All Ireland Traveller Health Study

Our Geels

Technical Report 2

Technical Report 3

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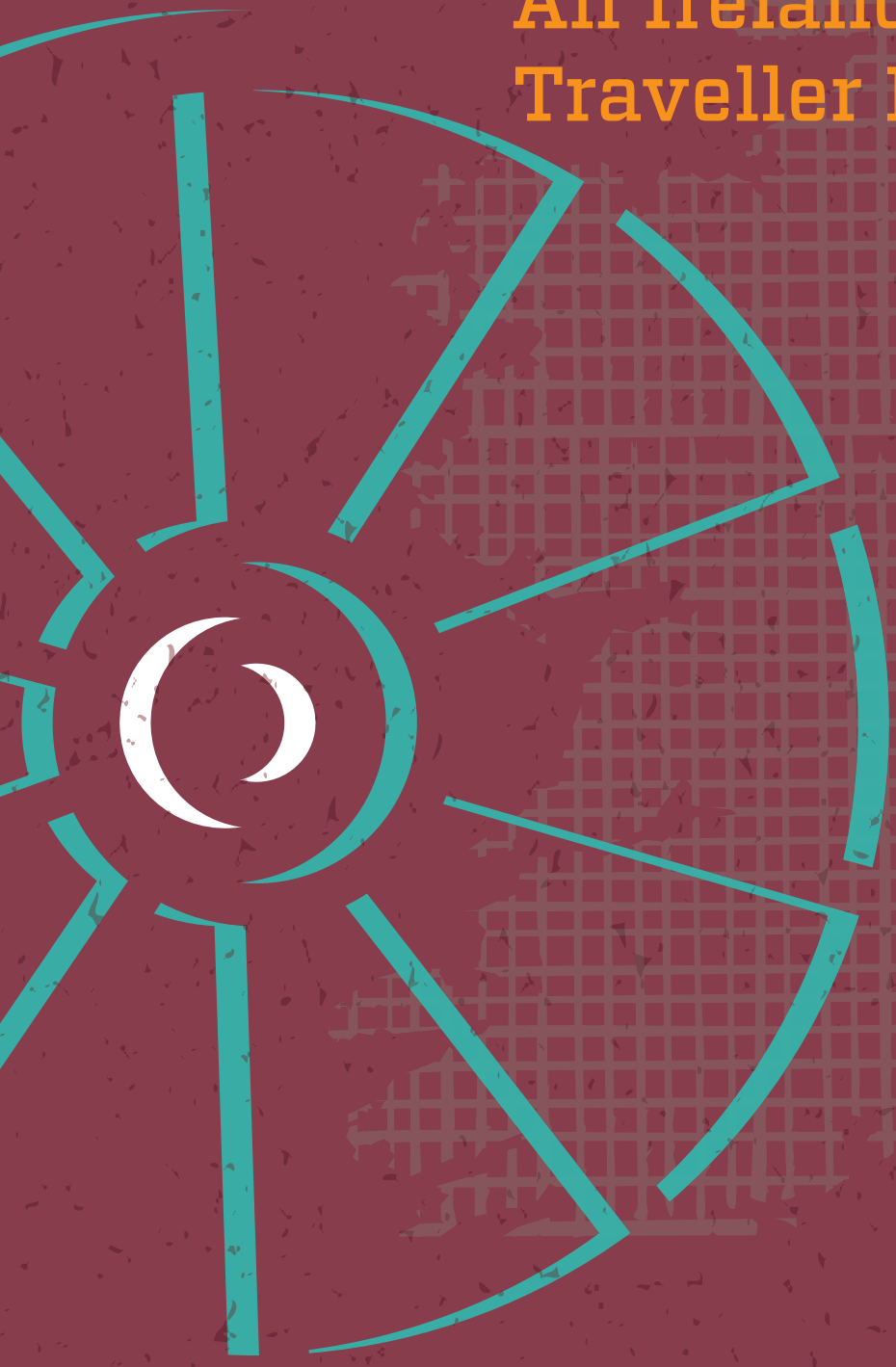

Demography & Vital Statistics

All Ireland Traveller Health Study

Demography & Vital Statistics Part A of Technical Report 2

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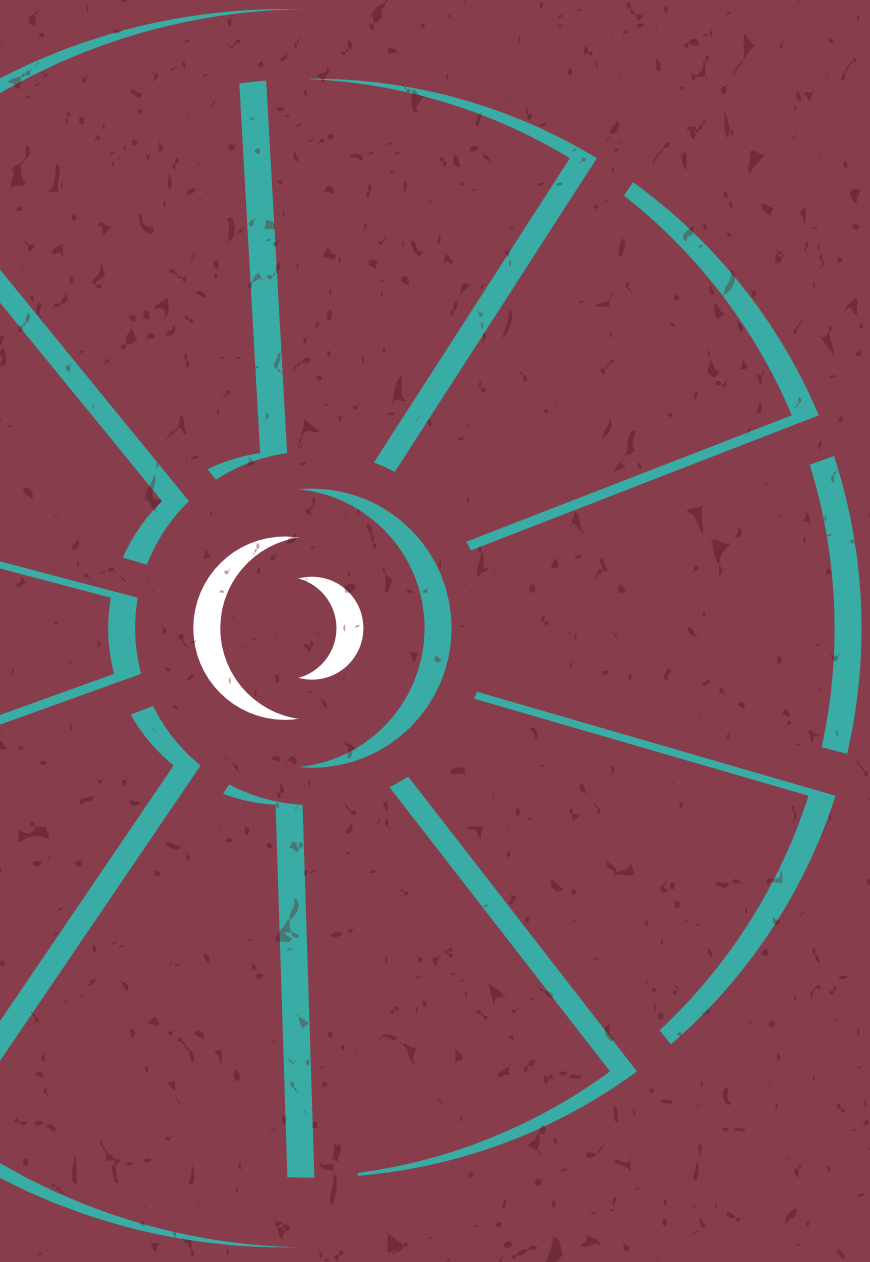
Table of Contents

List of Tables

List of Figures

The All Ireland Traveller Health Study



1. Introduction & Executive Summary

1.1 Introduction

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

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

The methods used and results relating to the count of the Traveller population are presented in Section 2 of the report. The methodologies underlying the mortality analyses are described in Section 3 of this report and the basic results presented in Section 4. Section 3 includes a fair deal of technical content and can be omitted at first reading. Section 4 has been drafted so that it can be read as a stand-alone section and therefore repeats some of the explanatory material in Section 3.

Comparisons are made with the general Irish population and with results from the previous Traveller census in 1987. Note that all comparisons are made with the entire population. This is legitimate because Travellers form only a small proportion of that population. For convenience we refer to the mortality data as relating to the year 2008 though technically Traveller mortality statistics relate to the 12-month period from 14th October, 2007.

1.2 Executive Summary

A census of the Traveller community in Ireland was undertaken in 2008 (early 2009 in NI). In total there were 40,129 Travellers living on the island of Ireland (IOI): 36,224 (90.3%) in ROI and 3,905 (9.7%) in NI. The age distribution of Travellers in both jurisdictions shows an extremely young population, with very few reaching old age. Since 1987, when the last census was carried out, there has been a slight increase in those living to older ages among Travellers but the contrast with the general population is stark (Barry and Daly, 1988).

In ROI there were 188 deaths among Travellers in 2008 and 11 in NI. Mortality analysis concentrated on ROI data to allow for comparative analyses. There were 124 (66.0%) deaths in males and 64 (34.0%) in females. No matter what way one examines the mortality data, the picture painted is a bleak one for Travellers. Compared to the general population, Travellers experience considerably higher mortality at all ages in both males and females. The problem stretches across the entire age spectrum and the disadvantage is seen from the very start of life. Infant mortality (deaths under 1 year of age) in Travellers is 3.6 times higher than in the general population and there are 10 more deaths in Traveller babies (per 1,000 live births) than would be expected in the general population.

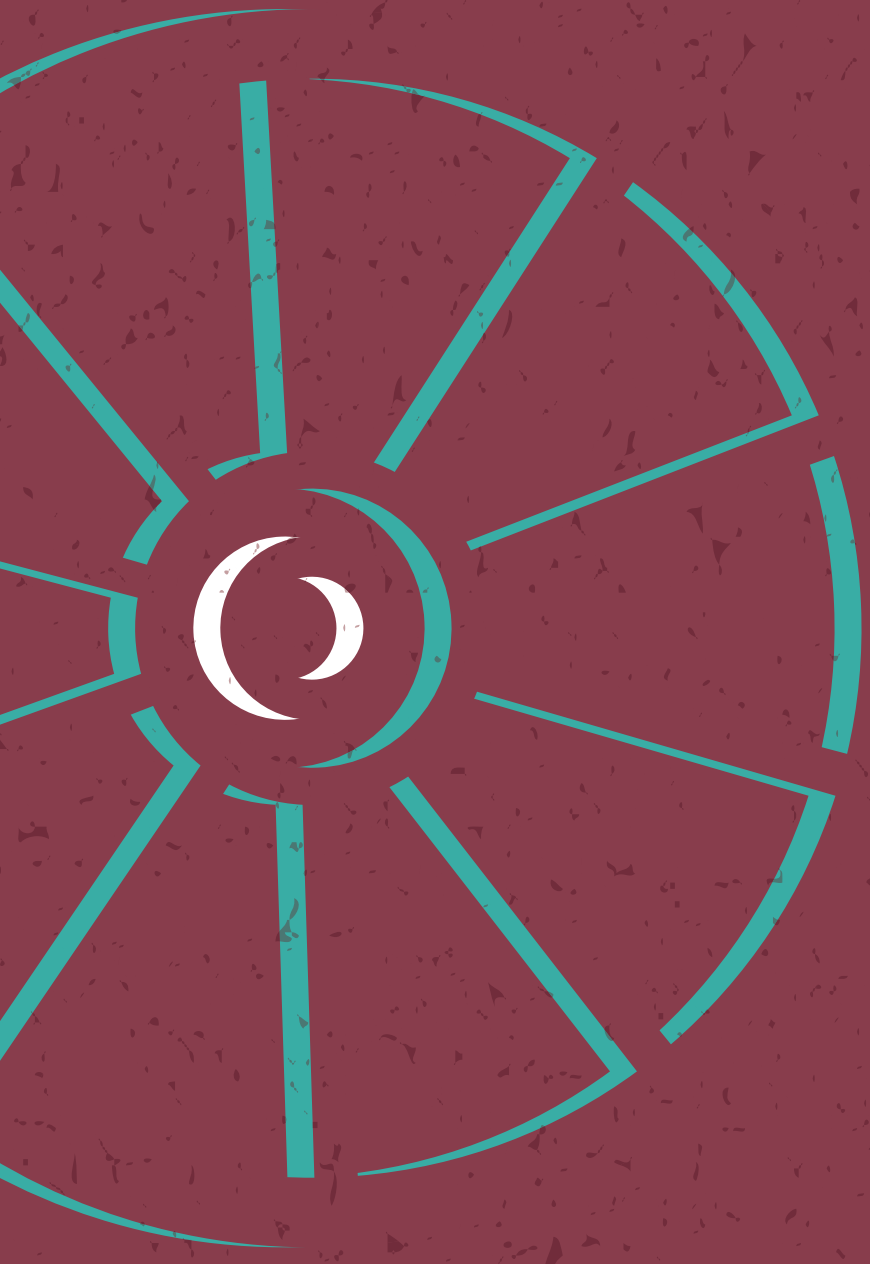
Allowing for the age differences between the Traveller and general population, overall Traveller mortality is 3.5 times higher. Traveller males have 3.7 times the mortality of males in the general population; for females the mortality is 3.1 times higher. Traveller males can expect on average to die 15 years before their counterparts in the general population, and females can expect to die 11 years earlier. The life expectancies of the Traveller community in the first decade of the 21st century mirror those observed in the general population of the late 1940s for males and of the early 1960s for females.

Compared to 1987, the mortality experience of male Travellers has not changed, while there has been a mortality reduction for female Travellers. This however is in the context of major health improvements in the general population in both sexes. For males, the gap in mortality has widened between Travellers and the general population; while for the women the gap has remained nearly the same. For Travellers as a whole the gap has widened.

The increase in Traveller mortality is seen across the broad spectrum of causes of death. For males, external causes of death (which include accidents, poisonings and suicides) were 5.5 times higher than in the general population and a higher percentage of external causes were attributable to suicides. There were 90 extra deaths in Traveller males in 2008 compared to what would be expected if Travellers had the same mortality as the general population. Over 30% of these excess deaths were due to external causes. In both males and females, Traveller deaths due to respiratory conditions and heart disease were considerably higher than expected. Cancer deaths were also increased but less markedly.

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

2. Traveller Demographics



2. Traveller Demographics

2.1 How We Did the Count

The carrying out of the census survey in the Traveller population has been described in Technical Report 1. We describe in this section how we used the information collected to determine the size of the Traveller population on the island of Ireland. The total Traveller population count was based on the number of Traveller families enumerated at the census, multiplied by the average family size estimated by analysis of census interview data. Age- and sex-specific numbers were derived by applying the age-sex distribution from census interview data to the total population count.

2.1.1 Family Count

During the census the project field coordinators in ROI and NI returned field reports of anonymised family codes with a comment on each code, marking the status of the family to the best of their knowledge. Information was gathered on whether a family was interviewed or not, and if not whether that was because they moved, refused or were unavailable. In addition, each project completed a telephone interview as soon as the census fieldwork was finished to clarify the numbers of families enumerated, response rate, number of interview records returned from the field and how they marked the families that were not interviewed. Information from the field report was correlated with information from the interview to confirm (1) the total family count in each project, (2) the number of families interviewed (3) the number of those who were not interviewed because they moved. Since those who moved out of the island of Ireland were not to be enumerated as part of the study population and because those who moved within the island would be enumerated in the area to which they moved, the number who moved was subtracted from the count in each project, and project counts were aggregated to reach the final Traveller count. Table 2.1 gives the distribution of the Traveller families with Traveller Health Units in ROI.

Table 2.1 Breakdown of Number of Traveller Families enumerated within Traveller Health Unit Regions.

Region	Traveller Families	%
South Eastern	1,043	11%
North Eastern	904	10%
Western	1,431	16%
Mid Western	997	11%
Midlands	1,049	12%
North Western	428	5%
Southern	1,439	16%
Eastern	1,763	19%
Total	9,056	100%

9,056 families were enumerated in ROI. More than 9,300 electronic-initiated interview files were initially received from the field in a single database. The database included files for a number of interview outcomes: consented interviews, refusals, unavailable families or moved families, in addition to invalid empty files and duplicates. All invalid files were removed. Duplicates and non-consented interviews (refusals, moved and unavailable families) were also removed. This left a total of 7,042 consented family interview records, giving a response rate of 78%. Table 2.2 shows the response rates for the family interviews broken down by THU regions in ROI.

Table 2.2: Response rates of Traveller Families by THU Regions

Region	Traveller Families enumerated	Traveller Families consented	Percentage response
South Eastern	1,043	734	70%
North Eastern	904	720	80%
Western	1,431	1187	83%
Mid Western	997	630	63%
Midlands	1,049	832	79%
North Western	428	404	94%
Southern	1,439	1,049	73%
Eastern	1,763	1,485	84%
Total	9,056	7,042	78%

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

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

2.1.2 Average Family Size

Information about average family size was derived from two sources in the census interview:

- The responses to the question: how many family members including yourself normally live with you?
- The actual number of individuals for whom census data (age, gender, education, occupation, marital status and institutionalisation) were inputted by the respondent.

In a considerable number of cases in ROI, the respondents counted more family members than they gave information for. This might be attributable to the cessation of the census interview before all family members had their census data inputted. Conversely, in other cases census data was given for more family members than were counted initially by the respondent. In some cases, that was due to non-response to the family count question. In many cases, there was one more individual for whom census data were inputted, who was not counted by the respondent. This is most probably due to failure of the respondent to include herself/himself in the count. Actual family size was considered to be the highest one given in either scenario.

The average family size based on the family count given by the respondent (when response was more than zero) was compared with the average family size computed from the highest family size given by either source. Table 2.3 gives the averages calculated.

Table 2.3: Average family size by source of information

Source	Approximate percentage of families with valid data	Average family size
ROI Respondent family count	97%	4.02
ROI Sources with the highest family size	97%	4.07
NI Respondent family count	92%	2.48
NI Sources with the highest family size	96%	2.49

Census data (age and sex only) were also reported in a non-formatted free text area on the data collection computers for some of the non-respondent families by the peer researchers. However these families were not included when computing the average family size because the reporting space allowed no more than 6 family members to have their data inputted. Their inclusion would have skewed the average family size downwards and given us a biased estimate.

Based on these findings we took the average family size to be 4.0 in ROI and 2.5 in NI.

2.1.3 Age and Sex Distribution of the Traveller Population

The age and sex distribution was based on the census data reported by respondent families at the census interviews. Some of the initial families surveyed in ROI did not give the age/sex information on family members due to a computer error, though the family size was recorded. These families did not contribute to the age/sex information recorded. Study coordinators were also allowed to input the number of family members of non-respondent families and the age and sex composition of the families by proxy. We first compared the age-sex distribution, based on responding family reports, to that based on both responding and non-responding families who had age and sex data reported for them. The difference between the two distributions, shown in Table 2.4, was minimal and we have based all our age/sex distributions on the 21,974 individuals on whom we had age and sex data in consenting families.

Table 2.4: Age-sex distribution in consenters and in all with information

Age	Males		Females	
	Consenters refused unavailable %	Consenters only %	Consenters refused unavailable %	Consenters only %
0-4	8.3	8.0	7.9	7.8
5-9	6.9	7.0	6.5	6.6
10-14	6.9	6.9	6.1	6.1
15-19	5.4	5.4	5.4	5.5
20-24	4.6	4.5	4.9	5.0
25-29	4.0	4.0	4.4	4.5
30-34	3.2	3.3	3.4	3.5
35-39	2.8	2.8	3.2	3.2
40-44	2.3	2.2	2.4	2.4
45-49	1.7	1.7	1.8	1.9
50-54	1.4	1.3	1.4	1.4
55-59	1.0	1.0	0.9	1.0
60-64	0.7	0.6	0.7	0.7
65-69	0.4	0.4	0.4	0.4
70-74	0.3	0.3	0.3	0.4
75-79	0.1	0.1	0.1	0.1
80-84	0.1	0.1	0.1	0.1
85+	0.0	0.0	0.0	0.0
Total	50.2	49.6	49.8	50.4

2.2 Traveller Demographics

2.2.1 Number of Traveller Families

For the purposes of this study, a family unit was defined as

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

However, on occasion the definition of family unit varied. For example, if siblings were living together or if a family considered another individual to be part of their family unit (e.g. a niece, a fostered child), the family decided who they considered to be part of the family unit. Only family members normally living together were included in the same family unit. This definition of family unit was based on that used in Volume 5 of the National Census, Ethnic or Cultural Background (Central Statistics Office, 2007c).

In the AITHS we enumerated 9,056 Traveller families in ROI and 1,562 in NI. We are confident that we identified all Traveller families through the mapping process which was carried out by the Travellers and Traveller organisations in ROI and NI. We received a very high family response rate of 80% (78% in ROI and 93% in NI). This level of coverage is important, as a concern that stakeholders have had in the past is the accuracy of the Traveller population count. An accurate count has implications for the provision of services such as accommodation and education and gives the required denominator data to monitor incidence and prevalence and other indicators.

Information on comparative numbers of Traveller families from other sources is available:

- The CSO has an ethnic and cultural background question in the census. This was first used in the 2006 census in which they identified 4,371 Traveller households (Central Statistics Office, 2007c). Traveller organisations suggest that this was an undercount as not every Traveller family may have been comfortable to identify themselves.
- The Department of the Environment, Heritage and Local Government (DEHLG) in ROI conducts an annual count of Traveller families through the local authorities. As this is used to assess accommodation needs the definition of a family includes unmarried Traveller men over 18 as a unit (as it is understood that they will marry at this age and require an additional unit of accommodation). In 2008 the DEHLG annual Traveller family count was 8,398 (National Traveller Accommodation Consultative Committee, 2008).
- The Housing Executive in the North of Ireland conducted an assessment of Traveller accommodation needs in 2008 and identified 531 Traveller families (Northern Ireland Housing Executive, 2008)

2.2.2 Traveller Count

Most national census population estimates are based on a direct actual count and non-response is not an issue or not permitted by legislation. This direct counting was the method employed in the 1987 census of Travellers (Barry and Daly, 1988). The AITHS census survey was based on the 'family' as the unit of observation and, following self-identification as a Traveller family, consent of the family was required to be included in the survey. As described previously a count was taken of families and recorded non-response. Table 2.5 shows how the family count and the average family size were used to estimate the Traveller population. The current study found the Traveller population on the island of Ireland was 40,129 with 36,224 (90.3%) in ROI and 3,905 (9.7%) in NI.

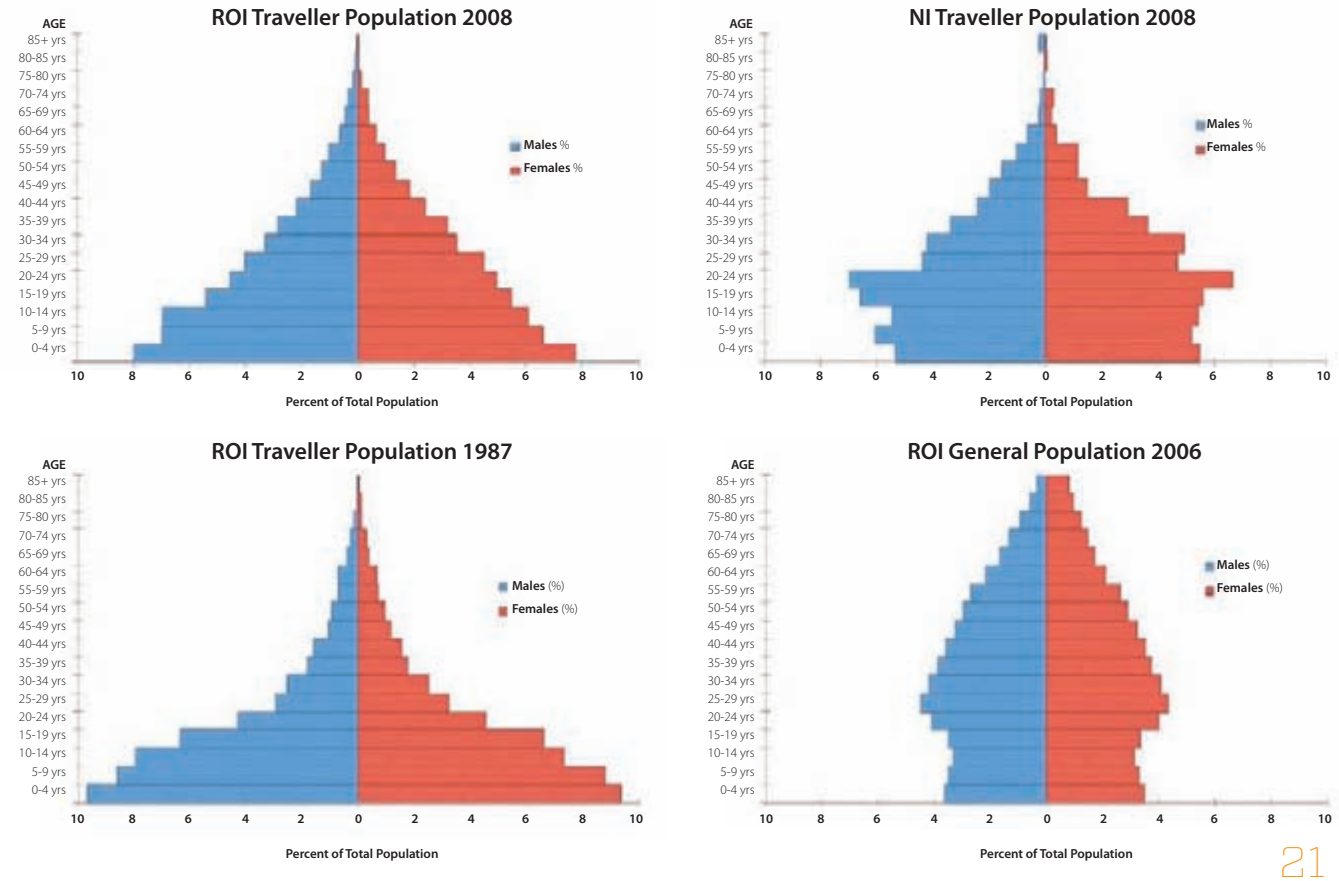
Table 2.5: Estimation of Traveller population (2008)

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

2.2.3 Age Pyramids

The population pyramids for ROI and NI Travellers together with those for the general population in 2006 and the original Traveller census in 1987 are given in Figure 2.1. The 4 pyramids are to the same scale.

Figure 2.1: Population pyramids for Travellers (a) in ROI 2008, (b) in NI 2009, (c) in ROI 1987 and for (d) the ROI general population 2006



Travellers have a very distinctive population profile. In ROI their population pyramid is very similar to that in developing countries, with a wide base that narrows steeply. This is indicative of a high birth rate and a young population. As Travellers get older, the population pyramid becomes narrower at the top. This is the consequence of high mortality rates at a younger age. A similar age profile is also observed among other ethnic minorities, such as the Aboriginal community in Australia (Australian Indigenous Health *InfoNet*, 2009).

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

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

The contrast between the Traveller community and the general population by age groups is summarised in Table 2.6. The following highlight the current differences between ROI Travellers and the general population:

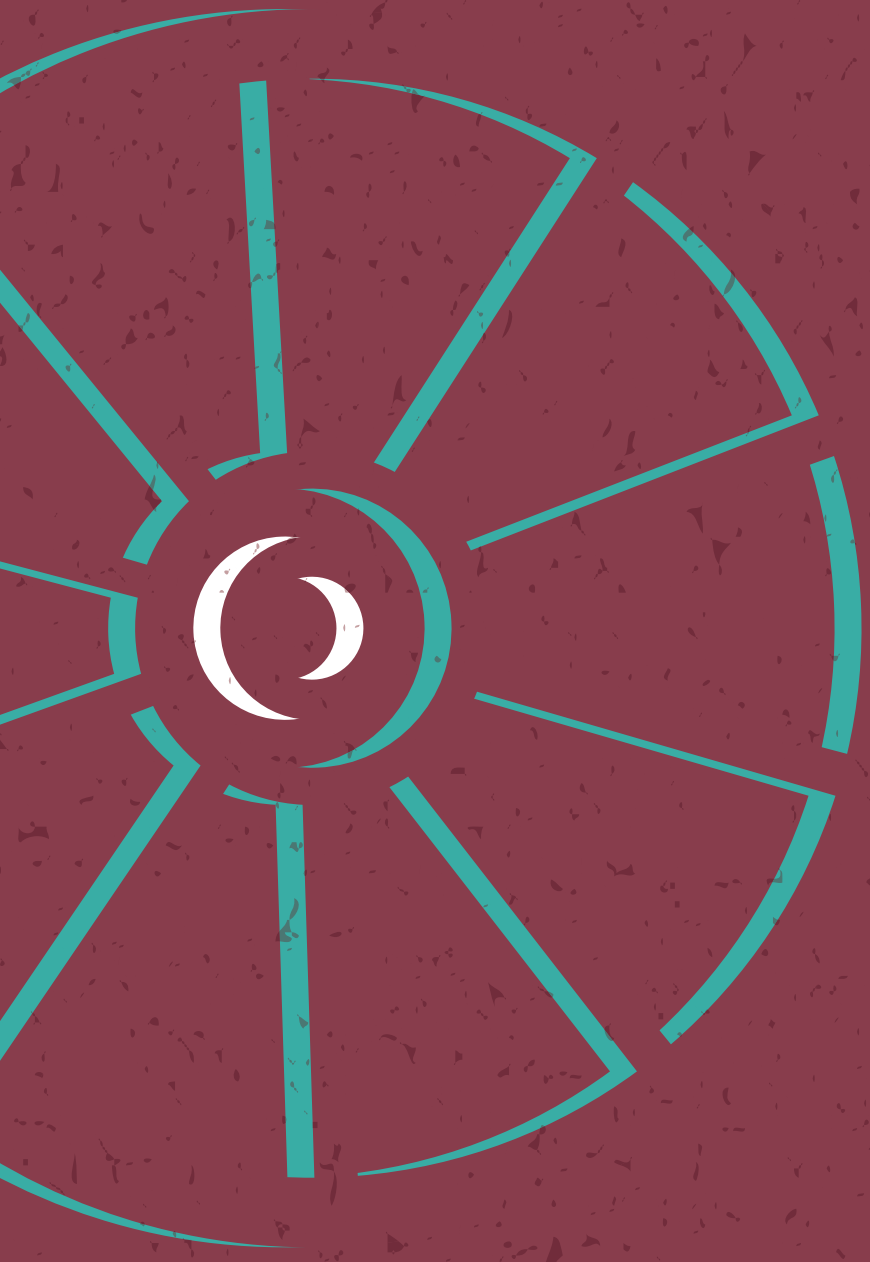
- 63% of Travellers under 25 compared with 35% nationally.
- 42% of Travellers under 15 compared with 21% nationally.
- 3% of Travellers 65 years or over compared to 13% nationally.

Table 2.6: Age distribution of Traveller and general populations

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

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

2. Methods of Mortality Calculations



3. Methods for Mortality Calculations

3.1 Introduction

This section describes the methods behind our mortality calculations. All our results are derived from the count of Traveller deaths and the size of the Traveller population as determined from the census and described in Section 2. In this section we describe how the number of deaths was determined and discuss the accuracy of the data. The analysis concentrates on ROI to allow meaningful comparison with the 1987 study results (which did not include NI) and to allow comparison with the published figures for ROI. The number of deaths in NI was too small for separate analysis.

This entire section is technical and can easily be omitted at a first reading of the report. All the results of the mortality study are presented in Section 4, which also describes how to interpret the various measures used.

3.2 Data Collection

Because there is currently no ethnic identifier included on the Irish Death Certificate or Death Registration forms, it is not possible to disaggregate official mortality data by Traveller status. The mortality study therefore was based on a retrospective identification of all Irish Traveller deaths that occurred on the island of Ireland during the 1-year period between 15th October, 2007 and 14th October, 2008.

It was not possible to replicate the prospective methodology used in the 1987 Health Research Board study, when deaths were identified by Public Health Nurses and Local Authority social workers, since the infrastructure at the Local Health Office (LHO) has changed.

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

3.2.1 Traveller Deaths in ROI

3.2.1.1 Initial Data Collection

As described in Technical Report 1, 450 Traveller Peer Researchers and 90 study coordinators, who were working in Primary Health Care for Traveller projects and Traveller organisations on the island of Ireland, were trained as local data collectors using laptop computers. During the consultation and training period we discussed the mortality study and piloted the question and form (the 'Blue Form' - Appendix A) that was used to document Traveller deaths. During the census, Traveller enumerators (Peer Researchers) identified and visited 10,618 Traveller families and offered them the opportunity to participate in the census.

One of the last survey questions in the census asked the key respondent: a) if any member of their immediate family had died in the previous year (the 12-month period previous to the ROI census date of the 14th October, 2008) and b) if any member of their extended family had died in the previous year. If the respondent answered 'yes' to either of the questions, the Peer Researchers filled in the information on the blue mortality form, which was colour-coded to distinguish it from the green consent form and the yellow birth/pregnancy form. We issued each of the study coordinators with Freepost envelopes to facilitate the return of the forms to the study team in UCD.

Public Health Nurses (PHNs) in ROI and Health Visitors (HVs) in NI were also asked to report (on a predesigned form – Appendix B) all deaths among Irish Travellers that they were aware of and which had occurred within the study time frame on the island of Ireland.

The issue of sensitivity of information arose during the data collection phase, as some Traveller Peer Researchers were concerned about seeking information about a death from a family who had suffered a bereavement. We acknowledged this concern and suggested that researchers should not ask such families directly but rather could obtain the information from the extended family instead. We also encountered some issues of ethical concern by PHNs in accessing what they considered confidential information on Traveller deaths.

A preliminary list of deaths was compiled from the Traveller, PHN and HV reports.

3.2.1.2 Checking Process

We checked and transferred the information on to a spreadsheet, and if necessary followed up with the study coordinators or PHNs for clarification. The Bereavement Grant had been considered as a further cross-referencing tool; however the feedback from the ground was that this grant was rarely accessed by Travellers as it was considered an insult to a family, that there would be insufficient funds to bury a family member.

There were 2 issues in dealing with this list of potential deaths - the elimination of duplicate reports and ensuring that we had not missed any Traveller deaths. Some challenges emerged from this process of eliminating duplicates. Travellers from the same area, or same extended family (which can be large and cover different parts of the county) can have the same given name and surname. It would not be unusual, for example, to have 6 people who are peers in age and gender with the same name. (Subsequently it was suggested to us that we should have included the parents' names on the death report form as well as the 'nickname', as this could have assisted the identification process.) Another challenge to emerge was the literacy issues of the peer researcher which sometimes resulted in incomplete forms.

The death reports we had received required careful checking to ensure they were not duplicates or that we were excluding any death through miss-assignment. We cross-checked all reports by name, reported date of death, age at death and cause of death.

Once duplicates were identified they were noted and the relevant forms were grouped together. In order to ensure accuracy of our list, we then looked for independent confirmations of each death. Reports from different people or projects constituted independent sources. We also used confirmations by PHNs, attendance at funerals, key Traveller informants, data from the Parish of the Travelling People and the Voice of the Traveller magazine.

We attended regional and national Traveller network meetings so we could opportunistically engage with a wide range of Traveller families in attendance to help us with this exercise and ensure completeness of information. When we broke down information on the forms received by county, it highlighted that some areas reported very low figures relative to their Traveller population estimates. These areas were followed up both by phone and through project visits (to meet local Travellers) to address these gaps. For example, in Cork, we made contact with the regional Traveller network, who contacted the Traveller women in advance of a prior-arranged meeting and asked them to try to ensure confirmation of any deaths they could identify using if necessary information from the undertakers or graveyard visits. This proved a very useful exercise.

During this time we also followed up and made contact with some key funeral undertakers, who Travellers reported were used by them locally, to see if we could access additional data. Some undertakers have computerised systems while the majority only have paper records. We had flagged it has a potential source if we required it, but given the timeframe it was not possible or necessary.

We also checked for confirmation with the Irish Sudden Infant Death Association (1999) annual report to see how many Traveller Sudden Infant Deaths were mentioned. (The ISIDA interview each family with a sudden infant death and document, when told, their ethnic or cultural background.)

In total, 166 unique deaths in Travellers were reported to us through these processes outlined above.

3.2.2 Traveller Deaths in NI

Because of the relatively small Traveller population in NI, the NI deaths were too few for separate analysis. 14 reports of Traveller deaths in NI were received which, after removal of duplicates, pertained to 11 deaths. 5 of these have been confirmed by the NI Social Research Agency (NISRA).

3.3 General Register Office (GRO)

There has been a change in the Death Registration process in ROI, which is governed by the Civil Registration Act (2004), enacted on 5th December, 2005. This change fundamentally shifts the burden of responsibility for registration of deaths to family members. The new death notification form, which details the cause of death, is completed by the GP or hospital doctor (depending on where death has occurred) and is sent on to the family of the deceased. The family must then present this form, with some additional information, to any Registrar of Births, Deaths & Marriages no later than 3 months from the date of death. The informing relative must also sign the Register of Deaths in the presence of a Registrar (www.groireland.ie/registering_a_death.htm).

This change in legislation may have led to a reduction of the numbers of Travellers registering deaths, as this is an onerous task, particularly for those with literacy difficulties, requiring a personal visit to the local Registrar's office. Though a legal requirement, the registration of a death is needed only when dealing with wills and probate; this is usually not an issue for Travellers. It is unknown if the change in legislation has resulted in a reduction in death registration in the general population.

Once a death has been officially registered the information is publically accessible through the General Register Office (GRO) and if sufficient information is available the registration details for each death can be retrieved. As the GRO does not include ethnic or cultural identifiers on the Death Certificate or the Death Registration forms, it is not possible to disaggregate mortality data by Traveller status. Traveller deaths had to be searched for in the GRO on the basis of the information reported to us (name, nickname, date of death, gender, county or town of death, date of birth, age at death, cause of death, and study coordinator's/PHN's/HV's contact details). Access to death records at the GRO was granted on the basis of Ministerial permission.

Death records were searched by the UCD team at the public search room in Dublin. The records could only be searched by surname, forename, date of death and county of death. Where there were no complete matches, the nearest matches were used. In total we identified 104 of the 166 Traveller deaths reported to us as registered in the GRO. Additional Traveller deaths which had not been reported to the team were uncovered opportunistically during the 5 days spent in the GRO. In some cases the

researcher was aware that the address was a Traveller halting site or group housing, and in other cases the individual was registered as a 'Tinsmith'. In total 22 Traveller deaths were found through GRO records that had not been reported to us. Thus we identified a total of 126 Traveller deaths in the GRO – 104 had been previously known to us and there were 22 extra. On top of that there were 62 Traveller deaths that had been reported to us but were not traceable in the GRO. The total number of Traveller deaths in ROI is thus 188.

The information available in the GRO does not include the official ICD-10 coding of the cause of death, which is assigned by the CSO in ROI. The CSO agreed to use data linkage to provide us with the official coding for the 126 deaths recorded in the GRO (see Section 3.4.3).

3.4 Data Accuracy

As described in the last 2 sections the 188 separate deaths among Travellers in the ROI can be categorised into 3 main groups according to the source of the information obtained: (1) 104 deaths reported to us and confirmed in the GRO (2) 62 deaths reported to us but not confirmed in the GRO (3) 22 deaths discovered opportunistically in the GRO which had not been reported to us. Table 3.1 summarises the source of death information. The question arises regarding the reliability of the information on the 62 deaths that did not have GRO confirmation.

Table 3.1: Source of information on 188 Traveller deaths

	Traveller-reported	Not Traveller Reported	Total
GRO-ascertained	104	22	126
Not GRO-ascertained	62	-	62
Total	166	22	188

3.4.1 Accuracy of Reported Death Count

Deaths were reported to us from a number of sources. Reports from the same Traveller Health Unit or from the same Traveller Project were not considered to constitute independent reports. Apart from such cases, multiple reports of a death, from independent sources, were taken as a definite indication that a death had occurred. In total 166 separate deaths were reported to us (104 confirmed by the GRO and 62 not confirmed). Just over half of these deaths (85/166; 51.3%) were reported by more than one independent source. The table below (Table 3.2) shows how the number of sources related to the confirmation rate (percentage of deaths discovered in the GRO).

Table 3.2: Confirmation rate of reported Traveller deaths

Source of Information	Number of Deaths	Number confirmed in GRO	Percentage confirmed In GRO
Single source	81	53/81	65.4%
>1 independent source	85	51/85	60.0%
Total reported deaths*	166	104/166	62.7%

*Excludes 22 opportunistic GRO deaths

The confirmation rate for deaths with more than one independent source was 60.0% compared to a higher figure of 65.4% when there was only a single source. Thus there is strong evidence that deaths reported by only a single source are as reliable an indication that death occurred as deaths reported by more than one source. This gives us a high degree of confidence in our accepting the veracity of singly reported deaths in this study. Our standardised mortality ratio (SMR) analyses (see below in Section 4.3) only required a count of the Traveller deaths and did not require age information.

The confirmation rate in the GRO for reported deaths is 62.7%, which is lower than the figure of 83.3% in the 1987 Census (Barry et al., 1989). However, as discussed, the onus of registration is now on relatives of the deceased whereas in 1987 registration was often (if not usually) performed by staff when death occurred in a hospital. Currently burials can take place without registration and there is, particularly for many in the Traveller community, no need to register a death.

3.4.2 Accuracy of Reported Age and Sex

We are accepting GRO-reported ages as a gold standard. For 62 deaths we had no GRO confirmation and had to rely on a reported age at death and gender rather than the GRO figure. To determine the accuracy of reported ages at death we compared the reported ages with the GRO-recorded age in the 104 reported deaths which had GRO confirmation. We took the mean age, rounded down to the nearest integer, of all reports for each death. There were 2 deaths where reported age was missing. In terms of accuracy 72/102 (70.6%) of reported ages were within ± 1 year of the actual age given by the GRO, and 93.1% of reported ages were within ± 5 years. We have used 10-year age groups for most of our analyses requiring age and, in this context, the reported ages can be considered fairly accurate.

On average the mean reported age was 0.9 years below the actual GRO-recorded age. Table 3.3 examines age accuracy by actual age at death in the deaths confirmed by the GRO. The largest discrepancies were in those aged 75 years and over (average reported age at death 3.19 years below the actual age). However, unlike in the general population, most Traveller deaths are at younger ages, and the upward bias in mortality estimates using reported ages in those without GRO confirmation is very small.

Table 3.3: Discrepancy between General Registry Office and reported ages at death by age group

GRO age at death (years)	No. deaths	Mean discrepancy in reported age at death (years)*	n(%) of reported ages within ± 5 years of GRO age
0-29	15	-0.47	15/15 (100.0%)
30-49	25	+0.24	25/25 (100.0%)
50-64	20	-0.65	19/20 (95.0%)
65-74	21	-0.52	20/21 (95.2%)
75+	21	-3.19	16/21 (76.2%)
All ages	102**	-0.90	98/102 (93.1%)

* A minus sign indicates reported age is less than GRO age.
** Reported ages missing in two deaths

Table 3.4 shows that accuracy in reported age was higher in deaths reported by more than one independent source.

Table 3.4: Discrepancy between General Registry Office and reported ages at death by source of information

Source of Information	No. deaths	Mean discrepancy in reported age at death (years)*	n (%) of reported ages within ± 5 years of GRO age
Single source	51	-1.49	45/51 (85.2%)
>1 independent source	51	-0.31	50/51 (98.0%)
All deaths	102**	-0.90	98/102 (93.1%)

* A minus sign indicates reported age is less than GRO age.
** Reported ages missing in two deaths

In all 104 deaths with GRO confirmation, there was complete agreement on the sex of the decedent. This of course is partially explained by our data checking procedures and how we matched reported deaths to a particular registered death.

In terms of data used for analysis we had GRO ages at death for all 126 of the GRO deaths (104 reported and GRO confirmed, and 22 GRO only). In the 62 deaths without a GRO confirmation, age was missing in 6 cases. For the 56 cases with a reported age only, the majority (33; 58.9%) were from more than one independent source. The means of the reported ages (rounded to the nearest integer) were used as the age at death for the 56 cases.

All analyses requiring age-specific data in this report are based on the exact ages for the 126 deaths with GRO data or, as described, on reported age for the 56 others. The fact that reported ages seemed to underestimate actual ages, when they could be compared, would tend to bias our mortality estimates upwards. However the 6 deaths with missing ages were excluded from all age-specific analyses, which would have a much larger downward biasing effect, giving an overall underestimate of Traveller mortality for the analyses requiring age. For analyses not requiring age at death (standardised mortality ratios for instance) all 188 deaths were included and there are no biases due to missing or reported data.

3.4.3 Accuracy of Reported Causes of Death

In summary, 104 of the Traveller deaths reported to us were traceable in the GRO office, 22 further opportunistic deaths were discovered in the GRO office, that we had no report of, and we had 62 deaths with only reported information. We decided, because of the small numbers involved to concentrate on a few causes of death only and chose the groupings used in Table 9 of the Yearly Summary statistics report (Central Statistics Office, 2009c). Additionally we classified suicides separately. The causes we used, together with their ICD-10 (WHO 2010) and the Eurostat abbreviated Cause of Death 65 codes (Eurostat, 2010) are given below in Table 3.5. ICD-10 is an international system used to classify illness and deaths and is based on alphabetical/numerical coding. It was adopted in Ireland in 2007.

Table 3.5: Tabulated causes of death

Grouping	ICD-10 Code	Eurostat Shortlist (65) Code
All cancers	C00 – D48	6
Heart disease and stroke	I00 - I99	33
Respiratory conditions	J00 - J99	37
External causes of injury and poisoning:	V01 – Y89	58
(Of which: Suicide)	(X60 – X84)	(63)
All other causes	remainder	remainder

3.4.3.1 CSO AND ICD-10

There are a number of relevant issues in relation to ICD-10 coding and how it is implemented by the CSO. One change from ICD-9 coding, used prior to 2007, is that ICD-10's 'External causes of injury' are mutually exclusive of other tabulated causes, and thus there is no separate additional 'External E-code' for such causes as there was in ICD-9. A death in ICD-10 classified in this group is not tabulated elsewhere in the standard one-cause tabulation. Another factor to note is that under ICD-10 there is a group of causes ('Alcohol abuse and drug dependence, toxicomania' (F10 – F16, F17 – F19) under the general heading 'Mental and behavioural disorders' (F00 – F19)).

There is an internationally recognised difficulty with ICD-10 in relation to the alcohol/drug toxicity F-codes (personal communication, CSO). The issue is that the categorisation is very similar to what could be classified under accidental poisoning as an external cause (X40 – X49) or indeed a suicide (X60 – X84). When Ireland started using ICD-10 coding in 2007, such deaths were classified, without clear criteria, into either the F10 – F19 codes or the X40 – X 49 codes. Practice, however, changed in mid-2009 and all deaths which might previously been included in the F category were instead classified under X. (The CSO did however keep record of the alternative coding as it now keeps multiple causes of death for an individual on its database.) Published death tabulations in 2008 (Central Statistics Office, 2009c) used the F-codes but, to be consistent with the current and later practice, we have merged them into the external causes for our analyses here.

3.4.3.2 Accuracy of Causes of Death

As we have described, we had 126 deaths registered in the GRO with full information (104 of these also had a cause of death reported to us and 22, opportunistically discovered in the GRO, had not been reported to us). The CSO supplied the official cause of death codes assigned by them for these 126 deaths. For all the 166 reported deaths (including those traced in the GRO) the reported causes of death on *each* report were coded into one of the above groups (Table 3.5) using standard coding rules by one of us (BQ). When there were multiple reports of a death a single 'reported' cause was then assigned based on the completeness of the reports and their sources. The reported cause was based on the single report if there was only one report.

We then compared the reported cause to the official CSO-coded cause in the 104 deaths with a reported cause of death and an official cause of death. Table 3.6 compares the distributions.

Table 3.6: Comparison between GRO-assigned and reported causes of death in 104 Traveller deaths

Cause of death	GRO-assigned cause n (%)	Reported cause of death n (%)
All cancers	18 (17.3%)	11 (10.6%)
Heart disease and stroke	29 (27.9%)	27 (26.0%)
Respiratory conditions	15 (14.4%)	12 (11.5%)
External causes of injury and poisoning	26 (25.0%)	23 (22.1%)
All other causes	16 (15.4%)	15 (14.4%)
Undetermined	0 (0.0%)	16 (15.4%)
All causes	104 (100.0%)	104 (100.0%)

As can be seen the agreement between the distribution of reported cause and GRO cause is reasonable but cancers are considerably lower as reported causes. There were no undetermined causes assigned by the GRO while 15% of the reports did not give a cause. This reflects the understandable lack of knowledge of the reporter of a cause of death in many situations.

The following table (Table 3.7) gives a picture of where disagreements arose by classifying the 104 deaths by each source together. When the reported cause was external then 22/23 (95.7%) were also classified by the GRO as external. When the reported cause was respiratory, there was 91.7% (11/12) agreement by the GRO. However only 21/27 (77.7%%) of the reported heart disease/stroke was confirmed by the GRO.

Table 3.7: Disagreement between GRO-assigned and reported causes of death in 104 Traveller deaths

	GRO-assigned cause of death					
Reported cause of death	**Cancers**	**Heart/Stroke**	**Respiratory**	**External**	**Other**	**Total**
Cancer	9	1	0	1	0	11
Heart disease and stroke	2	21	2	0	2	27
Respiratory conditions	1	0	11	0	0	12
External causes	0	0	0	22	1	23
Other	0	2	1	0	12	15
Undetermined	6	5	1	3	1	16
Total	18	29	15	26	16	104

On the basis of these results, where we could actually compare reported causes against the GRO-assigned cause, there is some lack of agreement. Since a valid comparison with the general population requires that the tabulated causes be accurate and be based on the same criteria used to categorise the general population deaths, we decided to compare cause-specific mortality in the Travellers to the general population using only the causes in the 126 GRO-confirmed deaths. We do not therefore formally analyse the causes of death in the 62 deaths that do not have a GRO-assigned cause. Our approach assumes that those deaths registered in the GRO are representative of the causes of all Traveller deaths and, for analysis purposes, we scale-up the 126 deaths to the known total death count of 188.

3.5 Death Rates

A mortality rate is calculated as the number of deaths in a particular sex/age group divided by the population in that sex/age group. It is important in analysing mortality to utilise age-specific rates rather than the count of deaths, especially, as in this situation, when the age distributions of populations to be compared are so very different. As already described, all analyses requiring age of death exclude the 6 deaths for which this information was missing.

Confidence limits for rates are based on a Poisson distribution for the number of deaths observed in a particular age-group. Exact Poisson limits were calculated using WINPEPI (Abramson, 2004).

3.5.1 Infant Mortality

For infant mortality calculations we needed deaths under the age of 1 year among live-born babies during our ascertainment period, together with the number of live births over that period. For national figures a separate count is taken of annual births, but we had no direct count of Traveller births for the year in question. We estimated Traveller births in the year prior to the Traveller census by taking the live population aged 0-1 years of age in the AITHS 2008 census (837 children) and adding on the number of infant deaths in the year (12 infant deaths). This gave us an estimate of 849 live births in ROI. We then calculated the infant mortality rate (IMR) as 12/849 = 14.1 per 1,000.

3.6 Standardised Mortality Ratios

Using crude mortality rates to compare the mortality experience of 2 or more populations with different age and sex structures can be misleading because mortality rates are affected by the age/sex distribution of a population as well as by its overall 'health'. Comparing age-specific rates between populations overcomes this problem, but involves a large number of comparisons. Ideally we would like a single number to compare between populations that took account of age and sex. Such a measure would reflect the real 'health' differences between populations that might be amenable to interventions. Age and sex are non-modifiable, and differences between populations due solely to age/sex distribution effects have no policy implications. Differences in health status between populations that are adjusted for age and sex effects can guide policies that address health inequalities.

A measure that adjusts for age and sex is called a standardised measure and one method of standardising mortality rates is to use what is called indirect standardisation. Indirect standardisation applies a set of age-specific mortality rates from a standard population to the age- specific number of persons in the study population. This gives an estimate of the number of deaths expected if the study population had experienced the same age specific mortality rates of the standard population. Standardised mortality ratios (SMRs) are calculated from the observed and expected number of deaths. This is usually done separately for males and females:

SMR = Observed deaths X 100 / Expected deaths

If the SMR for a population is greater than 100, mortality is higher in that population than in the standard (adjusted for age); if the SMR is less than 100, the mortality is lower than in the standard. The standard population itself has an SMR of 100.

Another way to compare the observed and expected number of deaths is by subtracting one from the other. This gives the Excess Deaths, which is a more direct measure of the impact of mortality differences:

Excess deaths = Observed deaths – Expected deaths.

(This assumes that the population of interest has a greater mortality than the standard population; if this is not the case the 'Excess Deaths' will be a negative number.)

The method of indirect standardisation was used to adjust for age differences in order to compare the mortality experience of the Traveller population to that of the general population. The method was also used to compare male and female Traveller mortality. For the general population rates we used deaths in 2008 from the CSO (Central Statistics Office, 2009c) and the 2006 enumerated population (Central Statistics Office, 2007b). Though a number of different population projections are available for 2008, we decided that opting for the well-defined census population was a more robust choice for the standard population.

95% confidence intervals for the SMR were estimated assuming that the deaths count followed a Poisson distribution (Daly and Bourke, 2000) and exact Poisson limits were calculated using WINPEPI (Abramson, 2004). The SMR is statistically significant at the 5% level if the 95% confidence interval does not include 100 (the SMR of the standard population).

To test if there is a statistically significant difference between two SMRs (as opposed to the comparison with the reference SMR of 100) we can perform a specific significance test. We have used the method described and implemented by Abramson (2004). A handy rule of thumb is to examine the two component 95% confidence intervals. If the 2 confidence intervals do **not** overlap we can declare a statistically significant finding. When 2 intervals **do** overlap however the difference may still be statistically significant, and the formal significance test has to be performed.

A different set of SMRs was produced for each type of comparison using the appropriate standard set of age-specific rates:

Comparison of male and female Traveller mortality in 2008:
Using total (male and female) 2008 ROI general population mortality rates as a standard, we calculated SMRs for the male and for the female 2008 Traveller populations. This allowed a comparison between male and female Traveller mortality without correcting for male/female differences in the general population.

Comparison of Traveller mortality with the general population
In order to compare the mortality experience of male and female Travellers in 2008 to that of their counterparts in the general population in the same year, we used the male ROI general population mortality rates and female ROI general population mortality rates as separate standards for male Traveller deaths and female Traveller deaths respectively.

Changes in the mortality gap over time
Using the results of the first Traveller Census and mortality studies in 1987 (Barry and Daly 1988; Barry *et al.*, 1989), and the population estimates and deaths for the general population in 1987, we calculated sex-specific SMRs for the 1987 Traveller population and the 1987 general population using the appropriate male or female 2008 ROI general population as a source of standard rates.

SMRs for cause

As discussed earlier we confined our cause-specific analyses to those 126 deaths for which we had GRO-assigned causes. However to allow for the fact that we actually had 188 deaths we scaled up the observed sex-specific deaths by cause to a total of 124 male deaths or 64 female deaths. Thus for instance where we actually had 15 male GRO-assigned causes of death due to cancer out of a total of 85 male GRO deaths (15/85 = 17.6%), we analysed cancer as 17.6% of the 124 total male deaths or as 21.9 'observed' male cancer deaths. This explains the fractional 'observed' deaths in some of the tables. Confidence intervals are based on the Poisson distribution for the actual number of deaths observed and the limits were scaled up in the same way as the actual number of deaths.

SMRs for Social Class

The definitions of social class are discussed in the next section but it is relevant here that social class is only defined in Irish tabulations for those aged 15 years or over. In comparing Traveller mortality with social class groups from the general population, we confined ourselves to deaths at age 15 years or over.

3.7 Social Class

As we described in the last sub-section we compared Traveller mortality with that of the entire general population using SMRs. To put Traveller mortality in context we also compared the experience of Travellers with that of lower socio-economic groups in ROI. Our calculations come with a proviso however and we outline below some of the issues with this analysis.

In the Irish context of official statistics there are a number of different definitions of a variable related to occupation or what is often broadly called social class. Two scales are currently in use for tabulating census data: (1) The Socio-economic group (SEG) scale and the (2) the Social Class (SC) scale. Both scales are based on occupation and the classifications aim to bring together 'persons with similar social and economic statuses' and are described in Volume 8 of the Population Census Report (Central Statistics Office, 2007d). The SEG scale is nominal and does not provide a direct ranking of groups in order of socio-economic importance. The SC scale is ordinal. Table 3.8 gives the descriptions assigned to the SEG scale categories.

Table 3.8: Irish Socio-economic group scale definitions

Irish Socio-economic Group (SEG) Scale (used in the Irish Census)	Irish Socio-economic Group Scale (used for classifying deaths)
A Employers and managers	0. Farmers
B Higher professional	1. Farm Labourers
C Lower professional	2. Higher Professionals
D Non-manual	3. Lower Professionals
E Manual skilled	4. Employers and Managers
F Semi-skilled	5. Salaried employees
G Unskilled	6. Non-manual wage earners
H Own account workers	7. Other non-manual wage earners
I Farmers	8. Skilled manual workers
J Agricultural workers	9. Semi-skilled manual workers
Z All others gainfully occupied and unknown	10. Unskilled manual workers

The original UK Social Class categorisation (I to V) was developed as an ordinal scale and was employed to analyse mortality gradients. The Irish SC scale is broadly similar to that in the UK. Unfortunately, however, mortality data in ROI are not coded to the SC scale used in the census but to a SEG scale similar but not identical to the census SEG scale. The two SEG scales are compared in Table 3.8.

Coding of mortality data to SEG is much more difficult than coding census data. The census coding is based on occupation and employment status, which is clearly ascertained in the detailed census questions. Coding of mortality data is based on the possibly imprecise reporting of the occupation of the deceased by a relative or whoever officially registers the death. A large percentage is classified as 'unknown' and the coding practices differ between the Census and mortality statisticians (Balanda and Wilde, 2001). These difficulties are well-known and are discussed elsewhere in detail (O'Shea, 2002; O'Shea and Kelleher, 2001; Balanda and Wilde, 2001).

For these reasons analysis of mortality by SEG in the Irish situation is limited in scope. Notwithstanding these difficulties we decided to compare Traveller mortality with two groups in the general population of low and high socio-economic group individuals using a similar approach to that used by the Institute of Public Health (Balanda and Wilde, 2001). We created a 'Low SEG' category by combining the categories 'Semi-skilled', 'Unskilled' and 'Agricultural workers'. These 3 categories are defined similarly in both the census and the mortality datasets and thus general population rates can be estimated. All others were classified into a 'High SEG'. SMRs for these groups were calculated and compared with SMRs for Travellers (in those aged 15 years and over).

3.8 Life Expectancy

Life expectancy is an age-standardised summary measure of mortality. It is based on applying the observed age-specific mortality rates in a particular year to a hypothetical cohort as it ages. It results in a measure of the average number of years expected to be lived by a person of any particular age.

Abridged period life tables were used to estimate life expectancy at birth for male and female Travellers in the Republic of Ireland. Abridged means that 5-year age groups were used (except for the first age group which was one year wide and the second group which was 4 years wide). The open ended group was 85 years and over. The age specific mortality rate input into the life tables was calculated using the estimated Traveller population by age and sex as denominator. The proportion of time contributed by deaths occurring in the first year of life and deaths in the age group 1-4 was estimated using the Coale and Demeney method (Preston *et al.*, 2000).

4. Mortality Results

This section considers the mortality of Travellers from a number of different points of view. The methodology underlying our approach was described in Section 3 and we concentrate here on results. We have tried where possible to present our findings in a comprehensible manner, and have given broad descriptions of some of the measures we have used. These repeat in a more accessible form some of the detailed material in the previous section and it should be possible to read this section of the report without reading Section 3.

In Section 3 we also considered carefully the reliability of the data. The General Register Office (GRO) is the repository of all registered deaths and is the source giving rise to the annual vital statistics report for mortality in ROI. We have used the registered information that was available for 126 of the 188 Traveller deaths. We were unable to trace information in the GRO for 62 Traveller deaths and had to rely on the reported data only.

We consider that our count of Traveller deaths does not include any non-Travellers, and if it is biased, it is because we may have missed some deaths in the community. We believe that our figures represent a true reflection of the mortality experienced by Travellers, or at worst are an underestimate of the true situation. We are confident that the reported ages of death that we had to use are sufficiently accurate, and given that we exclude 6 deaths with missing ages analyses, using ages at death may also underestimate the true situation.

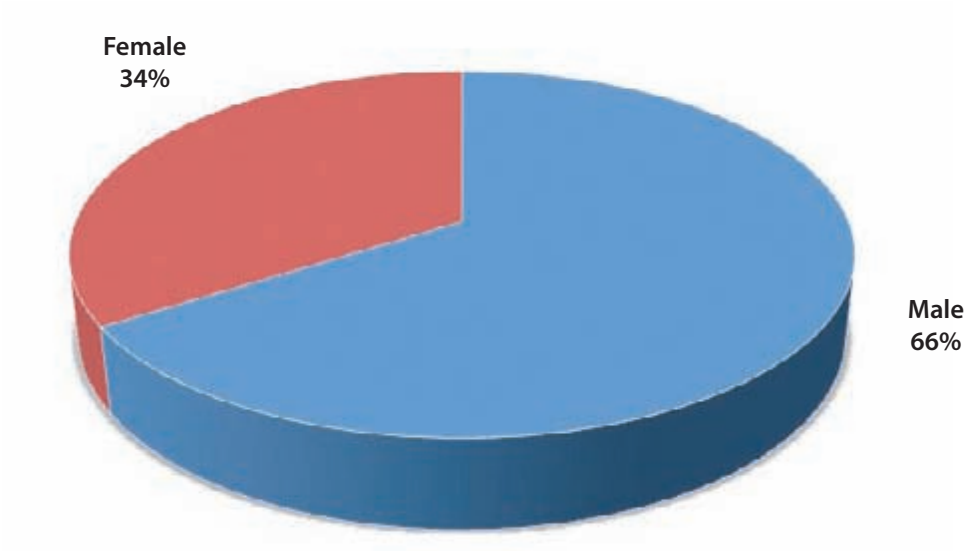
As we described in Section 3 we have some reservations about the reliability of reported causes of death that were not confirmed in the GRO and therefore we base our analysis of cause-specific mortality on the causes determined in the 126 GRO-confirmed deaths (scaled up).

4.1 Distribution of Traveller Deaths in ROI

There were 188 Traveller deaths in ROI in the year preceding the Traveller census of November 2008. We refer to these as Traveller deaths in 2008. They are compared with deaths in the general population for the calendar year of 2008.

The sex distribution of the 188 Traveller deaths is laid out in Figure 4.1 – 66.0% were males (124 deaths). This compares with the general population for 2008 which recorded only 51.1% male deaths (14,413 male deaths out of a total of 28,192). The percentage of male deaths in the 1987 Traveller census was 54.7% (46 out of 84), while in the 'Parish' Study (Brack and Monaghan, 2007) it was 70.0% (144/207 aged 2 years and over). In terms of numbers, male deaths are just under twice as common as female deaths in the Traveller.

Figure 4.1: Gender of ROI Traveller deaths (n = 188)



The next table (Table 4.1) shows the age distribution of the Traveller deaths compared to the general population.

Table 4.1: Age Distribution of Traveller and General Population Deaths in 2008*

Age group(Years)	Traveller Deaths (Number)	Traveller Deaths (%)	General Population Deaths (%)
Less than 1	12	6.59	1.03
1-4	0	0.00	0.16
5-14	3	1.65	0.26
15-24	12	6.59	1.18
25-34	23	12.64	1.65
35-44	20	10.99	2.63
45-54	23	12.64	5.26
55-64	26	14.29	10.34
65-74	31	17.03	17.58
75-84	23	12.64	31.12
85+	9	4.95	28.79
Total	182*	100.00	100.00

* Excluding 6 Traveller deaths with unknown age

Compared to the general population, Travellers are dying younger. In the general population 59.9% of deaths occur in those aged 75 years or over. In the Traveller population only 17.6% of deaths occur above that age. For deaths in those aged 85+ the figures are 28.8% in the general population and 5.0% in Travellers.

Of course Travellers have a much younger age profile than the general population and the more valid comparison is that of death rates (how many deaths per 1,000 persons) in different age groups. Since gender has a large influence on mortality Table 4.2 shows the situation separately for males and females. Apart from the fact that there were no deaths in Travellers in the 1-4 year age group, age-specific death rates are higher for Travellers in each and every age group in both males and females. In every age group Travellers die at a greater rate than in the general population. The excess mortality experienced by Travellers is not confined to a particular age group but is an endemic problem across all ages. What is also apparent is the much higher mortality in males than females. This will be examined in more detail later.

Table 4.2: Age-specific Mortality Rates per 1,000 in Traveller and General Populations 2008*

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

* Excluding 6 Traveller deaths with unknown age

4.2 Infant Mortality in ROI

Infant mortality has classically been considered a good indicator of a population's level of health and development. The infant mortality rate (IMR) is defined as the number of deaths under the age of 1 year in babies who were born alive per 1,000 live births. There were 12 Traveller infant deaths reported to us in ROI for 2008 (actually in the calendar year prior to the census) and we estimated that in that period there were 849 births. This gives a Traveller infant mortality rate of 12/849 or 14.1 per 1,000 live births. Table 4.3 gives the IMRs for the general population in 2008 (Central Statistics Office, 2009c) and the corresponding figures from the 1987 Traveller study.

Table 4.3: Infant mortality rates (per 1000 live births)

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

Infant mortality has fallen among Travellers since 1987, but greater improvements are seen in the general population. In absolute terms the excess infant mortality in Travellers is almost identical now to the figure in 1987. For every 1,000 births, 10 more Traveller babies die in the first year of life than you would expect in the general population, and this has remained so for the past 20 years. Looking at the gap between the Traveller and general population in terms of a relative difference, the situation has deteriorated since 1987. Traveller infants today are 3.6 times more likely to die than infants in the general population. In 1987 when rates were much higher in both groups, Traveller infants were 2.4 times more likely to die than infants in the general population.

4.3 Comparisons with the General Population

4.3.1 What is an SMR?

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

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

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

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

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

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

4.3.2 What is a Confidence Interval?

Because we have only studied Traveller deaths over a one-year period, the number of deaths we have is quite small. If we had studied mortality over 10 years, say, the numbers would be larger and more reliable in percentage or SMR terms. Essentially a confidence interval is a range in which we are fairly sure that the true answer lies. By true answer we mean the actual amount Traveller mortality is greater than that in the population. We use a 95% level of sureness or confidence.

For example the SMR for all Travellers is 348 with a 95% confidence interval of 300 to 402 (see Table 4.4 below). What this means is that in this study carried out in 2008 we found an SMR of 348. In 2008 Travellers had 3.5 times greater mortality than the general population. However if we had done the study in 2007 or 2006 or even last year we would expect to have got a similar answer, but not one exactly the same. All these estimates of the Traveller SMR would be close to the 'true' SMR which in fact we don't know. The confidence interval tells us that the true answer is most likely to be between 300 and 402 (we use 95% as our level of sureness). There is a degree of uncertainty about the SMR we calculated but the confidence interval gives us a range of values where the true answer should be.

If the confidence interval does not include 100 then we can be (95%) sure that the Traveller mortality is in reality greater than that in the general population (which has an SMR of 100), and that our result is not just a chance finding. The finding of a non-chance difference between 2 or more groups is often called a 'statistically significant' result and may be expressed by means of a p-value being less than 5% ($p < 0.05$).

When comparing two SMRs if the two 95% confidence intervals do **not** overlap we can also declare a statistically significant finding. When two intervals **do** overlap the difference may still be statistically significant, and a formal significance test has to be performed (see Section 3.6).

4.3.3 Traveller Mortality Compared to the General Population (2008)

Table 4.4 shows the SMRs for Travellers in 2008 with the expected mortality based on the total (male and female combined) 2008 general population. Male Travellers have a mortality 4.7 times higher than the average general population, and females have a mortality 2.3 times higher. Taking males and female together Irish Travellers in ROI have 3.5 times the mortality of the general population.

Table 4.4: SMRs for Travellers (2008) based on 188 deaths (age-standardized only)

	SMR (2008)	95% CI for SMR
General population (M + F)	100	-
Male Travellers	469	(390-559)
Female Travellers	232	(179-297)
All Travellers	348	(300-402)

This comparison, though it allows a direct contrast of male and female Traveller mortality, does not take account of the fact that in the general population male mortality is higher than female mortality. To compare like with like we should compare Traveller male mortality with the general population male mortality, and Traveller female mortality with the general population female mortality. Table 4.5 gives these results. Female travellers have just over 3 times the mortality of the general population females (SMR=309) and male travellers are 3.7 times higher. In total there were 134 extra deaths (90.7 in males and 43.3 in females) in Travellers in 2008 compared to what would have been the situation if the Travellers had the same mortality experience as the general population.

Table 4.5: SMRs for Travellers (2008) (age- and sex-standardised)

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

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

4.3.4 Traveller Mortality 1987 to 2008

We next compare Traveller mortality now with the situation in 1987. The following table (Table 4.6) and figures (Figures 4.2, 4.3 and 4.4) give the basic results. Though it is possible that the 1987 Traveller study underestimated mortality, the same could be said for our study. In both studies we are confident that the enumerated deaths belonged to the Traveller community, but we cannot be absolutely certain that all Traveller deaths were ascertained. Though the methodologies for the two studies were different the best comparison is through the available data and that is what we have done here.

Table 4.6: SMRs for Travellers 1987 to 2008

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

Figure 4.2: Standardised Mortality Ratios for male Travellers 1987 to 2008

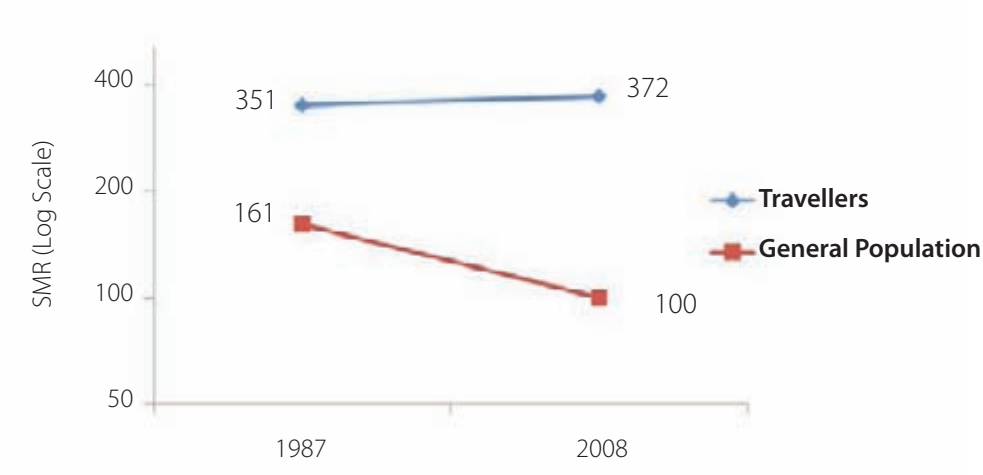


Figure 4.3: Standardised Mortality Ratios for female Travellers 1987 to 2008

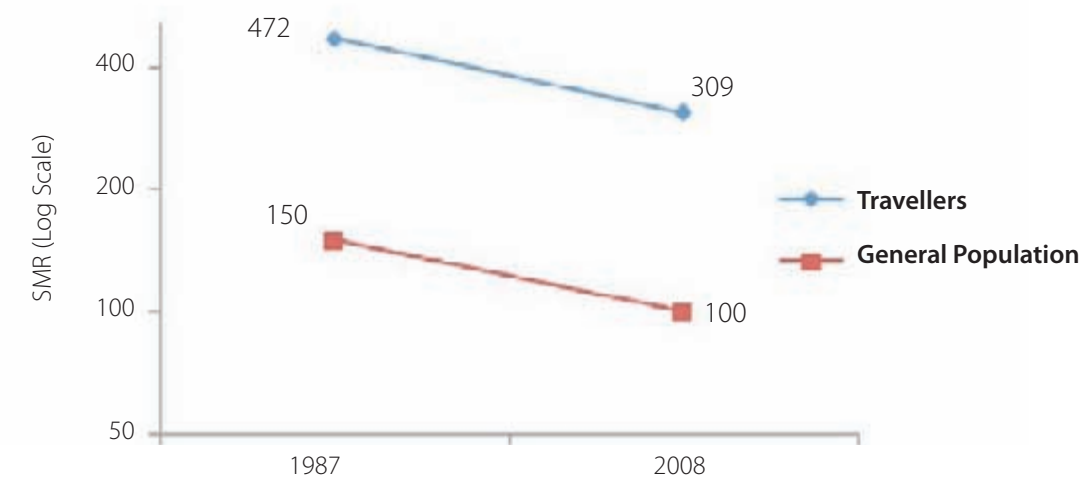
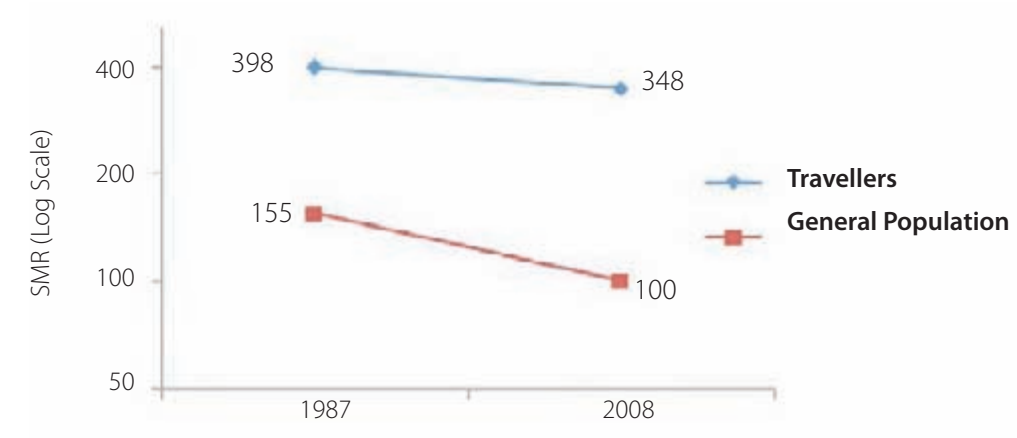


Figure 4.4: Standardised Mortality Ratios for all Travellers 1987 to 2008



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

- Compared to 1987, male Travellers in 2008 have shown no improvement and indeed have a slightly higher mortality (SMR of 372 versus 351).
- This is in the context of there being a major improvement in mortality in the general male population (SMR of 100 in 2008 versus 161 in 1987).
- As a consequence the gap between the Traveller and general populations has widened for males in the past 20 years. Traveller males had a 2.2 times (SMR of 351 divided by 161) higher mortality in 1987 while the figure in 2008 is 3.7 times higher.
- For female Travellers there has been a 35% reduction in mortality since 1987 (SMR of 309 compared to 472).
- This improvement is very slightly larger than the 33% reduction seen in the general female population (SMR of 150 compared to 100), though of course Traveller female mortality remains much higher than in the general population.
- The mortality gap between Travellers and the general population has essentially not changed in females. Female mortality was and is about 3 times higher than in the general population.
- Taking Travellers as a whole, combining males and females, Traveller mortality has fallen over the past 20 years but at a slower rate than in the general population. The mortality gap between Travellers and the general population has widened.

4.3.5 Comparison with High and Low Socio-economic Groups

To put Traveller mortality in 2008 in context, we compared the experience of Travellers with a High and Low socio-economic grouping (SEG) defined on the basis of Irish census data. Details are given in Section 3. Because of the way census data is tabulated, this analysis is confined to deaths aged 15 years or over. Data are based on deaths for which we had a valid age. Table 4.7 gives the basic results.

Table 4.7: Traveller mortality compared to general population SEGs (2008; age 15+ only)

	SMR	95% CI
Total General population (2008)	100	
High SEG	80	(79-81)
Low SEG	232	(227-237)
Travellers	277	(236-322)

In those aged 15 and over the Traveller SMR is 277 compared to 232 in the Irish Low SEG category and 80 in the high SEG category. Note that though the confidence intervals for the 2 SMRs for the Travellers and the Low SEG just overlap, the comparison here is statistically significant at $p = 0.03$ (see Section 4.3.2). There is a significant trend in mortality from High SEG, through Low SEG to the Travellers. This means that the differences are unlikely to be due to chance and Traveller mortality experience is indeed worse than a low socio-economic group in Irish society. Many Travellers of course would be likely to be included in the Low SEG category; this would suggest an even greater difference if we were able to compare Travellers with the Low SEG excluding Traveller.

4.4 Life Expectancy

Life expectancy is a measure of how long a person is likely to live. The figure is given for persons alive at different ages, and for someone of a particular age measures how many more years he or she has to live on average. The following table gives life expectancies for Travellers in 2008 and 1987, and for comparative purposes the corresponding figures for the Irish population. The population figures are taken from the official life tables for 2005-2007 and for 1985-1987 (Central Statistics Office, 2009a).

Table 4.8: Life expectancies 1987 and 2008

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

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

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

4.5 Causes of Death

4.5.1 Description of Causes of Death in Travellers

There were 188 deaths among Travellers in 2008 and 126 of these were confirmed in the GRO and assigned an official cause of death according to the ICD-10 classification. The official cause of death classification for these deaths was obtained directly from the CSO. The remaining 62 deaths have only a reported cause without GRO confirmation of cause of death. Because there were disagreements between the reported causes and the GRO-assigned causes in those deaths for which we had both sources, we decided to analyse cause-specific mortality based on the 126 GRO-confirmed deaths only. This also allowed full comparability with national statistics. We scaled up the 126 deaths to the full complement of 188 deaths. We discuss some issues related to the reported causes also.

We base much of our analyses on the 5 cause of death groupings used in the CSO Annual Vital Statistics reports (see Section 3.4.3). The causes of death in terms of these 5 groups are presented in Table 4.9. A listing of causes is given separately for the 126 deaths with GRO data, and for the 62 deaths for which we have reported causes only. The GRO-assigned cause rather than the reported cause is used for the 126 cases. The distribution of cause of death differs between these two main sources and the full data are given here for completeness. A more detailed breakdown of the GRO deaths is given in Table 4.10. Table 4.11 and Figures 4.5-4.7 give the sex breakdown by the 5 CSO groupings.

Table 4.9: Cause of death in 188 Travellers (2008)

Cause of death	GRO-assigned cause n (%)	Reported cause of death n (%)	All deaths
Cancer	24 (19.1%)	8 (12.9%)	32 (17.0%)
Heart disease and Stroke	32 (25.4%)	16 (25.8%)	48 (25.5%)
Respiratory conditions	16 (12.7%)	3 (4.8%)	19 (10.1%)
External causes of injury and poisoning	34 (27.0%)	17 (27.4%)	51 (27.1%)
All other causes	20 (15.9%)	12 (19.4%)	32 (17.0%)
Unknown	-	6 (9,7%)	6 (3.2%)
All causes	126 (100.0%)	62 (100.0%)	188 (100.0%)

Table 4.10: Causes of death, gender specific, in 126 Travellers with GRO-confirmed deaths (2008)

ICD-10 Code	Cause of death	Male GRO deaths	Female GRO deaths	Total GRO deaths
A00-B99	Certain infectious and parasitic diseases	2	0	2
C00-D48	Neoplasms	15	9	24
D50-D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0	0	0
E00-E90	Endocrine, nutritional and metabolic diseases	1	1	2
F00-F99	Mental and behavioural disorders	0	0	0
G00-H95	Diseases of the nervous system and sense organs	0	1	1
I00-I99	Diseases of the circulatory system	19	13	32
J00-J99	Diseases of the respiratory system	11	5	16
K00-K93	Diseases of the digestive system	5	1	6
L00-L99	Diseases of the skin and subcutaneous tissue	0	0	0
M00-M99	Diseases of the musculoskeletal system and connective tissue	0	1	1
N00-N99	Diseases of the genitourinary system	1	2	3
O00-O99	Pregnancy, childbirth and the puerperium	0	0	0
P00-P96	Certain conditions originating in the perinatal period	1	1	2
Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities	0	0	0
R00-R99	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	2	1	3
V01-Y89	External causes of morbidity and mortality	28	6	34
Total	All Causes	85	41	126

Table 4.11: Causes of death, gender specific, in 126 Travellers with GRO-confirmed deaths (2008)

Cause of death	Male GRO deaths n (%)	Female GRO deaths n (%)	All GRO deaths n (%)
Cancer	15 (17.6 %)	9 (22.0%)	24 (19.0%)
Heart disease and Stroke	19 (22.4%)	13 (31.7%)	32 (25.4%)
Respiratory conditions	11 (12.9%)	5 (12.2%)	16 (12.7%)
External causes of injury and poisoning	28 (32.9%)	6 (14.6%)	34 (27.0%)
All other causes	12 (14.1%)	8 (19.5%)	20 (15.9%)
All causes	85 (100.0%)	41 (100.0%)	126 (100.0%)

Figure 4.5: Causes of GRO-confirmed Traveller deaths: males and females; ROI (n = 126)

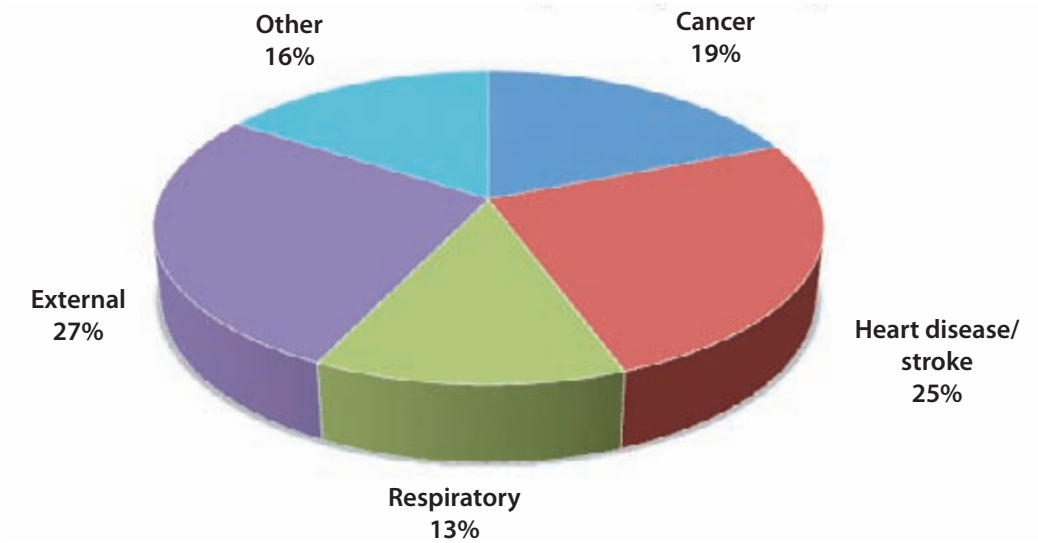


Figure 4.6: Causes of GRO-confirmed Traveller deaths: males; ROI (n = 85)

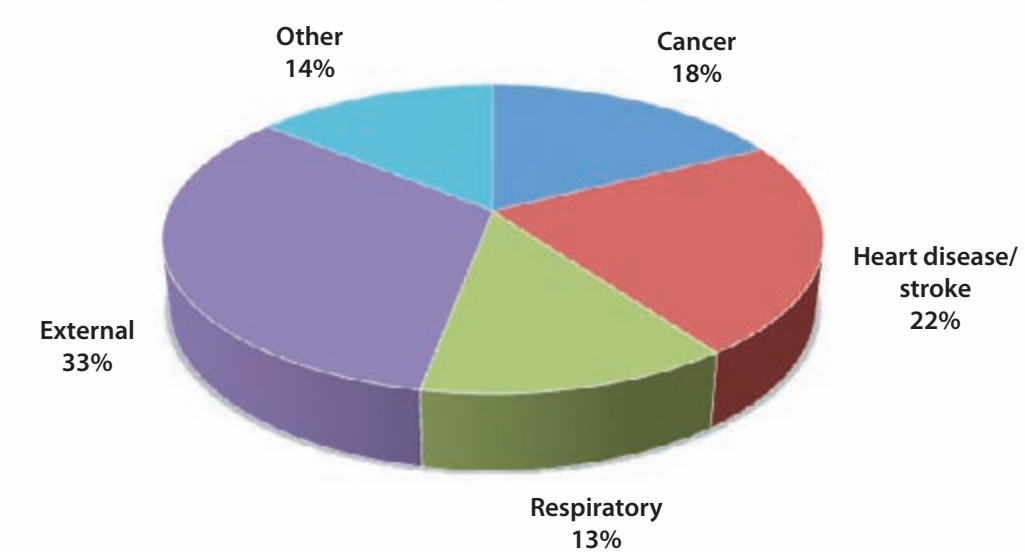
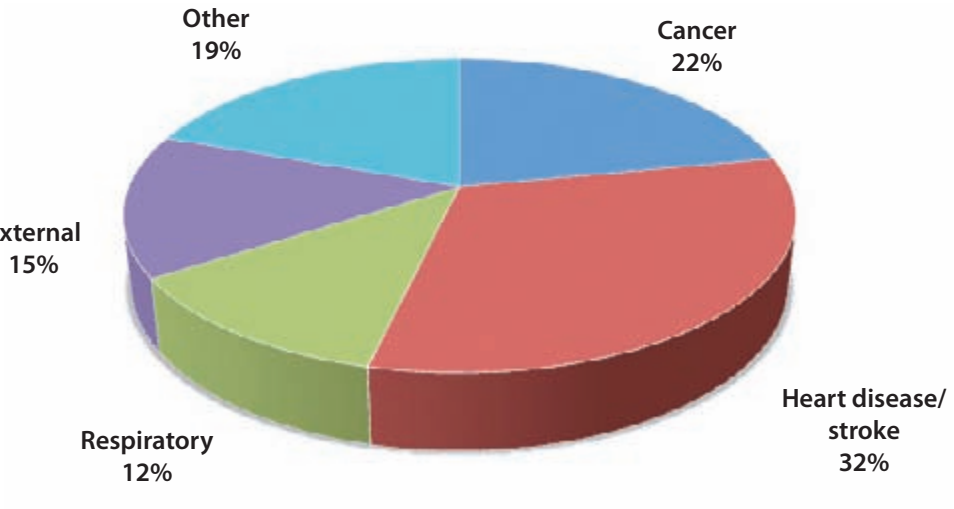


Figure 4.7: Causes of GRO-confirmed Traveller deaths: females; ROI (n = 41)



4.5.2 Cause-specific Mortality Compared to the General Population

As described earlier we compared causes of mortality between the Traveller and general populations based on the 126 deaths for which we had GRO confirmation. To allow for the overall level of mortality, we scaled up these 126 deaths to the total of 188 deaths (separately in males and females), which explains the fractional observed deaths in the tables. The following 2 tables (Tables 4.12 and 4.13) give the cause-specific SMRs for male and female travellers separately.

Table 4.12: Cause-specific mortality in male Travellers (2008) – (GRO-assigned causes, scaled up)

Males	Observed deaths	Expected deaths	SMR	95% C	Excess deaths in male Travellers
Cancer	21.9	9.0	242	(135-399)	12.9
Heart disease and Stroke	27.7	8.2	337	(203-536)	19.5
Respiratory	16.0	2.2	746	(373-1335)	13.8
External causes	40.8	7.5	548	(364-792)	33.3
All other causes	17.5	6.4	271	(140-474)	11.1
All male deaths	124.0	33.3	372	(297-460)	90.7

Table 4.13: Cause-specific mortality in female Travellers (2008) – (GRO-assigned causes, scaled up)

Females	Observed deaths	Expected deaths	SMR	95% CI	Excess deaths in female Travellers
Cancer	14.0	8.0	176	(80-334)	6.0
Heart disease and Stroke	20.3	4.1	489	(261-837)	16.2
Respiratory	7.8	1.5	536	(174-1252)	6.3
External causes	9.4	2.4	393	(144-855)	7.0
All other causes	12.5	4.7	263	(113-517)	7.8
All female deaths	64.0	20.7	309	(221-419)	43.3

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

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

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

4.5.3 Suicide and External Causes of Death

Though, as in the previous section, our final comparison with national vital statistics is based on the 126 GRO-confirmed deaths and the deaths in this group officially coded to suicide, we explore the question of reported suicides among all 188 deaths. Table 4.14 shows the number of GRO-assigned suicides and the number of extra suicides reported to us that were not recorded as such in the GRO office. As previously described in Table 3.1 in Section 3, 22 of the GRO-ascertained deaths had not been reported to us and therefore we only have the GRO-assigned cause of death for them. Table 4.14 breaks down the suicides by the source of the death information.

Table 4.14: Suicides among Travellers in 2008, by source of information

Source of information about the death	Total number of deaths	Number of suicides according to GRO classification	Number of EXTRA suicides reported to us	Suicides as % of all deaths
GRO only (not reported)	22	2	0	2/22 (9.1%)
GRO confirmation of a reported death	104	10*	1	11/104 (10.6%)
Reported deaths without GRO confirmation	62	0	8	8/62 (12.9%)
Total	188	12	9	21/188 (11.2%)

* 9 of these 10 GRO-classified suicides were reported to us as suicides

There was a total of 21 suicides (11.2%) among the 188 traveller deaths. 16 (76.2%) were in males. The proportion of deaths that were suicides differs by the source of the information on the death, ranging from 9% in the deaths opportunistically determined in the GRO without being reported to us, to 13% among those deaths not traceable in the GRO. This slightly higher percentage is likely to be due to coroner's cases which have not yet been released to the GRO.

It is interesting to note that among the deaths reported to us that were also traced in the GRO, 90% (9/10) of the GRO-assigned suicides had been reported to us as suicides. In this group also there was only one suicide reported to us that was not confirmed as such by the GRO. Thus the number of suicides was the same from both sources and it is apparent that the GRO's figures on suicides in Travellers are quite congruent with the numbers reported by the Travellers themselves. However it is possible that some of the suicides reported to us among the non-GRO-confirmed deaths may be coroner's cases and will eventually be registered with the GRO. This means that our decision, to base results on the GRO-confirmed deaths only, may have resulted in an underestimate of the proportion of suicides in the Traveller population. Thus the true rate of suicide among Travellers could be higher than the figure given here. An underestimate, such as this, is always preferable to an overestimate; the latter, presenting what may be a falsely bleak view of the situation, can always be dismissed because it may be an exaggeration. In the current instance the actual situation may be worse than we have described and cannot be played down.

Confining analysis to the GRO-classified causes of death, Table 4.15 shows the distribution of the mode of death in external causes. There is always a worry that alcohol or drug overdoses (comprising nearly half the male external-cause deaths) could be actually suicides though of course it is impossible to know. In the 12 GRO-confirmed suicides, 10 were by hanging and there was one drowning and one overdose.

Table 4.15: Mode of death among external causes of death in 126 GRO-confirmed deaths

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

Scaling up the 12 GRO-classified suicides to the total of 188 deaths, Table 4.16 shows how the suicide rates in Travellers compare with the general population.

Table 4.16: SMRs and excess deaths from suicide in Travellers – scaled up (2008)

	Observed suicides	Expected suicides	SMR	95% CI	Excess suicides in Travellers
Males	14.6	2.2	660	(316-1214)	12.4
Females	3.1	0.6	489	(59-1764)	2.5

The suicide rate in male Travellers is a statistically significant 6.6 times higher than in the general population. The female suicide rate is also higher but not at a statistically significant level.

We are taking for this report the number of suicides as the scaled-up GRO-confirmed suicides, which is 17.7. If all reported suicides were used the figure would instead be 21 (see Table 4.14). These correspond to crude suicide rates per 10,000 persons in ROI of 4.8 (GRO-confirmed data) or 5.8 (reported suicides). The study of suicides in Travellers 2000-2006 (Walker, 2008) gave a crude annual rate averaged over the period of 3.7 per 10,000, ranging from a low of 1.75 per 10,000 in 2002 to a high of 5.44 per 10,000 in 2005. This study used reported suicides and our estimate of 5.8 per 10,000 reported suicides for 2008 suggests an increasing trend.

5. Conclusions

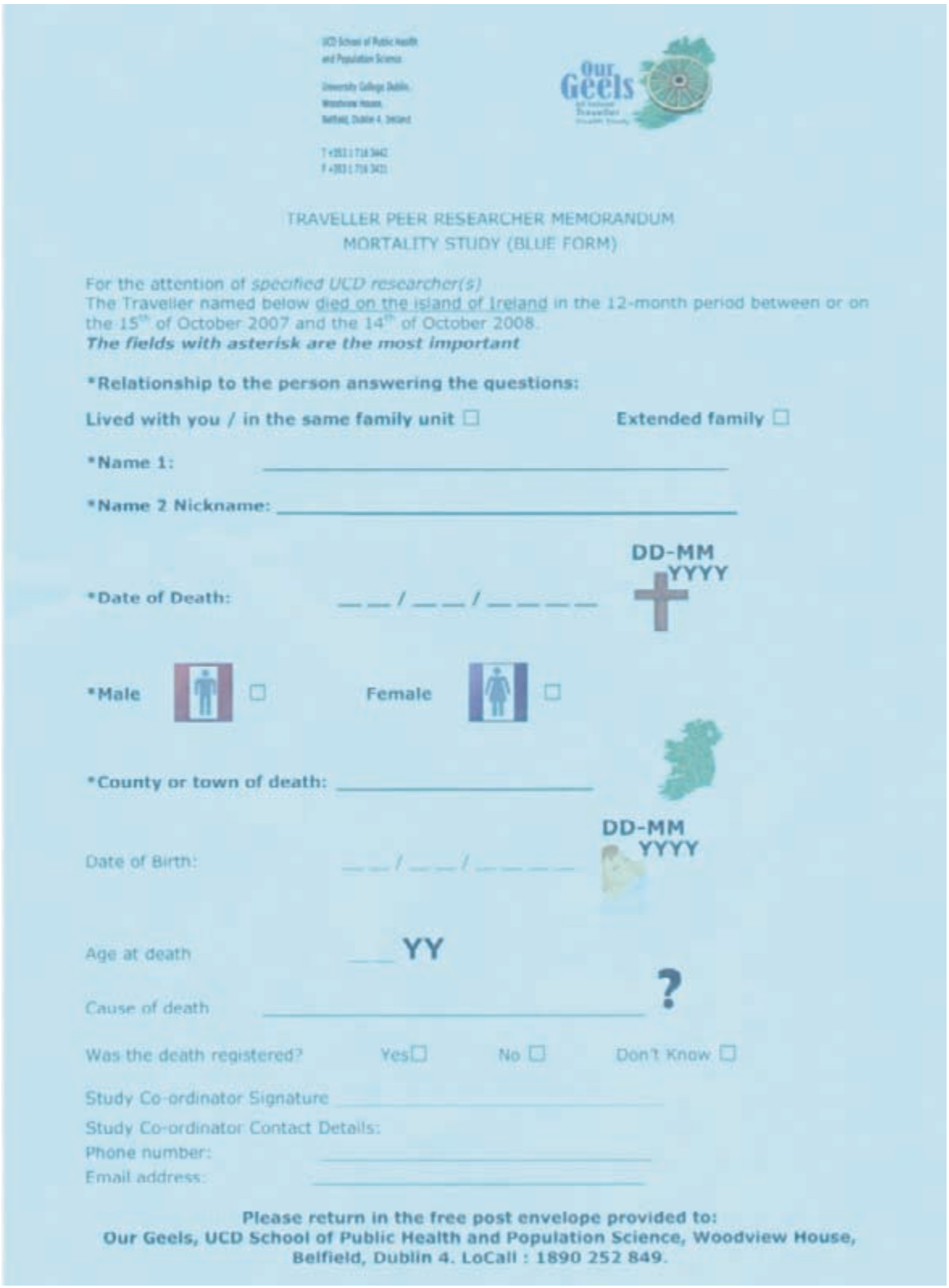
The following table summarises and illustrates just how disadvantaged the Traveller community is in 2008 in regard to mortality. The figures speak for themselves.

Table 5.1: Comparison of Traveller mortality in ROI with that of the general population

		Traveller population 2008	General population value or expected value
Proportion of population aged < 25 years		63%	35%
Proportion of population aged 65+ years		3%	13%
Infant mortality rate (per 1,000 live births)		14.1	3.9
Number of Traveller deaths		188	54
Excess deaths		134	0
All-cause SMR	(Males)	372	100
	(Females)	309	100
Life expectancy at birth	(Males)	61.7 yrs	76.8 yrs
	(Females)	70.1 yrs	81.6 yrs
Change in life expectancy since 1987	(Males)	0 yrs	+5.2 yrs
	(Females)	+4.8 yrs	+4.4 yrs
External cause SMR	(Males)	548	100
	(Females)	393	100
Respiratory disease SMR	(Males)	746	100
	(Females)	536	100
Heart disease and Stroke SMR	(Males)	337	100
	(Females)	489	100
Suicide SMR	(Males)	660	100
	(Females)	489	100

6. Appendix A

The Blue Mortality Form
(Filled in as Part of the Census)



TRAVELLER PEER RESEARCHER MEMORANDUM
MORTALITY STUDY (BLUE FORM)

For the attention of *specified UCD researcher(s)*
The Traveller named below died on the island of Ireland in the 12-month period between or on the 15th of October 2007 and the 14th of October 2008.
The fields with asterisk are the most important

***Relationship to the person answering the questions:**

Lived with you / in the same family unit ☐ **Extended family** ☐

***Name 1:** _____

***Name 2 Nickname:** _____

***Date of Death:** __ __ / __ __ / __ __ __ __ **DD-MM YYYY**

***Male** ☐ **Female** ☐

***County or town of death:** _____

Date of Birth: __ __ / __ __ / __ __ __ __ **DD-MM YYYY**

Age at death ____ **YY**

Cause of death _____ **?**

Was the death registered? Yes☐ No ☐ Don't Know ☐

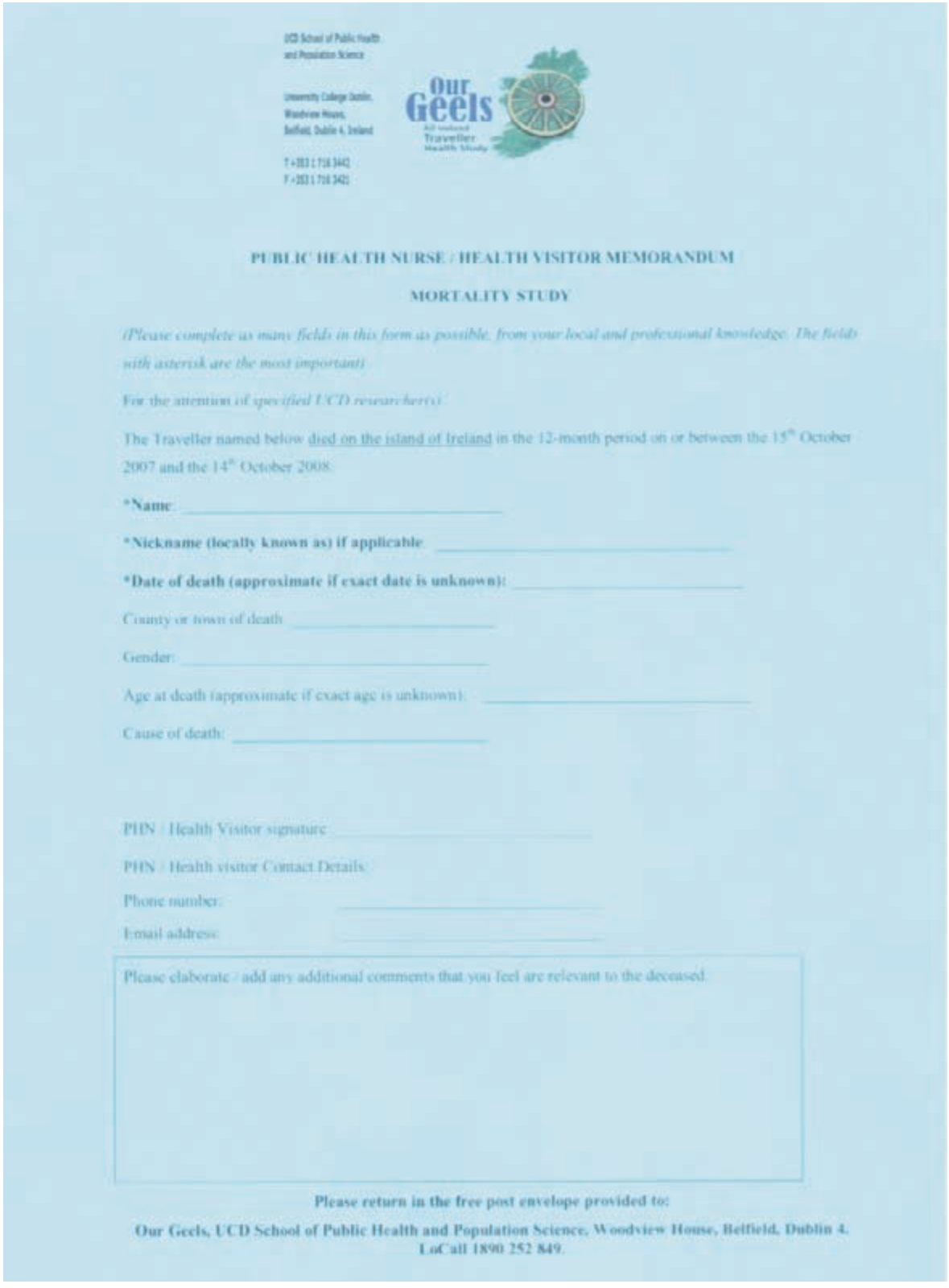
Study Co-ordinator Signature _____

Study Co-ordinator Contact Details:
Phone number: _____
Email address: _____

Please return in the free post envelope provided to:
Our Geels, UCD School of Public Health and Population Science, Woodview House, Belfield, Dublin 4. LoCall : 1890 252 849.

7. Appendix B

Mortality Form Used by Health Professionals



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Our Geels
All Ireland Traveller Health Study

PUBLIC HEALTH NURSE / HEALTH VISITOR MEMORANDUM

MORTALITY STUDY

(Please complete as many fields in this form as possible, from your local and professional knowledge. The fields with asterisk are the most important)

For the attention of specified UCD researcher(s)

The Traveller named below died on the island of Ireland in the 12-month period on or between the 15th October 2007 and the 14th October 2008.

***Name:** _____

***Nickname (locally known as) if applicable:** _____

***Date of death (approximate if exact date is unknown):** _____

County or town of death: _____

Gender: _____

Age at death (approximate if exact age is unknown): _____

Cause of death: _____

PHN / Health Visitor signature: _____

PHN / Health visitor Contact Details:

Phone number: _____

Email address: _____

Please elaborate / add any additional comments that you feel are relevant to the deceased.

Please return in the free post envelope provided to:

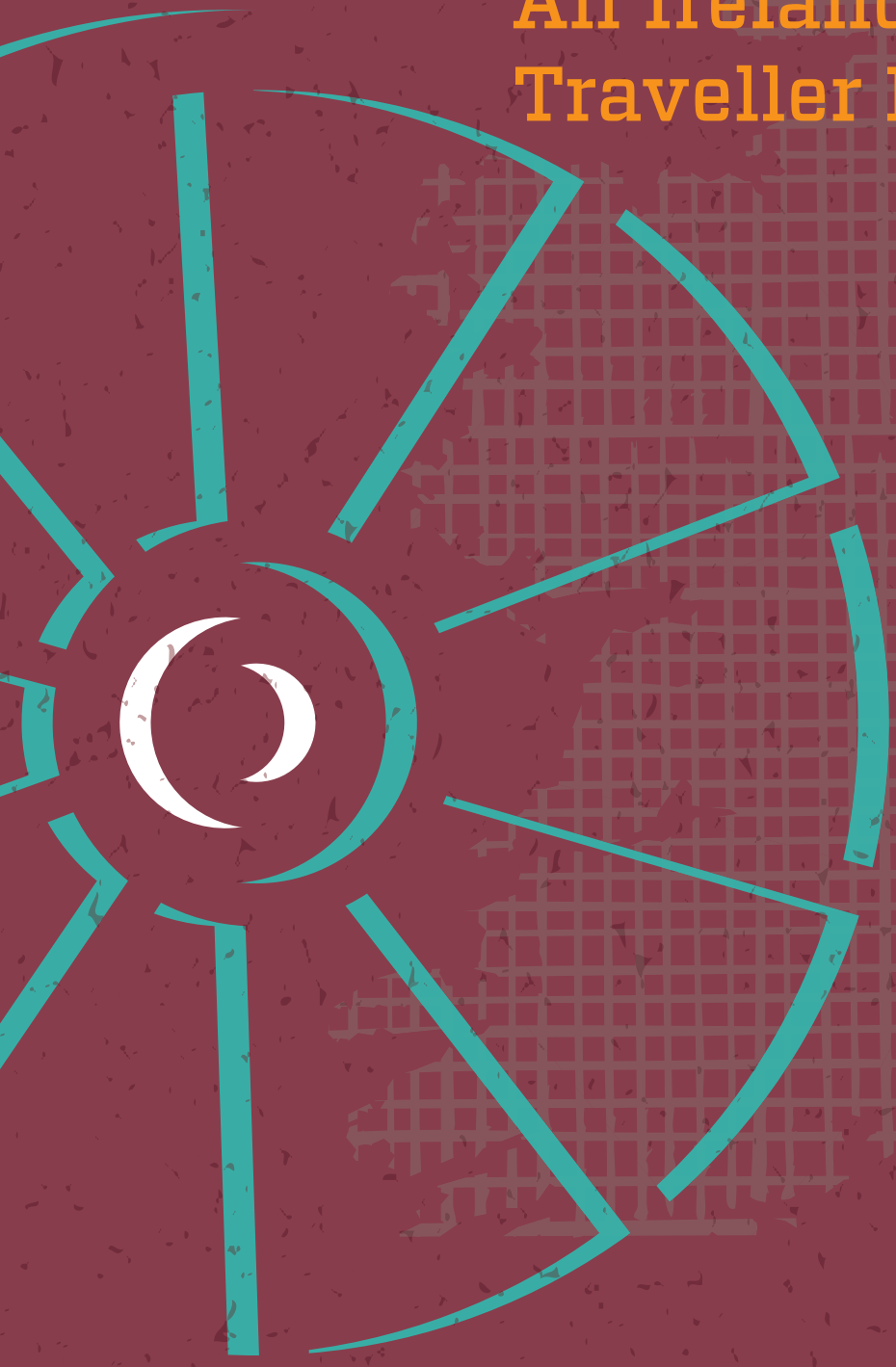
Our Geels, UCD School of Public Health and Population Science, Woodview House, Belfield, Dublin 4.
LoCall 1890 252 849.

Department of
Health, Social Services
and Public Safety

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

All Ireland Traveller Health Study

Our Geels



The Birth Cohort Study

All Ireland Traveller Health Study

The Birth Cohort Study
Part B of Technical Report 2

September 2010

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Summary

The birth cohort study is a longitudinal study of Traveller babies born on the island of Ireland over a 1-year period. This follow up study is ongoing and will end on 13th October, 2010. The study captures the health status, immunisation uptake, developmental milestones, health services use and health needs of Traveller babies in their first year of life. However, as the birth cohort study is still ongoing, this interim report only provides some results up to the period June 2010. Complete results will be available after the cohort has ended.

From our estimates and the birth cohort study data, there are approximately 1,000-1,400 births to the Irish Travellers per annum. There are more male babies born, which mirrors that of the general population both in ROI and NI. Traveller mothers are relatively young compared to the general population.

The annual crude birth rate of Irish Travellers has fallen compared to 1986 but is relatively still higher than the general population. This gap however has decreased. The general fertility rate and total fertility rate have also decreased. However, the annual crude birth rate, general fertility rate and total fertility rate for ROI Travellers are higher compared to NI.

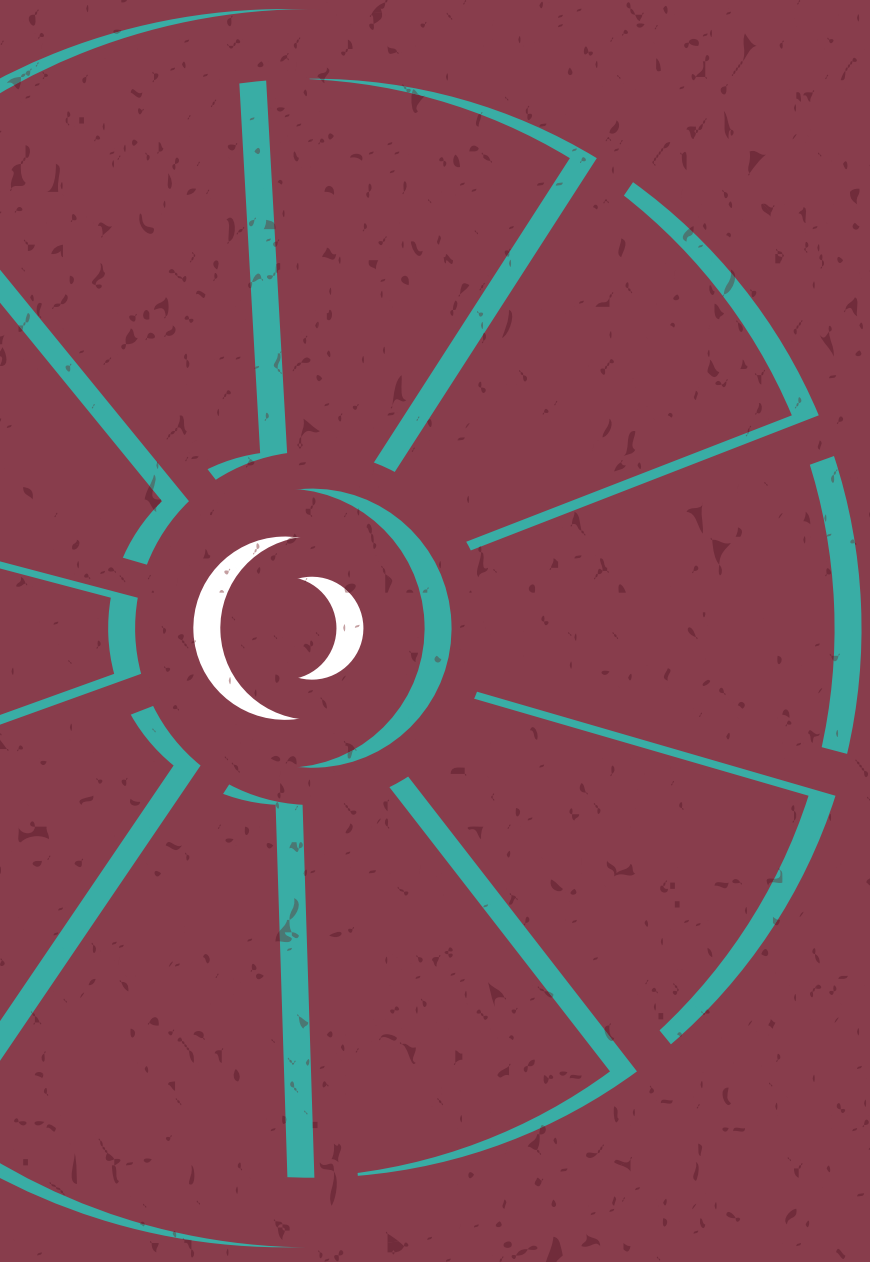
There are many challenges involved in conducting cohort studies, especially one involving a marginalised, minority group. A culturally sensitive approach needed to be taken throughout.

Table of Contents

List of Tables

List of Figures

The Birth Cohort Study



1. Introduction

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

This report describes the methodology for the birth cohort study followed by the estimates of Traveller births in a year. Next it describes the profile of the birth cohort study to date and the fertility indicators. Section 6 describes some of the challenges faced by the study so far.

2. Study Methodology

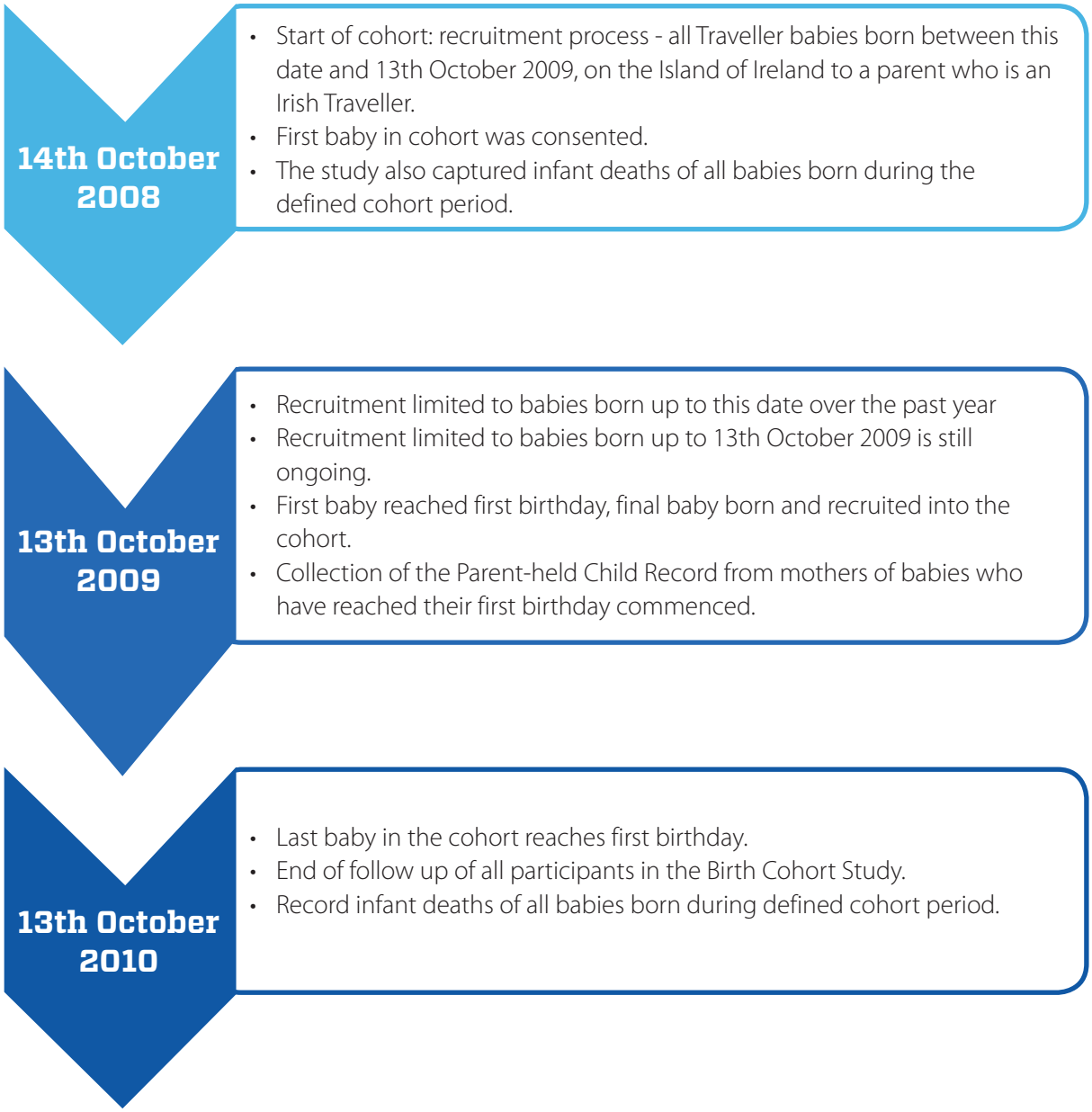
The birth cohort study is a study of Traveller babies born between 14th October, 2008 and 13th October, 2009, with babies followed up for 1 year (Figure 1). First-wave data collection ends on 13th October, 2010. This methodology section describes the procedures and components of the birth cohort study.

2.1 Study Participants

All Traveller mothers whose babies met the criteria below were invited to participate in the study. The inclusion criteria included:

- Traveller babies born on the island of Ireland;
- Traveller babies born between 14th October, 2008 and 13th October, 2009;
- Traveller babies with a parent who self-identifies as an Irish Traveller.

Figure 1: Time scale for the birth cohort study processes



2.2 Study Team Membership

The multidisciplinary study team membership is outlined in Table 1. Due to structural and organisational differences in NI, the team membership is slightly different there.

Table 1: Membership and function in the birth cohort study team

Function	Republic of Ireland	Northern Ireland
Main study coordinator	All Ireland Traveller Health Study team, UCD	All Ireland Traveller Health Study team, UCD
Consent	Public Health Nurses	AITHS main study coordinator for Northern Ireland
Study promotion and participant identification	Public Health Nurses Traveller health projects - project coordinators Traveller Community Health Workers (TCHW)	Health Visitors Traveller projects

This varied team membership and the scale of the study demanded a solid structure for the study. This included both the communication structure and the study coordination. The main study team in UCD was the hub in communication delivery, provided a central support system to standardise the study methodology and acted as the main communication source for all the other members. It was also important that when procedures were modified according to the needs of the study that these were communicated effectively to all the members.

2.3 Study Network and Communication Structure

The study required communication between UCD, the Traveller health projects and the Public Health Nurses (PHNs)/ Health Visitors (HVs). The study coordinators are the coordinators for the Traveller health projects across Ireland, and also act as the main person responsible at a local level for the All Ireland Traveller Health Study (AITHS) and coordinate the peer researchers.

Like the study coordinators, Local Health Office (LHO) areas elected a representative as the main PHN liaising with the study team in UCD. The elected representative usually held the position of Assistant Director of Public Health Nursing. In certain areas, this was the Director of Public Health Nursing, the Traveller Health Unit Coordinator or the Designated Traveller Public Health Nurse. The main person linked to the study team was known as the 'link-PHN'. There were 32 link-PHNs involved in the study. However, as the study progressed, extra link-PHNs were included due the geographical limitations and the amount of work which needed to be handled by each link-PHN.

In Northern Ireland (NI), a similar structure was employed; each of the 5 Trusts elected a dedicated Health Visitor (HV) as the link person involved for the study and a study Principal Investigator (PI). In most circumstances, the link-HV was the PI for the study. The role of the HVs in NI was slightly different than the role the PHNs in ROI. HVs were required to promote and then inform the main study coordinator in NI of any Traveller mothers who had verbally agreed to be formally consented. The link-HVs still form the main link between the study team and the HVs within their Trusts.

The Traveller project networks in some parts of NI were not as well established as many of those in ROI. In some circumstances, temporary projects were set up to aid the AITHS census. Thus the communication structure was mostly informal between the main study coordinator and local Traveller contacts.

For the purpose of participant protection and analysis, the data has been aggregated by Traveller Health Unit (THU) in ROI while for Northern Ireland it was aggregated for the whole of NI.

2.4 Study Promotion

PHNs, HVs, TCHWs and study coordinators formed the main group of health workers promoting the study to Traveller women. This was done using study leaflets and more importantly oral promotion. Radio, DVD and media were used for the AITHS census promotion and this included the birth cohort study.

2.5 Recruitment Strategy

The recruitment of participants was a 2-phase process.

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

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

Due to the lack of an ethnic identifier, PHNs and HVs used their local knowledge and other local registers to ensure all Traveller births were identified. These included the National Metabolic Screening register (ROI) and Birth Notification register. Both registers were not Traveller specific, thus potential participant recognition was based on local knowledge. Traveller health projects were also invaluable as a resource in potential participant identification. However, these projects were limited to certain areas.

2.6 Consenting Process

Each PHN who was ready to consent a potential participant was given a consenting pack. Included in this pack was a Parent-held Child Record (Figure 2). The participating mother carried this recording diary with her for a full year. When a Traveller mother consented to participate in the study, she also consented for linkage data to her maternity hospital record. However, the mother can waive the consent to hospital record access and still participate in the actual cohort.

2.7 Refusals

Enrolment into the study was as per ethical approval of the protocols in ROI and NI. If a mother refused, the PHNs informed UCD and gave a reason for the refusal. However, the PHNs re-promote the study on an ongoing basis. If a previously refused mother changed her mind, then the PHN followed the consenting procedure and informed UCD of this change. UCD then proceeded to remove a refusal and add the consent to the specified group. This allowed an accurate count of Traveller births in the LHO area.

2.8 Data

Data for the birth cohort study comes from 3 sources:

1. The consent form
2. The Parent-held Child Record (Figure 2)
3. Birth Notification forms- linkage data from the maternity hospitals.

Figure 2: The Parent-held Child Record used in the birth cohort study

Picture 1: (left) Margaret and baby Thomas (at 6 months old), one of the first babies in the birth cohort study with the team in Laois.

Picture 2 (left) Margaret and baby Thomas (at 1 year old on 14th October 2009). This later picture was taken with the team in Tallaght. The involvement of PHNs and Traveller Health projects is essential for the study. Also in picture are Freda and baby Johnny from Tallaght who are also participating in the birth cohort study. Far right is baby Thomas's elder brother, Johnny.

3. Population Birth Estimates

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

Estimate 1 was based on the Irish Census 2006 (CSO, 2007a) while estimate 2 was based on the 1986 Travellers' Health Status Study (Barry *et al.*, 1988) and the 2005 Vital Statistics Report (Department of Health and Children, 2006). In addition, the All Ireland Traveller Health Study 2008 provided the latest up-to-date census data on the Traveller population and was fully utilised to ensure that the birth cohort study captured the real number of Traveller births (Table 2). Detailed calculation methods and discussion on estimates are provided in Appendix A.

Table 2: Estimated number of Traveller births using different data sources

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

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

4. Preliminary Findings: the Birth Cohort Profile (June 2010)

As the birth cohort study is ongoing, the study can only profile some provisional results based on available data. It should be cautioned that results shown here are not final.

4.1 Pregnant Women Identified During Census

During the AITHS census, there were 670 women identified as being pregnant in ROI and 42 in NI. Of the 670 in ROI, 136 (20.3%) verbally consented for formal consent by the PHNs. 124 (18.5%) officially consented for the study. For NI, the AITHS census team did not ask for verbal consent due to delay in entering the field.

4.2 Study Ascertainment and Geographical Distribution of Births

980 live births were identified by the PHNs and HVs for the island of Ireland. Of these, 502 (51.2%) consented to the study. There were 465 (47.4%) refusals. There are 13 (1.3%) mothers who still have 'to be approached' in NI.

For ROI, there were 913 live births with 468 (51.2%) consented, while in NI there were 67 live births identified with 34 (50.7%) consented, 20 (29.9%) refusals and 13 (19.4%) 'to be approached' for consent. This is further detailed by region in Table 3. It should be noted that the consenting process is ongoing until the end of cohort on 13th October, 2010.

Table 3: The birth cohort study number of consents, refusals and 'to be approached' by regions

Region	The birth cohort study			
	Consents	Refusals	To be approached	Total
Republic of Ireland (THU)				
Eastern	138	81	0	219
Midland	48	38	0	86
Mid-Western	68	75	0	143
North Eastern	18	21	0	39
North Western	27	11	0	38
South Eastern	62	33	0	95
Southern	19	65	0	84
Western	84	112	0	196
Unknown	4	9	0	13
Total	468	445	0	913
Northern Ireland (Health and Social Care Trust)				
Belfast	8	1	0	9
Northern	0	1	0	1
Southern	16	13	5	34
South Eastern	5	1	0	6
Western	5	4	8	17
Total	34	20	13	67

'To be approached' status was included due to the time and geographical limitation in approaching the potential participants in Northern Ireland. This was due to the methodology and ethical requirement in NI. At the time of writing this report, the study team is still actively approaching these mothers for participation in the cohort.

The study's boundary was based on the administrative boundary of the Health Service Executive's LHO areas in ROI and Health and Social Care Trusts in NI. However, for the purpose of this report, data has been aggregated according to Traveller Health Units (THUs) and Northern Ireland (NI). Some of the analysis cannot be performed according to areas due to the small population size.

4.3 Refusals

To date, the refusal rates were 48.8% in the Republic of Ireland and 29.9% in Northern Ireland. Reasons for refusals are given in Table 4.

Table 4: Reasons given for refusal to participate in the birth cohort study

Reasons	n	%
No reason given	355	76.4%
Stress: baby in hospital, or families disputes	34	7.3%
No interest	20	4.2%
Left address/Travel out of country	15	3.3%
Partner refused	12	2.6%
Fear of being known to community	11	2.4%
Too much hassle	9	2.0%
Study makes no difference to Traveller health	9	2.0%
Total	465	100%

The majority of women who declined to participate in the study gave no reason for refusals (76.4%). 7.3% cited stress from the baby being in hospital or due to family disputes. 3.3% of the Traveller families left their residences before the PHNs, HVs or main study coordinator were able to approach the mothers for formal consent. Small percentages refused due to partner refusal, fear of their details being known due to the small community size or because they felt the study will not make any difference to Traveller health.

4.4 Number of Births

As of June 2010, there were 980 Traveller births identified on the island of Ireland for the period 14th October, 2008 to 13th October, 2009.

Of the 980 births, there were 7 twin pregnancies and 966 singleton pregnancies. There were 5 sets of twins included in the cohort. In this cohort, there were 257 (51.2%) male babies and 245 (48.8%) female babies. Based on this data, it was estimated that there were 502 male babies and 478 female babies born to the Traveller community on the whole island of Ireland. This was similar to the sex distribution for the Irish population (51.4% male babies in ROI and 51.5% male babies in NI) (Central Statistics Office, 2008; Northern Ireland Statistics and Research Agency, 2008).

There were 10 births that were classified as 'non-identifier' in the ROI. These were births the mothers of which do not identify themselves as Travellers. A further 13 cases were identified as Irish Travellers who gave birth outside the island of Ireland, thus do not meet the eligibility criteria of the cohort. Out of these 13, 9 subsequently resided in ROI and 4 in NI.

4.5 Maternal Age

The average age of Traveller mothers in the cohort is 25.9 (median=25; 25th percentile=21, 75th percentile=30).

4.5.1 Maternal Age: by 5-Years Age Group

The age of the mothers showed a younger age distribution with 74.3% under 30 years of age compared to 39.4% in ROI (CSO, 2008) and 50.8% in NI (NISRA, 2008: Figure 3, Table 5).

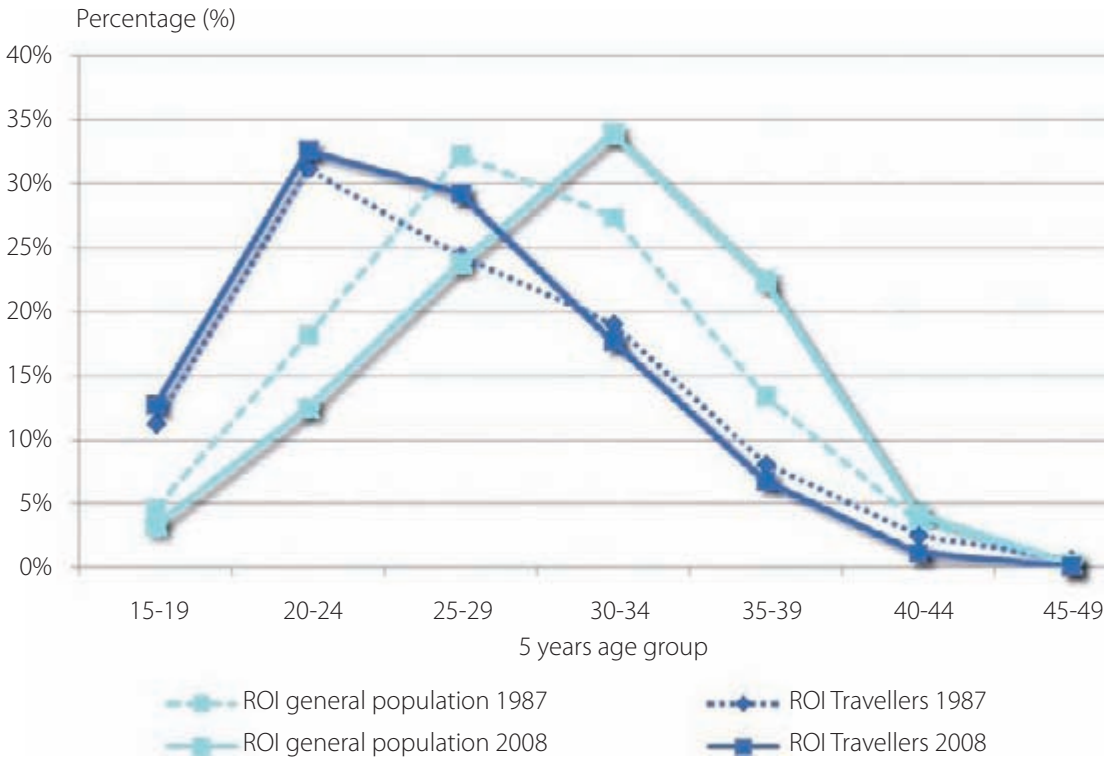
There has been a shift in age at maternity in ROI general population in 2008 compared to 1987 (Figure 4). In ROI general population, there has been a general overall shift to the right with women reaching maternity age at a later age. For ROI Travellers, the peak age of maternity is still at the 20-24 age group; however the numbers in the 25-29 age group have also increased with a drop in all the other older age groups.

Table 5: Age distribution of Traveller mothers compared to general population in IOI

Age group (years)	Traveller mothers (%) n=479	Republic of Ireland general population (%) n=75,065	Northern Ireland general population (%) n=25,631
15-19	12.7	3.2	5.6
20-24	32.6	12.4	16.6
25-29	29.2	23.8	28.6
30-34	17.7	33.9	29.2
35-39	6.7	22.4	16.7
40-44	1.0	4.1	3.2
45-49	0	0.2	0.1

Figure 3: Distribution of maternal age by 5-years age group: IOI Travellers, ROI general population and NI general population

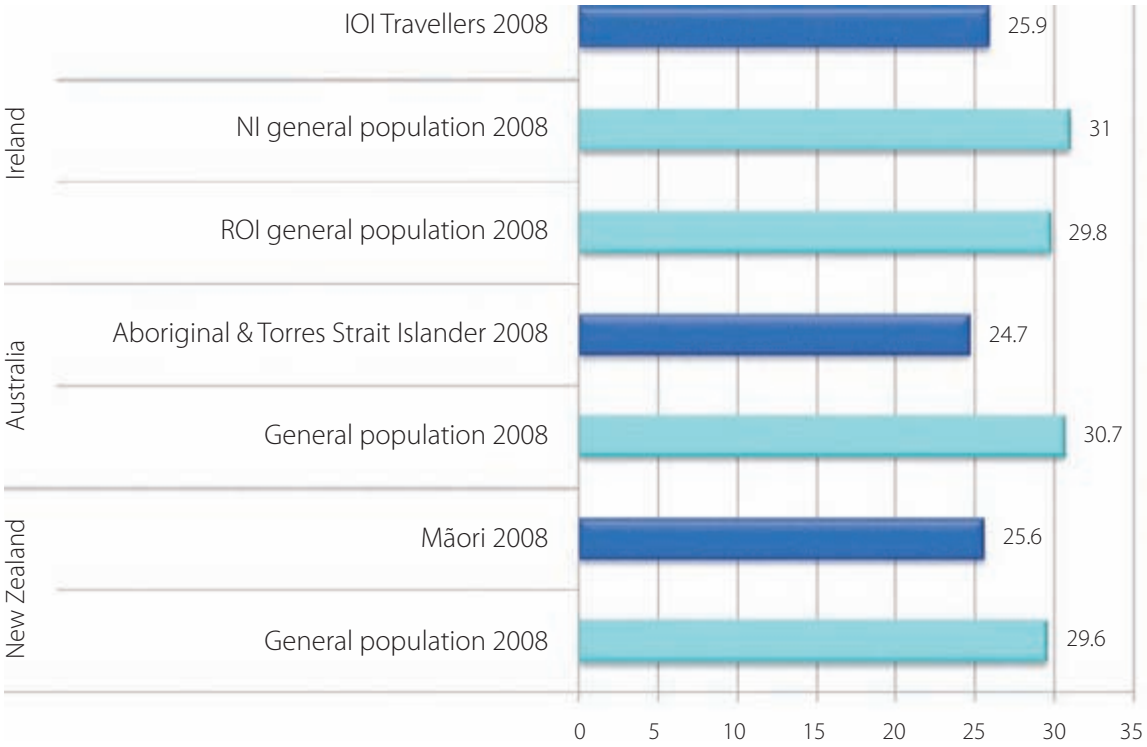
Figure 4: Distribution of maternal age by 5-years age group for ROI Travellers and general population during 1987 and 2008



4.5.2 Maternal Age: Comparison with Other Minority Groups

The average age of Traveller mothers in IOI is 25.9 compared to 25.6 New Zealand's Maori (Statistics New Zealand, 2010), 24.7 in Australian's Aboriginal & Torres Strait Islanders (Australian Bureau of Statistics, 2008) and 20 years for the Hungarian Roma population (Janky, 2006; p138). The average maternal age of all minority groups is lower compared to the general population of each referenced country (Figure 5).

Figure 5: Average maternal age of IOI compared to other minority groups and in comparison to the general population of the country

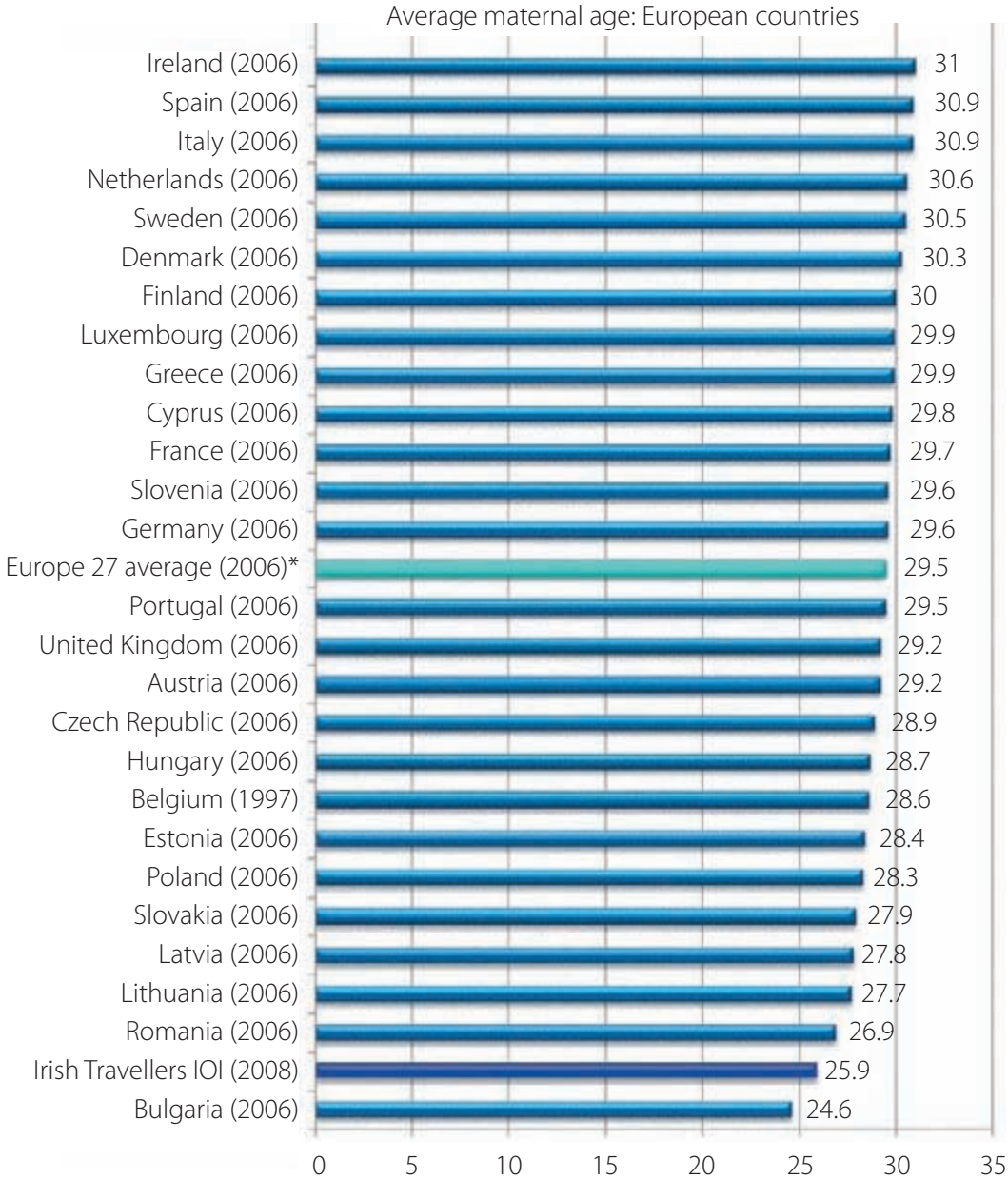


Sources:
Australian Bureau of Statistics (2008) available at: http://www.abs.gov.au/AUSSTATS/abs@.nsf/web+pages/statistics?opendocument#from-banner=GT
CSO (2008) available at: http://www.cso.ie/releasespublications/documents/vitalstats/2008/vstats_q42008.pdf
NISRA (2009) available at: http://www.nisra.gov.uk/archive/demography/publications/births_deaths/births_2009.pdf

4.5.3 Maternal Age: European Countries Average and World Average

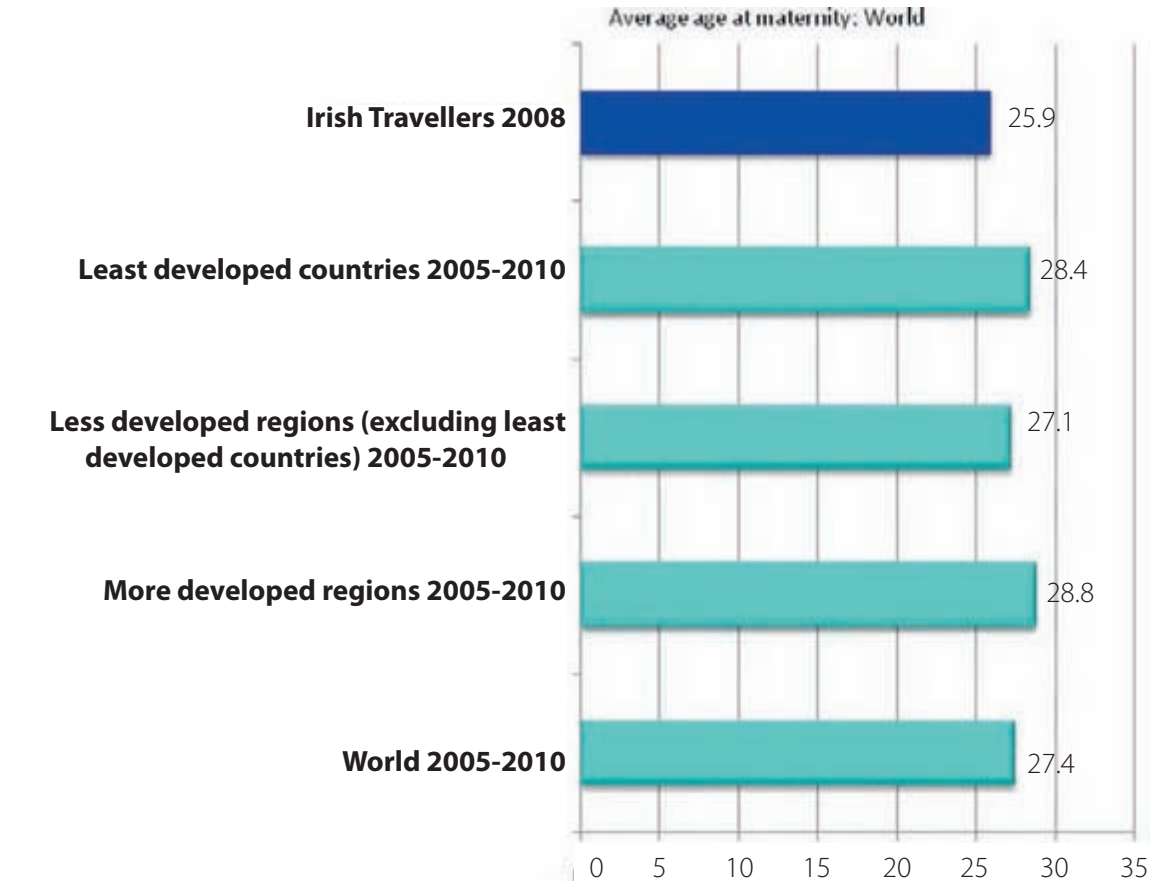
The younger average age of Traveller mothers was compared to the European countries average (Figure 6) and the world average (Figure 7). The average age of Traveller mother in Ireland was the second-youngest in Europe. They were second only to Bulgaria where the average mother age is 24.6 years.

Figure 6: Average age of mothers: European countries and IOI Travellers



Adapted from: Health Statistics, 2008 (Department of Health and Children, 2008, pg 39)- data source: EUROSTAT, Population Statistics, 2008. http://www.dohc.ie/statistics/health_statistics_2008.html

Figure 7: Average age at maternity - world average



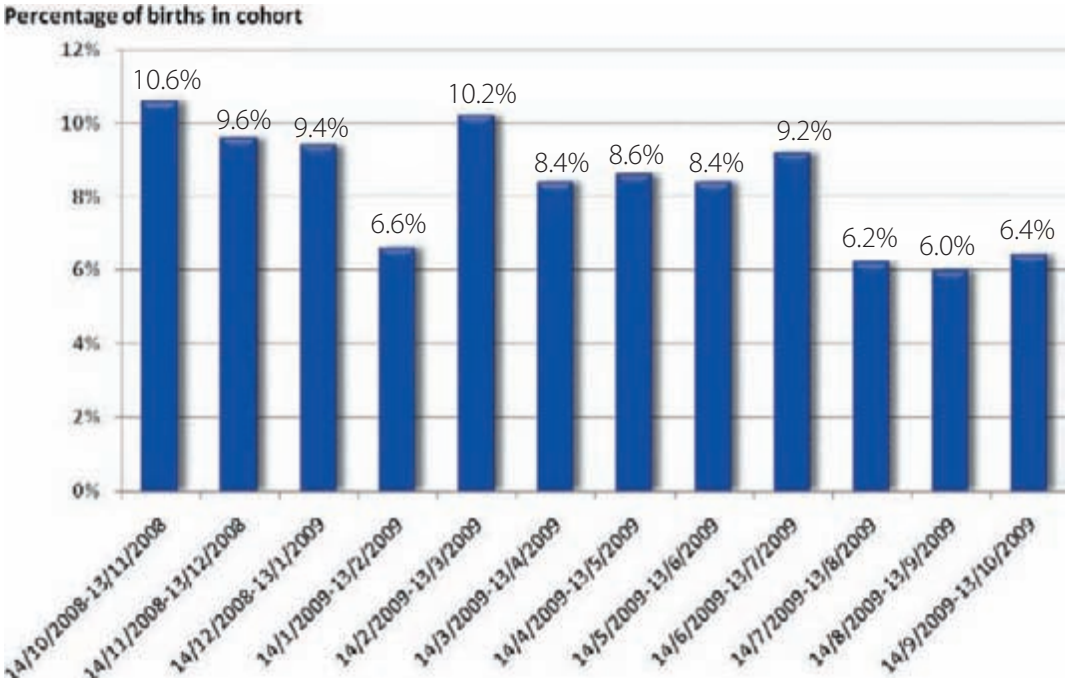
Adapted from: World Fertility Pattern 2009 (United Nations, 2010) Available from: http://www.un.org/esa/population/publications/worldfertility2009/worldfertility2009.htm

4.6 Distribution of Births by Month

As the birth cohort started on 14th October, 2008, the data presentation is based on mid-month to mid-month basis (e.g. 14th October, 2008 to 13th November, 2008).

The distribution of births was almost constant. However, there was a drop in the 4th and last 3 months in the cohort probably due to higher refusal rates (Figure 8); cross-check cannot be performed as no information was returned in the refusal forms.

Figure 8: Distribution of Traveller births by month of study



4.7 Infant Mortality

Up to April 2010, there were 6 reported perinatal deaths and 1 infant death in ROI and NI.

4.8 Health Service Utilisation: Maternity Hospitals

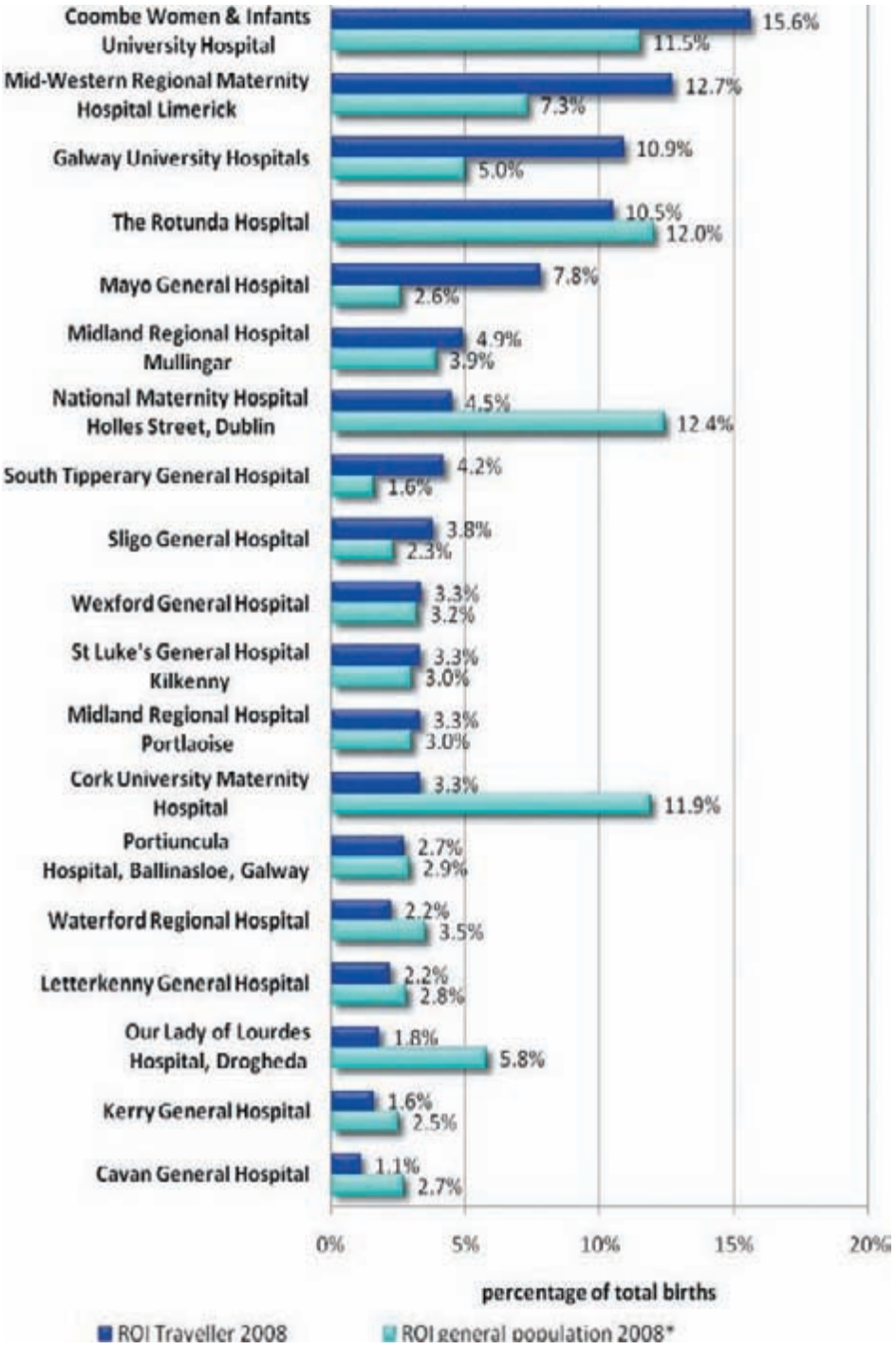
The birth cohort study attempted to capture the percentages of births occurring in each maternity hospital in ROI and NI. The breakdown by percentage of Traveller births and general population births according to maternity hospital is shown in Figures 9 and 10.

Only 30.6% of total Traveller births occur in the three Dublin maternity hospitals, as opposed to 35.9% of general population. 69.4% of Traveller births occur in other maternity units outside Dublin. Four major maternity units, namely the Coombe Women & Infants University Hospital; Mid-Western Regional Maternity Hospital Limerick; Galway University Hospitals and The Rotunda Hospital, Dublin account for almost 50% of all Traveller births in the cohort.

For Northern Ireland, the majority of Traveller births occur in the Belfast and Craigavon Area Hospital. This was 71% of all Traveller births in the cohort.

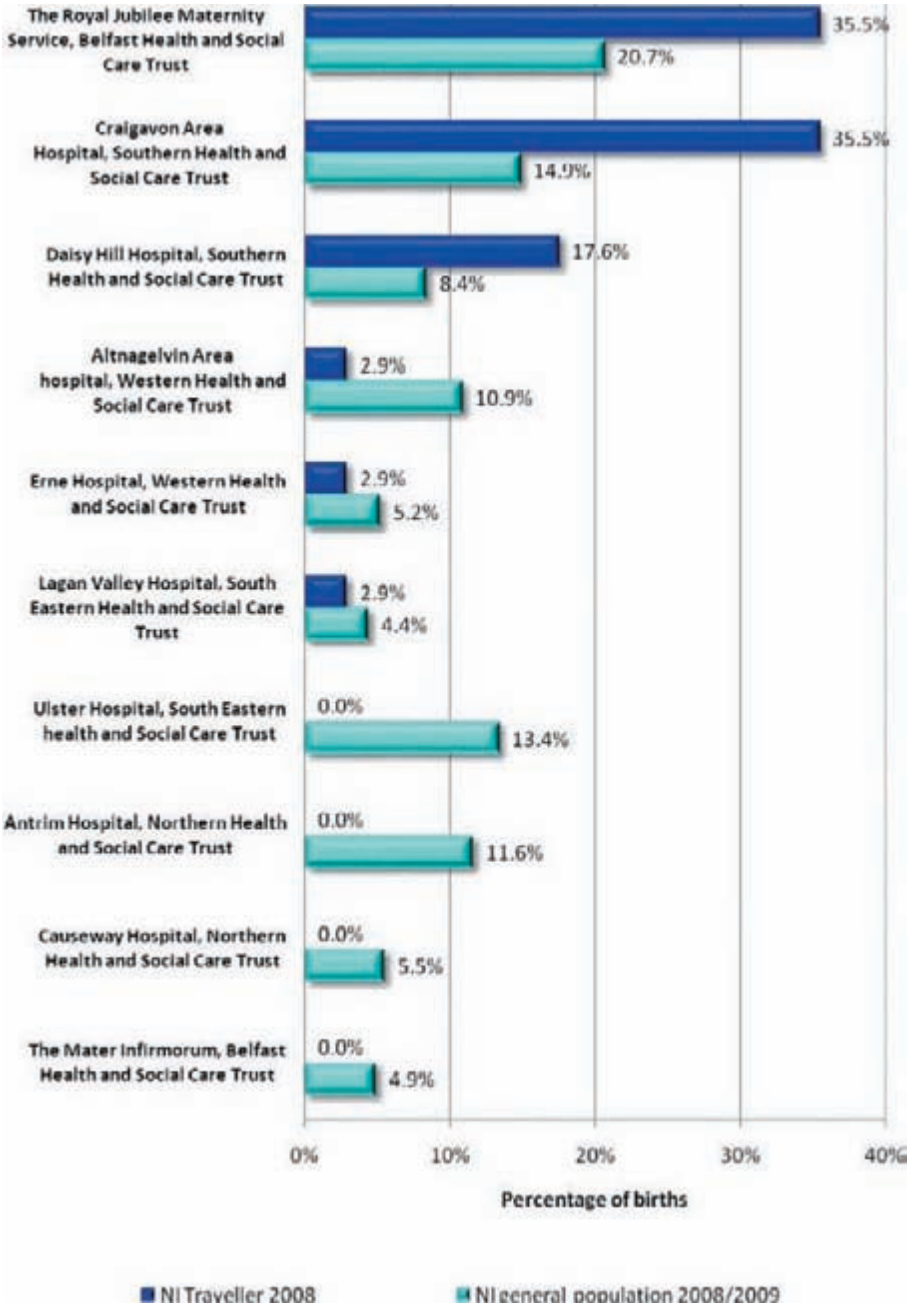
However, this analysis was limited to only the consented participants in the birth cohort study. As each maternity hospital has a dedicated catchment area, the number of Traveller births in each maternity hospital was also dependent on the ascertainment rate of the area. For areas with a low ascertainment rate or with a high refusal rate, then this might not be reflected in the volume of Traveller births for the particular maternity hospital.

Figure 9: Distribution of Traveller births recorded in the birth cohort study and the breakdown of recorded total live births in ROI (as percentage of total births nationally) in all maternity hospitals for 2008



Sources: Health Service Executive (2010) Data Provided by the Health Service Executive Performance Monitoring Unit.

Figure 10: Distribution of Traveller births recorded in the birth cohort study and the breakdown of recorded total live births in NI (as percentage of total births nationally) in all maternity units



Source: Department of Health, Social Services and Public Safety (2010), available at: http://www.dhsspsni.gov.uk/index/stats_research/stats-activity_stats-2/hospital_statistics.htm#hospital

5. Fertility Indicators

This section describes the annual crude birth rate, general fertility rate and total fertility rates for the Travellers. Comparisons with other groups are made when there is available data.

All calculations, including age-specific fertility rate, are included in appendix B and C.

5.1 Annual Crude Birth Rate

The annual crude birth rate is defined as 'the number of births actually occurring in a country in a given time period, divided by the population of the area as estimated at the middle of the particular time period. The rate is usually expressed as 1,000 per population' (Central Statistics Office, 2008).

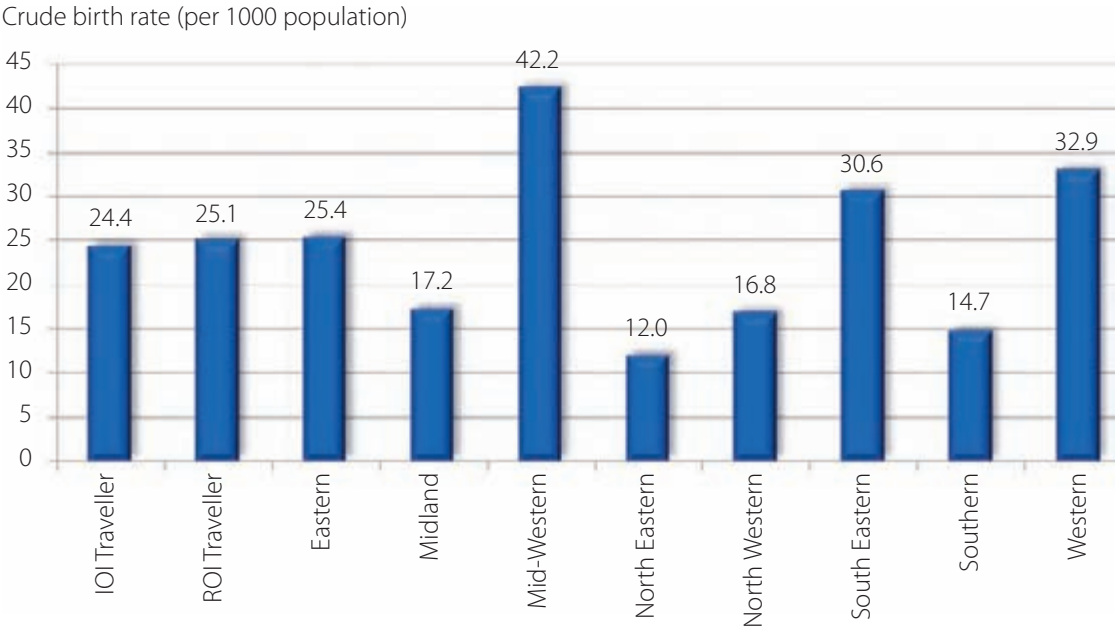
The overall annual crude birth rate (CBR) for the island of Ireland in the Travelling community was 24.4 per 1,000 population; 25.1 per 1,000 population for ROI and 17.1 for NI (Figure 11).

Figure 11: Annual crude birth rate (per 1,000 population) for Travellers on IOI, ROI and NI

5.1.1 Crude Birth Rate: Traveller Health Units

Crude birth rate for each THU varied, with the Mid-Western THU having the highest crude birth rate at 42.2 per 1,000 population. Western, South Eastern and Eastern THUs showed CBR higher than the ROI Traveller average. The Midland, North Eastern, North Western and Southern crude birth rates were below the ROI Traveller average of 25.1 (Figure 12).

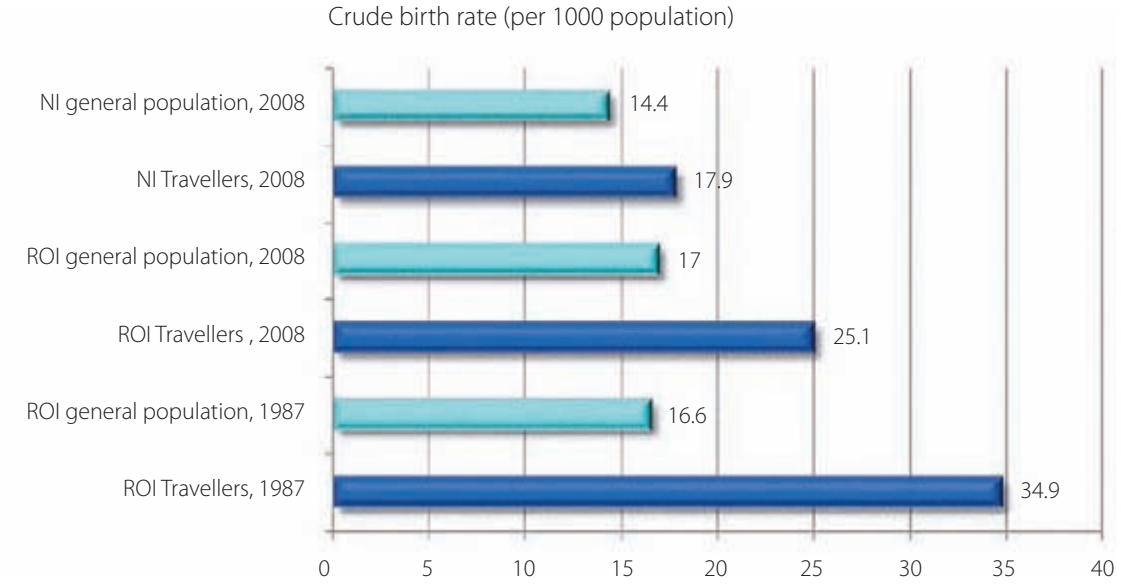
Figure 12: Crude birth rate (per 1,000 population) by Traveller Health Unit and in comparison with IOI and ROI Traveller average



5.1.2 Annual Crude Birth Rate: Comparison with General Population

Travellers in ROI have a higher crude birth rate than in NI. Overall, CBR for Travellers in both regions is high compared to the CBR in the corresponding general population. The CBR for the general population in ROI was 17.0 per 1,000 population (Central Statistics Office, 2008) and 14.4 for Northern Ireland (Northern Ireland Statistics and Research Agency, 2008). However, compared to the Traveller Health Status Study: Vital statistics of Travelling people, 1987 (Barry *et al.*, 1989) the CBR of Travellers in ROI has fallen (from 34.9 per 1,000 population to 25.1 per 1,000 population) (Figure 13).

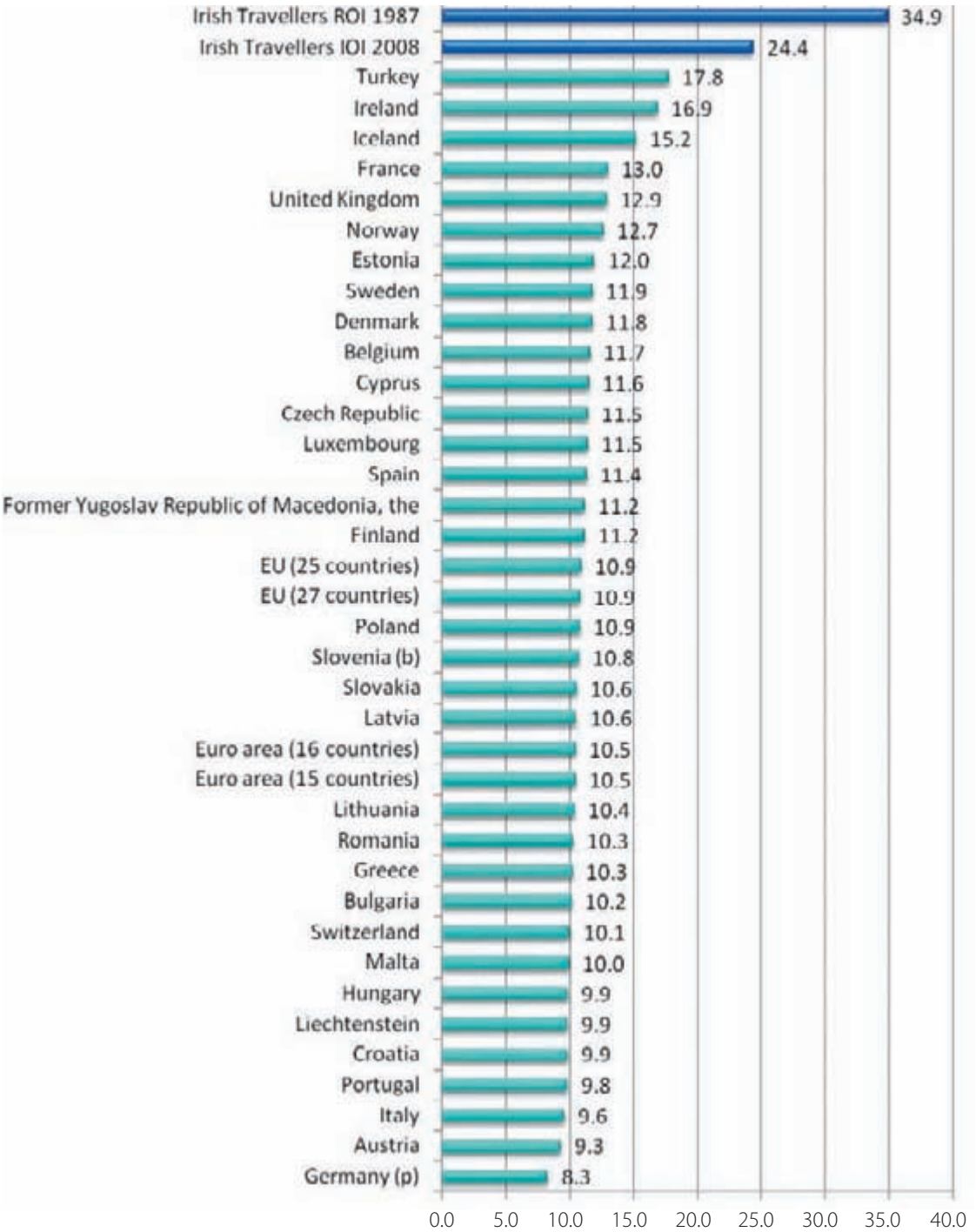
Figure 13: Crude birth rate of Travellers and general population in ROI and NI in 2008; crude birth rate of ROI Travellers and general population in 1987



5.1.3 Annual Crude Birth Rate: Comparison with European Countries

Figure 14 shows the CBR of Irish Travellers (IOI) compared to other European countries and European averages. The CBR of IOI Travellers is the higher than the CBR of any individual European country and of the European averages.

Figure 14: Crude birth rate (per 1,000 population): European countries (2008)



Source: EUROSTAT (2010) Available at: http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&language=en&pcode=tps00112&plugin=1

(p)- Provisional

(b)- break in series

5.2 Fertility Rates

Definitions (Central Statistics Office, 2008):

1. The General Fertility Rate (GFR) is the ratio of the number of live births during a given period to the female population aged 15-49.
2. The Age-specific Fertility Rate is the ratio of the number of live births to women in a given age group relative to the number of women in that age group.
3. The Total Fertility Rate (TFR) is the average number of children that would be born per woman if all women lived to the end of their childbearing years and bore children according to Age-specific Fertility Rates for that area and period. This is an indication of replacement rate for a population. A rate of 2.1 is considered to be the replacement level for the population of developed countries.

5.2.1 General Fertility Rates

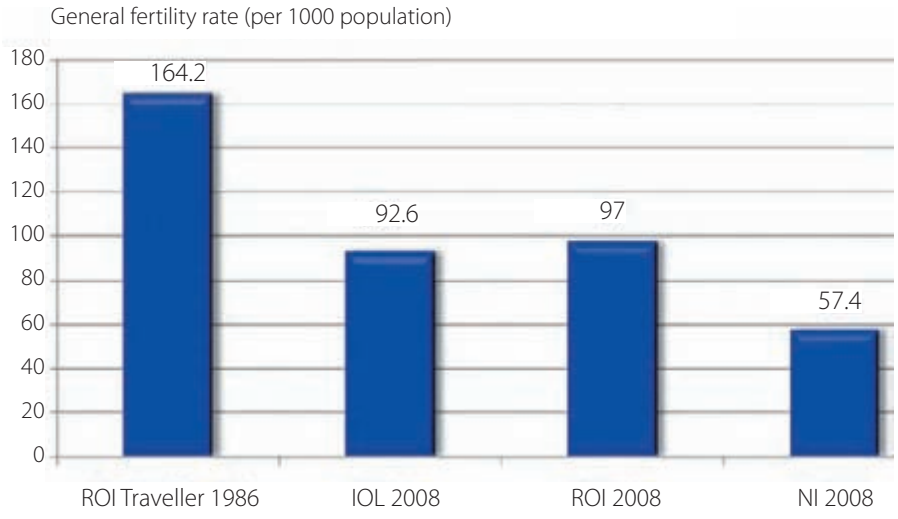
The GFR of Travellers in IOI has fallen. This was 92.6 per 1,000 population in IOI (Table 6); for ROI Travellers the rate was 97.0 per 1,000 population and for NI this was 57.4 per 1,000 population.

Table 6: General fertility rate for Travellers on IOI, ROI and NI in 2008

Indicators	Island of Ireland	Republic of Ireland	Northern Ireland
General fertility rates (per 1,000 female population age 15-49)	92.6	97.0	57.4

The GFR of the Travellers in ROI has dropped from 164.2 in 1986 to 97 in 2008 (Figure 15).

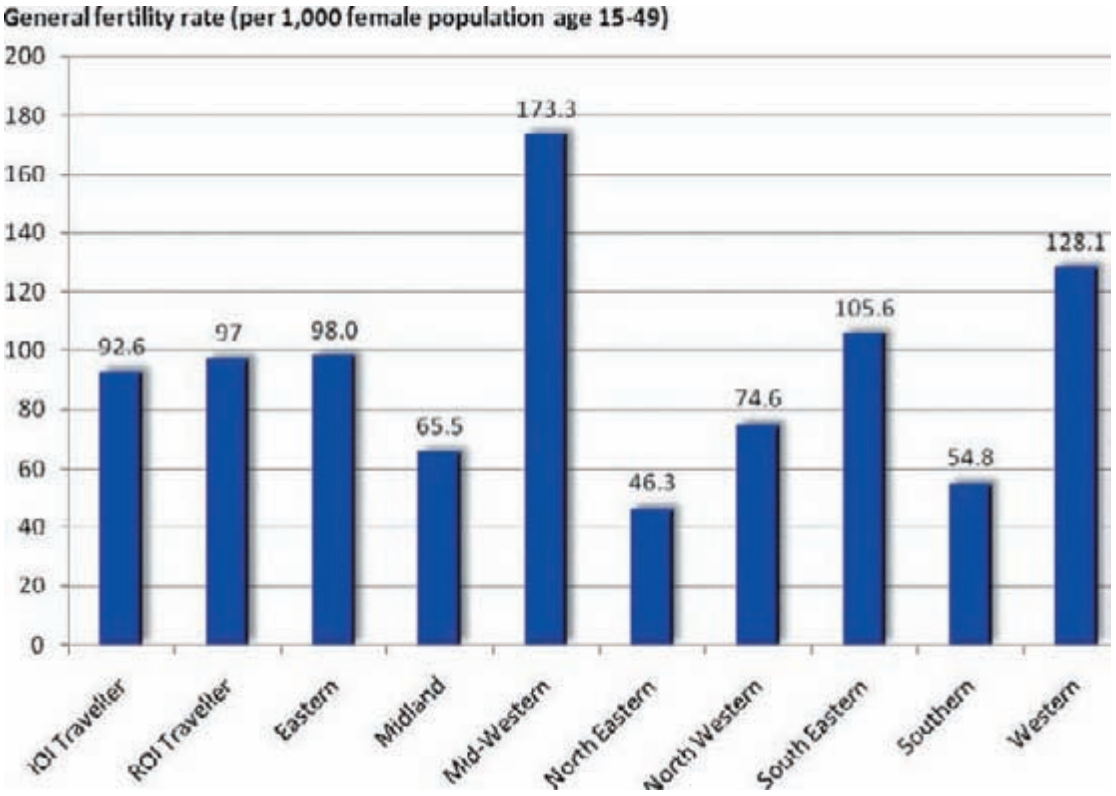
Figure 15: General fertility rate for Travellers on IOI, ROI and NI in 2008 compared to ROI Travellers in 1986



5.2.1.1 General Fertility Rate: Traveller Health Units

The Mid-Western THU showed the highest GFR at 173.3 per 1,000 female population age 15-49. The South Eastern, Western and Eastern THUs all have higher GFR than the ROI Traveller average. The GFR of the Midland, North Eastern, North Western and Southern THUs were below the ROI Traveller average (Figure 16).

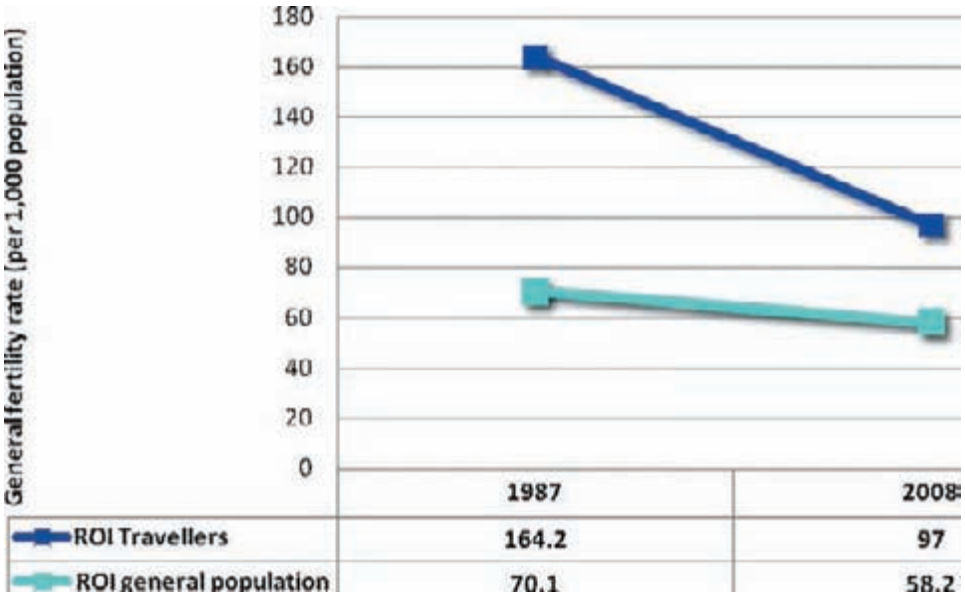
Figure 16: General fertility rate by Traveller Health Units



5.2.1.2 General Fertility Rate: Comparison ROI Travellers with ROI General Population

There has been a drop in the GFR of ROI Travellers and ROI general population since 1987. GFR for ROI Travellers dropped from 164.2 per 1,000 female population age 15-49 to 97, while the GFR for ROI general population dropped from 70.1 to 58.2 (Figure 17).

Figure 17: General fertility rate of ROI Travellers compared to ROI general population in 1987 and 2008.



2008 population estimate based on Population and migration estimate 2009 (CSO, 2009) available from: http://www.cso.ie/releasespublications/documents/population/current/popmig.pdf

5.2.2 Total Fertility Rates

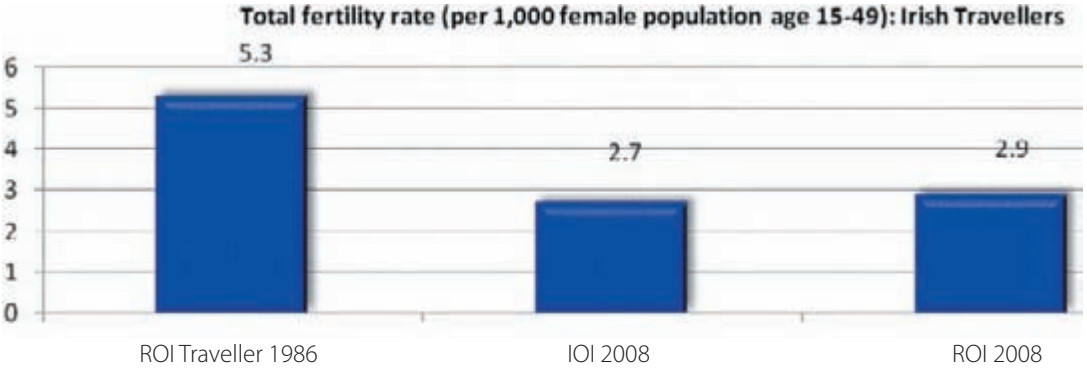
The TFR of Travellers in ROI was 5.3 per 1,000 female population age 15-49 in 1987. In 2008, the TFR for Travellers in ROI was 2.9 per 1,000 female population age 15-49. This was higher compared to the overall IOI figure of 2.7 per 1,000 female population age 15-49 (Table 7, Figure 18).

Table 7: Total fertility rate for Travellers on IOI, ROI and NI in 2008

Indicators	IOI	ROI	NI
Total fertility rate (per 1,000 female population, age 15-49)	2.7	2.9	NA

We were unable to calculate the total fertility rate for NI due to the small number of births.

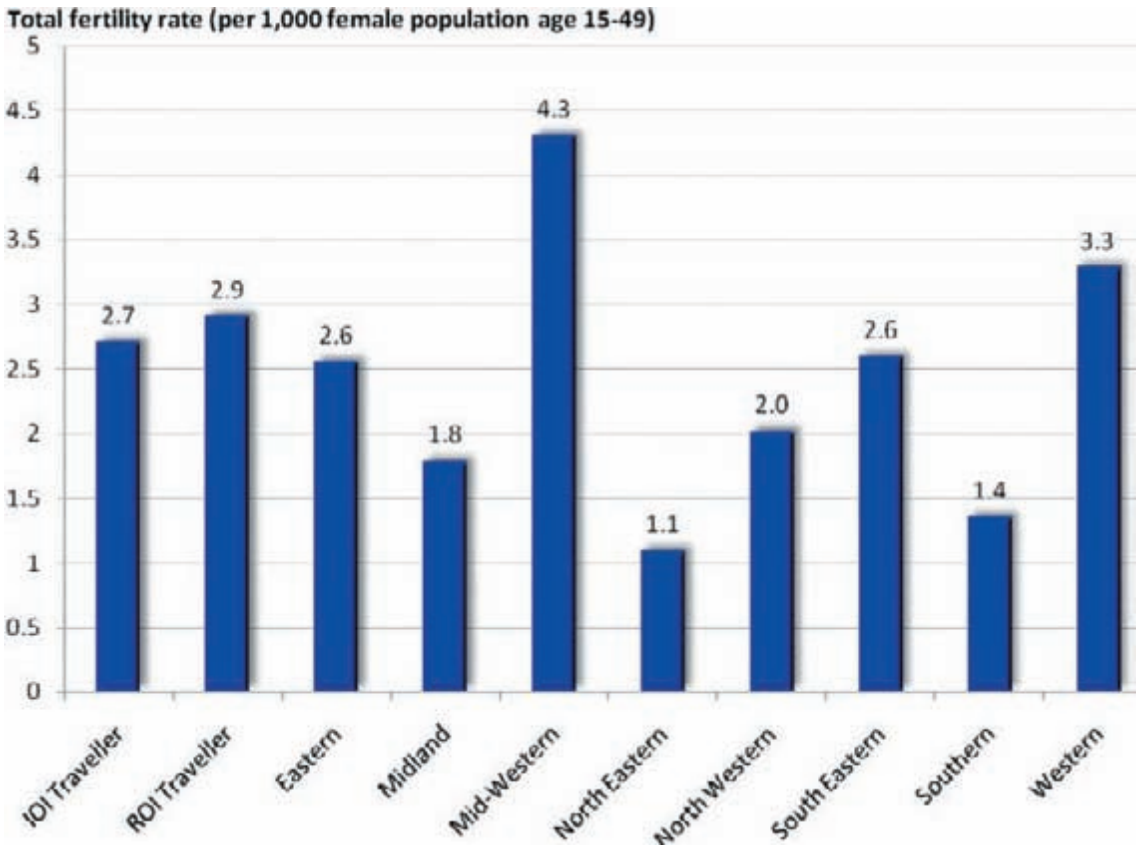
Figure 18: Total fertility rate of Travellers on IOI and ROI in 2008 compared to Travellers in ROI in 1986.



5.2.2.1 Total Fertility Rate: Traveller Health Units

The TFR for Mid-Western THU is the highest at 4.3 per 1,000 female population age 15-49, followed by the Western THU at 3.3. All the other THUs had TFR lower than the ROI Traveller average (Figure 19).

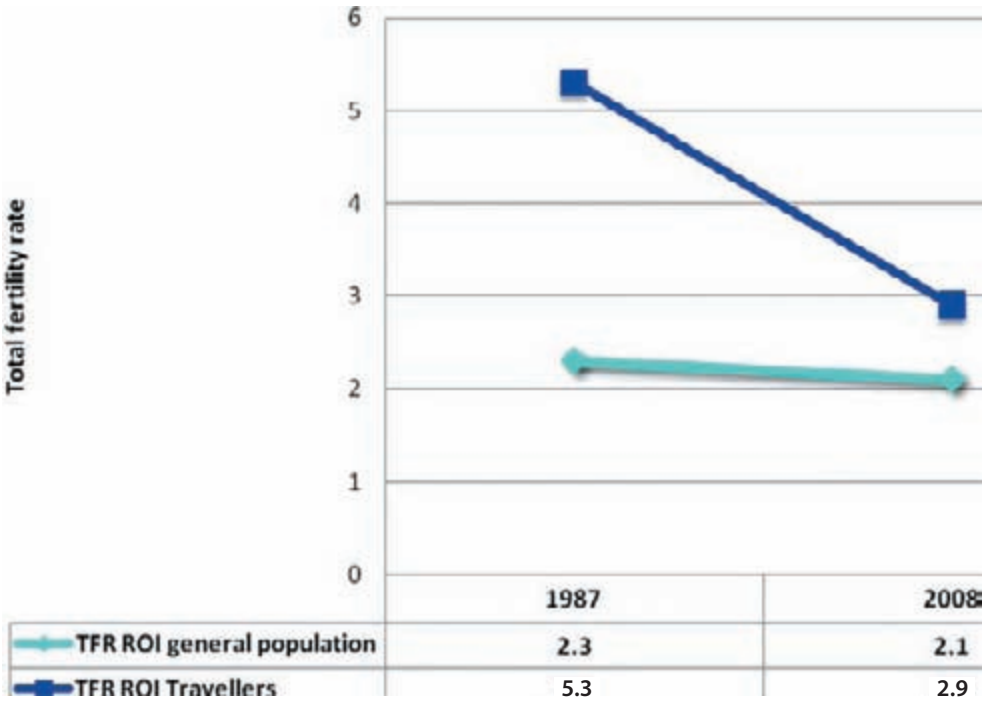
Figure 19: Total fertility rate by Traveller Health Units compared to IOI and ROI average



5.2.2.2 Total Fertility Rate: Comparison ROI Travellers with ROI General Population

Comparison was also made with the TFR of the general population in ROI for 2008 and 1987 (Figure 20). There was a greater fall in TFR of ROI Travellers over the period than in the general population (2.3 in 1986 to 2.1 in 2008).

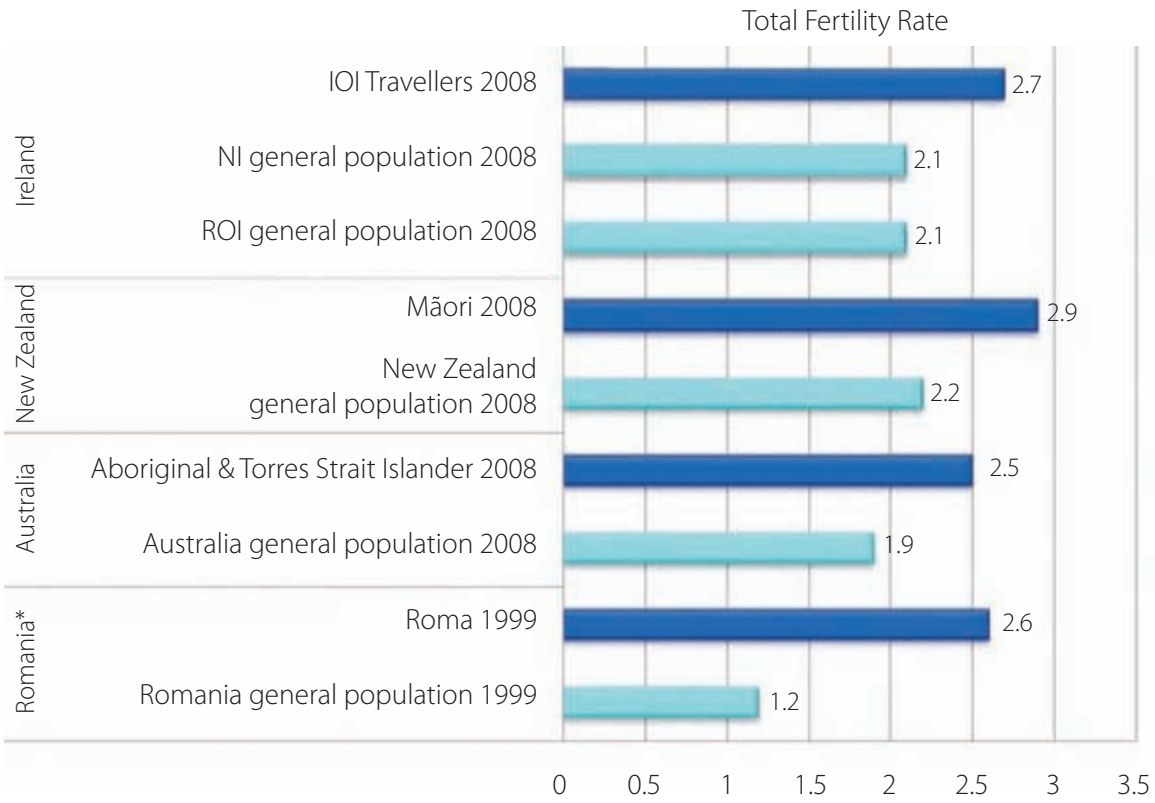
Figure 20: Total fertility rate for ROI Travellers compared to ROI general population in 1987 and 2008



5.2.2.3 Total Fertility Rate: Comparison with Other Minority Groups and Their Respective Population

The TFR of IOI Travellers was compared to the Australian Aboriginals, New Zealand Māori and the European Roma (Figure 21). All these minority groups have a TFR above 2.5 and each has a TFR higher than the relevant general population.

Figure 21: Total fertility rate of IOI Travellers, general population ROI and NI; other comparative ethnic groups and their respective countries

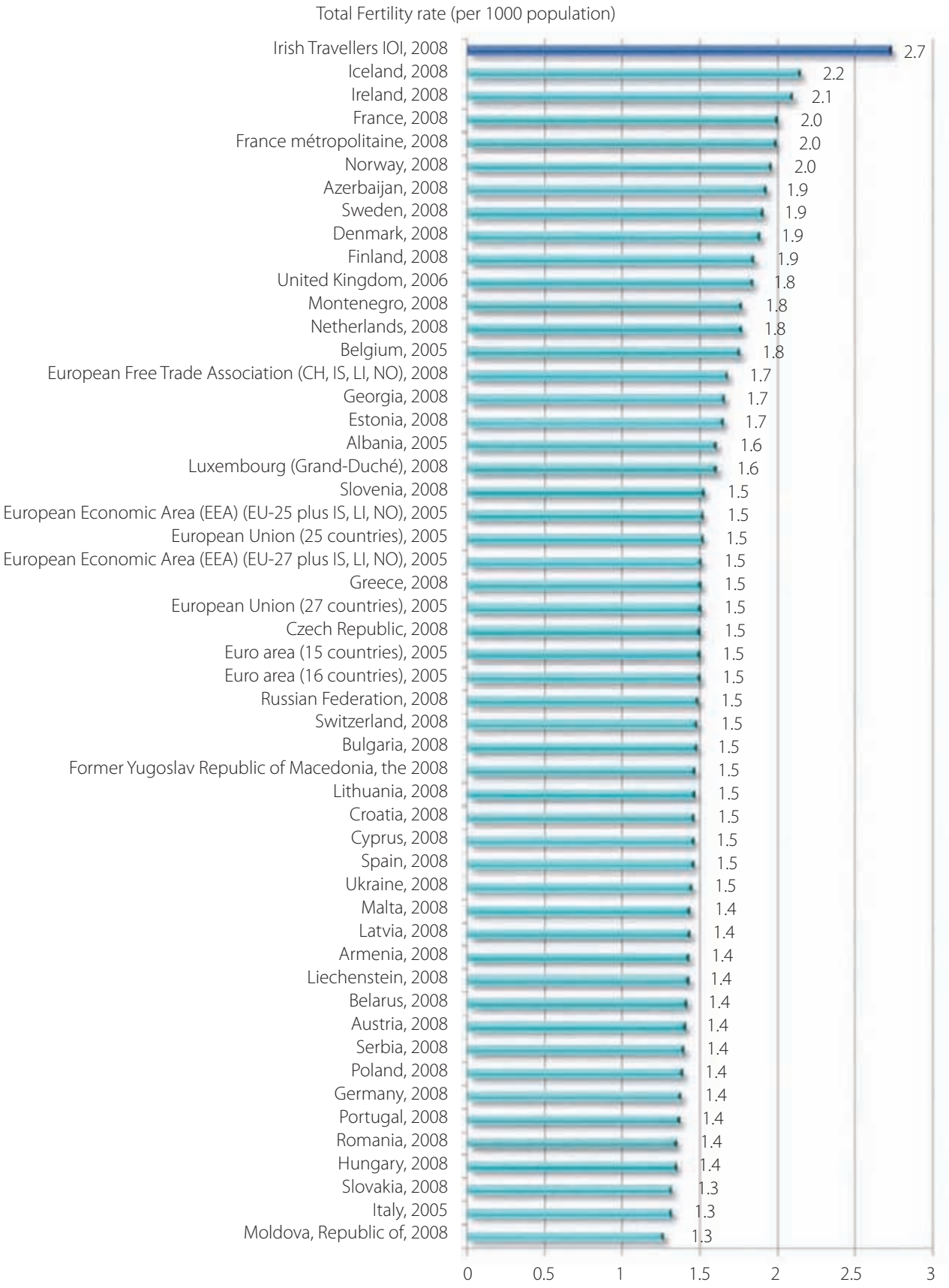


Sources:
Australian Bureau of Statistics (2008) available at: http://www.abs.gov.au/AUSSTATS/abs@.nsf/web+pages/statistics?opendocument#from-banner=GT
CSO (2009) available at: http://www.cso.ie/releasespublications/documents/vitalstats/2008/vstats_q42008.pdf
NISRA (2009) available at: http://www.nisra.gov.uk/archive/demography/publications/births_deaths/births_2009.pdf
Statistics New Zealand (2010) Available at: http://search.stats.govt.nz/search?w=births&button.x=0&button.y=0&button=Search&w_pre=Population&af_pre=
*quoted from UNDP 2002 Avoiding the dependency trap, pg 26. Available at: http://roma.undp.sk/

5.2.2.4 Total Fertility Rate: European Countries and World Average

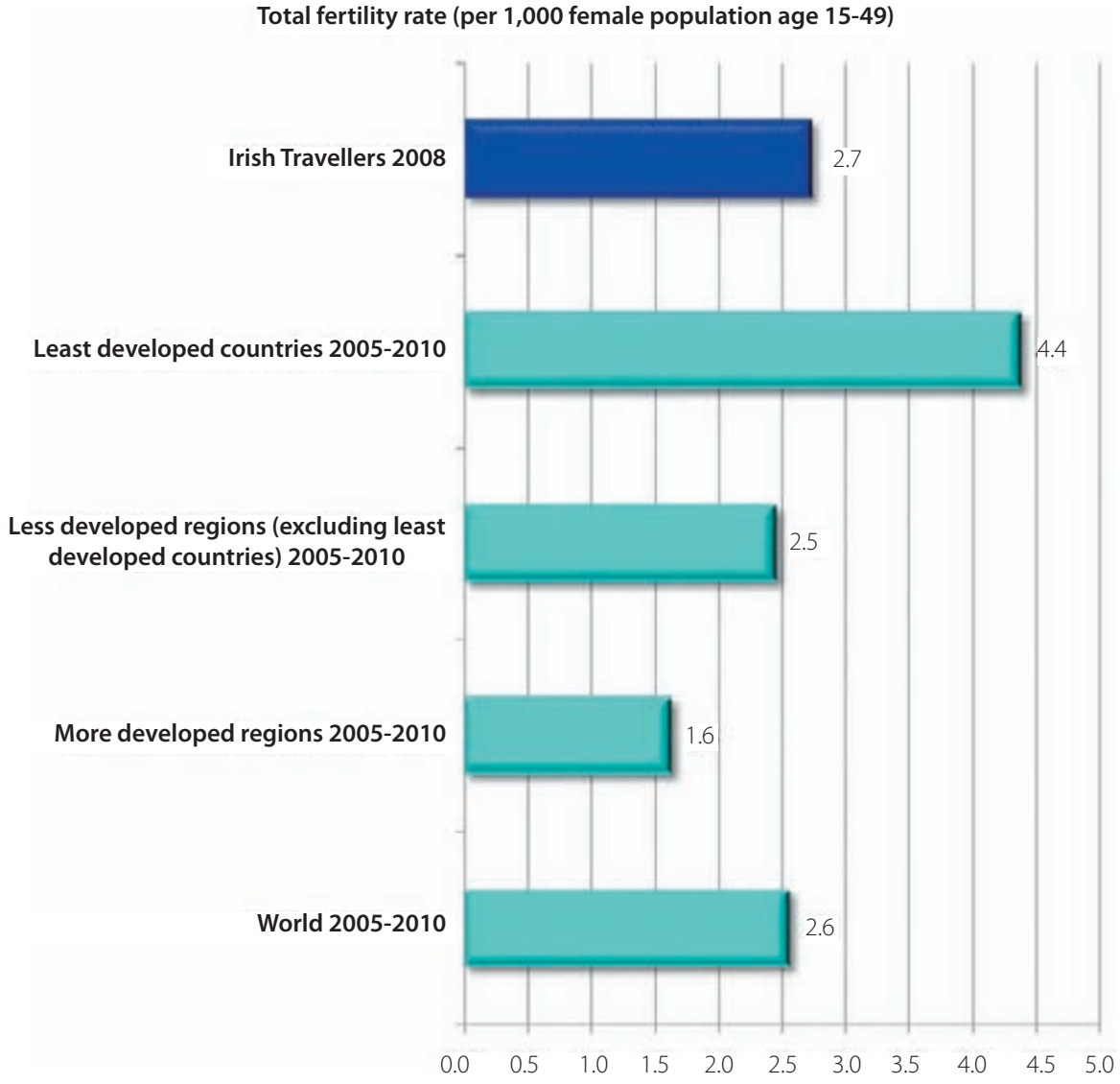
Irish Travellers have the highest TFR compared to the EU countries averages (Figure 22). When compared to the world averages, the Irish Travellers' TFR is above the average of 'less developed countries' (Figure 23). However, this needs careful interpretation as the United Nations' figure is an average of all countries.

Figure 22: Total fertility rate (per 1,000 female population age 15-49): European countries



Source: EUROSTAT (2010) Available at:
http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&language=en&pcode=tps00112&plugin=1

Figure 23: Total fertility rate: world average



Source: World Fertility Pattern 2009 (United Nations, 2010) Available from: http://www.un.org/esa/population/publications/worldfertility2009/worldfertility2009.htm

6. Challenges

This section describes some of the major challenges faced by the study. These include:

1) Study Promotion
One of the biggest challenges faced by the study team was promoting the study to the participants. Initial study promotion was through the census where pregnant women were identified, then invited to enter the study with formal promotion and consent by the PHNs. A valuable lesson learnt from a particular LHO area was the need to engage and promote the study not just by the PHN but with reinforcement from the Traveller Health projects and the Community Health Workers. Engagement and promotion by the Community Health Workers, usually Travellers themselves, allowed greater explanation via 'oral tradition'.

For the PHNs, study promotion and consent were an issue due to time constraints. The PHNs were expected to promote the study opportunistically during their routine engagement with the mothers. Despite the PHNs' enthusiasm, this was time consuming for both sides as there were routine first visit procedures which needed to be carried out and at the same time issues faced by new mothers to be addressed. This was resolved by allowing the PHN to promote and consent the mothers on their subsequent visits.

2) Consenting Participants
The PHNs had the lead role in promoting and officially taking consent from the potential participants. Time constraints often prevented PHNs from playing their role effectively. In some areas, there were constant changes in PHNs for the areas. This was exacerbated in some areas when changing PHN personnel created more confusion and a slower building of trust. In order to ensure that PHNs followed up on all Traveller births, link-PHNs used local registries, e.g. Birth Notification or National Metabolic Screening results, to double-check for the mother's status.

In Northern Ireland, the main study coordinator played the central role in taking consent from participants.

Due to the ethical requirements in Northern Ireland whereby the consent could only be carried out by the main study coordinator, geographical size of the region and time were the limiting factors in approaching the potential participants. This further added to the challenges of tracing and approaching potential participants.

An innovative method developed by the main study coordinator and the Health Visitors was to organise coffee mornings or health check events for all new mothers and their babies. This included events such as maternal and child health sessions and social sessions with 'Toybox'. All mothers, regardless of whether they agreed to participate in the study or not, were invited to attend. During these events, the main study coordinator and Health Visitor opportunistically promoted the study to all mothers. This was a successful method whereby most mothers who attended would consent for the study while some who had initially refused changed their mind and offered their consents. In

some circumstances, it was more appropriate for the main study coordinator to accompany the Health Visitors to the potential participant's residence. Health Visitor knowledge proved valuable for this procedure as this allowed the main study coordinator to approach the potential mothers at the time of day where these potential participants would be available.

3) Refusals

Recruitment into a cohort is always difficult due to the commitment required of the participants. This is expected to be higher from a marginalised minority group who would be wary of outsiders. In addition, the need to carry a Parent-held Child Record can be intimidating for any parent. The study ethical requirement prohibited collection of any details of Traveller mothers who refused to participate in the study. Thus no comparison can be made as to the basic demographic characteristics of those who refused, for example maternal age. However, the PHNs recounted from their experience that those who refused tended to be younger mothers and those who felt too busy or stressed. The sources of stress varied from a lack of time or an ill child requiring the mother's attention. Another interesting related experience was that of organised mass refusals among women in the same site. This was described as a 'matriarch' system where if the leading woman refused to participate or did not agree with the study, all the women in the site would refuse too.

4) Participant Follow-up

Participant follow-up is a major issue in any cohort. This was more pronounced in this cohort. The PHNs provided the contact detail of the participant, for example home address, postal address and mobile telephone details during the consenting process. However, postal correspondence did not always yield the needed response. This was due to movement of Traveller mothers for example visiting family or having moved away from the site. Some sites have no exact postal address, code or postal service. Thus in such cases, PHNs contact is invaluable in reaching the participants.

Having a mobile telephone number as a means of contact did not always help the situation as most of these phones remained unanswered or possibly disconnected or replaced as the mother's circumstance changed. Experiences from the PHNs and Traveller projects confirmed the frequent change of mobile phones. Consequently, PHNs, especially Designated Traveller PHNs, remained an important source if contact need to be made with the participants. The designated Traveller PHN network was helpful if a mother had moved out of an area to another area, as the designated PHN in the new area might be able to trace these mothers based on local knowledge. Sometimes contact was lost if the Traveller mother left the area with no details of next destination. This was reported as not uncommon.

Successful collection of the Parent-held Child Record was also an issue faced by the study team. When a baby reached his/her first birthday, the study team sent out a congratulatory letter to the mother and request for the Parent-held Child Record to be returned to UCD. However, the return rate has been poor to date. Some of the PHNs related that such a record and the need to participate in the study might be of little priority to the mothers, in the larger scheme of things and hence their delay in taking any form

of action. Furthermore, there was a need to visit the participant which sometimes requires multiple visits. There was also confusions on the ground as what the participants need to do with the record. Furthermore, sometimes the mother may have misplaced the record. In such circumstances, the PHNs' help was of great value as they ensured that these records were filled and returned to UCD. PHNs also reported the need to cross-check the records prior to returning them to UCD as these may not be filled by other health professionals or have incomplete data. This needs acknowledgement as this process adds to the PHN's workload. Similar experiences were described in Northern Ireland.

Besides requesting the PHNs to assist the mothers in returning the Parent-held Child Record, the Traveller Health Unit (THU), Traveller Health projects and TCHW were also asked to assist in this task.

5) Competing Agendas

During the course of the study, the birth cohort study had to compete with other studies involving Travellers. As the AITHS had a few components which were ongoing at the same time, this possibly distracted the attention of the study coordinators and even the participants from the birth cohort study. Furthermore, there were other studies which were competing for the attention of the participants and this led to some confusion in the community.

Other administrative issues within the health services challenged the working function of the PHNs and their support for the study. This included the economic downturn from the end of 2008 onwards which resulted in cutbacks within the health services. As a direct result, PHN travelling allowance was reduced and visiting frequencies were limited. In certain areas PHNs who have left posts or were on leave were not replaced, thus putting more pressure on other PHNs to cross-cover the workload. This not only limited the time available for study promotion but also follow up of participants. In addition, other urgent public health issues, e.g. Swine Flu vaccination programme for the general community and measles outbreak among the Travellers, resulted in PHNs being transferred to other services or to changes in job priority for them.

7. Discussion

The number of recorded births in the birth cohort study to date is close to the estimated births. The gender ratio in babies born to date is similar to that of the general population in ROI and NI. Traveller mothers are relatively younger than the general population in ROI and NI. Over the past 20 years, there has been a shift in average maternal age in ROI where Irish women are having children at an older age compared to their predecessors. This however has not really occurred amongst Travellers.

More Traveller births occur in maternity units outside of Dublin than in the general Irish population. Even within Dublin, there is a difference in the maternity hospitals that Traveller mothers attend. This may be due to catchment area of the hospitals and concentration of Traveller families within that catchment area. Furthermore, there is an unequal distribution in births between geographical areas, with more births in the Mid-Western and Western THUs compared to others. This pattern was similar in Northern Ireland where the births are concentrated mainly in Belfast and Craigavon Area Hospitals.

The CBR and fertility rates amongst Travellers have dropped since 1987. There is no interim data on this drop. The drop in fertility rate is not unique to the Irish Traveller population. Fertility rates around the world have started to drop since the 1970s, first in developed countries, followed by developing countries (WHO, 2004). The World Fertility Report 2003 (WHO, 2004) contributed this to 'major behavioural transformation related to union formation, marriage and the use of contraception'. Other authors stressed the importance of factors such as socioeconomic and cultural change (Barros *et al.*, 2008; Menken and Rahman, 2006; Lutz and Qiang, 2002; The ESHRE Capri Workshop Group, 2001).

Other determinants of fertility for example, early family formation and fecundity were not recorded. From the birth cohort, we know Traveller women tend to marry young and this can be used an indicator for early family formation. Fecundability can be linked to breastfeeding practices (Menken and Rahman, 2006). The ESHRE Capri Workshop Group (2001) defined fecundability as the probability of achieving a pregnancy within one menstrual cycle. In the case of the Travellers, as suggested in Technical Report 1, the reported breastfeeding uptake is low, which does not support the case of fecundability. The AITHS census report showed that 40.8% of Travellers in ROI and 50.4% in NI had used the contraceptive pill. This has a strong age pattern with women in the 30 to 44 years age group most likely to be on the contraceptive pill.

The rapid economic growth during the last 10 years has seen much socio-economic change and modernisation of the Irish State. However, there is no record of how this socioeconomic change has affected the Travellers. In order to make a valid comparison with the 1987 fertility rates, the comparative fertility-related socioeconomic indicators must be recorded similarly. However, this is not possible due to the difference in survey methods between the AITHS and the 1987 study. Another method to view this change is through the Traveller's own perception. The AITHS Consultative Study (see Technical Report 3: part A) suggested urbanisation of Travellers in certain areas. Furthermore, there has been recorded change in culture and lifestyle of Traveller women.

The Consultative Study describes various sociological changes that have occurred in the lives of Irish Travellers. This has been described as a community in 'transition'. This sociological 'transition' should not be confused with population demography transition.

Notestein (1957) proposed the theory of demography transition whereby all societies initially started off with high fertility and high mortality. During society development, mortality rates fell due to public health advances, while fertility rates remain high. This resulted in an explosion of population growth until at some point in time when the birth rates also started to decline, thus reaching a new equilibrium at low fertility and low mortality levels. However, this theory has not been able to fully explain some of the demographic changes occurring in the developing world. In order for this mortality decline, there has to be certain level of socio-economic development (Coale and Watkins, 1986). Menken and Rahman (2006) argue that there may not necessarily be a specific sequence to this or specific societal development, as has been experienced by some low- and middle-income countries.

Development of primary health care projects for Travellers may have an impact in increasing the sexual knowledge and health of Traveller women. However, this study did not include the evaluation of such projects. The use of contraception may contribute to the drop in the fertility rates of Traveller women, however it should be cautioned that there may be other factors which have not been investigated.

8. Conclusion

The current study demonstrated that Traveller births recorded in the birth cohort study are close to that estimated. The average age of Traveller mothers has not changed since 1987, however the average age of mothers in the general Irish population has increased. The difference in average maternal age is similar when compared to other minorities in Australia and New Zealand.

There has been a drop in the number of births to Travellers in 2008 when compared to 1987. The crude birth rate, general fertility and total fertility rates have all dropped among the Travellers in ROI. Comparison was not made for the Travellers in NI with regards to the 1987 study as the 1987 study only referenced to the Travellers in ROI. From this study, we have demonstrated that Travellers in NI have lower birth rate and general fertility rate compared to the Travellers in ROI. The total fertility rate of Travellers on the island of Ireland is still high compared to the general population, and still one of the highest in Europe.

The birth cohort study is currently ongoing and has many challenges that require the continued commitment and effort from all its multi-disciplinary team members.

Appendix A: Calculations for the Estimated Traveller Births

Estimate Based on the 2006 Census

In 2006, the Central Statistics Office (CSO) carried out the National Irish Population Census. For the first time, a specific ethnic identifier for the Traveller was included. The 2006 Census showed there was a total of 22,435 Travellers in the Republic of Ireland (CSO, 2007, pp38). The general Irish population at the time was 4,239,848. (CSO, 2007). There were 743 infants under one year old in the Traveller population (CSO, 2006, pp37).

For the All Ireland Traveller Health Study, the study team had initially estimated the population of the Travellers on the Island of Ireland to be 40,000 (cf Technical Report 1). The 2006 Census of 22,435 Travellers was only 56% of the estimated 40,000. By this convention, the under-1-year-old figure for the Traveller community should be factored up to give an estimated 1,324. This was the estimated number of births for a year.

Estimate Based on the 1986 Travellers' Health Status Study

In 1986, the Health Research Board commissioned the first Traveller health study, The Travellers' Health Status Study. The study had a census component which showed the population of the Travellers at that time was 15,888 in ROI. There were 544 live Traveller births recorded in the study during that year. The crude birth rate (per 1,000 population) calculated was 34.9 for Travellers and 16.6 for ROI. Based on the Department of Health and Children's 2005 Vital Statistics Report, the crude birth rate for the general population was 14.8 in 2005.

The 2005 crude birth rate was used as this was the most up-to-date data available when the initial calculation was carried out for the study proposal. Comparison of the crude birth rates of the general Irish population in 2005 and 1986 against the 1986 Traveller crude birth rate showed the crude birth rate for the Travellers was 2.1 times (2005) and 2.3 times (1986) that of the general population in Ireland (Table 8).

Table 8: Crude Birth Rate and ratio in 1986 and 2005 for the Traveller Health Status Study and Vital Statistics Report

Indicator	1986		2005	
	Travellers' Health Status Study	Vital Statistics Report (ROI)	Estimated for AITHS	Vital Statistics Report (ROI)
Crude Birth Rate (per 1,000 population)	34.9	16.6	31	14.8
Crude Birth Rate compared to 1986 Travellers' Health Status Study	1	2.3	1.1	2.1

For the AITHS, as previously mentioned, the study team estimated that there were 40,000 Travellers on the island of Island. The Irish national crude birth rate for 2005 was 14.8, which was 89% of the 1986 rate (16.6). By assuming that the Travellers too have had a similar percentage drop in their birth rate, then this would bring the estimated crude birth rate from 34.9 to 31. For an estimated total population of 40,000, this meant the estimated number of birth was projected to be 1,240 for the whole of Ireland.

Hence the estimated number of births for the study derived from the 2 sources was set at between 1,240 and 1,327.

Population Data from AITHS Census 2008

The All Ireland Traveller Health Study census provided another set of data which was utilised for population estimate. This included age-specific population count and number of pregnant women at the time of census.

All Ireland Traveller Health Study 2008 Census: number of pregnancies with potential live births

The number of pregnant women identified during the census should, after adjustment for miscarriage and stillbirths, give a general estimate of the potential number of births during the birth cohort study recruitment period.

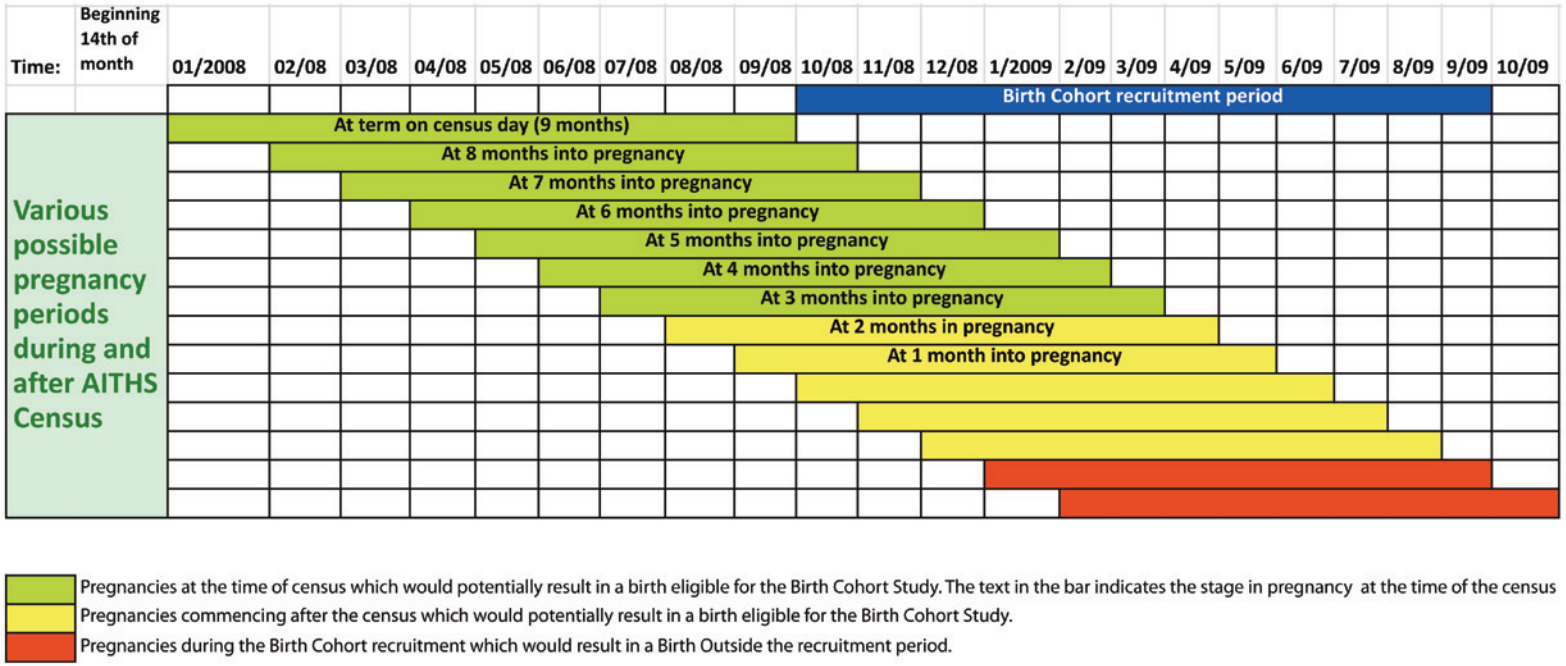
670 families reported presence of a pregnant woman in the household during the AITHS census in ROI, and 42 in NI. In order to estimate the 'true' number of pregnancies, adjustment was made for under-ascertainment of families during the census and possible double counting (Table 9).

Table 9: Actual number of reported pregnancies during the Census and adjusted Census-reported estimate

Region	Census	Adjusted estimate
ROI	670	833
NI	42	45
Total	712	878

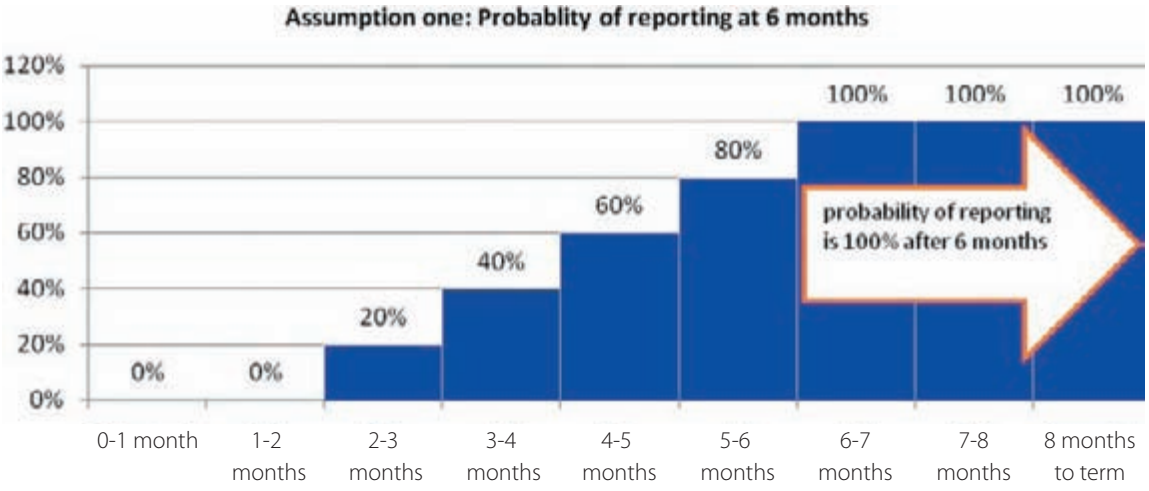
The self-reporting of pregnancy may vary from 2 months at the earliest to due date of 9 months (Figure 24). This reporting variation may depend on individual and cultural norms; some may not report the pregnancy until quite late into the pregnancy. There is no documented cultural norm for the declaration of pregnancy amongst Travellers. Some believe this may well be as late as 6 months into the pregnancy.

Figure 24: Schematic representation of pregnancy period and potential outcome period for birth cohort study



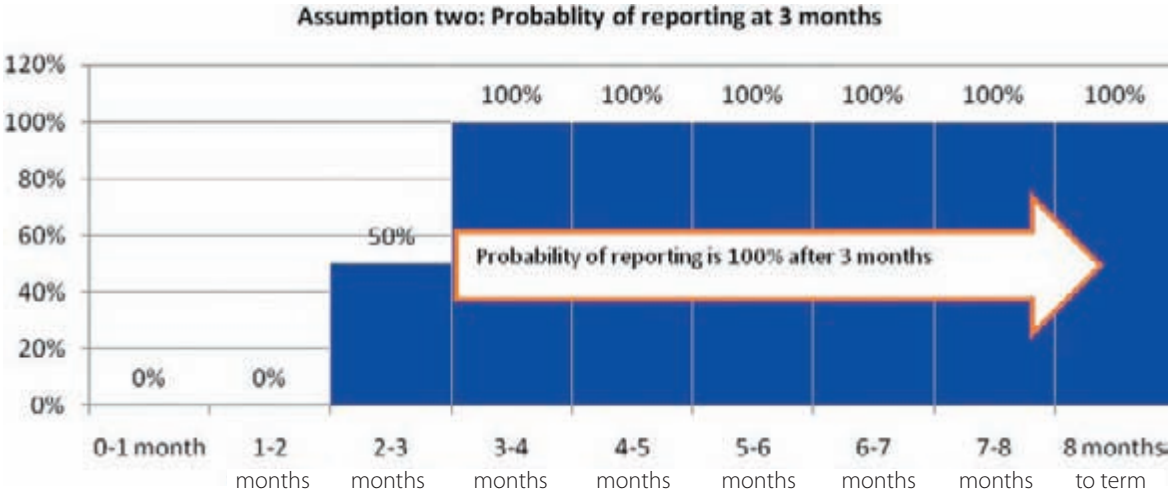
For the purpose of calculation, we first assume all pregnancies over 6 months at the time of census would be reported to us and that the probability of pregnancy reporting dropped for earlier months of pregnancy. We also assume that there is no reporting at 2 months or less. We then assume a linear drop between these two extremes. Figure 25 shows the probability of pregnancy reporting by month of pregnancy given these assumptions. For instance at 3 to 4 months we expect 40% of pregnancies to be reported to us and from 6 months onwards 100% to be reported. Births in the first 9 months of the birth cohort study can only arise from these women who were pregnant during the census. Averaging the monthly probability of reporting over the 9 month period (100 + 100 + 100 + 80 + 60 +40 + 20 + 0 + 0 = 500) we obtain a monthly average of 55% (500/9). This means that 55% of pregnancies over next 9 months were reported to us at census; this relates to the adjusted estimate of 878 pregnancies that should have been reported to us (Table 9). This leads to 1,596 pregnancies over 9 months or 177 births per month. This gives rise to an estimated 2,128 potential births over the 12-month period.

Figure 25: Probability of reporting pregnancies at 6 months



We repeated this with the alternative assumption that all pregnancies were reported from 3 months onwards. This gives rise to the monthly probability of reported pregnancies as shown in Figure 26. Averaging the monthly probability over a 9-month period (100 + 100 + 100 + 100 + 100 + 100 + 50 + 0 + 0 = 650) we obtain a monthly average of 72.2%. This means that 72.2% of pregnancies over next 9 months were reported to us at census. Applying this to our adjusted estimate of 878 births reported to us (Table 9) leads us to 1,216 births over 9 months, or 135 births per month. This gave rise to 1,621 potential births over the 12-month period.

Figure 26: Probability of reporting pregnancies at 3 months



So far in the calculations it is assumed that all pregnancies resulted in live births. However, these are overestimated figures, as these include miscarriages and stillbirths. The stillbirth rate (per 1,000 total births) among Travellers was 19.5 (CI 12.6-26.4) in 1986 compared to 6.9 in the general Irish population (Barry, 1996).

Miscarriages must also be taken into account in this calculation. A conservative figure for miscarriage rate in all pregnancies is 15 to 20% (Royal College of Obstetricians and Gynaecologists, 2006), although this may be as high as 30% in early pregnancies (Wilcox *et al.*, 1988; Whittaker, 1983). Miscarriage rates may also vary with ethnic groups. The miscarriage rate of African-Americans is higher than the white-American (Price, 2006). Parry (2007) reported significantly higher reported miscarriages in Gypsies and Travellers (29%) compared to settled group (16%), although there was no specific miscarriage rate suggested. All the published figures were for reported clinical pregnancy not taking into account the unreported miscarriages in the community; this may be difficult to ascertain (McLaren and Shelley, 2002; Royal College of Obstetricians and Gynaecologists, 2006; Savitz, 2006).

To estimate births, we first remove the miscarriage loss based on published rates; 20% of the estimated pregnancies were removed to account for this. The stillbirth rate of 19.5 per 1000 births was then applied after the miscarriage rate. This results in the final estimated births range illustrated in Table 10.

Table 10: Estimated pregnancies from the AITHS census and estimated births, adjusted for miscarriage and stillbirth rate

Assumption: reported pregnancy by gestation month	Estimated pregnancies	Miscarriage rate (20% of all pregnancies)	Stillbirths (19.5 per 1,000 births)	Final estimated births
Reporting of pregnancies at 6 months	2,128	426	33	1,669
Reporting of pregnancies at 3 months	1,621	324	25	1,272

Therefore, based on reported pregnancies in the AITHS census, the birth estimate ranges from 1,272 to 1,669.

All Ireland Traveller Health Study 2008 Census: Under-1 to 3 Years Old Demography

Based on the 2008 AITHS data, the population of Travellers from under-1 year old to 3 years old was obtained (Table 11). As mentioned in the AITHS census, 9,056 Travellers families in ROI and 1,562 families in NI were identified. The response rate was 78% in ROI and 93% in NI. In ROI, the average family size of the 7,042 families was 4, while the average family size in NI was 2.5. To derive an overall estimate of true total Traveller population, the enumerated families (9,056 in ROI and 1,562 NI) was multiplied by the average family size. This derived the estimated population of Travellers at 36,224 in ROI and 3,905 in NI (Figure 27). The estimated under-1 to 3-year-old population was based on this calculation. The final total number of under-1 to 3–year-old for IOI is shown in Table 12.

Table 11: Numbers of under-1-year-old to 3-year-old for ROI and NI during census; and final estimated number

Area	Age group	Census	Estimated
ROI	Under-1 year old	508	837.5
	1 year old	734	1,210.0
	2 year old	789	1,300.7
	3 year old	695	1,145.7
NI	Under-1 year old	21	24.2
	1 year old	85	97.9
	2 year old	98	99.1
	3 year old	84	96.7

Figure 27: Population estimate and adjustment made for the AITHS census and the birth cohort study

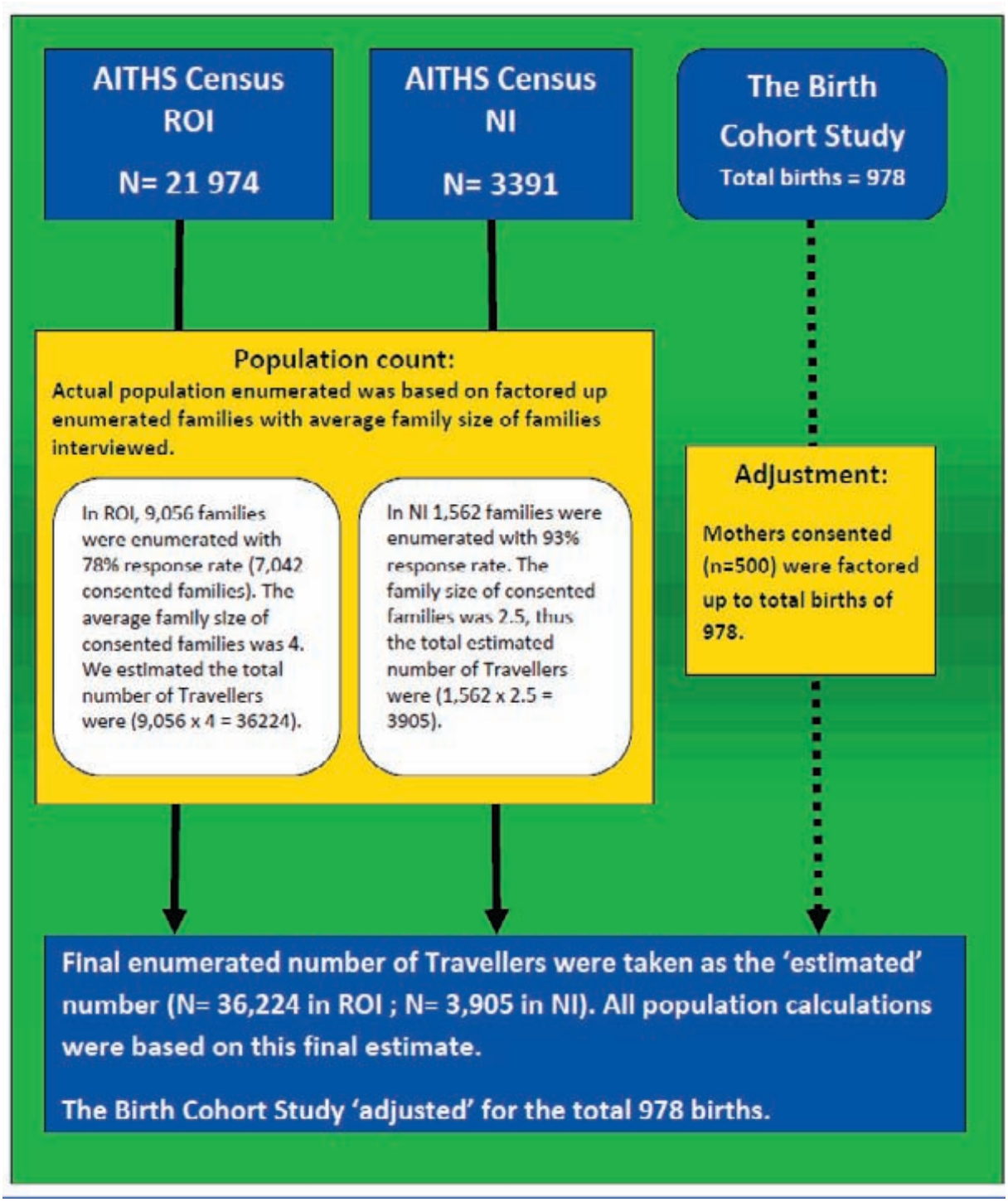


Table 12: Population estimate from the All Ireland Traveller Health Study 2008: ROI and NI

Age Group	Republic of Ireland (estimated)	Northern Ireland (estimated)	Total for island of Ireland (estimated, round up)
Under-1-year-old	837.5	24.2	862
1-year-old	1,210.0	97.9	1,308
2-year-old	1,300.7	99.1	1,400
3-year-old	1,145.7	96.7	1,242

Table 13: Population number of children from under 1 year old to 3 years old of Traveller children according to the 1986 Travellers' Health Status Study, 2006 national census and 2008 AITHS

Age Group	1986 Travellers' Health Study	2006 National Population Census	2008 AITHS (estimate)
Under-1-year-old	447	743	862
1-year-old	590	665	1,308
2-year-old	686	650	1,400
3-year-old	652	623	1,242

The AITHS census showed a larger number of Traveller population of under-1-year-old to 3-year-old compared to the 1986 Travellers' Health Status Study and the 2006 national population census (Table 13). The 1986 Travellers' Health Status Study and AITHS census both showed a decrease in the number of children from 3 years old to under-1-year-old. The AITHS census, however, showed a larger number in the under-1 to 3 years old population probably due to the better uptake of the study compared to the 1986 study. This was a reverse of the 2006 National census, which showed an increase in Traveller population of under a year old. We considered whether the smaller number of 862 in the AITHS census could be due to the under-reporting of under one year olds by the Traveller population (compared to the other age groups). The demography for the 1- and 2-year olds showed a population of approximately 1,200 to 1,400. The 3-year-old population showed a drop to 1,242. Taking this trend in the under-1-year old to 3-year-old demography from the 2008 AITHS census, assuming there was a constant mortality rate among this age group, the study estimated that there should be 800 to 1,400 Traveller births on the island of Ireland.

The study team had to review the estimated number of births based on these various resources. The range of the estimate varied from 1,000 to 1,400 births. Therefore, the study team decided that the 'corrected' estimated number of Traveller births was between 1,000 and 1,400 for the island of Ireland.

Appendix B: Calculation for Crude Birth Rate

The calculations for the annual crude birth rates are shown below:

Annual Crude Birth Rate: Island of Ireland
Total Traveller births: 978
Total Traveller population: 40,129
Annual Crude Birth Rate = (978/40,129) x 1,000 = 24.4

Annual Crude Birth rate: Republic of Ireland
Total Traveller births: 911
Total Traveller population: 36,224
Annual Crude Birth Rate = (911/36,224) x 1,000 =25.1

Annual Crude Birth Rate: Northern Ireland
Total Traveller births: 67
Total Traveller population: 3,905
Annual Crude Birth Rate = (67/3,905) x 1,000 = 17.1

Appendix C: Calculation for Fertility Rate

This section describes:

- The General, Age-specific and Total fertility Rates for Travellers on the island of Ireland (ROI and NI combined).
- The General, Age-specific and Total Fertility Rates for Travellers in the Republic of Ireland
- The General Fertility Rate of Travellers in Northern Ireland.

It was estimated that the AITHS census was successful in sampling 78% of the population in ROI and 93% in NI. Those who refused to consent were not included in the census. Women aged between 15-49 years old identified in the census were categorised into 5-year age groups (Table 14). As the AITHS census captured 78% of the census, it was appropriate that the total Traveller population was adjusted to make up to 100% of the estimated Traveller population in ROI. For NI, this was adjusted from 93%. This is with the assumption that the demography of those not captured was the same as those sampled in the census.

For crude birth rate by THU, a similar method was employed where the total number of births from the birth cohort study was used as the denominator while the population (as numerator) was taken and adjusted from the AITHS census.

Fertility Rates of Travellers on the island of Ireland:
For the calculation of the general, age-specific and total fertility rates of the Travellers on the island of Ireland, the population data from the AITHS census and the birth cohort study were combined.

From the population census, women in the 15-49 age groups were selected and adjusted according to the under-ascertainment from the census (78% for ROI and 93% for NI). This is illustrated in Tables 14 and 15.

Table 14: Population of Traveller women 15-49 years old according to 5-year age group from AITHS census and the population after adjustment made for under-ascertainment during AITHS census

Age Group (years)	AITHS census 2008	Estimated
Republic of Ireland		
15-19	1,203	1,983.1
20-24	1,090	1,796.9
25-29	985	1,623.8
30-34	776	1,279.2
35-39	705	1,162.2
40-44	526	867.1
45-49	412	679.2
Northern Ireland		
15-19	190	218.8
20-24	226	260.2
25-29	159	183.1
30-34	122	192.3
35-39	123	141.6
40-44	99	114.0
45-49	50	57.6
Total	6,666	10,559.2

Table 15: Summary of the Total (adjusted) Traveller women in 15-49 age groups for ROI and NI according to 5-year age group

Age Group (years)	ROI (estimated)	NI (estimated)	Total (estimated) census population
15-19	1,983.1	218.8	2,201.9
20-24	1,796.8	260.2	2,057.1
25-29	1,623.8	183.1	1,806.9
30-34	1,279.2	192.3	1,471.5
35-39	1,162.2	141.6	1,303.8
40-44	867.1	114.0	981.1
45-49	679.2	57.6	736.8
Total	9,391.5	1,167.7	10,559.2

From the birth cohort, the participants' ages were categorised and then adjusted for the refusals. This is illustrated in Table 16.

Table 16: Total consent and refusals in the birth cohort study (ROI and NI), and final total numbers of mothers in cohort after adjustment for refusals

Age group (consent) (years)	The birth cohort study	Total number of mothers for birth cohort adjusted for refusals (ROI +NI)
15-19	62	124.5
20-24	156	318.5
25-29	140	285.8
30-34	85	173.5
35-39	32	65.3
40-44	5	10.2
45-49	0	0
Missing	22	-
Refusals	464	-
Total	978	978

For general fertility and total fertility rate according to THU, the number of births from the birth cohort study was categorised according to their THU region. The THU population was taken from the AITHS census and factored up for estimated population in each THU.

General Fertility Rate for Travellers on Island of Ireland

The general fertility rate for the Travellers on the island of Ireland was 116.11. The calculation for this was derived from the total number of births and the total adjusted female Traveller population in the 15-49 age groups.

Total Traveller births on IOI: 978
Total 15-49 years old female (adjusted): 10,559.17
General Fertility Rate for Travellers on the island of Ireland= (978/10,559.17) x 1,000
= 92.62

Age-specific Fertility Rate and Total Fertility Rate for Travellers on the Island of Ireland

The age-specific fertility rate and the total fertility rate were derived from the breakdown of the female population age 15-49 into 5 years age group. Table 17 shows the adjusted rates for these.

Table 17: Total (adjusted) female population age 15-49 after adjustment for ROI and NI, total number of mothers in birth cohort study adjusted after refusals and age-specific fertility rate for the Travellers on the island of Ireland

Age group (years)	Total (adjusted) census population (ROI +NI) (a)	Total number of mothers for birth cohort adjusted for refusals (ROI +NI) (b)	Age-specific fertility rate (per 1,000 pop) (b/a x1,000)
15-19	2,201.9	124.5	56.6
20-24	2,057.1	318.5	154.8
25-29	1,806.9	285.8	158.2
30-34	1,471.5	173.5	117.9
35-39	1,303.8	65.3	50.1
40-44	981.2	10.2	10.4
45-49	736.7	0	0
Total	10,559.1	978	--

For the age-specific fertility rate for Travellers on the island of Ireland, the total number of mothers for birth cohort adjusted for refusals was divided by the total Traveller women according to the same 5-years age category. This is laid out in Tables 17, column 4.

For total fertility rate, the formula used was:

Total Fertility Rate = (Total of Age-specific Fertility Rate x5) / 1,000
= (548.05 x5) / 1,000
= 2,740.25 / 1,000
= 2.74

Thus the total fertility rate of Travellers on the island of Ireland was 2.74 per 1,000 women.

Fertility Rates of Travellers in the Republic of Ireland

Total fertility rate of Irish Travellers from the 1986 Travellers' Health Status Study was 5.3 (Barry, 1996) (Table 18).

To calculate the fertility rates of the Traveller population for 2008, data were derived from the birth cohort study and the All Ireland Traveller Health Study (AITHS).

Table 18: General fertility rates, total fertility rates and age-specific fertility rates of the general Irish population in 1987 and Travellers in 1986

	General Female Population ROI 1987	1986 Traveller Health Study
General Fertility rate (per 1,000 female population)	70.1	164.2
Total Fertility rate	2.3	5.3
Age-specific Fertility Rate:		
15-19	16.0	78.9
20-24	74.9	246.9
25-29	146.8	274.9
30-34	133.8	250.0
35-39	69.1	148.0
40-44	20.8	53.1
45-49	1.2	11.1

A similar method of adjustment was used as per the previous section on fertility rates for the island of Ireland. To account for under-ascertainment, the original census data was factored up to arrive at an estimated number for each 5-year age group (Table 19).

Table 19: The birth cohort study: 5-year age distribution of Traveller women between age 15 and 49 from the AITHS census and the assumed total population for ROI

Age group (years)	AITHS census 2008	Total estimated population for Traveller females 15-49 years old adjusted for under-ascertainment
15-19	1,203	1,983.1
20-24	1,090	1,796.9
25-29	985	1,623.8
30-34	776	1,279.2
35-39	705	1,162.2
40-44	526	867.1
45-49	412	679.2
Total	5,697	9,391.5

From the birth cohort study, all consenting mothers were categorised according to the 5-year age groups (Table 20). These consenting mothers comprised 51.6% of the total mothers who gave birth during this period. The number of consenting mothers was adjusted to make up for the 911 of all births in ROI, with the assumptions made that the mothers who refused had the same age distribution as those mothers who consented.

Table 20: The birth cohort study: number of consenting mothers in the birth cohort and adjusted number of Traveller mothers by age group

Age group (years)	Numbers of participants who consented in the birth cohort study (ROI only)	Total number of mothers for birth cohort adjusted for refusals (ROI only)
15-19	57	115.1
20-24	146	294.9
25-29	135	272.7
30-34	81	163.6
35-39	27	54.5
40-44	5	10.1
45-49	0	0
Missing	21	-
Total Consent	466	-
Total Refusal	445	-
Total Cohort (consent, refusal)	911	911

General Fertility Rate: Republic of Ireland

The general fertility rate for ROI was derived from the total Traveller birth in 2008 against the total female population age 15-49 years. This is illustrated below:

The General Fertility Rate for Travellers in ROI (2008) = (911/9,391.4681) x1,000
= 97.00

Age-specific and Total Fertility Rates: Republic of Ireland

For the age-specific fertility rates, the total estimated number of mothers for the birth cohort study (after being factored upwards for under-ascertainment) was divided by the total number of Traveller women in the same age group (Table 21, column 4).

Table 21: Total estimated female population by age group and total number of births to women in the birth cohort for 2008 among the Travellers and the calculated age-specific fertility rate

Age group (years)	Total estimated population for Traveller women age 15-49 (a)	Total adjusted number of mothers from birth cohort (b)	Age-specific fertility rates per 1,000 population (b/a x1,000)
15-19	1,983.1	115.1	58.1
20-24	1,796.9	294.9	164.1
25-29	1,623.8	272.7	167.9
30-34	1,279.2	163.6	127.9
35-39	1,162.2	54.5	46.9
40-44	867.1	10.1	11.6
45-49	679.2	0	0
Total	9,391.5	911	--

For the Total Fertility Rate, the formula below was used:

Total Fertility Rate = (Total of Age-specific Fertility rates x 5)/ 1,000

= (576.57 x5) /1,000

= 2.88

The total fertility rate among the Travellers (ROI only) for 2008 was 2.88 /1,000 women.

Age-specific Fertility Rates: Traveller Health Units

The age-specific fertility rates for each THU were calculated using the above method. The result of this is laid out in Table 22.

Table 22: Age-specific fertility rate according to THUs

THU	5-years age group						
	15-19	20-24	25-29	30-34	35-39	40-44	45-49
Eastern	34.8	187.2	168.9	82.9	10.8	26.5	0.0
Midland	49.4	132.0	89.1	49.5	6.1	29.2	0.0
Mid-Western	132.1	288.2	261.9	112.3	66.4	0.0	0.0
North Eastern	42.8	69.4	61.2	29.8	14.1	0.0	0.0
North Western	39.4	99.0	114.9	104.0	44.4	0.0	0.0
South Eastern	91.9	160.1	136.8	70.9	59.0	0.0	0.0
Southern	49.7	126.1	78.7	15.6	0.0	0.0	0.0
Western	69.2	174.9	322.1	64.3	24.9	0.0	0.0

Fertility Rates: Northern Ireland

The calculation for age-specific fertility rates and total fertility rate were not carried out for NI due to the size of the data. The general fertility rate for NI is discussed below.

The AITHS census (2008) for Northern Ireland identified 3,905 Travellers in NI with a 93% ascertainment rate. Of these, 1,014 were women aged 15-49 years old. To adjust for under-ascertainment, the total 15-49 years old female population was estimated to be 1,167.7.

The general fertility rate for Travellers in Northern Ireland was 57.4. Calculation for this is as per below.

Calculation for General Fertility Rate in Northern Ireland:

Total Traveller Births: 67
Total population of female Travellers 15-49 years (AITHS census 2008): 1,014
Total population of female Travellers 15-49 years (adjusted for under-ascertainment): 1,167.7
General Fertility Rate for Travellers in Northern Ireland (2008) = (67/1,167.7) x 1,000
= 57.4

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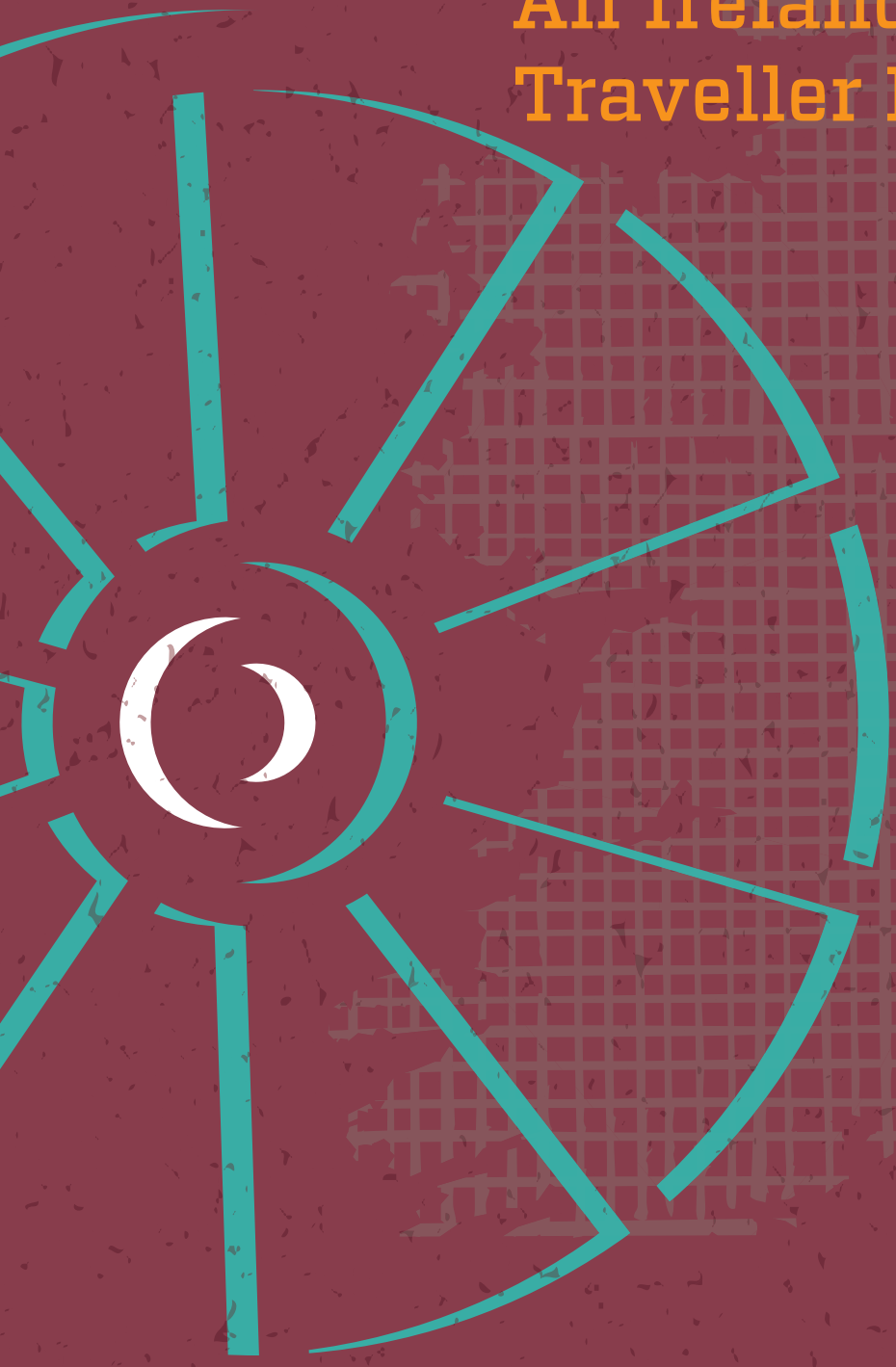
All Ireland Traveller Health Study

Our Geels



Travellers in Institutions

All Ireland Traveller Health Study

Travellers in Institutions
Part C of Technical Report 2

September 2010

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Summary

Due to low numbers and lack of an ethnic identifier it was not possible to extend the AITHS into most types of institutions. However, because recent Republic of Ireland (ROI) national census data shows that over 140 Irish Travellers were resident in prisons, and because Travellers sometimes self-identify in prisons for accommodation purposes, the study was extended into prisons in ROI.

The health of prisoners is a cause for concern globally, with high prevalence of mental health disorders, addiction and substance abuse, communicable diseases and chronic diseases. Despite the challenges to providing health services in a custodial environment, health service provision in prisons is a global public health priority and there have been significant developments in the Irish Prison Service (IPS) in this regard in recent years.

For the census all prison Governors in ROI were asked to provide the number of Travellers that they estimated to be resident in their prison during the AITHS census. The number of Traveller men estimated by the IPS to be in prison (299) was nearly double that reported through the census by Travellers themselves (150), however, the IPS-estimated number of Traveller women prisoners (21) was much closer to that reported by their families (18). Notwithstanding these differences, this study confirms that Travellers are over-represented in prison compared to the non-Traveller population, and according to Traveller families' responses to the AITHS census, Travellers comprised 4.6% of the prison population during the census as compared to 0.9% of the ROI population. The risk of a Traveller man being imprisoned was at least 5 times that of a non-Traveller man, and the risk for a Traveller woman was 18 times that of a non-Traveller woman.

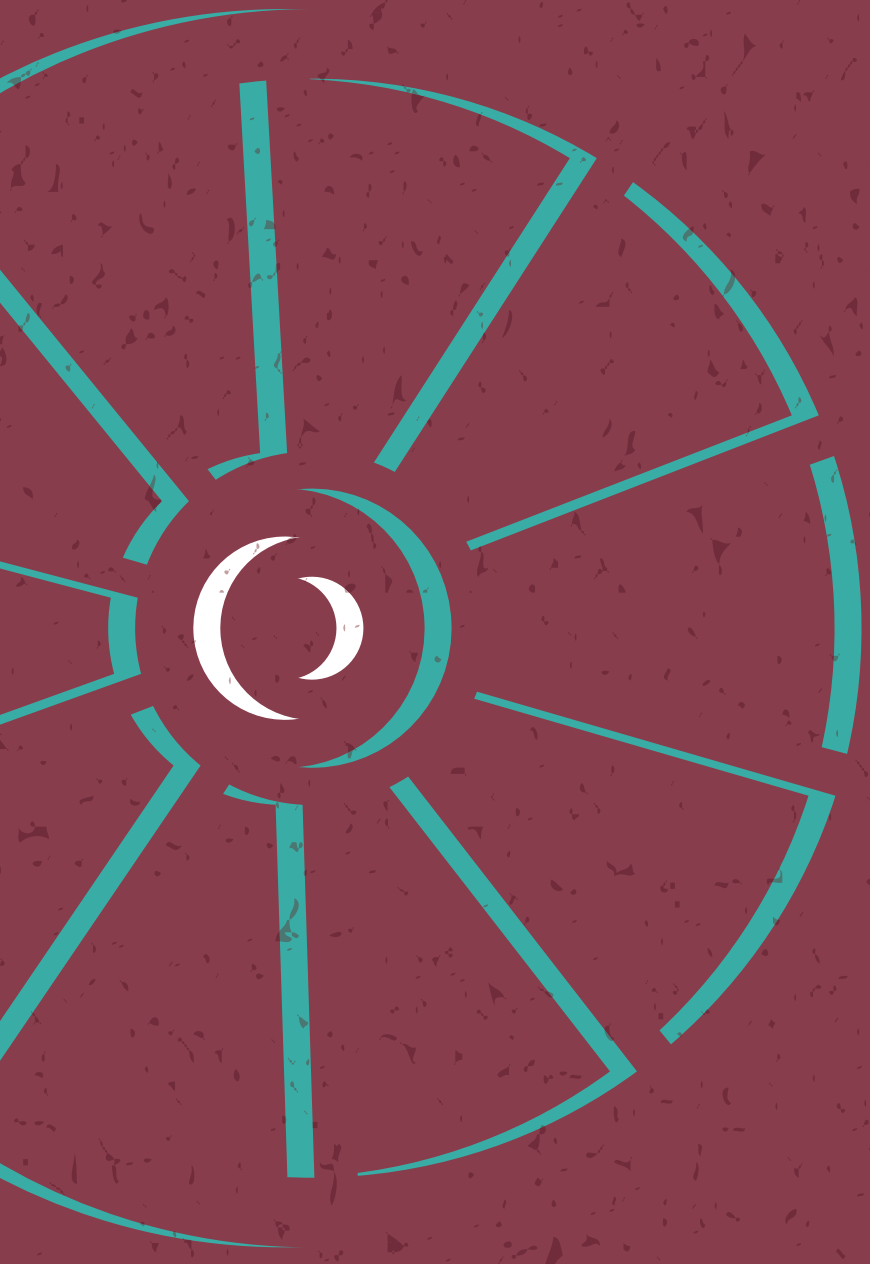
For the health status study, despite cooperation of all parties, because of low recruitment rates and data limitations the study could not be completed. However, valuable lessons that will benefit planning future research in this area were learned.

Table of Contents

List of Tables

List of Figures

Travellers in Institutions



1. Introduction

This part of the report describes the AITHS follow-up on Travellers resident in institutions or communal establishments at the time of the census.

The Republic of Ireland (ROI) national census results of 2002 and 2006 suggest that very small numbers of Travellers are resident in institutions; the types of institutions with the highest numbers of Traveller residents were hospitals, hostels, shelters, refuges and prisons (Central Statistics Office, 2004 and 2007c) (Table 1).

Table 1: Travellers enumerated in communal establishments in ROI censuses 2002 and 2006

Type of establishment	No of Institutions[1]		Total enumerated[1]		Travellers enumerated[1]		Travellers as % of total in Institution	
	2002	2006	2002	2006	2002	2006	2002	2006
Prison	20	15	3,237	3,133	194	145	5.9%	4.6%
Hospital	229	244	23,219	22,689	160	110	0.7%	0.5%
Shelter/Refuge/ Hostel	384	189	7,472	5,681	113	81	1.5%	1.4%

[1]Source of data: Irish censuses 2002 and 2006 (CSO, 2003b, 2004, 2007b, 2007c)

Extending the study to Travellers resident in institutions posed a challenge due to the low numbers of Travellers and the large numbers of institutions.

Inpatient stays in hospitals are temporary and normally relatively short, and in the absence of an ethnic identifier within hospital data systems, identification of Travellers in hospital and consequent follow-up was not possible or feasible. The need for an ethnic identifier for this purpose has previously been highlighted (Traveller Health Unit Eastern Region, 2000).

It is recognised that there is a difference between homelessness and inadequate accommodation for Travellers, that Travellers present to homeless services and that homelessness is a growing issue for Travellers; however, the extent of the problem is not fully known (Pavee Point, 2006). Due to lack of an ethnic identifier or ethnic monitoring within homeless services, and the likelihood that Travellers who are homeless are cut off from their families, Travellers in hostels are difficult to identify, even by the homeless service providers themselves (Kennedy, 2007).

Travellers are over-represented in young people leaving state care in ROI, accounting for 9% of those leaving the care of Health Boards and 12% of those leaving the care of the Special Schools system (Kelleher *et al.*, 2000). Travellers constituted approximately 12% of the total male Detention School population between 1991 and 2007 (Carr, 2009). Despite this over-representation, identification of Travellers in this population at any given time is not feasible.

Irish Traveller is not a category within the Irish Prison Service IPS data management system; however, it is known that Travellers are over-represented in the prison population. In the 2002 and 2006 Censuses, while Travellers represented approximately half of one percent of the total ROI population, Traveller prisoners (Table 1) comprised 5.9% and 4.6% respectively of the prisoner population (Central Statistics Office, 2003b, 2004 and 2007b, 2007c). Routine prison statistics do not identify Travellers in prison, thus Irish Travellers are likely to be counted as having Irish or UK nationality. This comprises 92.2% of ROI prisoners (Irish Prison Service, 2009a). However, the Forensic Mental Health Service (FMHS) routinely establish ethnicity, and in a study of 352 committals to Cloverhill prison over a 4-week period in 2000, Travellers accounted for 6% of male and 4% of female committals, and male and female Travellers had a relative risk of imprisonment compared to the settled community of 17.4 (95% CI 2.3-131.4) and 12.9 (95% CI 1.7-96.7) respectively (Linehan *et al.*, 2002). In 2002, 4.2% of remand prisoners self-identified as Travellers (Linehan *et al.*, 2005). In a 2003 study, Travellers were over-represented among both male sentenced and remand committals accounting for 5.4% of the sample, and among female committals accounting for 10.6% of the sample; both proportions compared to 0.6% in the community (Kennedy *et al.*, 2005).

The majority of the AITHS census survey of Irish Traveller families in ROI was carried out during a 6-week period commencing 14th October, 2008. A census question asked participating Travellers whether any of their family members was resident in an institution during the time period of the census. The range of possible institutions included: hospitals, long-term care (nursing homes), children's homes/in care, psychiatric care, hostels, Bed and Breakfast (B&B) accommodation, refuges, respite care, prisons, corrective institutions and homeless institutions. Results for ROI are shown in Table 2.

Table 2: Travellers in institutions in ROI as reported by Travellers in AITHS ROI census 2008

	Numbers in Institution	% of total Traveller Population[1]
Hospital	57	0.16
Long term care	65	0.18
Children's Home	41	0.11
Psychiatric care (Mental Hospital)	27	0.07
Hostel	13	0.04
Bed & Breakfast	3	< 0.01
Prison	168	0.46
Homeless	13	0.04
Corrective institution for young people	3	< 0.01

[1] Source: AITHS Census report: Traveller population 36,224

The AITHS census results are consistent with national censuses in ROI for 2002 and 2006, which enumerated very small numbers of Travellers in hospitals (160 and 110 respectively) and nursing/children's

homes (63 and 67 respectively) relative to the number of such institutions in the country. The numbers of Travellers in hotels, B&Bs and educational establishments were in single digits. Even if the numbers were greater, or the number of institutions smaller, in the absence of an ethnic identifier it was not feasible to ask persons in charge of most institutions to undertake a census of the number of Travellers in their institution. This was identified as an area which would prove challenging in the demographic advice provided for the AITHS project (Kobayashi, 2006).

Census reports in Northern Ireland (NI) provide information on the population that are resident in communal establishments (1.4%) and the proportion of the full population that are Irish Travellers (0.1%); however, the proportion of institutional residents that are Irish Travellers is not reported (Northern Ireland Statistics and Research Agency, 2002). The average number of prisoners in custody in NI in 2008 was 1,493, comprising 1,442 men and 51 women (Northern Ireland Prison Service, 2009). The number of institutional residents likely to be Irish Travellers was too low to permit follow up in institutions in NI (Northern Ireland Statistics and Research Agency, 2002).

The 2006 ROI census identified that the largest number of Travellers were located in shelters/refuges (81) and prisons (144). The lack of ethnic identifier in homeless accommodation (Pavee Point, 2006) precluded any follow-up in that domain. Despite a recommendation to the Irish Prison Service in 2002 that the ethnic origin of all inmates, including Travellers, be recorded on reception (Fitzpatrick and Associates, 2002), the sub-category of Irish Traveller has not been included in the IPS database.

Use of an ethnic identifier to facilitate data collection and planning for Irish Travellers in a variety of institutional contexts from hospitals to homeless shelters and within the prison and forensic mental health systems, has been called for by stakeholder and research groups (Fitzpatrick and Associates, 2002; Linehan *et al.*, 2002; Kennedy *et al.*, 2005; Fountain, 2006; Pavee Point, 2006) and its absence limited the opportunities to extend the study to all institutions. However, because of the available information about the ROI Irish Traveller prison population (Central Statistics Office, 2004, 2007c and Kennedy *et al.*, 2005), and because prisoners often self-identify by asking to be accommodated near to other members of the community, this part of the study focused on a census, and the health status, of Travellers resident in adult prisons in ROI.

2. Prisoner Health

Health in prisons is a priority of global public and population health (Møller *et al.*, 2007). In this section, the literature relating to general prisoner health is reviewed, with reference to the situation in Ireland and among Travellers where information exists. Ethnic minorities are over-represented in prisons globally, and information on recognized minorities, such as Australian Aboriginals and New Zealand Maori is provided where relevant. An overview of the prison health services, which is delivered in a different manner to the health service for the general community, is also provided.

2.1 Health Problems of Prisoners

In the UK, Watson *et al.* (2004) identified the main prison health themes in the international literature as mental health, substance abuse and communicable diseases, recognising that these 3 themes are inextricably linked. They reported that prisoners bring a wide spectrum of health problems to prison, such as mental health problems, substance abuse, smoking, and communicable diseases, including hepatitis and HIV, and that the prevalence is often greater than in the general population. In addition, prisoners were also at risk of a number of health problems while in prison. Harris *et al.* (2006), in a wide-ranging literature review on the health needs of prisoners in England and Wales, found that prisoners were more likely to have suffered from some form of social exclusion than the general population and from significantly greater degrees of mental health problems, substance abuse and worse physical health. It was also noted that most of the literature on the health needs of prisoners addresses the health needs of all prisoners, thus focusing on the needs of the majority prison population of young white males; the needs of discrete groups, such as women, older prisoners and ethnic minorities may thus be limited when planning healthcare in prisons.

The first general healthcare study of the Irish (ROI) prison population (Centre for Health Promotion Studies NUI Galway, 2000), which had a high response rate of 88%, found differences in health status between prisoners and the general population, including lower self-reported levels of excellent or very good health. Other relevant differences highlighted were higher rates of current cigarette smoking, lifetime drug use and alcohol consumption among prisoners. While diet was comparable to the general population, exercise patterns were better. However, a considerable burden of chronic illness was noted despite the prison population being relatively young (mean age 27 years, and 70% aged less than 35 years). The study found high intake of prescription medication and high consultation rates with prison health services. It confirmed mental health, addiction, and infectious diseases as priority issues, and primary health care, including health promotion, as priority health needs for prisoners. Almost a third of prisoners had schooling to primary level only and half of males had been unemployed prior to detention. A separate literacy survey shows that a significant number of prisoners in ROI are illiterate (Morgan and Kett, 2003). In the Irish general population education status (Kelleher *et al.*, 2003) and social disadvantage (O'Shea and Kelleher, 2001; Kelleher *et al.*, 2002; Fitz-Simon *et al.*, 2007) are known to be predictive of poor self-rated health status and this has previously been confirmed for the Irish prisoner population also (Hannon *et al.*, 2007). More recently, a study of nursing in the IPS confirmed mental health, infectious diseases, chronic diseases, health promotion, primary care, education and prevention as ongoing predominant health needs themes (Health Service Executive, 2009).

2.1.1 Mental Health in Prisons

Mental health problems among prisoners are a global issue. There is a disproportionately high rate of mental disorders in prisons, often because disorders are present prior to imprisonment, but also because mental health disorders may develop during imprisonment due to many factors, such as overcrowding, solitude or lack of privacy (World Health Organisation, 2005). Research in this area tends to focus on the prevalence of mental health disorders among prisoners compared to the general community. Fazel and Danesh (2002) carried out a systematic review of 62 surveys involving 23,000 prisoners from 12 different countries, which confirmed that the mental health of prisoners is an international problem of increasing proportions; while rates varied, prisoners were 2 to 4 times more likely to have psychosis and major depression and 10 times more likely to have anti-social personality disorder than the general population. A systematic review (Sirdifield *et al.*, 2009), based mostly on UK research, but which also included international studies, found that the literature reported a wide range of prevalence rates for the major mental health disorders in prisons, and that this possibly resulted from the use of different diagnostic screening tools, including self-reports. However, a common pattern was that the incidence of mental health disorders was often found to be higher in women and in ethnic minority groups.

A survey of prisoners in England and Wales (Singleton *et al.*, 1998) found that while prisoners represented only 0.1% of society, most prisoners had mental health problems, with only 10% of prisoners showing no evidence of any of 5 disorders considered in the survey (personality disorder, psychosis, neurosis, alcohol misuse and drug dependence) and 70% with more than one of the listed disorders, with higher prevalence for each disorder than in a similar survey of the general population. The rate of diagnosed mental health problems among black and ethnic minority prisoners was lower than among white prisoners. In Australia prevalence of any psychiatric disorder among prisoners is 80% compared to 30% in the community (White and Whiteford, 2006).

In New Zealand, despite over-representation within prison, no significant differences were found in lifetime rates of mental disorder between Māori and other ethnic groups (Tapsell and Mellsop, 2007). In a qualitative study of mental health in prisons in the English Midlands, Durcan (2008) identified a wide variety of issues impacting on mental health for prisoners including (a) pre-prison: chaotic lives prior to being in prison, often including abuse and homelessness, and a history of mental ill-health; (b) prisoner experiences: being in prison, separation, bullying, lack of someone to trust, self-harm, worries about children, having nothing to do; and (c) gaps in service provision including poor mental health screening and limited support for prisoners' mental health. On a positive note, inreach services were found to be making a difference.

In ROI, mental health issues among prisoners were noted in the General Healthcare Study of Prisoners (Centre for Health Promotion Studies NUI Galway, 2000), with nearly half of men and 75% of women prisoners considered 'cases' (using General Health Questionaire-12), i.e. may be significantly in need of psychiatric treatment, and 37% of men and 64% of women prisoners describing themselves as moderately or extremely anxious or depressed. Issues for Irish prisoners' mental health were most recently highlighted in the Report of the Expert Group on Mental Health Policy – A Vision for Change

(Department of Health and Children, 2006), which described the role of the Forensic Mental Health Services (FMHS), which is primarily concerned with the mental health of persons who come into contact with law enforcement agencies, the Garda Síochána, the Courts and the Prison Service. The FMHS operates an inreach service to prisons, with psychiatrists and forensic nurses visiting prisons on a routine basis, and arranging transfers to the Central Mental Hospital or other psychiatric hospitals as necessary.

Prisons also provide services in the areas of psychology service and social work (probation and welfare) which are relevant to mental health. Research carried out by the FMHS demonstrates the extent of mental health problems among prisoners: 19% of remand prisoners suffered from a mental illness, adjustment disorder or personality disorder during the screening process; 22% had been mentally ill in the 6 months prior to screening, and 31% had a lifetime psychiatric diagnosis (Linehan *et al.*, 2005). In another study rates for all mental illnesses combined ranged from 16% (committals) to 27% (sentenced) for men, and 41% (committals) to 60% (sentenced) in women; rates of psychosis were 3.9% for male committals to prison, 7.6% among those on remand and 2% among sentenced men; the rate of psychosis for women was 5.4% (Kennedy *et al.*, 2005). Linehan *et al.* (2005) found that 28% of remand prisoners had a lifetime history of deliberate self-harm. Prisoners were also found to have greater mental health co-morbidity and it was noted in FMHS studies that there is over-representation of Traveller and homeless populations within prisons.

Cemlyn *et al.* (2009) reported that, despite no supporting official statistics, in the UK staff that work with prisoners consider that Travellers and Gypsies are over-represented in prison suicides. In ROI prisons, 29 of the 43 deaths in custody between 1988 and 1996 were suicides, giving an average of 3 per year; this showed an increase on the average of 1 per year for the period 1980 to 1987 (Dooley, 1997). Of the 75 deaths in prisons between 2000 and 2008, 18 were confirmed suicides, and some inquest results are pending (Irish Prison Service, 2009a). There is no mention of any Traveller deaths in prison, possibly due to lack of an ethnic identifier, however Traveller groups have noted that Travellers in prison are a high-risk group for suicide (Pavee Point, 2005).

Traveller prisoners' mental health has been specifically highlighted in a number of the studies carried out by the FMHS (Linehan *et al.*, 2002; Kennedy *et al.*, 2005; Linehan *et al.*, 2005; Duffy *et al.*, 2006). In reviewing the case register of admissions for the three years 1997 to 1999, Travellers accounted for 3.4% of forensic psychiatric admissions compared to 0.38% of the general population at that time; it was noted that the over-representation in psychiatric admissions reflected an over-representation of Travellers among prison committals. Travellers were found to have more learning disability and less severe mental illness than other groups studied (Linehan *et al.*, 2002).

2.1.2 Substance Abuse in Prisons

Sirdifield's systematic review found that alcohol misuse is a major issue in prisons worldwide in addition to drug misuse, with studies reporting up to 67% of prisoners with a substance abuse disorder; furthermore, many offenders have used drugs during their current sentence (Sirdifield *et al.*, 2009). In Ireland, Dooley (1997) estimated the proportion of the prison population with a recent background of

major drug abuse at over 40%. The General Healthcare Study of Prisoners (Centre for Health Promotion Studies NUI Galway, 2000) identified that 72% of male and 83% of female prisoners had taken drugs at some stage in their lives, while 63% of males and 83% of female prisoners had taken drugs other than cannabis and marijuana within the previous 12 months. The report also noted that prisoners tended to be heavier and more frequent drinkers than the general population. Nearly half of Irish prisoners with a history of injecting drugs continued to do so while in prison, and 21% of prisoners who used drugs reported that they had started to inject while in prison (Allwright *et al.*, 2000). Linehan *et al.* (2005) and Kennedy *et al.* (2005) reported between 61% and 79% of prisoners to be addicted to alcohol or other drugs.

Among Traveller prisoners the relative risk of self-reported drugs and alcohol problems combined for remand Traveller prisoners in contrast to remand white European prisoners was 1.46 (95% CI 1.11-1.9) (Linehan *et al.*, 2002). In a study of remand prisoners, all Travellers interviewed had a history of alcohol dependence and abuse and 98% had a lifetime history of substance abuse disorders (Kennedy *et al.*, 2005).

The National Drugs Strategy (interim 2009-2016) identifies both prisoners and Travellers as at-risk groups and target groups for intervention, treatment and rehabilitation (Department of Community, Rural and Gaeltacht Affairs, 2009). The strategy acknowledges the limited data available on the number of Travellers who present for drug treatment. Fountain (2006) acknowledged the difficulty in ascertaining prevalence due to lack of an ethnic identifier but reported that while usage appeared to be lower, the geographic prevalence pattern among Travellers broadly mirrors national prevalence patterns of the general population. In focus group and one-to-one interviews with Traveller prisoners, Fountain reported that the perception among participants was that access to drugs is easier in prisons and that many Travellers take drugs for the first time in prison or increase their use of drugs while inside. The report also noted that the issues related to drugs and Travellers are closely associated with marginalisation and inequality, therefore Travellers are more likely to be exposed to the risk factors that lead to drug use.

2.1.3 Communicable Diseases in Prisons

The problem of HIV/AIDS in prisons is an international problem and Watson *et al.* (2004) present evidence of this from studies carried out in Africa, Australia, Ireland, Pakistan, Spain, UK and USA, with high prevalence rates reported. Other communicable diseases noted internationally include syphilis, hepatitis and tuberculosis (TB). In ROI, 9% of Irish prisoners were infected with hepatitis B, 37% with hepatitis C and 2% with HIV (Allwright *et al.*, 2000).

2.1.4 Chronic Disease in Prisons

While the prisoner population tends to be relatively young, being in prison can in itself be a health hazard, and prisoners tend to lead lifestyles that are more likely to put them at risk of ill health. Chronic diseases such as lung disease, heart disease, diabetes, epilepsy, diseases of the reproductive system and cancer are common problems in prisons worldwide (Møller *et al.*, 2007).

In Ireland, the NUI Galway study on prisoner health reported that the rate of self-reported general health as being excellent or very good was 29% for male prisoners and 16% for females; while the majority of prisoners were mobile (85%) and self-caring (97%), 42% of men and 59% of women prisoners reported moderate or extreme pain or discomfort (Centre for Health Promotion Studies, 2000). 22% of males and 29% of females reported a long-standing illness, and in male prisoners this was associated with older age groups, poor self-reported health and shorter sentences. Intake of prescription medications among Irish prisoners was high (30% male and 74% female). In all cases prisoners had poorer health status than the general population. The vast majority of prisoners were current cigarette smokers (91% men and 100% women) (Centre for Health Promotion Studies, 2000). A number of factors were identified, which were independently predictive of poor self-rated health: level of education, General Health Questionnaire (GHQ) Psychiatric caseness, prescribed medication, chronic self-limiting illness and reported verbal abuse by prison officers (Hannon *et al.*, 2007).

In New South Wales, despite Aboriginals being over-represented in the prison population, few significant differences were found between Aboriginal and non-Aboriginal prisoner health status across a range of self-reported physical and mental health measures, despite significant differences in socio-demographic factors; both male and female Aboriginals rated their health more positively than non-Aboriginals, although not significantly so (Kariminia *et al.*, 2007).

2.2 Healthcare Provision in Prisons

The WHO (Møller *et al.*, 2007) advocates that that people who are in prison have the same right to healthcare as everyone else, and there are numerous international standards to support this. Close links between prison-administered health services and public health are recommended and some countries have begun to move prison health towards being part of the general health services of the country rather than under the responsibility of the prisons (Møller *et al.*, 2007) thus totally separating custodial/disciplinary and healthcare functions. Health-promoting prisons and primary health care are high priorities for prison health services globally. In the UK, the drive for improvement of prison health services has led to primary care trusts (National Health Service [NHS]) taking over responsibility for commissioning or providing healthcare for prisoners in their area (Harris *et al.*, 2006).
In Ireland, the Irish Prison Service (IPS) has a statutory responsibility for provision of primary healthcare services in each prison under part 10 of the Prison Rules (Department of Justice, Equality and Law Reform, 2007). There have been major developments and improvements in IPS healthcare services in recent years.

2.2.1 Irish Prison Healthcare Services

An expert group was set up in 1999 to review structures and organisation of prison health care services in Ireland following recognition in a series of reports over the previous decade that healthcare provision in Irish prisons was failing to keep up with international standards, evidenced by factors such as an absence of nurses and the limited number of hours during which doctors were present (Health Service Executive, 2009).

The 'Report of the Group to Review the Structure and Organisation of Prison Healthcare Services' (Irish Prison Service, 2001), referred to as the Olden Report, recommended that there should be equivalence of care between the prison population and the general population, development of healthcare standards, and a multidisciplinary approach. This report noted the disproportionate representation of Travellers in prison, and that prisons facilitate accommodating Traveller prisoners in shared cells in recognition that Travellers cope poorly with the stresses associated with close confinement in prison. The report recommended that special prisoner groups should receive special attention from health care staff, and in the context of this recommendation, suggested, because of the nomadic nature of Travellers, that a primary aim of prison health care should be to seek to remedy existing health deficits while Travellers were in prison and to establish the links for Travellers with healthcare structures in the general community.

The recommendations of the Olden report are noted in the national health strategy 'Quality and Fairness, a Health System for You' and advancement of the report's recommendations is one of the sub-objectives under the strategy's target to reduce health inequalities (Department of Health and Children, 2001). A Prison Health Working Group was established in 2002 and comprised representation from the Irish Prison Service, Department of Justice, Equality and Law Reform, Department of Health and Children and Health Boards. Under the auspices of this group a Needs Assessment was established to assess the primary healthcare needs of the prison population and the 'Irish Prison Health Care Needs Assessment' was published in 2003 (Irish Prison Service, 2003). It recommended that the Irish prison health care service should reflect the Irish Primary Care Strategy model and recommended improvement in many areas such as governance, human resources, services, and others. The need to address the special needs of minority groups, such as women, juveniles and ethnic minorities is noted; no specific reference is made to Travellers. With the exception of the 2001 Olden report, Traveller prisoners are neither noted as a separate group, nor singled out for comment in most Irish Prison Service health-related documentation.

Following implementation of many of the recommendations of the 2003 'Needs Assessment' report, there has been an increase in both the range of services and the human resources available to the healthcare directorate, and this is evidenced in individual prisons with services such as: the implementation of a nursing management structure, professional pharmacy services, addiction counselling services, addiction nursing and other specialised nursing posts, and the provision of a variety of inreach services, in the domains of dental, mental and addiction services. Visiting committee reports for 2008 (Department of Justice, Equality and Law Reform, 2008 a-n) make reference to overall health services, mainly commenting on resources provided, including new resources, and improvements required, and to recent improvements in the services. In particular, note is made in a number of reports about increase in healthcare staff resources (nurses, nurse managers, psychologists, addiction counsellors), and generally to improvements to drug addiction and counselling services in individual prisons. A number of reports make note of improvements to psychiatric services, including inreach services and the links with the Central Mental Hospital (CMH); only one visiting committee (Cork) noted an urgent need for improvement in mental health services. The HSE made provision for 10 additional beds in the CMH in December 2008 and 21 consultant-led inreach sessions per week are provided in Irish prisons (Irish Prison Service, 2009a). No issues associated with ethnic minorities, or Travellers, were raised in any of the 2008 visitors' reports.

The Healthcare Directorate developed a broad set of healthcare standards in 2004, and these were most recently updated in 2009; although no specific reference is made to Travellers, the standards include providing culturally appropriate healthcare (Irish Prison Service, 2009b).

In 2008, the IPS employed 20 doctors on a full or part-time basis; other specialist services are arranged by a private contract or service level agreement with the Health Service Executive. There were nurse managers in all the closed prisons and complex nurse managers in three main prisons: (Mountjoy/ Dochas, Port Laoise/Midlands and Cloverhill/Wheatfield).

The IPS 2008 annual report (Irish Prison Service, 2009a) documented the significant developments for 2008 as:

- Completion of implementation of the new nursing management structure;
- Introduction of professional pharmacy services to all prisons (except Cork);
- Additional beds in Central Mental Hospital (mentioned above); 21 consultant-led inreach forensic mental health sessions available weekly in all Dublin prisons, Port Laoise and Midlands prisons;
- Addiction counseling services rolled out to 13 prisons/places of detention, delivering approximately 1,000 hours per week of prisoner access to addiction counselling; addiction nursing posts were assigned to Mountjoy prison; and methadone treatment is available in 8 prisons, accessing 80% of the prison population; a consultant-led inreach addiction service is available in Cloverhill, Wheatfield and Mountjoy;
- Contract awarded for the provision of Drug Treatment Pharmacy Services in Mountjoy/Dochas;
- Publication of a Drug Treatment Clinical Policy;
- Other inreach services include dental services to the Dublin prisons;
- A focus on the introduction of the computerised Prison Medical Record System (PMRS), permitting access to prisoner medical records through a central secure electronic database, from any computer terminal within the service system, facilitating better clinical decision making.

2.2.2 Irish Prison Nursing Services

Nurses were first recruited to the IPS in a full-time capacity in 1999, and in 2008 there were 117 nurses employed nationally (Health Service Executive, 2009). The key services currently provided are primary care and chronic disease management, addiction and mental health services (Irish Prison Service, 2009a). In the UK, healthcare services in prisons became part of the National Health Service (NHS) in 2006, with a requirement to provide health services of the same range and quality as the general public receives in the community (Department of Health and the Home Office, 2007). In Ireland, the role of the Health Service Executive (HSE) remains peripheral to prison healthcare delivery, however, on foot of

a recommendation of the 2001 Olden report, and because nurses deliver the majority of professional healthcare to prisoners nationally, a review of nursing in the prison service was recently published by the HSE Nursing and Midwifery Planning and Development Unit (2009), based on research carried out in partnership with the IPS. While the focus was on the role of the nurse, this report confirmed the five major health needs for prisoners as addiction, chronic illness, infectious diseases, mental health and health promotion.

2.3 Traveller Health in Irish Prisons

With the exception of the publications associated with the FMHS, there is little documented about the health status of Travellers in prison in ROI, although some work carried out in the UK reflects on issues associated with Irish Traveller prisoners that may impact health. On a positive note, in a qualitative study in the UK, Power (2004) found fitness and exercise to be a recurring theme among Irish Traveller men in prison in the UK. However, he also found evidence of negative stereotyping and racism towards Irish Travellers in British prisons and a lack of recognition of Irish Traveller ethnicity and culture. He reported highly negative attitudes and behaviours from some prison staff towards Irish Travellers in prison in the UK. Irish Traveller men in prison were often isolated from family, especially if families were nomadic, as literacy problems mitigated against communication and facilitation of visits. He also noted the lack of understanding of Traveller culture and ethnicity in British prisons with very little knowledge of Irish Travellers included in Prison Service training.

In Ireland, all new recruits that joined the Irish Prison Service since 2005 are eligible to undertake a Higher Certificate in Custodial Care, offered in Port Laoise, by Sligo Institute of Technology. Modules include social and health topics such as: Sociology and Criminology, Health and Society, Ethics, Introduction to Social Psychology, Human Rights and Prison Law, and Equality and Diversity. This training is likely to improve Irish prison officers' understanding of, and possibly reflection on, the issues that affect minority groups and the health issues associated with all prisoners.

3. Study Methodology

In 2008, the Irish Prison Service (IPS) administered 14 prisons in ROI, including 2 prisons that accommodate women. The prison population varies considerably on a daily basis; in 2008 the number of committals was 13,557 and the average daily population was 3,544, comprising 3,420 males and 124 females (Irish Prison Service, 2009a). National censuses of 2002 and 2006 show that while 0.08% of the total population of ROI were in prison on census nights, the proportion of the Irish Traveller community that was in prison was between 0.6 and 0.8%.

3.1 Irish Prison Service: Traveller Prisoner Census

In February 2009, the IPS Research Ethics Committee (REC) approved data collection for a Traveller prisoner census. Governors in the 14 ROI prisons were asked to provide the number of Traveller prisoners in their prison on 3 specific dates during the time of the AITHS community Census (14th October, 2008, 28th October, 2008 and 11th November, 2008), based on Irish Travellers who self-identified, such as by requesting to be accommodated adjacent to other members of the Traveller community. Governors were invited to provide any comment that they considered would be of interest to the aims of the study. No Traveller names were required in the data collected. The IPS subsequently provided data on the total number of prisoners in custody on the same 3 dates.

3.2 Irish Prison Service: Traveller Health Status Study

Following consultation, UCD and the IPS Healthcare Directorate agreed a protocol for extending the health status study into prisons, taking into account the constraints associated with identifying Traveller prisoners, the logistics of external researchers accessing prisoners and the availability of prison staff to accompany researchers during data collection. Methods of data collection used in previous studies were not considered feasible for logistical reasons - for example, collecting data at time of committal (Linehan *et al.*, 2002) or administering self-completion health questionnaires to prisoners (Centre for Health Promotion Studies NUI Galway, 2000). For this study the IPS disseminated promotional information targeting Traveller prisoners (information flyers and posters), and facilitated access to Traveller prisoners to 2 UCD researchers who were trained health professionals, in order to to gain Traveller prisoners' consent to collect specified data from their prison medical record. The protocol was approved by the IPS REC and an application for exemption from ethical approval was approved by the UCD Human Research Ethics Committee by July 2009. Security clearance for researchers to enter relevant prisons was received in October 2009.

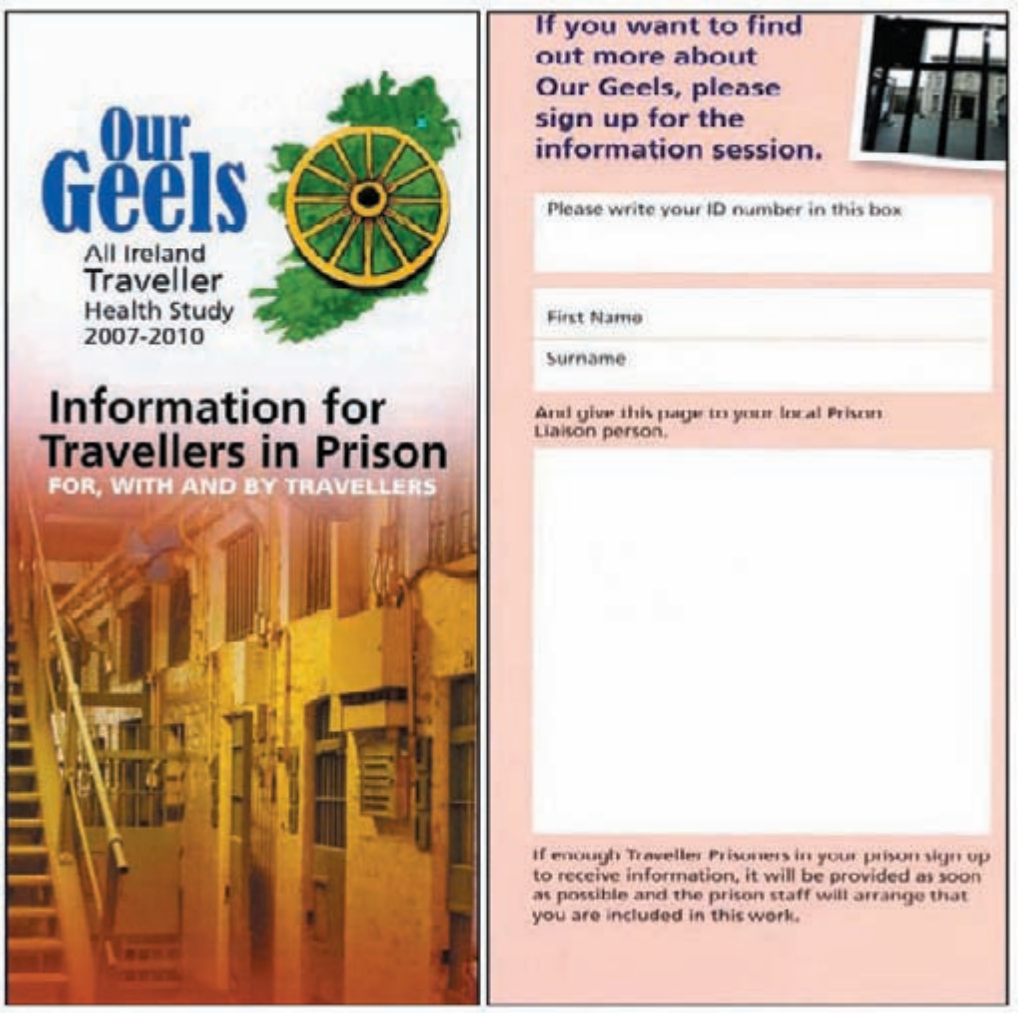
For security reasons and because of lack of audiovisual facilities the dedicated Our Geels DVD could not be used in prisons. Information flyers and posters, containing images and text that would be attractive and of interest to Traveller prisoners, and of a size that was feasible for display in the prisons, were prepared in association and consultation with Pavee Point (Figures 1 and 2). Choice of prisons took into account the census estimate of Traveller prisoners in each prison and the advice of IPS staff that were familiar with local security conditions. Due to the low number of female prisoners only male prisons were included. A pilot process was carried out in a single prison between November 2009 and January 2010. An additional 3 prisons with large populations were targeted, between January and April 2010, with the aim of recruiting a sample of 100 Traveller prisoners, to allow comparative analysis.

Figure 1: Information poster (A3) displayed in participating prisons

In each prison, a liaison person was appointed (in all cases a member of the IPS nursing staff), who met and was briefed by the UCD researchers, and who subsequently briefed staff and prisoners and disseminated the information documentation. Posters were displayed in common areas of the prison: food collection areas in each division, the school, library, gym, surgery and chaplaincy. The posters invited Traveller prisoners to participate in the study and to express interest by contacting the nursing staff and asking for a brochure.

Nursing staff also actively disseminated brochures. Brochures contained a page permitting interested Traveller prisoners to 'sign-up' for the information session (Figure 2). Staff were aware of and willing to accommodate prisoners with literacy difficulties. It was noted during the pilot process that Traveller prisoners had good relationships with the prison chaplains, and chaplains were subsequently included in the staff asked to communicate information about the study to relevant prisoners.

Figure 2: Cover (L) and 'sign-up' sheet (R) from the brochure disseminated in prisons



On 'Consent Day' in each prison, Traveller prisoners who had expressed interest in participating were brought either singly or in groups of 2 or 3 to a dedicated room, where researchers informed them about the project and provided a copy of the data collection form, explaining the nature and purpose of the data being sought. Questions on the form comprised a subset of the health status questions asked in the community during the AITHS. Interested participants consented in writing; consent was witnessed by 2 researchers.

UCD researchers were provided with access to relevant individual medical records to collect the data.

3.3 Qualitative and Health Service Provider Studies

The aim of the qualitative semi-structured interviews was to explore Traveller health status, uptake of health and social services, health needs and health determinants as perceived by key individuals who work with, and have knowledge of, Traveller prisoners. Three personnel relevant to the Traveller prisoner community participated: a senior member of the IPS Healthcare Directorate, a nominee of the Forensic Mental Health Services and a representative of Traveller Family Support Services in Exchange House. Interviews were held in April 2010 in accordance with the health service provider semi-structured interview protocol. Two focus groups (one male, one female) were arranged, in consultation with the Family Support Service in Exchange House, with Travellers who were ex-prisoners. Setting up the groups took some time because of the sensitivity involved in recruitment and because many Travellers that engage with Exchange House do so because they are in crisis. On the day, for a variety of reasons, none of the clients who had agreed to attend were able to do so, and it was deemed unlikely that rearranging the event would be successful.

Three key stakeholders associated with prisoner health were interviewed as part of the qualitative study, and 6 prison nurses were invited to participate in a health service provider Computer-Assisted Telephone Interview (CATI). Outcomes from prisoner-associated qualitative and health service provider input are integrated into Technical Report 3.

4. Findings

4.1 Census

14 prisons (100%) responded to the IPS census request, however, not all prisons were able to provide the requested data. Three all-male prisons, with large prisoner populations, responded that the prison information system ethnic identifier did not contain a field for Irish Travellers, and that they could not identify Traveller prisoners. Both prisons accommodating females responded, giving an average estimate of 21 female Traveller prisoners. Based on the average number of male prisoners in custody on the 3 dates, the number of male Traveller prisoners was estimated by scaling up the number of male Traveller prisoners from the 11 responding prisons, giving an estimate of 299 male Traveller prisoners (Appendix 1).

Table 3: Prisoners in custody, including estimated Traveller prisoners, by gender

	IPS Prisoners in custody (average) during census Oct/Nov 2008[1] n (%)	IPS estimated Traveller Prisoners in custody (average) during census Oct/Nov 2008[2] n (%)	Traveller reporting of Travellers in Prison Oct/Nov 2008[3] n (%)
Male	3,537 (96.5%)	299 (93.4%)	150 (89.3%)
Female	129 (3.5%)	21 (6.6%)	18 (10.7%)
Total	3,666 (100%)	320 (100%)	168 (100%)

Sources: [1]Irish Prison Service; [2]AITHS Prison Census Oct/Nov 2008; [3]AITHS Census Oct/Nov 2008

The IPS estimate of female Traveller prisoners was very similar to that reported by Traveller families during the AITHS census; however, the IPS estimate of male Traveller prisoners was almost double that reported by Traveller families (Table 3). Based on the number of Traveller prisoners estimated by the IPS, Travellers accounted for 8.7% of the prison population; according to Traveller families' responses to the AITHS census, Travellers accounted for 4.6% of the prison population (Table 4). It is not possible to verify which source provides the true number of Travellers in prison, and subsequent analysis was carried out using both figures.

Table 4: Traveller prisoners as a proportion of all prisoners in custody

	Average number of Prisoners in custody during census Oct/Nov 2008[1]	IPS estimates of Travellers in custody Oct/Nov 2008[2]	Traveller estimates of Travellers in custody Oct/Nov 2008[3]
		Travellers as % of prisoners in custody Oct/Nov 2008	Travellers as % of prisoners in custody Oct/Nov 2008
	n	n (%)	n (%)
Male	3,537	299 (8.5)	150 (4.2)
Female	129	21 (16.3)	18 (14.0)
Total	3,666	320 (8.7)	168 (4.6)

Sources: [1]Irish Prison Service; [2]AITHS prison census Oct/Nov 2008; [3]AITHS census Oct/Nov 2008

Table 5: National Census records of Traveller prisoners in custody by gender

	Total prisoners enumerated in census[1]		Traveller prisoners enumerated in census[1]		Travellers as % of total in custody[1]	
	2002	2006	2002	2006	2002	2006
Male	3,122	3,018	183	132	5.9%	4.4%
Female	115	115	11	13	9.6%	11.3%
Total	3,237	3,133	194	145	5.9%	4.6%

[1]Source: National Irish censuses 2002 and 2006 (Central Statistics Office, 2003b, 2004, 2007b, 2007c)

Table 6: Risk of imprisonment

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

Based on the IPS estimate of Traveller prisoners, the risk of a Traveller being imprisoned was 11 times that of a non-Traveller (RR 11.0, 95% CI 9.8-12.3), and for Traveller women the risk was 22 times that of non-Traveller women (RR 22.0, 95% CI 13.8 - 35.1).

When calculated using the Traveller-reported prisoner population, the risk of a Traveller being imprisoned was more than 5 times that of a non-Traveller (RR 5.5, 95% CI 4.7–6.4), and for Traveller women the risk was 18 times that of non-Traveller women (RR 18.3, 95% CI 11.1-30.1).

The relative risk of imprisonment was higher for female Travellers than for males in both analyses. In the general population men are 27 times more likely to be imprisoned than women (RR 27.5, 95% CI 23.06-32.76) (based on 2006 census), whereas Traveller men were 8 times more likely to be imprisoned than Traveller women (RR 8.6, 95% CI 5.27-14.01) (based on Traveller estimates of Travellers in prison). Sources of data for relative risk calculations are provided in Appendix 1.

4.2 Health Status Study

The recruitment process for the health status survey yielded 26 Traveller prisoners, (36% of all Travellers estimated by the IPS to be in custody in participating prisons on consent day). Most prisoners who attended the session had not previously heard of the study through their families. While every Traveller that attended the information session consented, it became evident as the process progressed that many Traveller prisoners were either unable or reluctant to attend. The reasons for this were varied. Some Travellers that had expressed interest in advance were otherwise engaged when the researchers were present (for example in court or with visitors). To circumvent this, researchers visited the prisons at the weekend (no visitors or official business on Sundays); however, many simply declined to attend on the day. On the other hand, some Travellers who had not expressed interest in attending did so when a friend or cellmate returned from the information session and encouraged them to participate. During the information session, a number of Travellers expressed concerns, such as whether participation (or not) would affect a pending temporary release, whether the Governor might see their medical history, or whether this study was linked to random drug testing. Some prisoners expressed a preference to telling the researchers their medical history over it being taken from their record. One prisoner expressed willingness to participate because he '…had nothing to hide'. All of these concerns were allayed and these prisoners did consent, however a potential for self-selection bias emerged. In addition, on completion of the consenting and data collection process in three prisons, and with knowledge that recruitment in the fourth prison was affected by logistical issues in the prison, it became clear that in order to achieve the target sample of 100 it would be necessary to extend the process into many more prisons, which was not feasible.

Data collection was carried out on an iterative basis, and access to the electronic medical records was provided, where possible, at the end of consent day. During data collection it was not possible to collect reliable and consistent data on all of the desired variables, in some cases because of the way the electronic system recorded medical history and in others because some data fields (e.g. smoking and drinking habits) were not completed in all records. In some cases it was possible to check consistency of data by reviewing narrative data in the records.

Taking into account the poor response rate and incompleteness of the data for some important variables, the data collection process was discontinued.

Because the achieved sample was small (n=26) and not representative, the limited findings cannot be reliably compared with those from any other study, such as the NUI Galway Prisoner Health study (Centre for Health Promotion Studies, 2000), or the AITHS.

The mean and median age of the participating group was 28 years (SD 7.6), with 65% aged less than 30 years. In the total male prisoner population 53% are aged less than 30 (Irish Prison Service, 2009a). Among the 20 sentenced prisoners 65% had sentences of less than 12 months; this suggests that among those that were willing to participate, offences were relatively minor. Among all male sentenced prisoners in 2008, only 15% were serving sentences of less than 12 months (Irish Prison Service, 2009a). Based on these preliminary analyses, it was considered possible that a self-selection bias might exist among participants.

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

Table 7: Summary of Traveller prisoner health status recruitment process

Prison	A	B	C	D	Total
IPS estimates of Travellers in custody Oct / Nov 2008	Not known	30	58	30	118+
Traveller prisoners who expressed interest in advance of consent day	13	29	9	-	51
IPS estimates of Travellers in custody on consent day	16	31	25	-	72
Total number of prisoners in custody on consent day	420	552	530	-	1,502
Estimated no. of Travellers in custody as % of all prisoners in custody on consent day	3.8%	5.6%	4.7%	-	4.8%
No. of Traveller prisoners that attended the information session (no. consented)	9(9)	15 (15)	2(2)	-	26 (26)
Consent rate %: Travellers in custody who consented as % of information session attendees	100%	100%	100%	-	-
Response rate %: Travellers who consented as % of IPS estimate of Travellers in custody on consent day	56%	48%	8%	-	36%

5. Discussion

Absence of an ethnic identifier was a major barrier both to accessing and recruiting Traveller prisoners and to collecting data in institutions. Follow-up in in prisons relied on prison personnel's knowledge of Travellers' identity for the census and on active self-identification by Travellers (health status study). Three prisons specifically noted that it was difficult to identify Travellers, making comments such as '*…no separate record is maintained …in respect of Travellers*,' '*…we could not be sure that it would be 100% accurate (as to who is a traveler* [sic]*)*'. However, 11 prisons did provide estimated numbers, with one commenting that '*…they are not asked nor do they disclose whether or not they are from the traveller* [sic] *community*', and that their numbers were based on prisoners being identified as from '*… this* [Traveller] *community by experience, familiarity, name, address, disposition, characteristics and so on*.' It is possible that this method of providing numbers was used by most prisons that provided numbers and may be part of the explanation for the difference in IPS and Traveller-reported male prisoner numbers. When trying to recruit Travellers to the health status study, it was necessary to rely on Traveller self-identification in response to promotional documentation and information disseminated by prison staff. Issues of trust and a history of suboptimal engagement with structured services are likely to have played a role for those that did not respond. For those that did attend the information session, a number expressed concerns around what would be done with the information and who would have access to it – mostly within the prison system.

The IPS census estimates of Traveller prisoner numbers were very close to the number reported by Traveller families for female prisoners, but not for males, where the IPS estimated number was double that reported by families. The reasons for the difference between the IPS and Traveller families' estimates of male numbers are likely to reflect the fact that the IPS had to estimate the numbers, the sensitivity around any family volunteering information that a family member is in prison or that some Traveller prisoners had become dissociated from their family. However, whether using IPS (320) or Traveller estimates (168) of Travellers in custody, Travellers were over-represented in prisons in ROI at between 4.6% and 8.7% of all prisoners in custody, a multiple of the proportion of Irish Travellers in ROI population (0.5% in 2006 Census; 0.9% in AITHS census 2008) and this is reflected in the high relative risk of imprisonment. Traveller men are at least 5 times more likely to be imprisoned than non-Travellers; Traveller women are at least 18 times more likely to be imprisoned than women in the general population.

In particular Traveller women were over-represented. The gender distribution among the Irish population and among Irish Travellers is almost half and half (plus or minus 2%) according to censuses of 2002, 2006, and the AITHS census (2008). According to the IPS Traveller Prisoner census and Traveller family reports, male Traveller prisoners accounted respectively for 8.5% and 4.2% of all male prisoners, while female Traveller prisoners respectively accounted for 16.3% and 14.0% of all female prisoners. Using either method of estimating the numbers, the risk of imprisonment for Traveller men is lower than that for Traveller women. This contrasts with the findings of the 2000 Forensic Mental Health Service (FMHS) study where male and female Travellers accounted for 6% and 4% of all male and female

prisoners respectively (Linehan *et al.*, 2002), and there are consequent differences in the relative risk of imprisonment in the 2 studies, where Linehan's relative risk for Traveller men (17.4) exceeded that for Traveller women (12.9). The difference in findings of the 2 studies may be explained by a number of differences in methodology. The FMHS study focused on committals in two Dublin-based prisons - Cloverhill, the largest remand prison, and Dochas, the larger of the 2 female facilities; Department of Environment figures were used for Traveller population statistics as the census did not collect this data at that time. However, in a later FMHS study, using different methodologies and including both sentenced and remand committals from all prisons, Irish Travellers were found to be more prevalent in remand centres outside Dublin (11.4%) compared to Cloverhill (1.6%), and the rate of female Traveller committals within all female committals (10.6%) exceeded the male committal rate (5.4%) (Kennedy *et al.*, 2005).

Minority groups are often over-represented in prison. In Australia and New Zealand, where ethnic identification is based on prisoners' preferred ethnic choice, Indigenous (Aboriginal) and Maori populations are a routine sub-group for analysis in official statistics. In Australia in 2009, 25% of all adult prisoners, (25% of male and 28% of female prisoners) were indigenous, and indigenous adults were 14 times more likely to be imprisoned relative to other Australians (Australian Bureau of Statistics, 2009). Female Aboriginal prisoners comprised 8% of all Aboriginal prisoners (Krieg, 2006). The rate of imprisonment for Maori was 5-8 times higher than for other ethnicities in New Zealand (Department of Corrections, 2008), and Maori women are particularly over-represented in comparison to other ethnicities; they comprise 60% of female offenders. Reasons proposed for over-representation include socio-economic factors, alcohol and other drug misuse and mental health problems (National Indigenous Drug and Alcohol Committee, 2009; Department of Corrections, 2008). It should be borne in mind that in this study more than 99% of Irish Travellers were not in prison.

Traveller prisoners receiving medical care prior to detention have access while in prison to medical, nursing, psychiatric pharmacy and dental services, and psychological and social supports. While supportive of health promotion in prisons, healthcare staff of the IPS pointed out that singling out any minority group for health promotion activities does not always work in a custodial setting and can risk breaching individual medical confidentiality; however, for any prisoner with a chaotic lifestyle, such as homeless prisoners or prisoners with addiction or serious mental health issues, detention in prison can provide an opportunity for compliance with treatment regimes that require, often multiple, follow-up that may not be feasible for them in the community (such as vaccination against communicable diseases or access to dental and mental health services).

Travellers and prisoners are 2 minority groups whose health is a cause for concern. Traveller prisoners have double disadvantage and are a cohort worthy of further investigation. Currently, research on Traveller prisoner health can only be easily carried out if data collection is based on all prisoners, if ethnicity is established, and Traveller health is analysed as a sub-group, or if some means of Traveller

self-identification is used; the latter might be too much to expect within a custodial setting. Our attempt to get Traveller prisoners to single themselves out for identification failed to yield a reliable sample, though those that were assessed seemed typical of disadvantaged prisoners. Previous studies (Linehan *et al.*, 2002; Kennedy, 2005) had the benefit of the ethnic identifier used routinely on all Central Mental Hospital admissions. Including 'Irish Traveller' as a value in the existing ethnic identifier field in the prisons' IT system was recommended as part of a prisons' cultural awareness study in 2002 (Fitzpatrick and Associates, 2002), and such a move would facilitate Traveller health to be reported as part of routine high-level health status monitoring, and would also facilitate targeted recruitment of Travellers for future health research in this area.

6. Appendix 1

Estimation of Male Traveller Prisoner Population
a) 3,537 male prisoners recorded by IPS in 14 prisons during the AITHS census (100%).
b) 2,564 male prisoners recorded by IPS in 11 prisons during the AITHS census (72.5% of a).
c) If 217 male Traveller prisoners estimated by IPS in 11 prisons during AITHS census comprise 72.5%, then 100% is 299.

Note: the distribution of male Traveller prisoners across all male prisons is not known, however there is no reason to expect the male Traveller distribution in the three large male prisons that did not return estimates for the census period to differ from the male Traveller distribution in prisons that did return estimates.

Relative Risk
Sources of data for calculating Relative Risk of imprisonment for Travellers as compared to non-Travellers:

a) Total, male and female non-Traveller populations from National census 2006 minus b);
b) Total, male and female Traveller populations from AITHS census 2008;
c) Total, male and female prisoner populations from IPS records of average prisoners in custody during AITHS census 2008 minus d);
d) Total, male and female Traveller prisoner populations from i) IPS estimates of Traveller prisoners during AITHS census, and ii) Traveller reports of family members in prison from AITHS census 2008.

Sources of data for calculating Relative Risk of imprisonment for Traveller males/females as compared to non-Traveller males/females:

a) Male/female non-prisoner population from National census 2006 minus b);
b) Male/female prisoner population from IPS records of prisoners in custody during AITHS census 2008;
c) Male/female Traveller population from AITHS census 2008 minus d)
d) Male/female Traveller prisoner population from Traveller reports of family members in prison, AITHS census 2008.

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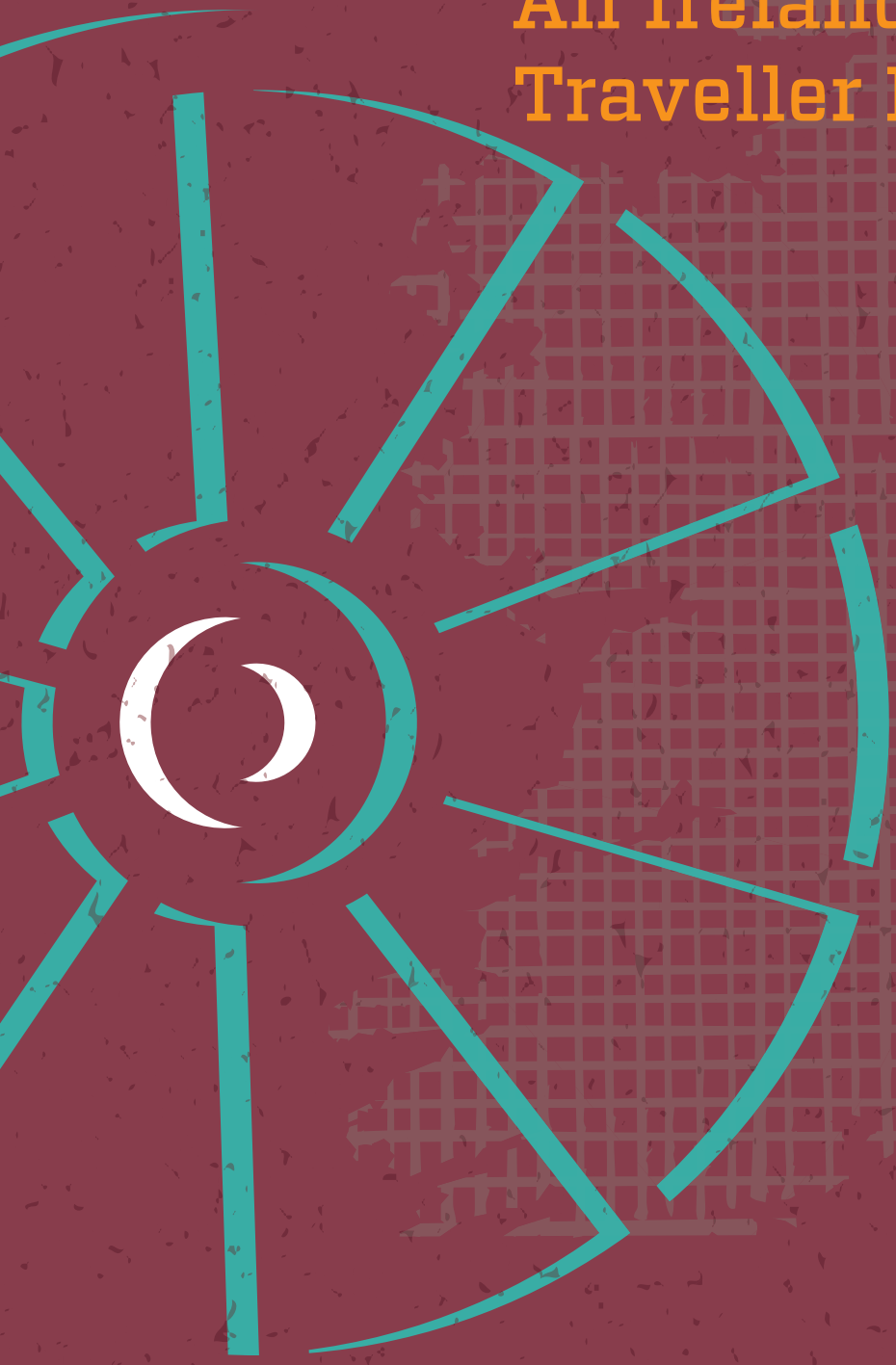
All Ireland Traveller Health Study

Our Geels



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