therapists, pharmacists, dentists, and opticians as well as more senior health officials will be invited to participate. Area-based partnerships such as Health Action Zones, childcare partnerships etc. will provide useful networks. A quota sampling procedure will be used; with some adjustments to ensure regional sample sizes are adequate. An average of 200

providers in each region will be involved.

8. SUB-STUDY 3: STUDY OF BIRTHS AND DEATHS

The objectives of this sub-study are to:

1. calculate mortality indicators such as cause-specific age standardized mortality rates, standardized mortality ratios, and life expectancy
2. assess birth and early childhood outcomes such as birth rates, fertility, perinatal mortality, infant mortality, congenital anomalies, uptake of child health services, and breast feeding.

This sub-study will build on the Health Research Board's Travellers' Health Status Study 1987, benefiting from the lessons learnt from that study and extending it to the whole island. The range of health status indicators used will also be extended, and baseline information for future monitoring will be provided.

The sub-study will comprise a study of the deaths and deaths that occur in the Traveller community.

Mortality study

The number of deaths provides the numerator for mortality rate and life expectancy calculations.

As in the Traveller Health Status Study 1987, a complete enumeration of all Traveller deaths identified by local authority social workers, (public health) nurses and area medical officers is required. In 1987, 84 deaths and 11 stillbirths were involved.

This study will follow steps, similar to the ones used in the Traveller Health Status Study 1987:

1. An anecdotal listing by (public health) nurses and Traveller organizations of all Traveller deaths that occur during the study period
2. Collection of further details (about the deceased and the circumstances of their death) from the General Registrar Office's death records
3. Comparisons with other populations

A number of changes will be made to the 1987 protocols to strengthen the quality of the information collected. These changes concern:

- deaths in prisons, care homes, hostels and hospitals that may not be counted as Traveller deaths
- consent to approach and search records for anecdotally reported deaths (In 1987, 70 out of the 84 deaths were found)

A copy of the data collection form used in 1987 for the anecdotal listing of deaths is available.

All deaths that occur in the first year of the study will be included.

Birth cohort study

As in the Traveller Health Status Study 1987, a complete enumeration of all Traveller births identified by (public health) nurses will be required. In 1987, 554 live births were involved.

This study will follow steps, similar to the ones used in the Traveller Health Status Study 1987:

1. An anecdotal listing by nurses, hospitals and health visitors of all births.
2. Collection of further details (about the new-born and the circumstances of their birth) from the birth notification form
3. First post-natal visit (first domiciliary visit) to collect details about parental consanguinity, uptake of ante-natal and perinatal health services
4. Visit at first birthday (or visit closest to first birthday)
5. Comparison with other populations

A number of changes will be made to the 1987 protocols to strengthen the quality of the information collected. These changes concern:

- a more complete enumeration of all births
- consent to collect further details from the birth records for anecdotally reported births
- maximizing participation in the visits at first birthday.

The data collection forms used in 1987 are available.

All births that occur in the first year of the study will be included.

9. SUB-STUDY 4: POPULATION ESTIMATES

Accurate estimates of the gender-age population of the Traveller community form the denominators of mortality rates calculations.

A number of agencies currently collect information that may be useful:

- The 2001 Census in Northern Ireland and the Northern Ireland Housing Executive's Traveller Accommodation needs assessment in 2002. These two counts appear relatively similar.
- The 2002 Census in the Republic, the Department of Environment, Heritage and Local Government's annual counts of Traveller households and household sizes, and a number of the Primary Health Care for Travellers Projects (in various areas). There appear to be some differences in these counts.

The Traveller Health Status Study 1987 used the annual count of Traveller households undertaken by local authority management and social workers. The social worker on the Community Care Study Team ensured consistency across the

study of births and deaths, and the population estimation.

In the Republic of Ireland, the National Traveller Accommodation Consultative Committee will be asked to strengthen the Department of the Environment, Heritage and Local Government's annual counts by

- 1) addressing undercounts associated with possibly low participation;
- 2) addressing overcounts associated with possible duplication; and
- 3) including the gender and age of the members of each household.

This would be a natural extension of the Traveller Health Status Study 1987 when the Department of the Environment (at the time) facilitated each stage of the census of Travellers. Collaboration with the Northern Ireland Housing Executive would see this methodology extended to Northern Ireland.

Triangulation of the population estimates obtained with the sources described above will be used to assess the validity of the procedure.

10. TIMETABLE

The Travellers' All-Ireland Health Study Advisory Committee should be established as early as possible. The study would then proceed in three phases:

Phase 1: Procurement/Study preparation

Phase 2: Pilot Study

Phase 3: Study Implementation

Phase 1 includes negotiation of practical arrangements in the regions, the appointment of the All-Ireland Research Team, appointment of Regional Research Teams, introductory research training and the development of standardized research tools.

Pilot study will be undertaken in one study region.

Study Implementation will commence in Year 1, Month 11. The study of health issues as perceived by Travellers, and the health and social services studies, will be 'rolled out' across the regions during the first year of the study (Year 1, Month 11- Year 2, Month 10). All deaths and births that occur during this period will be included in the study. The first birthday visits of newborns will continue over the second year (Year 2, Month 11- Year 3, Month 10). The population estimation will be co-ordinated with the census conducted by the Department of Environment, Heritage and Local Government in the Republic.

When the starting date for the study is finalized, due consideration of the impact of summer periods and health services reforms on the timetable will be needed.

Table 5: Study Timetable

MILESTONE	YEAR	MONTH
Formation of the All-Ireland Travellers' Health Study Advisory Committee	1	1
<i>Phase 1: Procurement /Study Preparation</i>		
Initial negotiations about practical arrangements in the regions: Community mapping (population, resources, agencies, etc) Local management Identifying Traveller peer-researchers, services researchers, public health researchers and demography researchers	1	2-5
Appoint All-Ireland Research Team	1	2-4
Finalise negotiations	1	5
Appoint Regional Research Teams	1	5
Finalise arrangements for ongoing support	1	5
Develop standardized research tools Local, regional, North and South, All-Ireland issues to be explored Develop research resources, protocols, training procedures	1	4-7
Introductory research training	1	1-6
<i>Phase 2: Pilot study</i>		
Specialised training in pilot study region	1	8
Pilot study in one study region	1	8-10
<i>Phase 3: Study Implementation</i>		
Specialised training in other study regions	1 2	11-12 1-10
Ongoing research support	1 2	11-12 1-10
Sub-study 1: Health issues as perceived by Travellers	1 2	11-12 1-10
Sub-study 2: Health and social services studies	1 2	11-12 1-10
Sub-study 3: Study of births and deaths Recruitment/first interviews First birthday interviews	1,2 2,3	11-12, 1-10 11-12, 1-10
Sub-study 4: Population estimation	2	3-7

11. STUDY OUTPUTS

All reports will be subject to internal peer reviewing prior to publication; this should involve at least one member from the National Travellers' Health Advisory Committee (in the Republic) and an appropriate partnership body (in Northern Ireland) (see Figure 1).

The key study outputs are listed in Table 6.

Table 6: Study outputs

OUTPUT	TIMING
<i>General</i>	
Glossary of terms and definitions	Year 1, regularly updated
Minimum data sets	Year 1, regularly updated
Repository of research tools	Year 1, regularly updated
Research training manuals: <ul style="list-style-type: none"> • introductory • specialized 	Year 1, regularly updated
Code of practice	Year 1, regularly updated
<i>Study reports</i>	
Sub-study 1: Health issues as perceived by Travellers: <ul style="list-style-type: none"> • Regional reports • All-Ireland report 	Staggered over Year1/Year 2 Year 2
Sub-study 2: Health issues as perceived by service providers <ul style="list-style-type: none"> • Regional reports • All-Ireland report 	Staggered over Year 1/Year 2 Year 2
Sub-study 2: Models of good practice	Year 2
Sub-study 3: Mortality in the Traveller community	Year 2
Sub-study 3: Births in the Traveller community	Year 2
Sub-study 3: Early childhood outcomes in the Traveller community	Year 3
Sub-study 4: Traveller population on the island	Year 1

12. BUDGET

It is assumed that the activities and operation of the Travellers' All-Ireland Health Study Advisory Committee are funded by the two health departments. The basis of the cost-sharing between the two health departments will be negotiated by those departments.

Some aspects of this research project are built onto functions already performed by health and social service providers as part of their routine work. This budget does not include the cost of these functions; rather it only costs the additional workload associated with the study.

Finally, this budget assumes that the office support for the Regional Co-ordinators is available within existing organizations. The Department of Health, Social Services and Public Safety in Northern Ireland considers that Traveller organizations in that jurisdiction require additional infrastructure support in order to participate fully in this study. It is estimated that the cost of this support (accommodation, computer equipment, office phone, travel (including accommodation and subsistence) and mobile phone charges) is STG £9,640. The Department of Health and Children will consider the needs of the regions in the Republic (health board areas) on a case-by case basis.

Table 6: Costings

<i>Co-ordination</i>	
a) National	
Whole study (co-ordinator, admin support, expenses)	€100,000
Sub-studies (4 co-ordinators)	€ 80,000
b) Regional (9 co-ordinators)	€135,000
<i>Fieldwork</i>	
a) Sub-study 1: Travellers' perceptions (2,000 + 1,000 families)	€ 90,000
b) Sub-study 2: Health & social services studies (1,800 providers, models of good practice, audits)	€ 60,000
c) Sub-study 3: Study of births and deaths (Recruitment, initial interview, data abstraction, tracking, final interview, analysis, reporting)	€100,000
d) Sub-study 4: Population estimates (enhancement of census)	€ 20,000
<i>Training and support</i>	€100,000
<i>Production costs</i> (Production of questionnaires, tapes and other data collection materials (national and regional))	€100,000
<i>Estimated total</i>	€785,000

13. OTHER ISSUES

In this section we highlight a number of issues, not covered above, that are critical to the success of the study.

Government commitment

During the regional consultations, many people expressed the view that in spite of the numerous research projects and consultation processes, Travellers reported little improvement in their daily lives. It was very clear that without a commitment to properly fund the study, to encourage and facilitate the participation of Travellers and service providers, and to act on the findings of the study; Travellers would continue to feel that they are the subjects of research that has no tangible benefits for them.

Effective participation

A properly supported strategy to promote participation in the study is required. It should include:

- Awareness raising to highlight the benefits to the Traveller community of identifying and participating
- Space on the websites of the two departments, Pavee Point Travellers' Centre and Traveller Movement (NI)
- Regular bulletins emailed or posted to all interested individuals and organizations
- Newspaper, magazines and journals articles and presentations

Data issues

All research participants will be assured of full confidentiality. No names or information that can identify individuals will be imported into any database or appear in any published material.

Proper data protection procedures that adhere to the legislation in both Northern Ireland and the Republic will be developed. There will be a Code of Practice governing the collection, storage and exchange of data, all data handling will be carried out in accordance with this code.

Ownership and access to data will be managed by the National Travellers' Health Advisory Committee in the Republic and the appropriate partnership body in Northern Ireland.

Opportunities for future research

This study represents a significant base on which further studies can be built. For

example:

- The birth cohort study could be extended to allow further follow-up of children and families. This would add a longitudinal dimension to the study.
- The study has the potential to contribute to debates about the health and social services needs of other minority groups, and could trigger research projects specifically tailored to local needs.
- Given the research capacity that this study will build within the Traveller community, there will also be opportunities for Travellers to develop other research and evaluation projects that they identify as useful and desirable
- The minimum data sets of the study will contribute to a basket of Traveller health indicators that could be updated on a regular basis as part of the ongoing monitoring of health status and health needs.

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APPENDIX 1. PRIORITY HEALTH ISSUES

The (draft) table below is based on the priority issues identified in the key policies and strategies on the island (DoHC (1994, 2001, 2002); DHSSPS (2002); OFM/DFM, (2003)

Table A1: Priority health topics

<i>Health conditions</i>	
Women's health	Antenatal/postnatal and maternity services Screening services Women and violence programmes
Children's health	Child development Immunisation
Men's health	
Mental health	
Addiction (alcohol and drugs)	
<i>Health services issues</i>	
General Medical Services	Access to GP services ¹ Access and renewal of medical cards
Public Health Nursing Services	Designated PHN services
Childcare and Family Support Services	Family support services Children in care
Services for older people	
Consanguinity and genetic counselling	
Health information services	Ethnic identifier
Disability Services	Data collection
Dental health services	
General hospital services	Dental Treatment Services Scheme Specialist Dental Clinics for Travellers Accident and Emergency
Health promotion services	Inpatients Outpatients
Community services	Community Welfare Services Speech therapy Ophthalmic services (eyes) Aural services (ears)

<i>Key areas that impact on Travellers' health</i>
Lack of recognition of Travellers culture and ethnic identity
Individual and Institutional level racism
Social exclusion
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
Lack of culturally appropriate provision
Issues related to partnership and participation
Lack of data on Travellers' health and health needs
Any other key issues that emerge throughout the research process

1. In Northern Ireland, the extent and nature of GP registration is a key aspect of "Access to GP services". In the Republic, GMS registration is an aspect.

APPENDIX 2: DATA DEFINITION ISSUES

Who is a Traveller?

A standard definition of a Traveller is needed for this study. The Travellers' Health Status Study 1987 took a person to be a Traveller if the local authority social worker (census enumerator) believed them to be a Traveller, and the person agreed with that assessment. The Race Relations (Northern Ireland) Order (1997) and the Equal Status Act (2000) (Republic of Ireland) defines the Irish Traveller community as "a community of people commonly so called who are identified (by themselves and others) as a people with a shared history, culture and traditions, including, historically, a nomadic way of life on the island of Ireland". It is suggested that this study use this definition of Traveller community, and rely on self ascription to identify individual Travellers. This means that individual who do not wish to be identified as Traveller will not be included. More general issues around why some individual may not wish to be identified as Traveller may emerge in the qualitative research.

Classification of accommodation

The classification of accommodation conditions needs to be standardized. In the Traveller Health Status Study 1987, the public health nurse classified accommodation conditions as either a local authority house, other house, chalet,

caravan (serviced site), caravan (un-serviced site), caravan (roadside) and other. Subsequent studies have found considerable variation in the conditions and services available to Travellers living in a given accommodation type, and have highlighted the need for a more relevant classification scheme. In addition, accommodation history and not just current accommodation circumstances is required. When considering the impact of accommodation type on health, it is also crucial to keep in mind the issue of choice.

APPENDIX 3: EXAMPLES OF QUALITATIVE RESEARCH METHODS

It is vital that the methods used are appropriate to people's circumstances. While older Travellers may prefer to explore health topics by telling their life stories, young people may communicate better through narrative workshops or art projects. Likewise, while semi-structured interviews may be preferred by Heads of Discipline, front line service providers may choose to express themselves through focus groups.

It is proposed that a number of methods are combined with an emphasis on participative methods that fully involve Travellers at all stages in the research process. Balcazar et al. (2003) has pointed out four principles of participatory methods which are applicable to both Travellers and service providers. These are:

- The active role of individuals in defining, analysing and solving identified problems
- The opportunities to authenticate the analysis of people's social reality
- Awareness among people themselves of their own resources and strengths
- The opportunities for improving people's quality of life

The qualitative studies will use the following methods.

Individual interviews

In most cases, and for reasons of methodological rigour, an interview schedule or general direction is decided prior to the interview. *Open ended in-depth interviews* allow the interviewee to introduce and elaborate themes he or she finds important. Open ended interviews provide a method for collecting narratives, life-stories and other forms of case-studies. *Semi-structured and structured interviews* allow for closer comparison of the replies of different interviewees. With all types of interviews, it is sometimes beneficial to interview the same respondents on several occasions. This allows both interviewer and interviewee to reflect and expand on emerging themes.

Group interviews

Group discussions have a dynamic dimension which allows respondents to react and build upon responses of other group members. This may generate data that

may not have been uncovered in individual interviews. *Focus groups* with particular groups may facilitate more comfortable and easier discussion than individual interviews as group members may gain support from sharing a peer culture. However, group discussions make it impossible for the facilitator to guarantee confidentiality and participants may be reluctant to discuss personal matters. The same group may meet at regular intervals over a period of time, setting themselves certain questions to answer. Such *group inquiry processes* are particularly helpful in terms of negotiating solutions to specific problems.

Participant observations

Participant observation is the most common method in social and cultural anthropological research. The method involves participation in the life of the study population. This is based on the belief that to fully understand a culture, one needs to see it 'acted out' and not simply based on one's understanding of normative statements from informants. That is, one tries to incorporate both what people say they do and what they actually do.

Other methods

In addition, a selection of other methods may be used where appropriate. These include:

- *Free listing, pile sorting and rank ordering.* This involves participants freely listing items seen to be related to a topic, e.g. childhood diseases or service uptake. This is then sorted into categories and then ranked if appropriate.
- *Narrative analysis.* Autobiographic accounts of topics or experiences.
- Collection of *medical folklore* from oral or written sources; including folk explanations and traditional cures
- *Social network analysis.* This involves charts that describe associations between people. This may be useful in relation to experiences of social exclusion/inclusion.
- Analysis of written or *visual material*, including drama, art, video and photographs. It may be particularly useful to use drama, for example, as a way of illustrating experiences of barriers to service uptake.
- *Projective techniques* including *structured vignettes*. Respondents are asked to comment on an image/text. This is useful in revealing hidden assumptions about levels of understanding and of a subject's belief system.

APPENDIX 4: MEMBERSHIP OF THE TRAVELLERS' ALL-IRELAND HEALTH STUDY GROUP

NAME	ORGANISATION
Michael Sweeney (Chair)	Department of Health, Social Services and Public Safety, Northern Ireland
Kevin Balanda	Institute of Public Health in Ireland
Mary Cunningham	Traveller Movement (NI)
Anna-May Harkin	Department of Health and Children, Republic of Ireland
Rosaleen McDonagh	Pavee Point Travellers' Centre
Hugh Magee	Department of Health and Children, Republic of Ireland
Teresa Maguire	Health Research Board
Mary O'Reilly	Department of Health and Children, Republic of Ireland
Maura O'Shea	Western Health Board
Brigid Quirke	Pavee Point Travellers' Centre