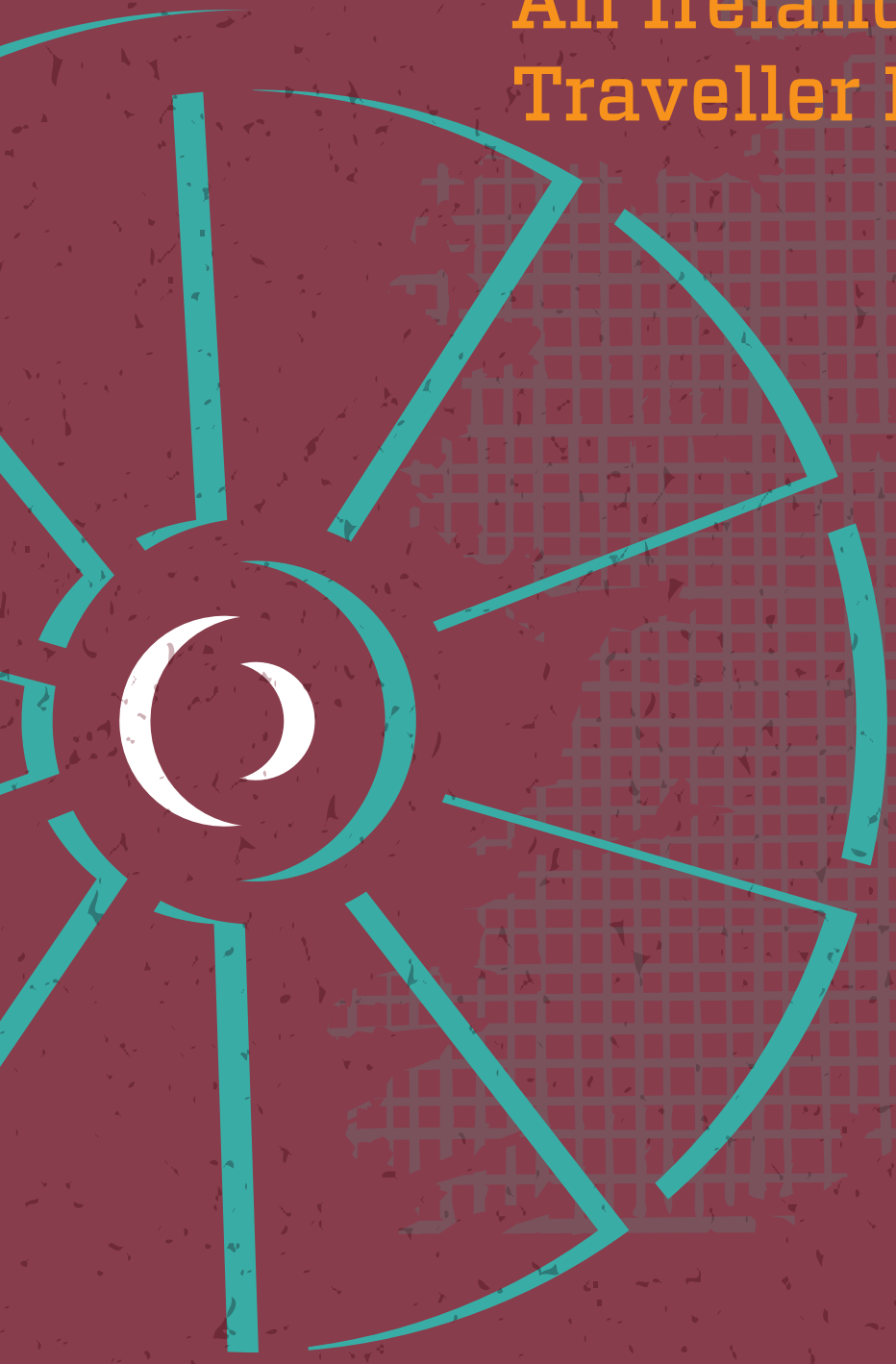
All Ireland Traveller Health Study

Our Geels



The Birth Cohort Study Follow Up

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The Birth Cohort Study Follow Up

Part D of Technical Report 2

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Drafting Team:
Dr Noor Aman Hamid
Professor Leslie Daly
Dr Patricia Fitzpatrick

Executive editor:
Professor Cecily Kelleher
For the All Ireland Traveller Health Study Team

All Ireland Traveller Health Study Team
School of Public Health, Physiotherapy and Population Science
University College Dublin

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Republic of Ireland:

Chairperson of the Directors of Public Health Nursing Forum:
Marianne Healy

Link-PHNs:
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Directors of Public Health Nursing:
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National Network Nurses who work with Travellers

All Public Health Nurses

Pavee Point Travellers' Centre, Primary Health Care for Travellers Projects, project coordinators, Traveller Peer Researchers and Community Health Workers

Office of the Registrar General & General Register Office (Research Room, Dublin): Declan Roche, Jennifer Ryan and Staff

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Peter McEvoy - Community Services Manager, Mullingar
Patricia Geoghegan - Health Centre Mullingar
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Northern Ireland:

Birth Cohort Coordinators: Dolores Atkinson, Brigid McDonagh

Link-Health Visitors/PI: Anne Robinson, Jackie McBrinn, Mary Duggan, Julie McConville, Ruth Carroll, Martina Marshall, Gay McCrossan, Kathy Jackson, Leona Camley, Ciara Dowdell, Maureen Jamison, Patricia Conway and Deirdre McKillen

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Executive summary

Introduction and Aim

The birth cohort study was a one year follow-up of all Traveller babies born on the island of Ireland between 14th October 2008 and 13th October 2009. The mother had to self-identify as an Irish Traveller. The aim of study was to assess the health status of Traveller infants and their mothers, quantify health service use, conditions needing health services and to examine why Traveller infants die.

Methods

There were three sources of data in this study. Traveller mothers were approached by Public Health Nurses either during pregnancy or post-delivery and asked to consent to inclusion in the study. The consent form allowed us to map where and when Traveller births occurred. Consenting mothers carried with them a Parent-held Child Record (PHCR) to record immunisations, illness and all health services use during the first year of life. The consenting Traveller mothers also permitted access to their maternity records. The National Perinatal Reporting System data was used for general population comparisons in Republic of Ireland (ROI). The main report details findings with comparison across all Irish socioeconomic groups and also with both Irish and European mothers and their babies who were born in Ireland.

Results

There were 986 Traveller births during this period. A total of 508 Traveller mothers and their infants consented to participate in the cohort (overall response rate 51.5%). In ROI, there were 918 births with a response rate of 51.4% (472 mothers consented) and in Northern Ireland (NI) 68 births with a response rate of 52.9% (36 mothers consented). Traveller parents, both fathers and mothers, are significantly younger than the general Irish population, with an average age of 27.5 years for a Traveller father and 25.9 for a Traveller mother. This represents an average of seven years difference for fathers and six for mothers when compared to the general Irish population. Just 20% of Traveller fathers were employed while 82% of Traveller mothers were fulltime housewives.

The linked maternity hospital data showed that almost all (98%) Traveller infants were booked in for delivery and all (100%) were delivered in hospital. Traveller mothers tend to have more spontaneous deliveries and a lower Caesarean section rate than the general population. Length of stay for Traveller mothers post Caesarean section was comparable to the general population but for other methods of delivery was slightly longer than the general population; length of stay of Traveller babies was comparable to that of the general Irish population.

Average gestational age at birth was 39 weeks, similar to the general population; mean birth weight was also comparable. However, when birth weight was examined by categories of weight, there was an excess of Traveller infants seen in the lower birth weight categories. By nine months, the main parameters of growth showed little difference between Traveller babies and the general Irish population.

Traveller mothers tend to have higher parity and more stillbirths than the general population. They also tend to have shorter intervals between pregnancies. Traveller mothers tend to visit their doctor later in the early stages of pregnancy and to book into maternity hospitals later than the general population.

Breastfeeding rates are very low among Traveller mothers. Maternity hospital data showed that 3.2% of Traveller mothers intended to breastfeed while the PHCR data showed that 2.2% of mothers actually breastfed once discharged from hospital.

Recorded immunisation uptake is low among Travellers; BCG immunisation rates are highest (71.8%). The '6 in 1' (or '5 in 1' in NI) shows a fall in uptake across the three doses over six months, with only 66% of Traveller infants recorded to have completed the '6 in 1' or '5 in 1'. After the Public Health Nurses/ Health Visitors (59%), the General Practitioner was the second most frequently accessed health professional (47%) followed by Accident and Emergency services (26.2%). The highest reasons for consultation were respiratory-related, gastrointestinal-related and ear-related (mostly ear infection) conditions.

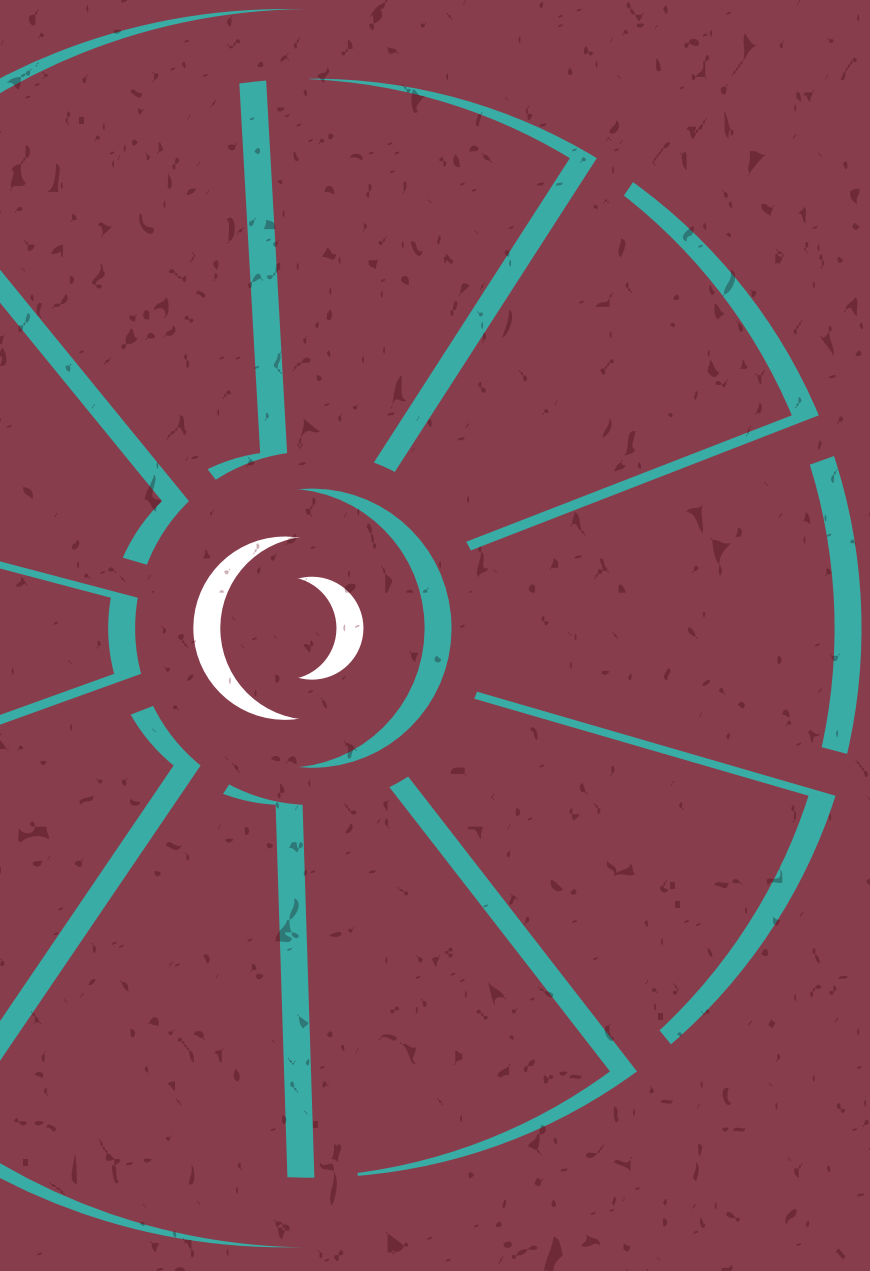
There were 12 infant deaths detected in the one-year infant follow up, 11 in ROI and 1 in NI. Calculated ROI Traveller infant mortality rate for 2008/2009 was 12.0 per 1,000 live births, which represents a fall since the last major Traveller Health study in 1987; however the rate was 3.7 times the infant mortality rate of the general population in 2009, which represents a wider gap compared to 1987, as the infant mortality rate in the general Irish population has fallen to a greater extent in the interval. The current Traveller infant mortality rate is one of the highest in Europe. The infant mortality rate ratio for Travellers is high when compared to other minority groups internationally.

The calculated neonatal and post-neonatal mortality rates were 5.4 and 6.5 per 1,000 live births respectively. There has been some improvement in neonatal mortality but with a reciprocal higher post-neonatal mortality rate compared to 1987. This suggests that some Traveller infants with serious medical conditions are now living beyond the 28 days period. The causes of death in Traveller infants were prematurity, congenital conditions and one accidental death.

Conclusion

This is the final report of the All Ireland Traveller Health Study, *Our Geels*, which addresses the longitudinal follow-up of the participant mothers and infants one year after birth of the children. The findings will have important policy implications for the Traveller community. The demographic profile, compared to the general Irish population and also across social classes, gives us a clear picture of current Traveller families. In the main report we made a number of recommendations around prioritising maternal and child health services and educational opportunities for young Traveller parents. This longitudinal follow-up serves to reinforce those recommendations. The introduction of a unique identifier for Travellers would facilitate attentive support to Traveller mothers when they present for health care. The Primary Health Care for Travellers Projects present a strong opportunity for peer-led health promotion initiatives for Traveller mothers. We hope these recommendations will be acted upon for the families who put their trust in this study.

Chapter 1:
Introduction



Introduction

The first birth cohort report published in September 2010 outlined the methodology and protocol and presented preliminary results and fertility indicators for Irish Travellers (Hamid *et al*, 2010). The follow up period for the birth cohort ended on 13th October 2010. This final report forms part of the All Ireland Traveller Health Study (AITHS) technical report series.

Briefly, the birth cohort study was a cohort of Traveller babies who met the following criteria:

1) Traveller babies born between 14th October 2008 and 13th October 2009
2) Born on the island of Ireland
3) Babies whose mothers self-identify as Irish Travellers

The All Ireland Traveller Health Study, including this birth cohort study, received ethical approval from University College Dublin's Human Research Ethics Committee and Office for Research Ethics Committees Northern Ireland (All Ireland Traveller Health Study Team, 2010).

1.1 Rationale for a Traveller birth cohort

In this section, we will first briefly describe two major public health research tools: cross-sectional survey and longitudinal cohort study. Then we will describe the concept of 'life course epidemiology' which is relevant to chronic disease development. This complements the approach used by the All Ireland Traveller Health Study, the social determinants of health.

1.1.1 Cross-sectional survey and longitudinal cohort study

In public health research, different research methods provide different data and outcomes. Two main quantitative research tools which provide the best source of evidence informing public health policy are the cross-sectional survey and the longitudinal cohort method. The AITHS provided cross-sectional evidence of Traveller health status and services.

The longitudinal study or cohort study is a method whereby a cohort of subjects is followed-up over a certain time period. The strength of the cohort study includes (Feinleib & Breslow, 2004; Martin, 2008):

- Time sequence between exposure and outcome can be clearly observed
- Many different disease outcomes can be observed in relation to a variety of exposures
- Disease rates and risks for each exposure can be estimated

However, cohort study has its drawbacks, which are:

- Costly in terms of time and resources due to its lengthy follow-up period
- Fatigue from cohort participation and management
- Analysis bias may occur from participants who were lost in the follow-up stage or potential participant refusal to join cohort.

A birth cohort refers to *'the location of an individual in historical time as indexed by their year of birth'* (Kuh *et al*, 2003). In other words, a birth cohort is a study design whereby babies (and their mothers) are invited to participate into a cohort during pregnancy or shortly after birth; most cohorts invite potential mothers with their babies into the cohort after birth (Calderwood *et al*, 2007) while some are recruited before pregnancy or during pregnancy (O'Mahony, 2001).

Some of the major findings with regards to population health over the past 50 years have been from cohort studies. For example, adult cohort studies include the Framingham Heart Study (Framingham Heart Study, 2011), the Whitehall Cohort (Marmot & Brunner, 2005); birth cohort studies include the Millennium Cohort Study (Calderwood *et al*, 2007), the Lifeways Cross-Generation Cohort Study (O'Mahony *et al*, 2001), the Avon Longitudinal Study of Parents and Children (Golding *et al*, 2001), the Australian Aboriginal Birth Cohort (Sayers *et al*, 2003) and the Pelotas Birth Cohort Study (Barros *et al*, 2008), among others.

1.1.2 Life course approach and epidemiology

The life course approach was widely used first in sociology and psychology and later adapted into medicine/public health. A life course approach is a theoretical model on how factors (biological, sociological and psychological) during life development may influence development of studied outcome in later life.

Kuh & Ben-Shlomo (2004) defined life course epidemiology as *'the study of long-term biological, behavioural, and psychosocial processes that link adult health and disease risk to physical or social exposures acting during gestation, childhood, adolescence, earlier in adult life, or across generation'*. The purpose of life course epidemiology is to build and test theoretical models that postulate pathways linking exposures across the life course to health outcomes in later life (Kuh *et al*, 2003).

Life course epidemiology stems from health research in the 1980s and 1990s which emphasised chronic diseases prevention and epidemiology. This first concentrated on adult risk factors including biological processes as a result of adult health behaviour. For example, smoking was associated with cardiovascular diseases, respiratory diseases and lung cancers. This has been the central theme in most health strategies to encourage healthier lifestyles during this period.

Interest in adult chronic disease stemmed from research in the development of cardiovascular diseases, specifically the patho-physiological development of artherosclerosis, a process whereby fat cells are deposited in arteries. A lifestyle model of arteriosclerosis development was associated with high cholesterol and an unhealthy lifestyle in an adult. This, in addition to other factors, contributed to the development of ischaemic heart disease. However, it was noted that children's arteries also contain fatty streaks which suggested that the artherosclerosis process begins early in life, thus risk factors for disease development had to start earlier in life. This adult lifestyle model thus was gradually extended to childhood.

At the same time, a different line of research challenged the lifestyle model of chronic disease development. During the development of the lifestyle model for chronic disease development, inequalities in health between different social groups were observed (this led to the present day social inequalities in health and social determinants model of health). Researchers in ecological study during the 1970s and 1980s investigated the effect of physical and social environment and early life experiences on health. Studies during this period found strong correlation in geographical area between past infant mortality and adult death from cardiovascular diseases. In 1986, David Barker using an historical cohort, showed that adult mortality from cardiovascular diseases was related to infant birth weight (Barker & Osmond, 1986). This led to the concept of insult during the 'sensitive' or 'critical' developmental period which causes permanent damage in adult life time and thus development of chronic disease. The 'fetal origin of adult disease' or 'biological programming' hypothesis proposed that "environmental exposures such as under-nutrition during critical period of growth and development in-utero may have long term effects on adult chronic disease risk by 'programming' the structure or function of the organs, tissues, or body systems" (Kuh & Ben-Shlomo, 2004).

The 'fetal origin of adult disease' has now been further refined and renamed 'Developmental origin of health and disease' (DOHaD) (Gluckman & Hanson, 2009).

The 'fetal origin of adult disease' approach concentrated initially more on biological process with less emphasis on socio-cultural processes. A life course approach however has to balance both biological and psychosocial processes and investigates how these interact with each other to produce the outcome condition (Heikkinen, 2010).

1.1.3 Life course models

Kuh *et al* (2003) identified 4 broad causal models for life course epidemiology. These models are not mutually exclusive, sometimes are overlapping (Heikkinen, 2010) and may have varied relative roles in different health outcomes (Asthana & Halliday, 2006).

In the *critical period model*, there is a critical period when, if an exposure occurs, it will have lasting effects on the structure or function of the organs, tissues and body systems. This effect is not modifiable in later life. This model has its origin from Barker's biological programming hypothesis. This model is also defined by key social transitions where biological and social elements interact with each other to produce the variation in health (Bartley *et al*, 1997).

An extension of this model, *the 'critical period model with later effect modifiers'*, refers to the same mechanism as the critical period model however with an added exposure in later life may interact with previous early life exposures which may either enhance ('synergism') or diminish ('antagonism') the outcome effect.

The third model, the *'accumulation of risk model'* assumes the gradual accumulation of risks to health over the life course but results in the final outcome with no greater contribution if it occurred during the sensitive period. The biological system is affected with the overall accumulation (frequency,

intensity and duration) of these exposures. Risks exposures can also be independent or clustered. In the clustered scenario (also known as 'accumulation model with risk clustering'), the risks can be due to individual or family socioeconomic circumstances for example, individuals from poor socioeconomic backgrounds (as a cluster) may have a higher risk of smoking, live in poorer living conditions, have a higher risk of poverty, poorer educational achievement and suffer more stress.

The *'chain of risk model'* or *'pathway model'* is a variation of the accumulation model but refers to a sequence of linked exposures that leads to impaired function and increased risk. This can be viewed as a chain of events which leads to another and so on. Each exposure may increase risk of subsequent exposure and may also have an independent 'additive effect' on later function as in the chain of risk model. As an alternative, there may also be a 'trigger effect' where a chain of events is triggered with only the final chain having a marked effect.

Kuh & Ben-Shlomo (2004) describe these models as not mutually exclusive and suggest they may operate simultaneously. It may also be difficult to distinguish the models empirically, and in developing standardised and acceptable methods of combining cumulative exposures.

Temporal ordering of exposures is an important element of life course epidemiology. How these exposures relate to each other requires a *time-related study design* (i.e. a longitudinal or cohort study). The United States Department of Health and Human Services developed a concept paper on life course model for maternal child health service planning framework which summarised four essential elements of life course theory, which are:

1) *Today's experiences and exposures influence tomorrow's health (timeline)*
2) *Health trajectories are particularly affected during critical or sensitive periods (timing)*
3) *The broader community environment-biologic, physical and social- strongly affects the capacity to be healthy (environment)*
4) *While genetic make-up offers both protective and risk factors for disease conditions, inequality in health reflects more than genetics and personal choice (equity)*
   (U.S. Department of Health and Human Services, 2010)

Thus from a study design point of view, with a sound theoretical background to inform the methodology, birth cohort has been the method of choice in providing the evidence and development of DOHaD and the life course approach (Batty *et al*, 2010).

From a Traveller health perspective, there is both historical and updated evidence (All Ireland Traveller Health Study Team, 2010; Barry *et al*, 1989) that Travellers have higher morbidity and mortality from chronic diseases and in most cases, have higher prevalence rates than the general population (All Ireland Traveller Health Study Team, 2010). Establishment of a Traveller Birth Cohort is an opportunity to further investigate how life course factors produce chronic conditions in Travellers. This study will not only look at Traveller infants' health during the important first year of life but will also further inform health policy of Travellers in the future. The Traveller birth cohort study is unique due to its follow-up on a nomadic minority.

1.2 Cohort profile update since the last report

The birth cohort study employed two main methods for data collection. These were:

1) Parent-held Child Record (PHCR) - a specially designed diary which all consenting mothers carried with them for a one year period.
2) Linkage-data from the maternity hospitals - the birth notification form (BNF01/2003), completed by the hospital, or midwife, after birth of baby, and was used for hospital linkage.

The cohort profile is relatively unchanged since the last report; an additional four babies gave an overall total of 986 births, with 508 (51.5%) mothers consented to the study. Eight mothers refused hospital record access but participated in the main follow up section (Figure 1.1).

The crude birth rate of Irish Travellers was 24.4 while the total fertility rate of Irish Travellers is 2.7 per 1,000 population (Hamid *et al*, 2010).

1.3 Follow up of mothers

During the follow up period, we continued to engage with participating mothers through newsletters about the study and using a mass text messaging system. We also asked the PHNs to inform the study team of any change in address of the mothers or any major events experienced by the mothers/families or babies. For those who had moved to a different area, we notified the link-PHN in the area to highlight this move and ensure follow up.

1.4 Traveller mother movement

Overall, at least 30% (n=152) of the mothers were noted to change their address (moving of accommodation) or move out of their original area. Some who moved within the same LHO were not informed to the study team as the follow-up remained the responsibility of either the same PHN or designated PHN. 19.7% (n=30) of those who moved were lost in the process despite the team's best effort. The movement resulted in losses to follow up including from county to county, across the border to Northern Ireland (and vice versa), to the United Kingdom and to Europe. In most cases there was no forwarding address for those who moved out of the island of Ireland, although some who travel actively made contact with the PHNs upon their return. Sometimes a family left without notifying the PHNs or register with the PHNs in the next area although a small number were picked up by the Primary Health Care for Travellers Projects (PHCTPs) in the next area.

The movement of Traveller mothers in the cohort of 30% is somewhat higher than the reported number from the AITHS census in ROI (21.5% reported to be 'on the road' at least once in a year) but lower than the number from Northern Ireland (37.4%).

1.5 Report layout

In this report, we present the final prospective follow up findings of the birth cohort study. This includes the maternity hospital linkage data, data from the Parent-held Child Record (PHCR) and infant mortality. These are chapters 2, 3 and 4. This is followed by a brief conclusion and recommendations.

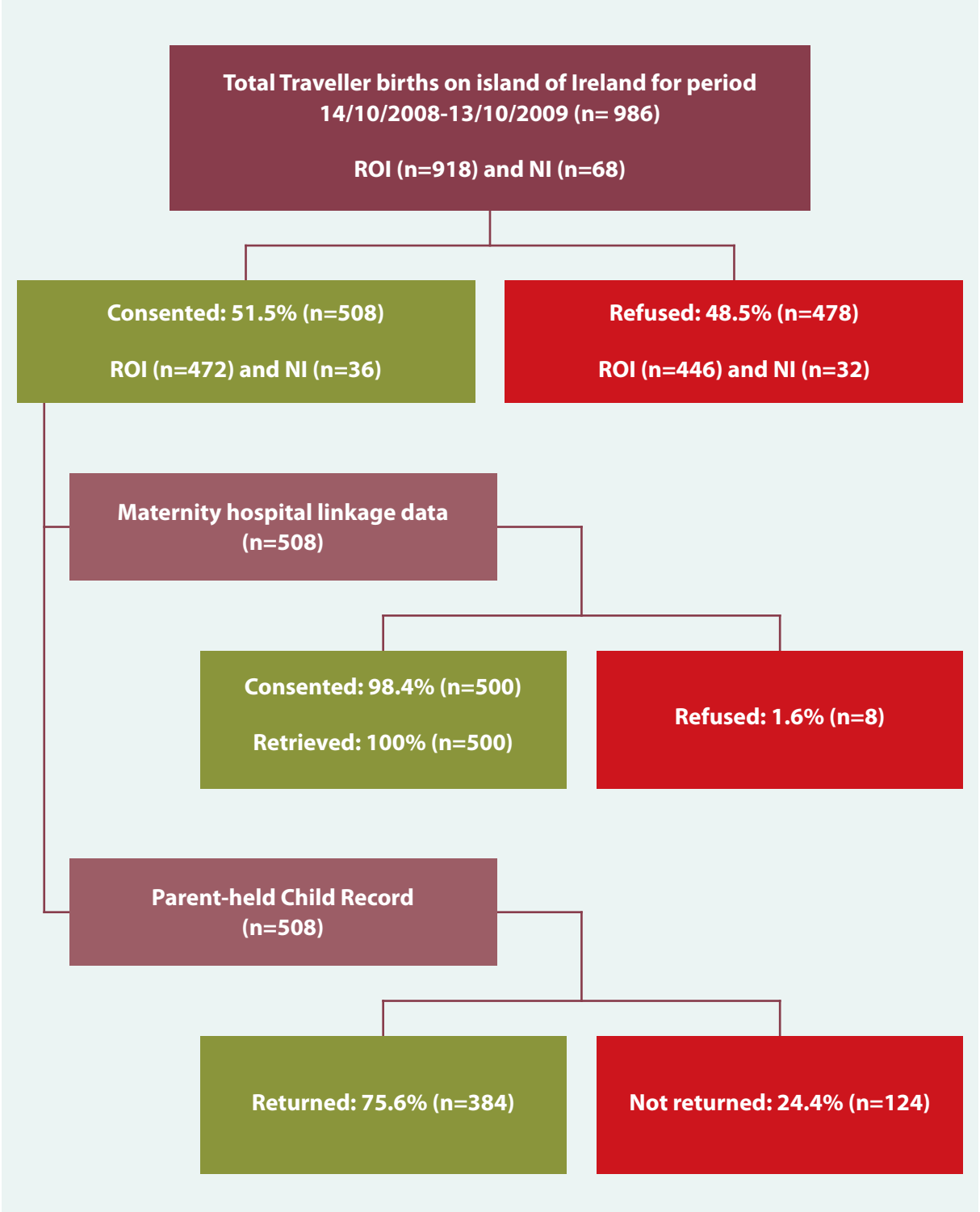
For comparison purposes, we first made comparison between Travellers in the Republic of Ireland (ROI Travellers) and Northern Ireland (NI Travellers). However, we advise caution when reviewing the results due to the small numbers in the NI Travellers group. For this reason, we have grouped the ROI and NI Travellers as one group in most parts of the report. The combined ROI and NI Travellers are referred to as 'Irish Travellers'.

1.6 Statistical analysis

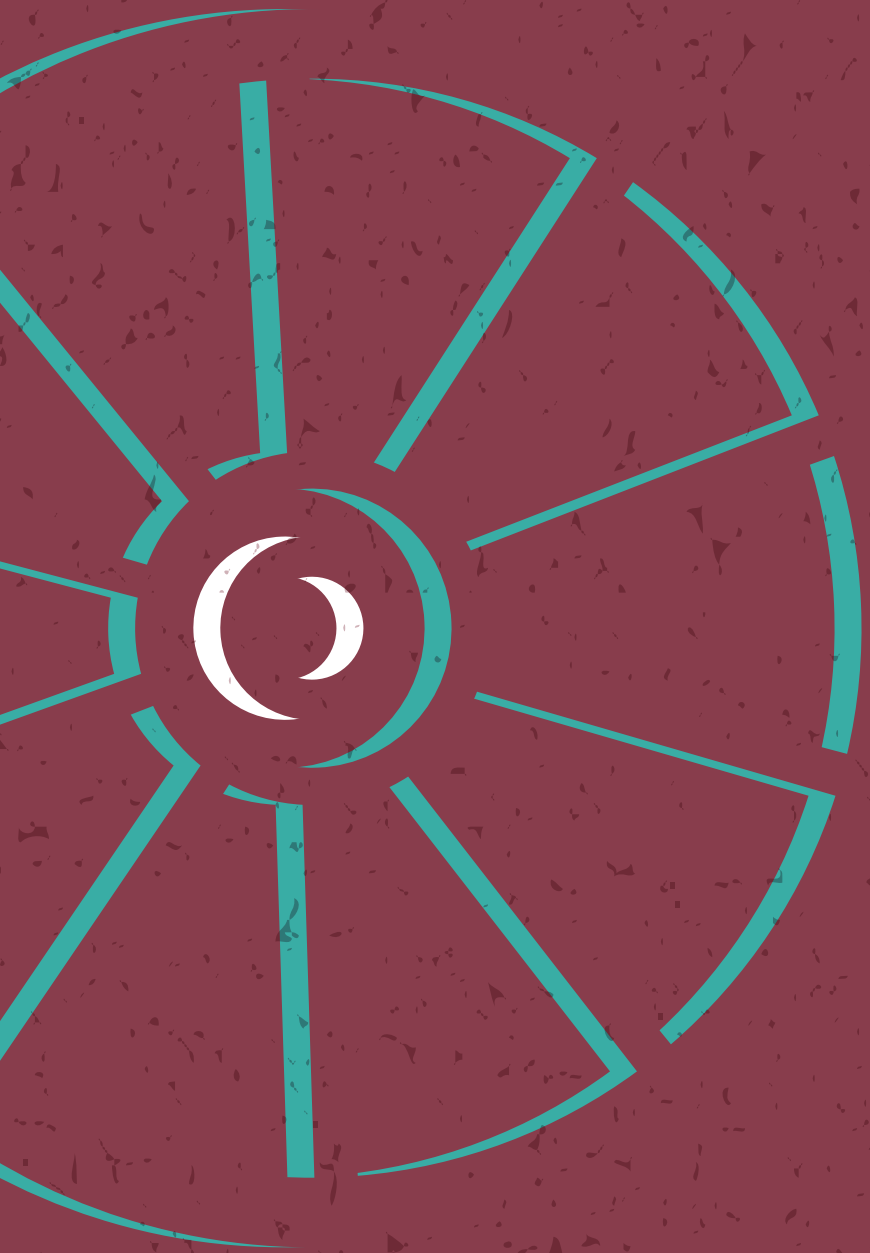
For descriptive statistics, we include the total number of participants (n) and give the proportion as percentage (%). We have also included the range, standard deviations (SD) and 95% confidence interval (95% CI). The standard deviation describes the spread of the data while the 95% CI describes the range of values within which we are 95% confident the true mean value lies.

When statistical analysis was made, we used the Chi-square test for comparison of proportions; for comparison of means, we used the unpaired t-test for two groups and ANOVA for more than two groups (Daly and Bourke, 2000).

Figure 1.1: Breakdown of Traveller births on island of Ireland and numbers retrieved according to each study component



Chapter 2:
Maternity Hospital Linkage Data



Maternity Hospital Linkage Data

2.1 Introduction

This study had a linkage component to each maternity hospital where the baby was delivered. During the consenting process, we requested that Traveller mothers also consent for the study team to access their maternity maternal records. Only a small number of mothers (n=8) refused this linkage component.

2.2 Methodology

2.2.1 Data requested

The study team requested the Birth Notification Form (BNF01/2003) from each maternity hospital. A sample copy of this form is attached in appendix A. Relevant information in the BNF01/2003 utilised for this study is shown in Table 2.1.

Table 2.1: Relevant data utilised in the Birth Notification Form (BNF01/2003)

Baby's details:	**Parents' details:**
• Place of birth: Hospital, domiciliary or other • Baby's date of birth • Baby's gestation week • Baby's birth weight • Baby's gender	• Father's address, date of birth, nationality and employment • Mother's address, date of birth, nationality and employment • Mother's marital status
Mother's obstetric characteristics:	**Antenatal details:**
• Previous number of live births • Previous number of stillbirths • Previous number of miscarriages • Rubella status	• Date of first visit to doctor • Date of first visit to hospital • Type of antenatal care
Birth details:	**Maternity hospital utilisation:**
• Type of delivery • Planned feeding method • Was BCG immunisation given	• Was booking into hospital planned • Date of admission • Date of mother's discharge • Date of infant's discharge

When a baby is born, the midwife (or personnel who attended to the birth) fills out the Birth Notification Form. In total, there are 4 copies to this form which are sent to relevant parties; these include:

1. **Registrar of births**
2. **Director of Public Health**
3. **National Perinatal Reporting System (NPRS)**
4. **Hospital copy**

However, it should be noted that copy number one and three do not have all the details. Copy number one, the top most copy, is sent to the Registrar of births and does not contain the antenatal details, birth details and General Practitioner details. Copy number three, the NPRS copy, does not contain the parents' names, addresses or General Practitioner's details. The 'Director of Public Health' and 'Hospital copy' copies have complete information. Further description on this and data quality control has been discussed by NPRS (2010).

The Public Health Nursing team is notified of a birth by the maternity hospital using the '36 hour Birth Notification (Notification of Births Act, 1915)' form.

2.2.2 Maternity hospital data request procedure

All maternity hospitals in the Republic of Ireland and Northern Ireland were contacted. Only hospitals in the Republic of Ireland use the BNF01/2003. However, not all hospitals were able to forward the BNF01/2003 form. In such cases, the '36 hour Birth Notification' form was requested. When neither copy of these forms was available, the hospital liaised with the Registrar of births in the community and retrieved the 'Registrar of births' copy of the BNF01/2003.

In Northern Ireland, there was no specific form for recording similar data as the BNF01/2003. As a result, the study team requested the mother and infant discharge summaries. There were no father details, limited obstetric details, and no admission details on these forms. Accordingly, analysis cannot be performed on this section for the NI Traveller group. Where appropriate, we acknowledge this by referring to 'ROI Travellers' instead of Irish Travellers.

Overall, although there were variations and different methods of retrieval, we obtained 100% (all mothers who consented for this part of the study) of the linkage data. However, due to the variations in data recorded and quality of recording for all forms, there were varied differences in the number of cases according to each variable in the hospital data set for the Travellers group.

2.2.3 Comparative data

The study team requested the latest dataset held by the National Perinatal Reporting System (NPRS), based in the Economic & Social Research Institute (ESRI), which receives copy number three of the BNF01/2003. The NPRS dataset reflects all births which occurred in ROI over a one-year period. This dataset was used in all analyses in this chapter.

The NPRS provided an anonymised dataset for the year 2008 (latest). Parents' dates of birth, infant's exact 30-day calendar date (month of birth was given), county of birth and maternity hospital where birth occurred were not provided. Instead NPRS provided the age of parents to the study team. Only live births data were used.

Due to the retention of the actual calendar 'date' by NPRS (for baby's date of birth), we used a proxy date as the baby's date of birth. The baby's date of birth in the NPRS dataset (for this study) was created by combining 'calendar date of mother's admission to hospital' and the actual month of birth of the baby.

a) Irish Travellers, NPRS Irish and NPRS European comparison

For comparative purposes, we have selected only Irish-born mothers from the NPRS data. This is based on 'Irish' status in the mother's nationality variable. This will be referred to as 'NPRS Irish' throughout the report. We selected only Irish-born mothers as a direct comparison given that Traveller mothers in the birth cohort are all 'Irish' by origin. Other European mothers are referred to as 'NPRS European'. All other non-Europeans were removed from analysis.

b) NPRS Irish Socioeconomic Group (SEG)

Infant socioeconomic group (SEG) was based on the paternal occupational status as recorded by the NPRS. We used the methodology employed by the Institute of Public Health in Ireland (2006) to categorise the SEG. The father's occupational status and subsequent SEG groupings are presented in Table 2.2.

We have selected only Irish-born mothers in the general population for comparison of socioeconomic groupings. Throughout this report, 'NPRS Irish SEG' is used to mean 'Irish-born mothers' whose SEG is based on their spousal occupation.

Table 2.2: Spouse's occupation used to construct NPRS Irish SEG

NPRS recorded occupation	Socioeconomic group
Farmers and farm managers	Farmers
Higher professionals	SEG-A
Lower professionals	
Employers & managers	SEG-B
Salaried employees	
Intermediate non-manual workers	SEG-C
Other non-manual workers	
Skilled manual workers	
Semi-skilled manual workers	SEG-D
Unskilled manual workers	
Other agricultural occupations and fishermen	
Unemployed	Unknown/unemployed
Not-classifiable	
Not applicable (father's occupation only)*	
Home duties	
Missing/not stated	Not classified

*NPRS coded this when marital status of mother is given as single/widowed/separated/ divorced/ father's occupation was left blank

2.3 Results

A total of 508 mothers consented for the birth cohort study; 500 of these gave full consent for all linkage part of the study.

2.3.1 Paternal characteristics

2.3.1.1 Father's age

Traveller fathers are considerably younger than either the general Irish population or immigrant European population (Table 2.3). Over a third (34.9%) of Traveller fathers are less than 24 years of age, whereas older fathers, over the age of 40 (4%) are rare (Table 2.4). Accordingly the age distribution for Travellers is markedly skewed to the left compared with other groups (Figure 2.1).

Table 2.3: Mean age of fathers - ROI Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

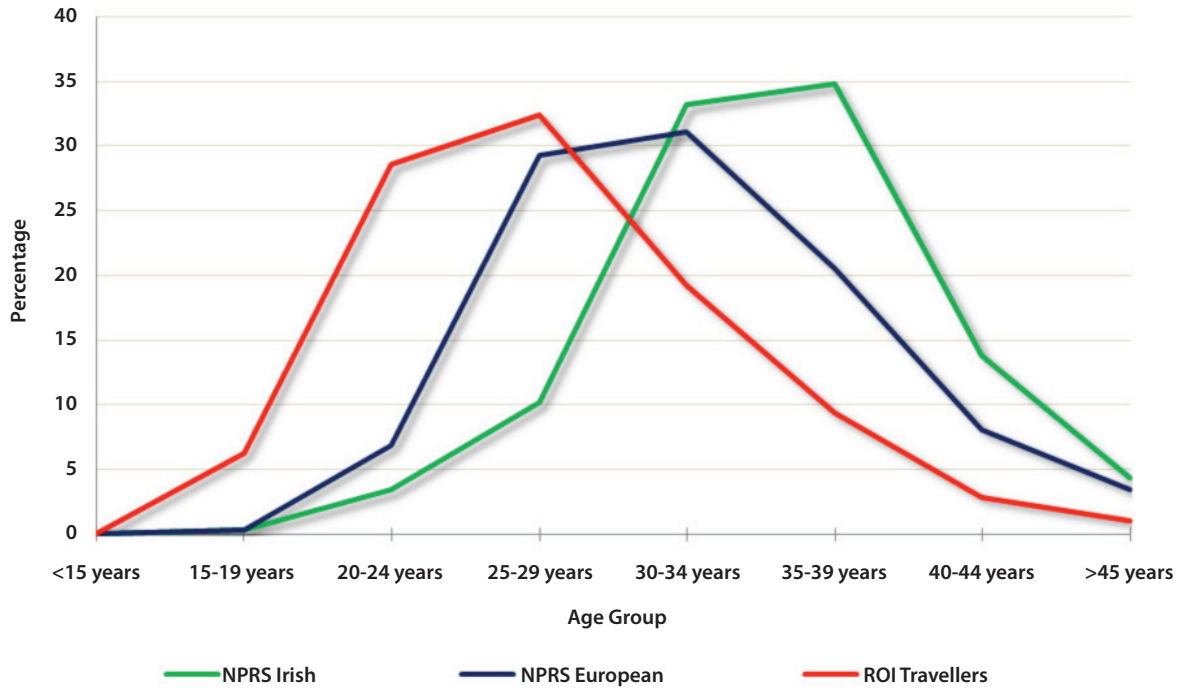
	n	mean (years)	range	standard deviation (SD)	95% confidence interval (CI)
ROI Travellers	447	27.5	17-47	6.0	26.9-28.1
NPRS Irish	41,772	34.6	15-74	5.7	34.5-34.6
NPRS European	7,443	31.8	15-64	6.0	31.7-32.0
NPRS Irish SEG:					
Farmers	1,524	37.5	20-64	5.3	37.2-37.7
SEG-A	5,213	36.1	16-65	4.7	36.0-36.2
SEG-B	4,618	35.6	19-62	4.8	35.5-35.7
SEG-C	17,690	34.8	15-64	5.7	34.1-34.2
SEG-D	2,542	33.6	15-56	6.0	33.3-33.8
Unknown/ unemployed	1,646	30.7	15-74	7.7	30.4-31.0

Note: NI Travellers not available

Table 2.4: Age distribution of fathers - ROI Travellers, NPRS Irish and NPRS European

Age group	ROI Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<15 years	0.0	0	0.01	2	0.0	0
15-19 years	6.3	28	0.3	90	0.4	21
20-24 years	28.6	128	3.4	1,064	6.9	376
25-29 years	32.4	145	10.2	3,177	29.3	1,590
30-34 years	19.2	86	33.2	10,352	31.2	1,690
35-39 years	9.4	42	34.8	10,868	20.6	1,117
40-44 years	2.9	13	13.8	4,318	8.1	441
>45 years	1.1	5	4.3	1,350	3.5	190
Total	100.0	447	100.0	31,221	100.0	5,425

Figure 2.1: Age distribution of fathers - ROI Travellers, NPRS Irish and NPRS European

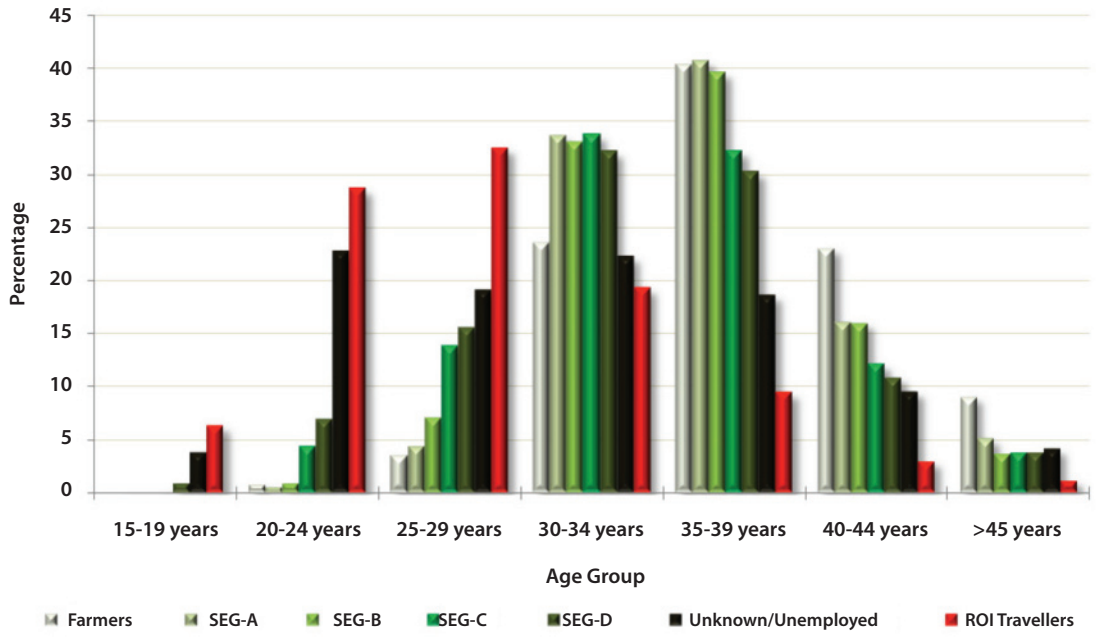


In reviewing the age distribution compared to the general Irish population according to SEG, Travellers most closely resemble the pattern for the Unknown/unemployed group, with younger fathers being more common in that group (Table 2.5). There are relatively fewer older Traveller fathers compared to any other grouping however (Figure 2.2).

Table 2.5: Age distribution of fathers - ROI Traveller and NPRS Irish SEG

Age group	NPRS Irish SEG												ROI Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ Unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
<15 years	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.1	2	0.0	0
15-19 years	0.0	0	0.0	2	0.0	1	0.2	42	0.8	20	3.8	62	6.3	28
20-24 years	0.7	11	0.4	22	0.9	40	4.4	771	6.9	175	22.7	373	28.6	128
25-29 years	3.5	54	4.3	224	7.0	324	13.8	2,438	15.5	395	19.1	314	32.4	145
30-34 years	23.5	358	33.6	1,750	33.0	1,524	33.7	5,959	32.1	816	22.2	366	19.2	86
35-39 years	40.3	614	40.6	2,119	39.6	1,828	32.1	5,685	30.2	767	18.6	306	9.4	42
40-44 years	23.0	350	16.0	834	15.9	736	12.1	2,135	10.8	275	9.5	156	2.9	13
>45 years	9.0	137	5.0	262	3.6	165	3.7	660	3.7	94	4.1	67	1.1	5
Total	100.0	1,524	100.0	5,213	100.0	4,618	100.0	17,690	100.0	2,542	100.0	1,646	100.0	447

Figure 2.2: Age distribution of fathers - ROI Travellers and NPRS Irish SEG



2.3.1.2 Father's occupation

64.4% of Traveller fathers are unemployed compared to 2.8% of Irish and 4.1% of European fathers (Table 2.6).

Table 2.6: Father's occupation - ROI Travellers, NPRS Irish and NPRS European

Occupation group	ROI Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Farmers and farm managers	0.2	1	4.8	2,098	0.4	31
Other agricultural occupations and fishermen	0.2	1	1.3	576	1.4	107
Higher professionals	0.0	0	10.6	4,624	5.8	431
Lower professionals	0.0	0	5.9	2,595	4.6	341
Employers and managers	0.2	1	11.1	4,879	7.1	532
Salaried employees	2.1	10	3.1	1,370	1.5	111
Intermediate non-manual workers	0.6	3	11.2	4,897	7.1	532
Other non-manual workers	1.1	5	10.0	4,368	16.9	1,258
Skilled manual workers	1.3	6	30.8	13,504	34.0	2,534
Semi-skilled manual workers	8.2	39	4.6	2,029	11.1	829
Unskilled manual workers	6.3	30	1.1	500	2.1	153
Unemployed	64.3	306	2.8	1,225	4.1	305
Not classifiable	3.6	17	1.9	820	2.4	176
Not applicable (father's occupation only)*	11.6	55	0.5	290	1.2	91
Home duties	0.4	2	0.2	82	0.2	15
Total	100.0	476	100.0	43,807	100.0	7,446

*NPRS coded this when marital status of mother is given as single/widowed/separated/ divorced/father's occupation was left blank

Table 2.7: Father's SEG - ROI Travellers and NPRS Irish SEG

Groups	ROI Travellers		NPRS Irish	
	%	n	%	n
Farmers	0.2	1	4.8	2,098
SEG-A	0.0	0	16.5	7,219
SEG-B	2.3	11	14.3	6,249
SEG-C	2.9	14	52.0	22,769
SEG-D	14.7	70	7.1	3,105
Unknown/Unemployed	79.8	380	5.5	2,417
Total	100.0	476	100.0	43,807

2.3.2 Maternal characteristics

2.3.2.1 Mother's age

Traveller mothers in both ROI and NI are younger than either NPRS Irish or European mothers (26 years versus 31.6 and 28.8 years) (Table 2.8).

Table 2.8: Mean age of mothers - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

	n	mean (years)	Range	SD	95% CI
ROI Travellers	471	25.9	16-44	5.6	25.4-26.4
NI Travellers	36	26.0	16-40	6.6	23.8-28.2
Irish Travellers	508	25.9	16-44	5.7	25.4-26.4
NPRS Irish	58,172	31.6	15-51	5.6	31.5-31.6
NPRS European	10,671	28.8	14-51	5.3	28.7-28.9
NPRS Irish SEG:					
Farmers	2,086	34.7	18-49	4.4	34.5-34.9
SEG-A	8,263	34.1	19-50	3.8	34.3-34.5
SEG-B	7,380	33.8	18-51	4.1	33.7-33.9
SEG-C	29,162	31.5	15-49	5.0	31.5-31.6
SEG-D	3,722	31.0	17-48	5.4	30.7-31.1
Unknown/ unemployed	6,930	26.6	15-47	6.4	26.5-26.8

The age distribution of mothers is given in Table 2.9 and shown also in Figure 2.3. Travellers are significantly younger on average than the other groups ($p<0.001$) and there are predominantly more Travellers in the 15-19 year old category (13.2%) than the Irish (2.2%) or European (2.2%) groups.

Table 2.9: Age distribution of mothers – Irish Travellers, NPRS Irish and NPRS European

Mother's age	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<15 years	0.0	0	0.0	3	0.1	4
15-19 years	13.2	67	2.2	1,030	2.2	187
20-24 years	32.1	163	10.3	4,814	18.5	1,581
25-29 years	29.7	151	19.0	8,825	37.2	3,185
30-34 years	16.3	83	35.3	16,405	26.5	2,267
35-39 years	6.9	35	27.3	12,723	12.8	1,092
40-44 years	1.6	8	5.4	2,537	2.6	227
>45 years	0.2	1	0.4	182	0.2	17
Total	100.0	508	100.0	46,519	100.0	8,560

Figure 2.3: Age distribution of mothers - Irish Travellers, NPRS Irish and NPRS European

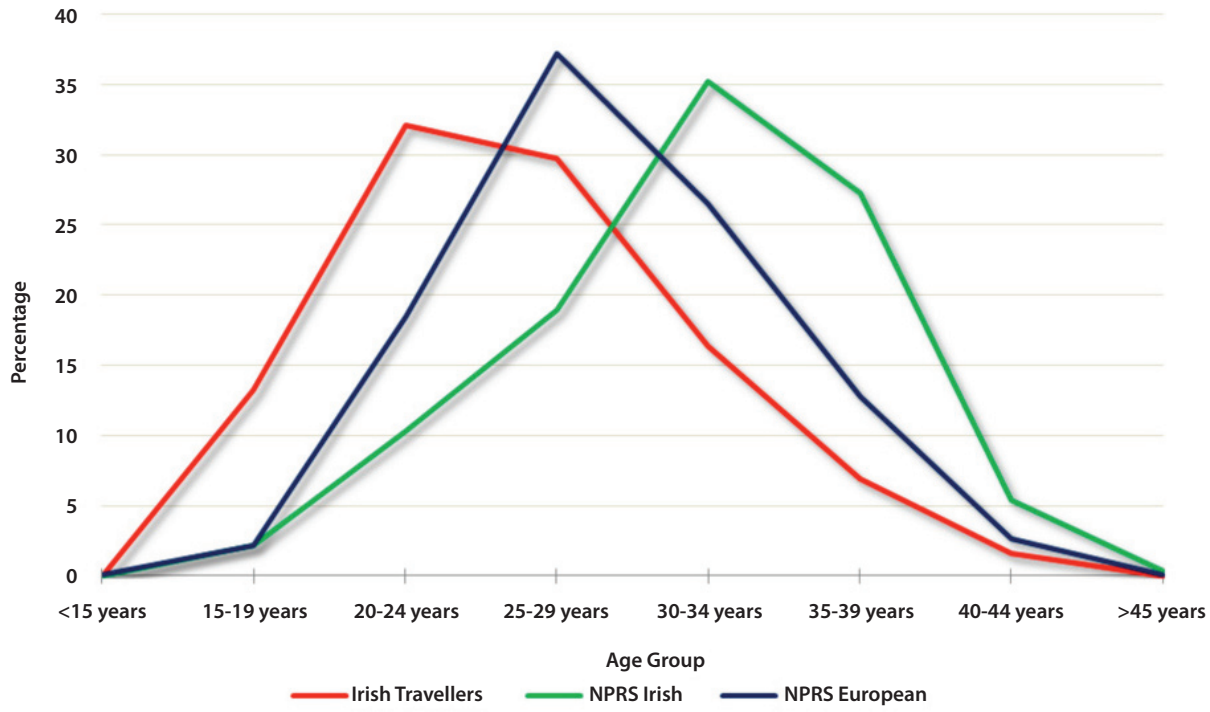
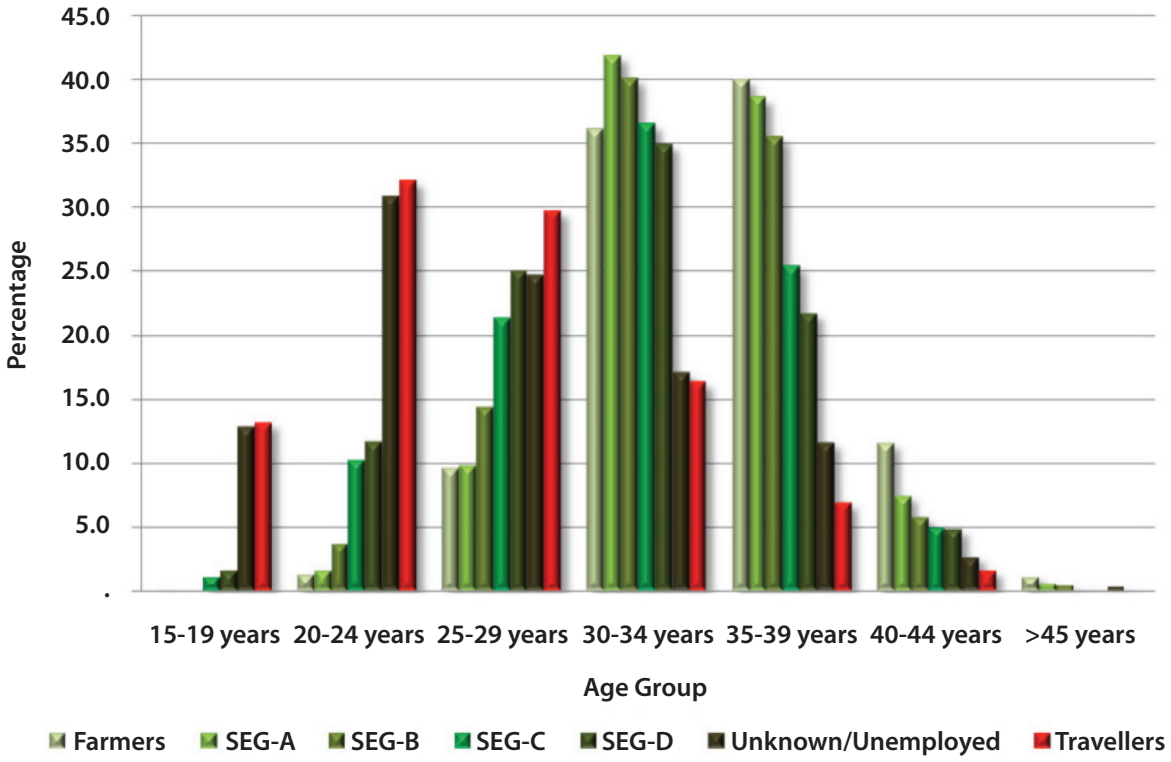


Table 2.10: Age distribution of mothers - Irish Travellers and NPRS Irish SEG

Age group	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
15-19 years	0.2	3	0.0	1	0.1	7	1.1	264	1.6	46	12.8	706	13.2	67
20-24 years	1.3	21	1.7	109	3.7	221	10.2	2,388	11.7	344	30.9	1,701	32.1	163
25-29 years	9.7	162	9.9	648	14.4	856	21.4	4,995	25.0	737	24.7	1,360	29.7	151
30-34 years	36.2	607	41.9	2,754	40.1	2,389	36.6	8,533	34.9	1,029	17.1	941	16.3	83
35-39 years	40.0	671	38.6	2,539	35.5	2,117	25.4	5,936	21.7	640	11.6	640	6.9	35
40-44 years	11.6	194	7.5	490	5.7	341	5.0	1,162	4.8	141	2.6	145	1.6	8
>45 years	1.1	19	0.5	35	0.4	26	0.3	65	0.3	8	0.3	19	0.2	1
Total	100.0	1,677	100.0	6,576	100.0	5,957	100.0	23,343	100.0	2,945	100.0	5,512	100.0	508

The Traveller age distribution is again skewed to the left compared with other social groups but as with Traveller men, the Unknown/unemployed is closest to the Traveller distribution (Figure 2.4). There is a social pattern in that those in A, B, C and Farmers SEG categories tend to be older than D, Unknown/ unemployed and Travellers.

Figure 2.4: Age distribution of mothers - Irish Travellers and NPRS Irish SEG



2.3.2.2 Mother's occupation

Almost 90% of Traveller women are housewives or unemployed compared to only 22% of the Irish mothers and 32% of their European counterparts (Tables 2.11 and 2.12) ($p<0.001$). Less than 3% of Traveller mothers are in some form of employment.

Table 2.11: Mother's occupation - Irish Travellers, NPRS Irish and NPRS European

Occupation group	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Farmers and Farm managers	0.0	0	0.1	79	0.1	7
Other agricultural occupations and fishermen	0.0	0	0.1	64	0.3	29
Higher professionals	0.0	0	6.7	3,902	4.5	478
Lower professionals	0.0	0	15.5	9,009	6.4	680
Employers and managers	0.0	0	8.6	5,032	5.4	582
Salaried employees	0.2	1	1.9	1,094	1.0	110
Intermediate non-manual workers	0.2	1	24.6	14,320	19.8	2,117
Other non-manual workers	1.8	9	12.3	7,148	16.2	1,732
Skilled manual workers	0.0	0	1.9	1,131	1.6	170
Semi-skilled manual workers	0.2	1	2.6	1,510	8.6	917
Unskilled manual workers	0.4	2	0.0	4	0.0	3
Unemployed	7.4	37	2.5	1,484	5.3	571
Not classifiable	2.8	14	3.3	1,948	3.3	349
Home duties	82.0	410	19.6	11,421	27.1	2,894
Missing/not stated	5.0	25	0.1	62	0.4	40
Total	100.0	500	100.0	58,208	100.0	10,679

Table 2.12: Mother's SEG - ROI Travellers and NPRS Irish SEG (based on mother's own occupation)

Groups	Irish Travellers		NPRS Irish	
	%	n	%	n
Farmers	0.0	0	0.1	79
SEG-A	0.0	0	22.2	12,911
SEG-B	0.2	1	10.5	6,126
SEG-C	2.0	10	38.8	22,599
SEG-D	0.6	3	2.7	1,578
Not classifiable	2.8	14	3.3	1,948
Unemployed	6.8	37	2.5	1,484
Home duties	82.0	410	19.6	11,421
Total	100.0	500	100.0	58,208

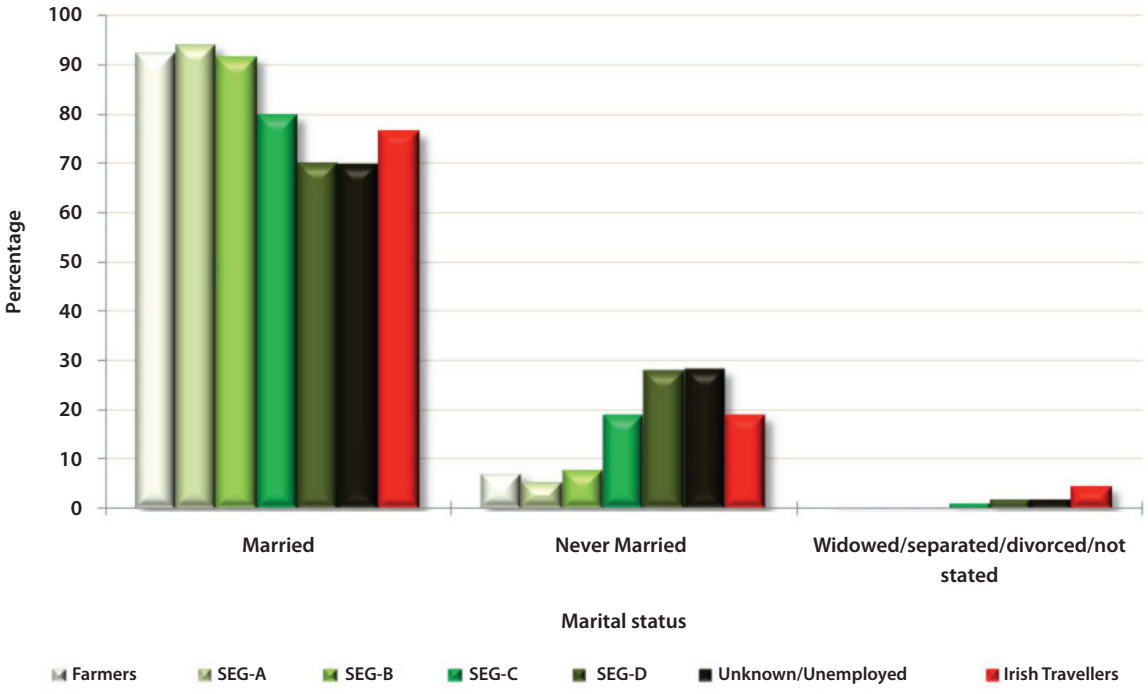
2.3.2.3 Mother's marital status

A majority of all mothers are currently married; with Travellers (76.6%) being most likely to be so, compared with 66.4% of Irish and 58.3% of European origin mothers (Table 2.13). There is a social gradient to this category (Figure 2.5).

Table 2.13: Mother's marital status - Irish Travellers, NPRS Irish and NPRS European

Marital status	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Married	76.6	376	66.4	38,643	58.3	6,228
Never Married	18.9	93	32.2	18,757	38.5	4,111
Widowed	0.0	0	0.1	57	0.1	11
Separated	4.5	22	0.8	475	1.0	112
Divorced	0.0	0	0.4	238	2.0	212
Not Stated	0.0	0	0.1	38	0.1	5
Total	100.0	491	100.0	58,208	100.0	10,679

Figure 2.5: Marital status - Irish Travellers and NPRS Irish SEG



2.3.3 Obstetric characteristics

In this section, we describe the obstetric characteristics of Traveller mothers, NPRS Irish, NPRS European and NPRS Irish SEG.

2.3.3.1 Mother's parity

Maternal parity indicates a mother's total number of previous live and stillbirths (NPRS, 2008, pg 116). Nulliparous refers to women who gave birth for the very first time, while parous refers to women who had given birth one or more times.

Parity status of Traveller mothers in ROI and NI, NPRS Irish, NPRS European and NPRS Irish SEG is given in Table 2.14.

Table 2.14: Mother's parity status - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

Groups	Nulliparous		Parous	
	%	n	%	n
ROI Travellers	21.0	95	79.0	358
NI Travellers	31.4	11	68.6	24
Irish Travellers	21.7	106	78.3	382
NPRS Irish	40.1	23,357	59.9	34,840
NPRS European	58.0	6,253	42.0	4,524
NPRS Irish SEG:				
Farmers	29.7	620	70.3	1,468
SEG-A	42.7	3,563	57.3	4,791
SEG-B	41.0	3,051	59.0	4,384
SEG-C	40.5	11,884	59.5	17,469
SEG-D	37.5	1,400	62.5	2,333
Unknown/unemployed	39.1	2,821	60.9	4,389

Figure 2.6 shows distribution of parity by age group for both nulliparous and parous women. Nulliparous Travellers are again shown to be younger on age distribution than NPRS European and NPRS Irish mothers ($p<0.001$). Parous Travellers are also younger on average than the other comparison groups ($p<0.001$).

Figure 2.6: Mother's parity by 5-year age group - Irish Travellers and NPRS Irish

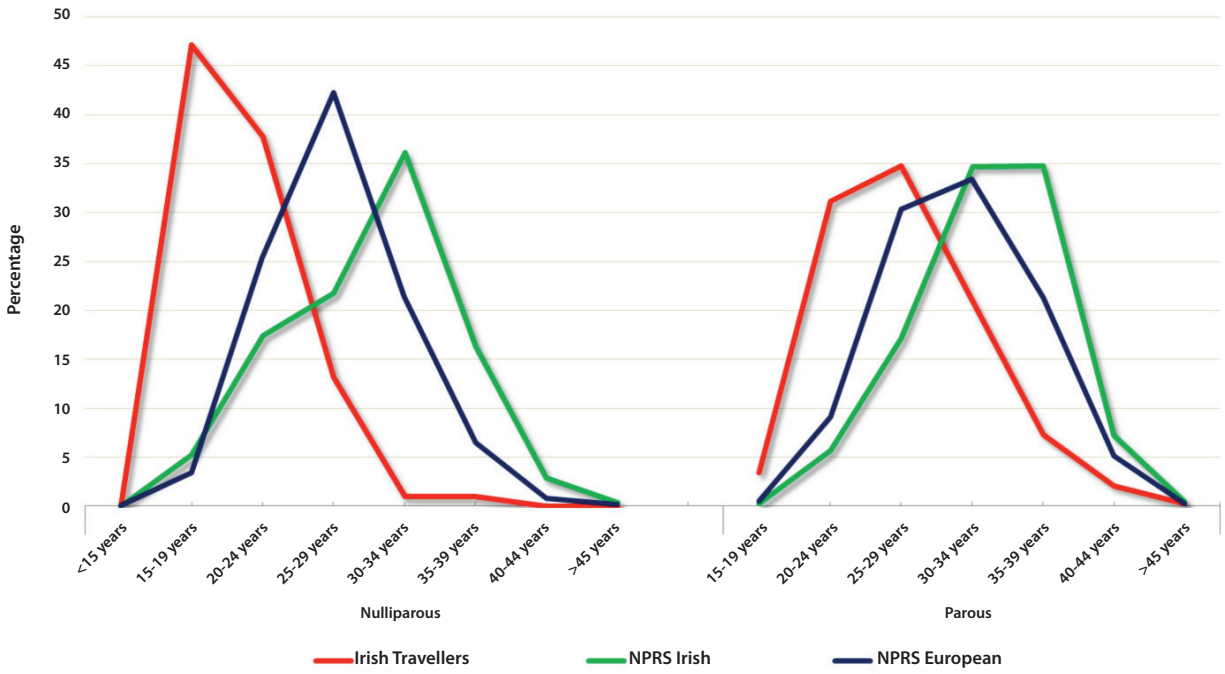
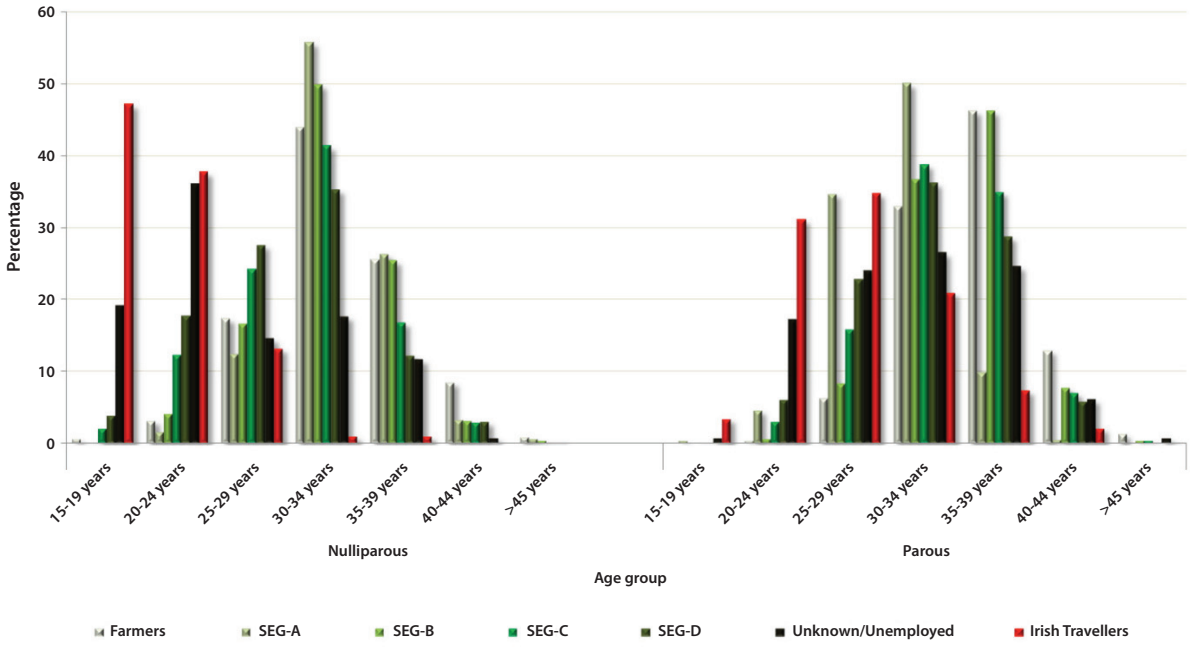


Figure 2.7: Mother's parity by 5-year age group - Irish Travellers and NPRS Irish SEG



In Figure 2.7 age distribution according to Irish SEG is shown relative to Travellers. A gradient is again observed in the population for both nulliparous and parous women; those in SEG-A and B are least likely to be in the two youngest age categories and most likely to be in the 30-34 year old category. By contrast there are virtually no nulliparous Travellers aged 30 or over. In parous women, Travellers again tend to be considerably younger than other groupings and least likely to be in the over 40 age groups.

Parity amongst those mothers who already had a live or stillbirth is given in Table 2.15. Compared with NPRS Irish and European women, Traveller mothers show a wide distribution and nearly a third of those mothers (30.3%) had 4 or more births. 10.7% of mothers had 6 or more births, compared with 0.9% of Irish and 1.3% of Europeans. Parity according to Irish SEG is compared with Travellers in Table 2.16. Again, there is a gradient in the general population with the Unknown/unemployed mothers more likely to have more children but with Traveller mothers most likely to report higher numbers of previous pregnancies.

Table 2.15: Number of previous births in parous women - Irish Travellers, NPRS Irish and NPRS European

Number of births (live and still births)	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
1	27.0	103	54.4	18,949	65.2	2,950
2	26.7	102	29.4	10,226	22.5	1,016
3	16.0	61	10.7	3,745	7.4	337
4	10.7	41	3.4	1,199	2.4	110
5	8.9	34	1.1	393	1.2	55
6 or more	10.7	41	0.9	329	1.3	57
Total	100.0	382	100.0	34,841	100.0	4,525

Table 2.16: Number of previous births in parous women - Irish Travellers and NPRS Irish SEG

	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
1	43.5	638	55.8	2,673	58.6	2,568	56.3	9,827	52.1	1,215	46.1	2,024	27.0	103
2	32.2	472	31.2	1,496	30.2	1,325	28.8	5,039	30.9	720	26.7	1,172	26.7	102
3	16.1	237	10.6	509	8.8	386	10.3	1,801	10.5	245	12.9	566	16.0	61
4	5.7	83	1.6	77	1.9	83	3.2	558	4.2	99	6.8	299	10.7	41
5	1.9	28	0.5	22	0.3	14	0.9	151	1.1	25	3.5	153	8.9	34
6 or more	0.7	10	0.3	14	0.2	8	0.5	93	1.2	29	4.0	175	10.7	41
Total	100.0	1,468	100.0	4,791	100.0	4,384	100.0	17,469	100.0	2,333	100.0	4,389	100.0	382

2.3.3.2 Previous live births

Previous live births in parous women are shown in Tables 2.17 and 2.18 and the distribution illustrated in Figure 2.8. There is a higher average number of births among Travellers than the other two groups, with most general Irish and Europeans having had just one or two previous live births. When this is examined according to SEG, the Unknown/unemployed group more closely resembles the Traveller mother pattern than other groups (Table 2.19).

Table 2.17: Mean number of previous live births (parous women) - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

Group	n (%)*	mean	range	SD	95% CI
Irish Travellers (parous women, n=382)	379 (99.2)	2.8	1-9	1.8	2.7-3.0
NPRS Irish (parous women, n=34,841)	34,710 (99.6)	1.7	1-12	1.0	1.7-1.7
NPRS European (parous women, n=4,525)	4,510 (99.7)	1.6	1-13	1.0	1.5-1.6
NPRS Irish SEG:					
Farmers (parous women, n=1,468)	1,464 (99.7)	1.9	1-11	1.0	1.9-2.0
SEG-A (parous women, n=4,791)	4,772 (99.6)	1.6	1-8	0.8	1.6-1.6
SEG-B (parous women, n=4,384)	4,369 (99.7)	1.5	1-7	0.8	1.5-1.6
SEG-C (parous women, n=17,469)	17,404 (99.7)	1.6	1-11	0.9	1.6-1.6
SEG-D (parous women, n=2,333)	2,325 (99.8)	1.7	1-12	1.1	1.7-1.8
Unknown/unemployed (parous women, n=4,389)	4,369 (99.6)	2.1	1-12	1.7	2.0-2.1

*percentage as a proportion of parous women in the same group

Table 2.18: Number of previous live births (parous women) - Irish Travellers, NPRS Irish and NPRS European

Number of live births	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
0	0.8	3	0.4	131	0.3	15
1	27.7	106	54.6	19,013	65.3	2,957
2	25.9	99	29.2	10,170	22.2	1,004
3	15.4	59	10.6	3,695	7.4	335
4	11.3	43	3.3	1,159	2.4	109
5	8.4	32	1.0	365	1.1	52
6 or more	10.5	40	0.9	308	1.2	53
Total	100.0	382	100.0	34,841	100.0	4,525

Figure 2.8: Number of previous live births in parous women - Irish Travellers, NPRS Irish and NPRS European

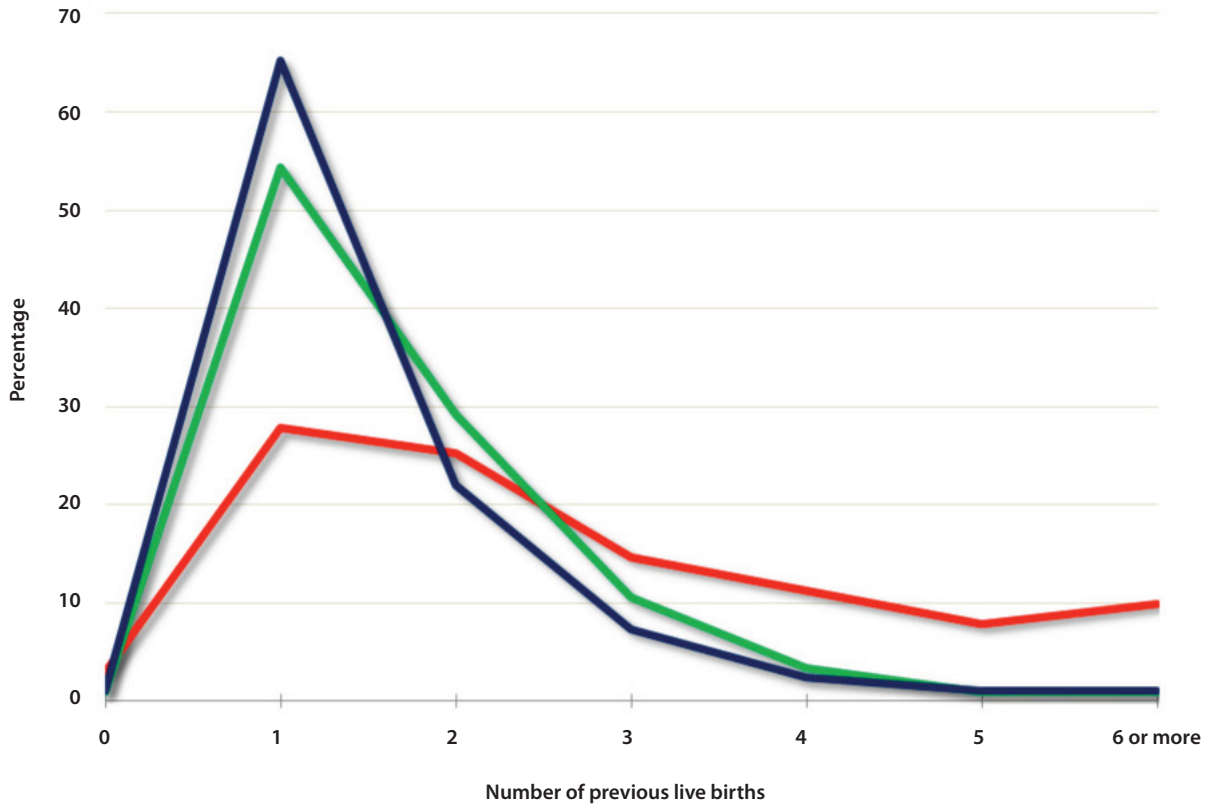


Table 2.19: Number of previous live births (parous women) - Irish Travellers and NPRS Irish SEG

Number of previous live births	NPRS Irish SEG												ROI Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
0	0.3	4	0.4	19	0.3	15	0.4	65	0.3	8	0.5	20	0.8	3
1	43.5	639	56.1	2,690	58.7	2,572	56.4	9,857	52.3	1,221	46.2	2,029	27.7	106
2	32.6	478	31.0	1,484	30.2	1,323	28.6	5,001	30.8	719	26.5	1,163	25.9	99
3	16.2	238	10.3	492	8.7	382	10.2	1,778	10.4	242	12.8	563	15.4	59
4	5.1	75	1.5	72	1.7	73	3.1	546	4.0	94	6.8	299	11.3	43
5	1.8	26	0.4	21	0.3	13	0.8	138	0.9	22	3.3	145	8.4	32
6 or more	0.5	8	0.3	13	0.1	6	0.5	84	1.2	27	3.9	170	10.5	40
Total	100.0	1,468	100.0	4,791	100.0	4,384	100.0	17,469	100.0	2,333	100.0	4,389	100.0	382

2.3.3.3 Previous stillbirths

The number of stillbirths in parous women is shown in Tables 2.20, 2.21 and Figure 2.9. Whilst 95% of Irish Travellers reported no such event, nonetheless the rates seen at 5% far exceed that reported by either Irish (1.6%) or European women (1.3%) ($p<0.001$).

The Unknown/unemployed group also have appreciably higher stillbirth rates than other social groups, but at 2.2%, the rate is still less than Travellers 5% (Table 2.22, Figure 2.10).

Table 2.20: Mean number of stillbirths (parous women) - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

Group	n (%)*	mean	range	SD	95% CI
Irish Travellers (parous women, n=382)	19 (5.0)	1.0	1-2	0.2	0.9-1.2
NPRS Irish (parous women, n=34,841)	574 (1.6)	1.1	1-5	0.4	1.1-1.1
NPRS European (parous women, n=4,525)	59 (1.3)	1.1	1-3	0.4	1.0-1.2
NPRS Irish SEG:					
Farmers (parous women, n=1,468)	28 (1.9)	1.3	1-5	0.9	1.0-1.7
SEG-A (parous women, n=4,791)	79 (1.6)	1.1	1-3	0.4	1.0-1.2
SEG-B (parous women, n=4,384)	67 (1.5)	1.0	1-2	0.2	1.0-1.1
SEG-C (parous women, n=17,469)	258 (1.5)	1.1	1-3	0.4	1.1-1.2
SEG-D (parous women, n=2,333)	44 (1.9)	1.2	1-4	0.6	1.0-1.4
Unknown/unemployed (parous women, n=4,389)	97 (2.2)	1.1	1-3	0.4	1.0-1.1

*percentage as a proportion of parous women in the same group

Table 2.21: Mean number of previous stillbirths (parous women) - Irish Travellers, NPRS Irish and NPRS European

Number of previous stillbirths in parous women	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
0	95.0	463	98.4	34,267	98.7	4,466
1	4.7	18	1.5	523	1.2	55
2 or more	0.3	1	0.1	51	0.1	4
Total	100.0	382	100.0	34,841	100.0	4,525

Figure 2.9: Number of previous stillbirths (parous women) - Irish Travellers, NPRS Irish and NPRS European

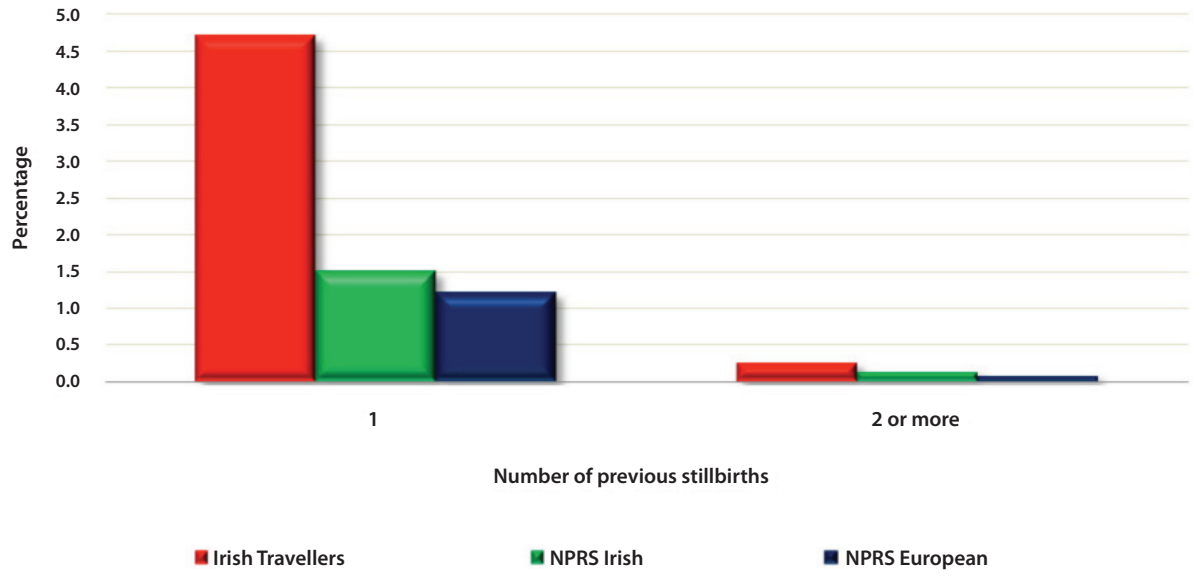
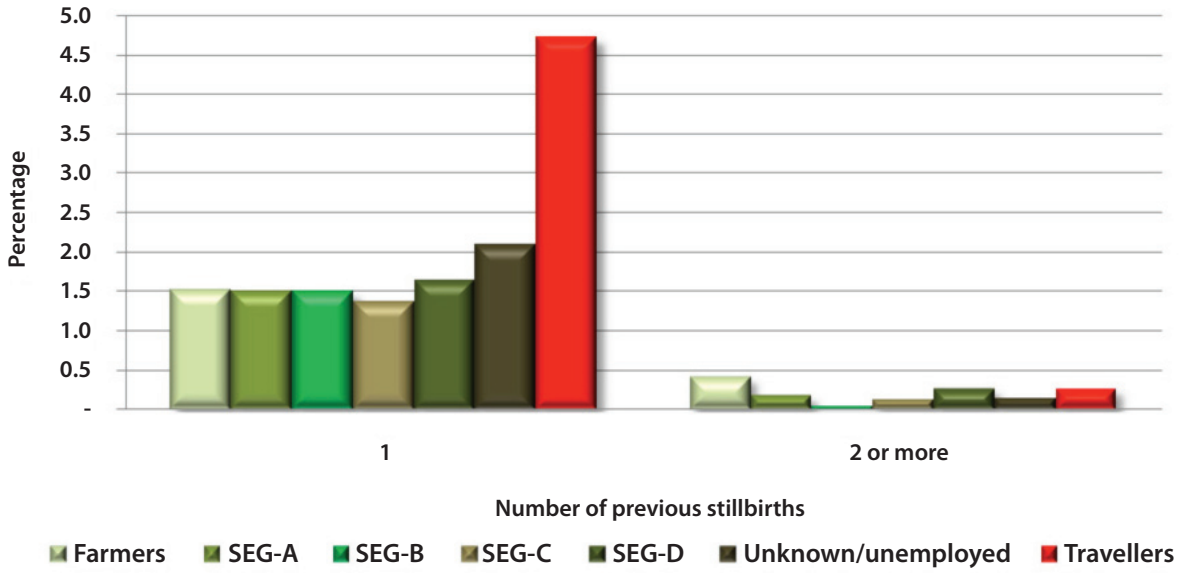


Table 2.22: Number of previous stillbirths in parous women - Irish Travellers and NPRS Irish SEG

Number of previous stillbirths	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
0	98.1	1,440	98.4	4,712	98.5	4,317	98.5	17,211	98.1	2,289	97.8	4,292	95.0	363
1	1.5	22	1.5	71	1.5	65	1.4	236	1.6	38	2.1	91	4.7	18
2 or more	0.4	6	0.2	8	0.0	2	0.1	22	0.3	6	0.1	6	0.3	1
Total	100.0	1,468	100.0	4,791	100.0	4,384	100.0	17,469	100.0	2,333	100.0	4,389	100.0	382

Figure 2.10: Number of previous stillbirths (parous women) - Irish Travellers and NPRS Irish SEG



2.3.3.4 Previous miscarriages

Miscarriage is defined as pregnancy loss within 24 weeks of pregnancy (Royal College of Obstetricians and Gynaecologists, 2006). In this analysis, number of miscarriages was based on self-reported miscarriages.

The mean number of miscarriages for nulliparous and parous women is given in Tables 2.23 and 2.24. In absolute terms, rates of miscarriages (per woman) are also higher in Travellers compared with NPRS Irish and European mothers (Table 2.25 and Figure 2.11) ($p<0.001$). These rates are higher compared to most social groupings, except for Farmers and SEG-B (Table 2.26). In part this may be explained by higher parity generally among Travellers.

Table 2.23: Mean number of miscarriages (nulliparous women) - Irish Travellers, NPRS Irish, NPRS European, and NPRS Irish SEG

Group	n (%)*	mean	range	SD	95% CI
Irish Travellers (nulliparous women, n=106)	15 (14.2)	1.4	1-3	0.6	1.0-1.7
NPRS Irish (nulliparous women, n=23,357)	3,373 (14.4)	1.3	1-7	0.6	1.2-1.3
NPRS European (nulliparous women, n=6,153)	783 (12.7)	1.2	1-5	0.5	1.2-1.2
NPRS Irish SEG					
Farmers (nulliparous women, n=620)	103 (16.6)	1.3	1-4	0.5	1.2-1.4
SEG-A (nulliparous women, n=3,563)	517 (14.5)	1.3	1-7	0.7	1.2-1.4
SEG-B (nulliparous women, n=3,051)	517 (16.9)	1.3	1-5	0.7	1.2-1.4
SEG-C (nulliparous women, n=11,884)	1,710 (14.4)	1.3	1-5	0.6	1.2-1.3
SEG-D (nulliparous women, n=1,400)	206 (14.7)	1.3	1-5	0.7	1.2-1.4
Unknown/unemployed (nulliparous women, n=2,821)	320 (11.3)	1.3	1-5	0.7	1.2-1.3

*percentage as a proportion of nulliparous women in the same group

Table 2.24: Mean number of miscarriages in (parous women) - Irish Travellers, NPRS Irish, NPRS European, and NPRS Irish SEG

Group	n (%)*	mean	range	SD	95% CI
Irish Travellers (parous women, n=382)	133 (34.8)	1.7	1-9	1.3	1.5-2.0
NPRS Irish (parous women, n=34,841)	9,765 (28.0)	1.4	1-12	0.8	1.40-1.43
NPRS European (parous women, n=4,525)	1,074 (23.7)	1.4	1-8	0.9	1.4-1.5
NPRS Irish SEG:					
Farmers (parous women, n=1,468)	421 (28.7)	1.4	1-7	0.8	1.4-1.5
SEG-A (parous women, n=4,791)	1,413 (29.5)	1.5	1-12	0.9	1.4-1.5
SEG-B (parous women, n=4,384)	1,286 (29.3)	1.4	1-6	0.7	1.3-1.4
SEG-C (parous women n=17,469)	4,809 (27.5)	1.4	1-10	0.8	1.4-1.4
SEG-D (parous women, n=2,333)	613 (26.3)	1.4	1-9	0.8	1.4-1.5
Unknown/unemployed (parous women, n=3,169)	1220 (27.8)	1.5	1-6	0.8	1.4-1.6

*percentage as a proportion of parous women in the same group

Table 2.25: Number of miscarriages (all women) - Irish Travellers, NPRS Irish and NPRS European

Number of previous miscarriages	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
0	69.7	340	77.4	45,059	82.6	8,818
1	19.5	95	16.6	9,664	13.4	1,428
2	4.7	23	4.2	2,463	2.8	296
3	3.3	16	1.2	702	0.9	94
4 or more	2.9	14	0.5	313	0.4	40
Total	100.0	488	100.0	58,201	100.0	10,676

Figure 2.11: Number of previous miscarriages (all women) - Irish Travellers, NPRS Irish and NPRS European

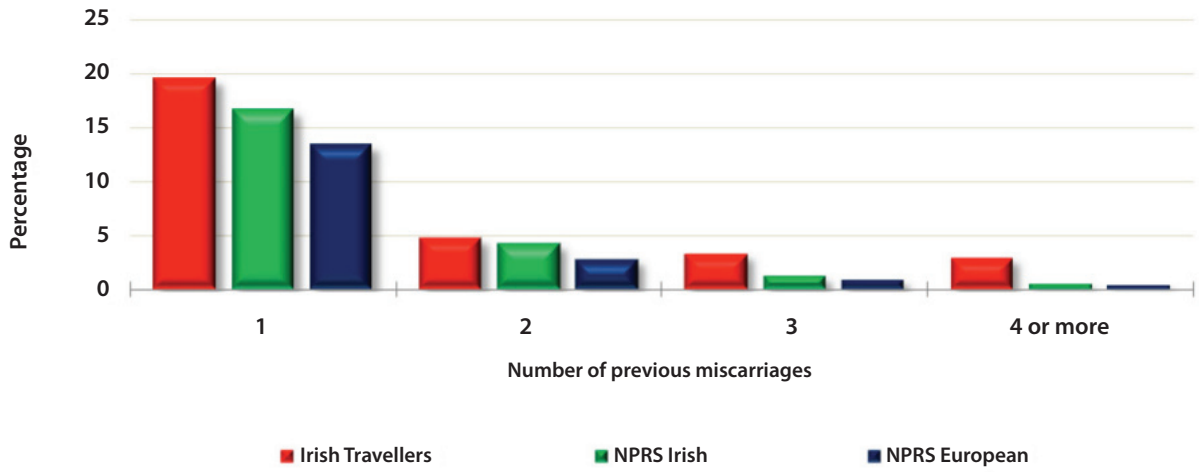
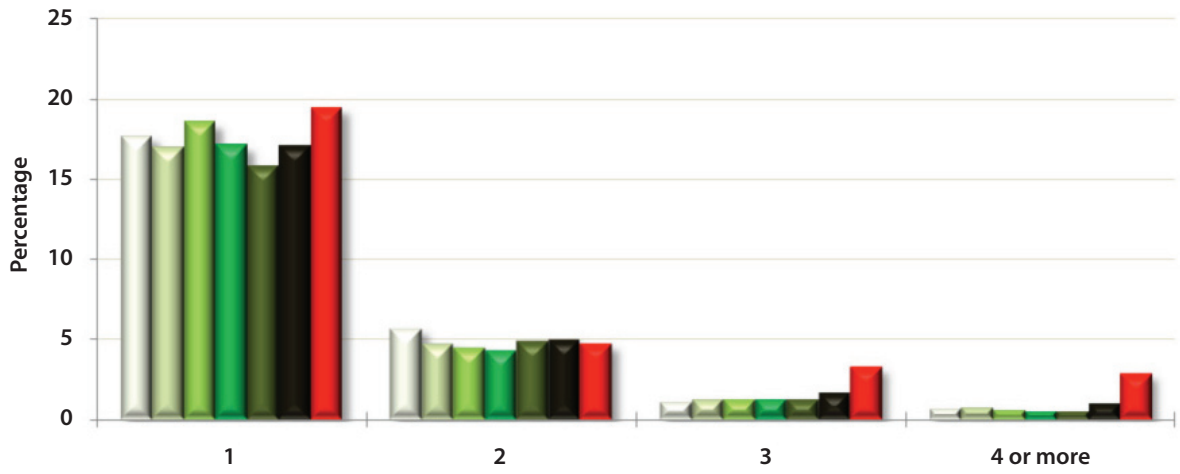


Table 2.26: Number of previous miscarriages (all women) - Irish Travellers and NPRS Irish SEG

Number of previous miscarriages	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
0	74.8	1,563	76.9	6,424	75.7	5,632	77.8	22,832	78.1	2,914	78.6	5,672	69.7	340
1	17.7	369	16.6	1,387	18.1	1,347	16.6	4,881	15.5	578	15.3	1,100	19.5	95
2	5.6	118	4.6	384	4.3	323	4.0	1,161	4.7	175	4.2	301	4.7	23
3	1.1	23	1.2	101	1.2	90	1.2	348	1.2	46	1.3	94	3.3	16
4 or more	0.8	16	0.7	59	0.6	43	0.5	135	0.5	20	0.6	46	2.9	14
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,213	100.0	488

Figure 2.12: Number of previous miscarriages (all women) - Irish Travellers and NPRS Irish SEG



2.3.3.5 Miscarriage rate per number of pregnancies

When calculated miscarriage as a function of total number of pregnancies, the rate for the Travellers is lower (Table 2.27). However, the number of miscarriages is based on maternal self-reporting. The Traveller rate in this analysis may differ in Traveller women who did not consent to participate in the study as we did not have access to their data.

Table 2.27: Percentage of miscarriages of total pregnancies-Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

Group	Total miscarriages (m)	Total pregnancies (p)	Percentage (m/p) x100%
Irish Travellers	255	1,354	18.8
NPRS Irish	18,100	77,740	23.2
NPRS European	2,488	9,581	25.9
NPRS Irish SEG:			
Farmers	740	3,537	20.9
SEG-A	2,517	9,673	26.0
SEG-B	2,224	8,629	25.8
SEG-C	7,759	33,324	23.3
SEG-D	1,089	4,859	22.4
Unknown/ unemployed	865	4,383	9.7

2.3.3.6 Number of live born children who died subsequently

The mean number of children who died after a live birth is given in Table 2.28. The number of children who died after live birth is given in Tables 2.29 and 2.30. Whilst 94.7% of Travellers had no such experience, 5.3% did, much higher than the 1.5% of the general population. The SEG-D group is somewhat higher than other groups, but not as high as the Travellers.

Table 2.28: Mean number of live born children who died subsequently (parous women) - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

Group	n (%)*	Mean number of deaths	Range	SD	95% CI
Irish Travellers (parous women, n=376)	20 (5.3)	1.9	1-5	1.4	1.3-2.6
NPRS Irish (parous women, n=34,841)	529 (1.5)	1.0	1-2	0.1	1.0-1.0
NPRS European (parous women, n=4,525)	68 (1.5)	1.0	1-3	0.3	1.0-1.1
NPRS Irish SEG:					
Farmers (parous women, n=1,465)	20 (1.4)	1.0	1-2	0.2	1.0-1.1
SEG-A (parous women, n=4,791)	58 (1.2)	1.0	1-2	0.2	1.0-1.0
SEG-B (parous women, n=4,384)	55 (1.3)	1.0	1-2	0.1	1.0-1.1
SEG-C (parous women, n=17,469)	266 (1.5)	1.0	1-2	0.2	1.0-1.0
SEG-D (parous women, n=2,333)	45 (2.9)	1.1	1-2	0.2	1.0-1.1
Unknown/unemployed (parous women, n=4,389)	85 (1.9)	1.1	1-2	0.3	1.0-1.2

*percentage as a proportion of parous women in the same group

Table 2.29: Number of live born children who died subsequently (parous women) - Irish Travellers, NPRS Irish and NPRS European

Number of live born children who died subsequently	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
0	94.7	356	98.5	34,312	98.5	4,457
1	3.2	12	1.5	517	1.5	66
2	0.8	3	0.0	12	0.0	1
3 or more	1.3	5	0.0	0	0.0	1
Total	100.0	376	100.0	34,841	100.0	4,525

Table 2.30: Number of live born children who died subsequently (parous women) - Irish Travellers and NPRS Irish SEG

Number of live born children who died subsequently	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
0	98.6	1,448	98.8	4,733	98.7	4,329	98.5	17,203	98.1	2,288	98.1	4,304	94.7	356
1	1.4	20	1.2	57	1.3	55	1.5	259	1.9	45	1.8	81	3.2	12
2	0.0	0	0.0	1	0.0	0	0.0	7	0.0	0	0.1	4	0.8	3
3 or more	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	1.3	5
Total	100.0	2,157	100.0	1,465	100.0	4,456	100.0	4,076	100.0	15,366	100.0	1,531	100.0	376

2.3.3.7 Birth intervals

Birth interval is the difference in months between the most recent birth and the previous birth. Birth interval information is reported for ROI Traveller mothers only, as the data were not sufficient for Northern Ireland. The average interval for Traveller mothers since previous pregnancy is lower than other groups (Table 2.31) ($p<0.001$). This shows a U-shaped gradient in the general population for the 12-24 months particularly, with SEG-A and Farmers tending to have a shorter birth interval than others (Figure 2.13). Most Traveller mothers (70.7%) reported having a child within the previous 3 years; 9% had a child within the last year, compared with 2.6% of NPRS Irish and 2.5% of NPRS European (Table 2.32).

Table 2.31: Mean birth interval (in months) (parous women) - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

	n	mean (months)	range (months)	SD	95% CI
ROI Travellers	324	32.0	9-115	19.2	29.7-33.9
NPRS Irish	34,221	44.7	7-332	33.3	44.3-45.0
NPRS European	4,405	54.6	8-275	41.5	53.4-55.8
NPRS Irish SEG:					
Farmers	1,436	38.4	9-285	26.8	37.0-39.8
SEG-A	4,719	38.1	8-307	28.3	37.3-38.9
SEG-B	4,336	41.6	9-264	30.2	40.7-42.5
SEG-C	17,164	46.7	7-332	34.6	46.2-47.2
SEG-D	2,277	49.0	9-266	36.9	47.5-50.5
Unknown/unemployed	4,282	46.8	8-255	34.7	45.8-47.8

Table 2.32: Birth intervals - ROI Travellers, NPRS Irish and NPRS European

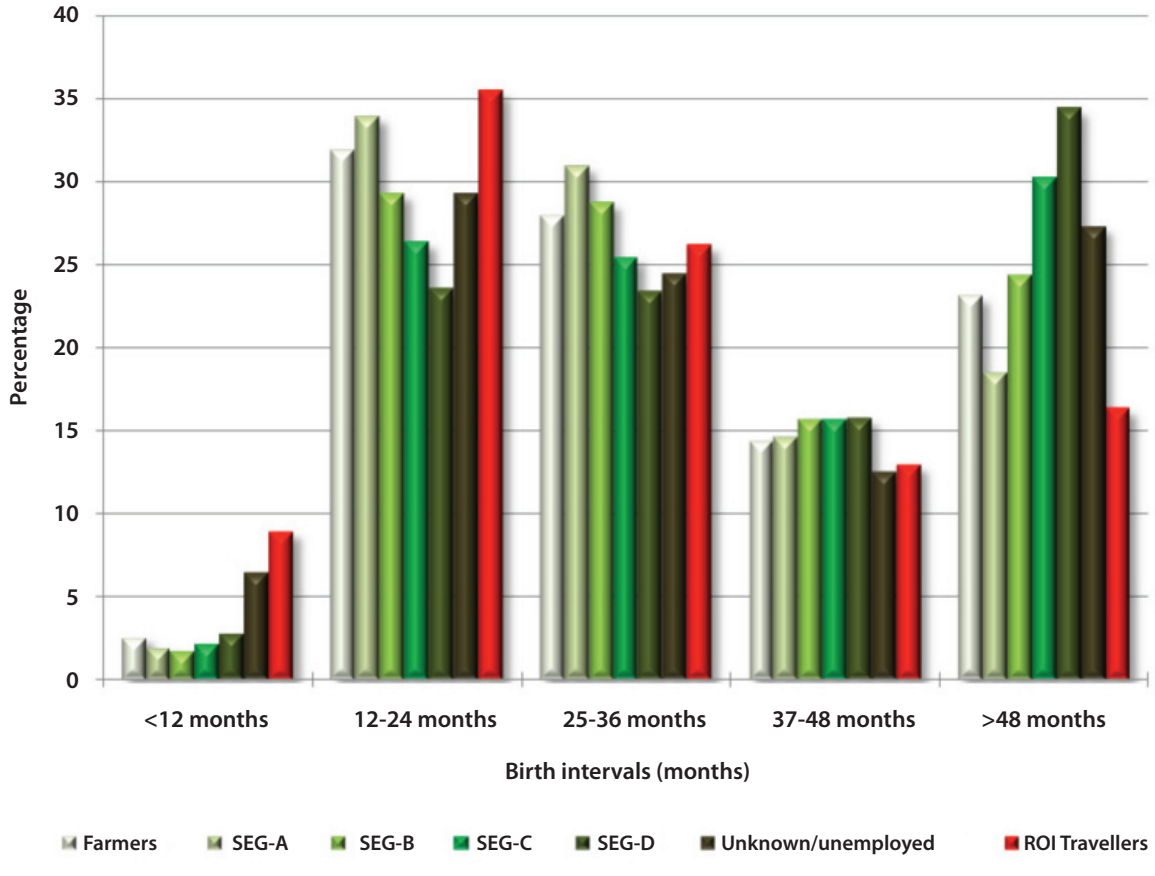
	ROI Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<12 months	9.0	29	2.6	884	2.5	109
12-24 months	35.5	115	26.8	9,204	22.8	1,004
25-36 months	26.2	85	25.2	8,623	18.8	830
37-48 months	13.0	42	15.0	5,138	12.9	570
>48 months	16.4	53	30.4	10,436	43.0	1,898
Total	100.0	324	100.0	34,285	100.0	4,411

While the intervals of less than 12 months and 12-24 months show some distribution according to SEG in the general population, ranging from 1.9% of SEG-A to 6.5% of Unknown/unemployed SEG, Travellers have the highest rates at 9.0% (Table 2.33, Figure 2.13).

Table 2.33: Birth intervals - Irish Travellers and NPRS Irish SEG

Birth intervals	NPRS Irish SEG												ROI Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
<12 months	2.6	37	1.9	92	1.8	80	2.2	384	2.7	62	5.3	229	9.0	29
12-24 months	32.0	460	33.3	1,574	28.5	1,240	25.2	4,333	22.7	517	25.1	1,075	35.5	115
25-36 months	28.0	402	30.2	1,427	28.3	1,229	24.2	4,170	22.8	519	20.4	876	26.2	85
37-48 months	14.3	206	14.4	678	15.6	678	15.3	2,639	15.6	356	13.5	581	13.0	42
>48 months	23.2	333	20.1	951	25.7	1,118	33.0	5,678	36.2	826	35.6	1,528	16.4	53
Total	100.0	1,438	100.0	4,722	100.0	4,345	100.0	17,204	100.0	2,280	100.0	4,289	100.0	324

Figure 2.13: Birth intervals - ROI Travellers and NPRS Irish SEG



2.3.3.8 Rubella status

Rubella status was known for 95.8% of Irish and 93.8% of European origin mothers, but was less, at 89.3% for Travellers (Table 2.34 and Figure 2.14). Clarity of this information can be influenced by several factors, including late booking, unbooked patients, and unavailability of results at time of delivery, unavailability of patient-held record at time of delivery or delivery coupled with early discharge. Again, this shows a modest social pattern from 96.6% in SEG-A and B to 95.5% in the Unknown/unemployed group, but is still lowest in Travellers (Table 2.35 and Figure 2.15). It is possible that low rubella immunity relates to a generally low uptake of immunisation by Travellers.

Table 2.34: Mother's rubella status - Irish Travellers, NPRS Irish and NPRS European

Rubella Status	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Yes	69.8	307	90.8	52,871	88.4	9,436
No	19.5	86	5.0	2,935	5.4	581
Not known	10.7	47	4.1	2,402	6.0	662
Total	100.0	440	100.0	58,208	100.0	10,679

Figure 2.14: Mother's rubella status - Irish Travellers, NPRS Irish and NPRS European

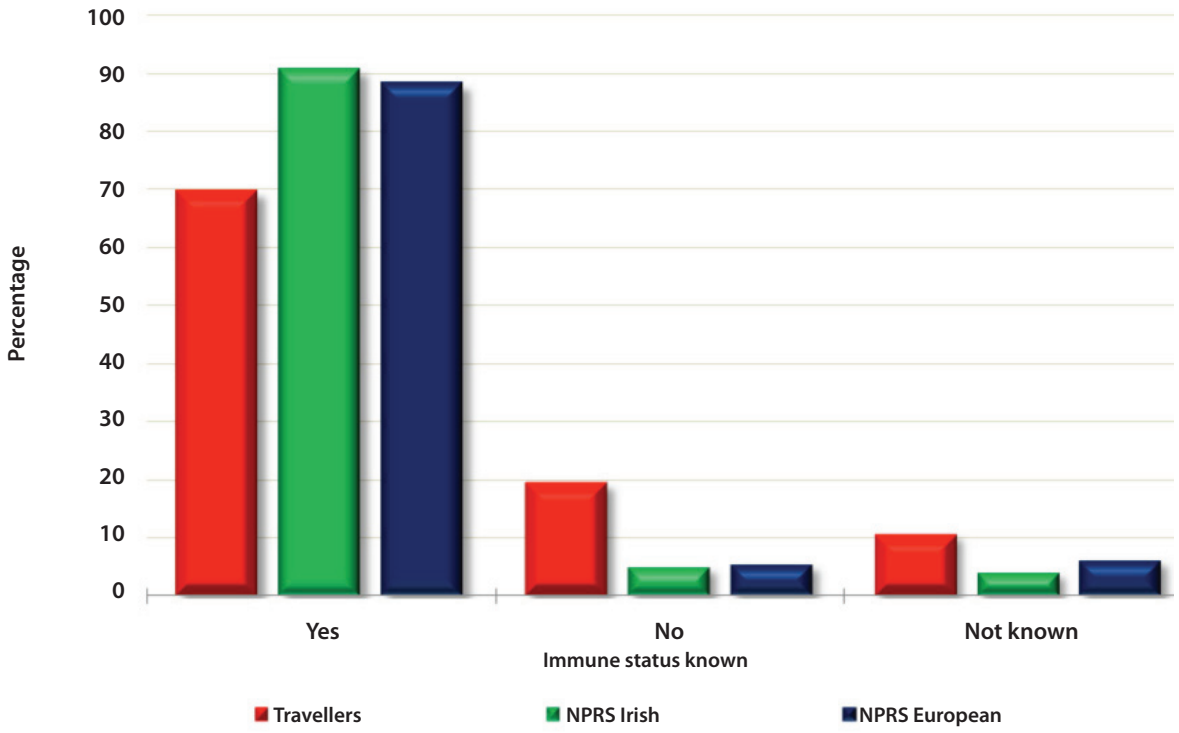
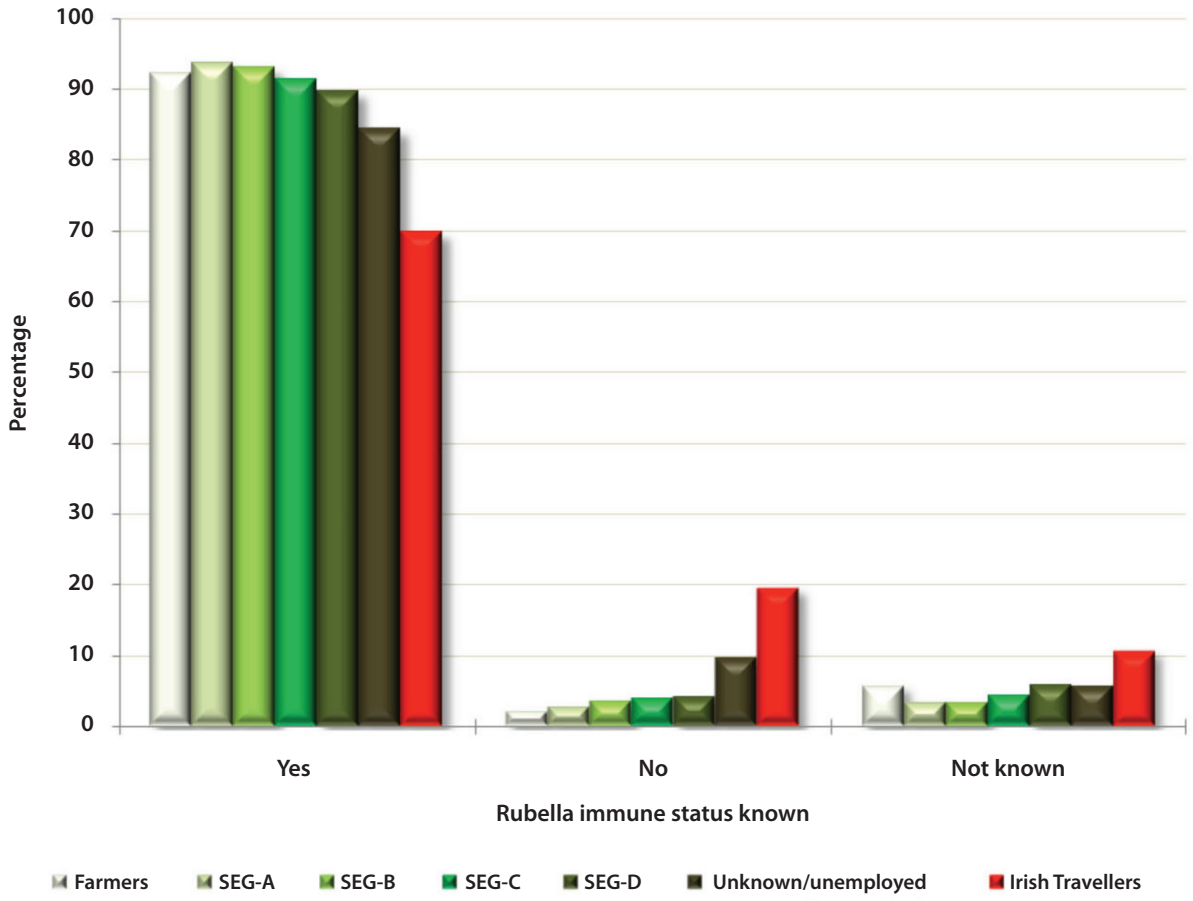


Table 2.35: Mother's rubella status - Irish Travellers and NPRS Irish SEG

Rubella status	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Yes	92.1	1,925	93.4	7,806	93.1	6,925	91.0	26,728	89.9	3,356	84.7	6,113	69.8	307
No	2.1	44	3.2	268	3.6	270	4.8	1,403	4.5	168	10.8	779	19.5	86
Not known	5.7	120	3.4	281	3.2	240	4.2	1,226	5.6	209	4.5	321	10.7	47
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,213	100.0	440

Figure2.15: Mother's rubella status - Irish Travellers and NPRS Irish SEG



2.3.4 Antenatal care

2.3.4.1 Type of antenatal care

Pattern of antenatal care for ROI and NI Traveller mothers is given in Table 2.36. These differ according to jurisdiction, with 90.6% of Travellers in NI receiving combined care compared to 81.5% of ROI Travellers (p=0.01). This is likely to reflect different health care delivery policies. When compared to other categories a notable pattern is observed - 76.6% of Irish mothers report combined hospital and GP care (Table 2.37). This is further elucidated when examined by SEG, in that 36.6% of SEG-A and 32.7% of SEG-B mothers report hospital care only, partly because of private practice, whereas Travellers resemble the Unknown/unemployed group most closely (Table 2.38). It should be noted that 2.1% (n=9) of Traveller mothers have no antenatal care.

Table 2.36: Type of antenatal care - ROI and NI Travellers

Antenatal care type	ROI Travellers		NI Travellers	
	%	n	%	n
Hospital/Obstetrician	14.7	58	9.4	3
General Practitioner only	0.3	1	0.0	0
Hospital & G.P. combined	81.5	322	90.6	29
None	2.3	9	0.0	0
Midwife only	1.0	4	0.0	0
Unknown	0.3	1	0.0	0
Total	100.0	395	100.0	32

Table 2.37: Type of antenatal care - Irish Travellers, NPRS Irish and NPRS European

Antenatal care type	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Hospital/Obstetrician	14.3	61	22.4	13,053	10.4	1,112
General Practitioner only	0.2	1	0.2	100	0.2	18
Hospital & G.P. combined	82.2	351	76.6	44,571	88.3	9,427
None	2.1	9	0.2	104	0.7	74
Midwife only	0.9	4	0.6	335	0.4	39
Unknown	0.2	1	0.1	45	0.1	9
Total	100.0	427	100.0	58,208	100.0	10,679

Table 2.38: Type of antenatal care - Irish Travellers and NPRS Irish SEG

Antenatal care type	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Hospital/ Obstetrician	21.2	442	36.6	3,058	32.7	2,428	19.4	5,681	10.6	394	14.5	1,048	14.3	61
General Practitioner only	0.1	3	0.2	14	0.3	21	0.2	47	0.0	1	0.2	14	0.2	1
Hospital & G.P. combined	78.1	1,631	62.6	5,229	66.3	4,928	79.6	23,354	88.7	3,311	84.5	6,094	82.2	351
None	0.1	3	0.1	7	0.1	7	0.2	45	0.1	4	0.5	38	2.1	9
Midwife only	0.5	10	0.5	44	0.6	45	0.7	204	0.6	22	0.1	10	0.9	4
Unknown	0.0	0	0.0	3	0.1	6	0.1	26	0.0	1	0.1	9	0.2	1
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,213	100.0	427

2.3.4.2 Formal booking visits

Table 2.39 records whether delivery booking was made and the figures for Travellers are positive at 98%. However when compared to other SEG groupings, there is a small but statistically significant difference (Table 2.40) ($p<0.001$).

Table 2.39: Hospital booking visits - Irish Travellers, NPRS Irish and NPRS European

Booking visits	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Yes	98.0	397	99.0	57,551	98.3	10,475
No	2.0	8	1.0	580	1.7	185
Total	100.0	405	100.0	58,131	100.0	10,660

Table 2.40: Hospital booking visits - Irish Travellers and NPRS Irish SEG

Booking visits	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Yes	98.7	2,060	99.3	8,281	99.3	7,374	99.1	29,049	98.5	3,674	98.3	7,089	98.0	397
No	1.3	27	0.7	57	0.7	49	0.9	269	1.5	56	1.7	120	2.0	8
	100.0	2,087	100.0	8,338	100.0	7,423	100.0	29,318	100.0	3,730	100.0	7,209	100.0	405

2.3.4.3 Gestational age at first visit to doctor and hospital

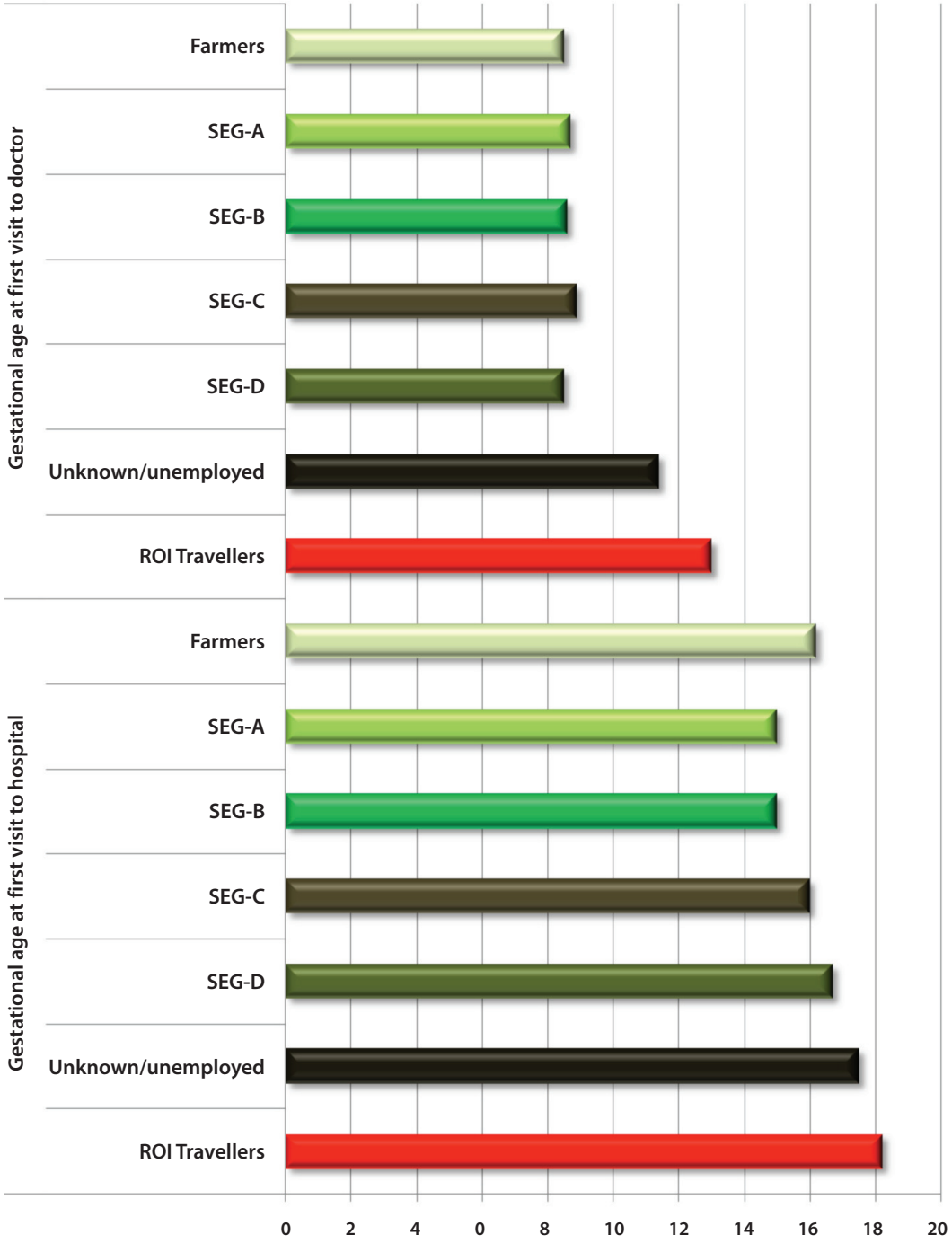
Gestational age at first visit to doctor and hospital is given for ROI Travellers only. The mean for first visit to doctor at 13 weeks is higher for Travellers, than Irish or Europeans, and mean for first hospital visit is higher at 18.2 weeks than the general Irish, but not Europeans (Table 2.41). Travellers are more likely to present later in pregnancy than other SEG groups (Figures 2.16 to 2.20).

Table 2.41: Mean gestational age at first visit to doctor and hospital - ROI Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

	n	mean	range	SD	95% CI
Gestational age at first visit to doctor*					
ROI Travellers	182	13.0	4-39	7.5	11.9-14.1
NPRS Irish	31,192	9.1	4-42	5.6	9.0-9.1
NPRS European	5,145	11.0	4-41	6.9	10.8-11.2
NPRS Irish SEG:*					
Farmers	1,405	8.5	4-41	4.7	8.3-8.8
SEG-A	4,048	8.7	4-42	5.2	8.5-8.9
SEG-B	3,561	8.6	4-40	5.1	8.5-8.8
SEG-C	16,320	8.9	4-41	5.4	8.8-8.9
SEG-D	2,410	8.5	4-37	4.9	8.3-8.7
Unknown/unemployed	2,471	11.4	4-40	7.2	11.2-11.7
Gestational age at first visit to hospital					
ROI Travellers	387	18.2	6-40	7.3	17.5-19.0
NPRS Irish	55,593	16.0	4-42	5.8	15.9-16.0
NPRS European	10,465	18.8	4-42	6.6	18.6-18.9
NPRS Irish SEG:					
Farmers	1,913	16.2	4-41	6.0	16.0-16.5
SEG-A	7,882	15.0	4-42	5.6	14.9-15.1
SEG-B	7,096	15.0	4-41	5.3	14.7-15.0
SEG-C	28,086	16.0	4-42	5.6	16.0-16.1
SEG-D	3,603	16.7	4-41	5.6	16.6-17.0
Unknown/unemployed	7,050	17.5	4-41	6.6	17.3-17.6

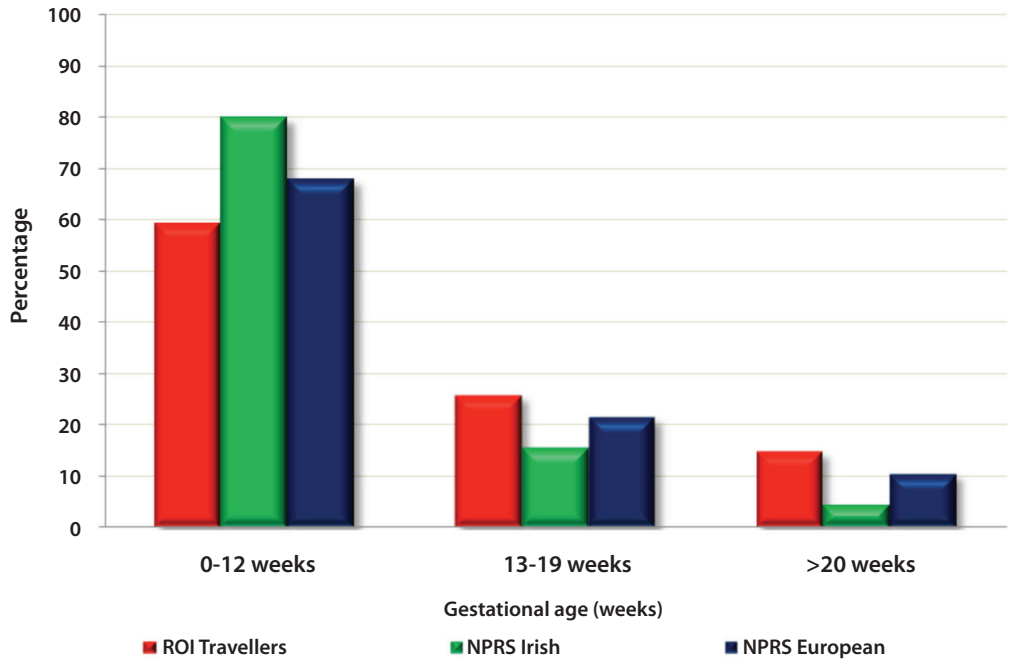
*Small data set for both Travellers and NPRS

Figure 2.16: Mean gestational age at first visit to doctor and hospital - ROI Travellers and NPRS Irish SEG



Whilst this shows some social comparability with the Unknown/unemployed, the tradition for Travellers to present after the first trimester is complete is confirmed with these findings.

Figure 2.17: Gestational age at first visit to doctor - ROI Travellers, NPRS Irish and NPRS European



A gradient with SEG is seen, but with Travellers most likely to present late (Figure 2.17, 2.18, 2.19 and 2.20).

Figure 2.18: Gestational age at first visit to doctor - Irish Travellers and NPRS Irish SEG

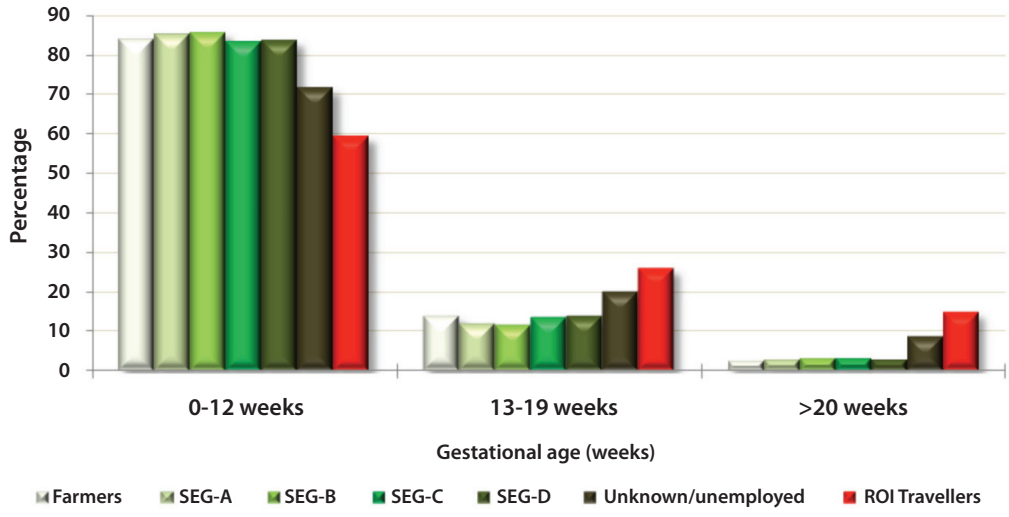


Figure 2.19: Gestational age at first visit to hospital - ROI Travellers, NPRS Irish and NPRS European

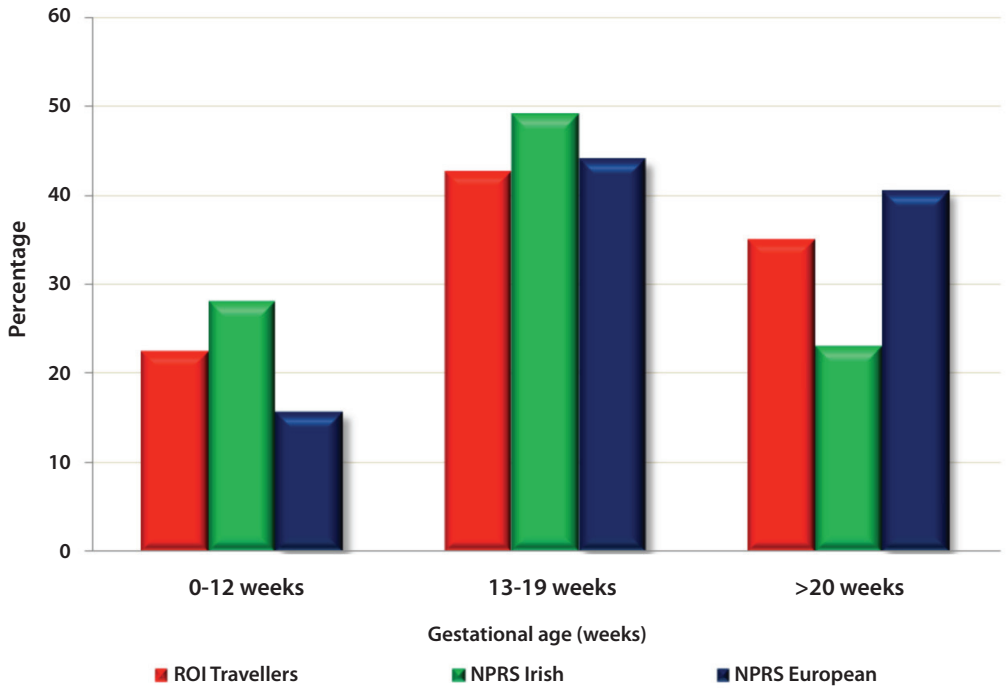
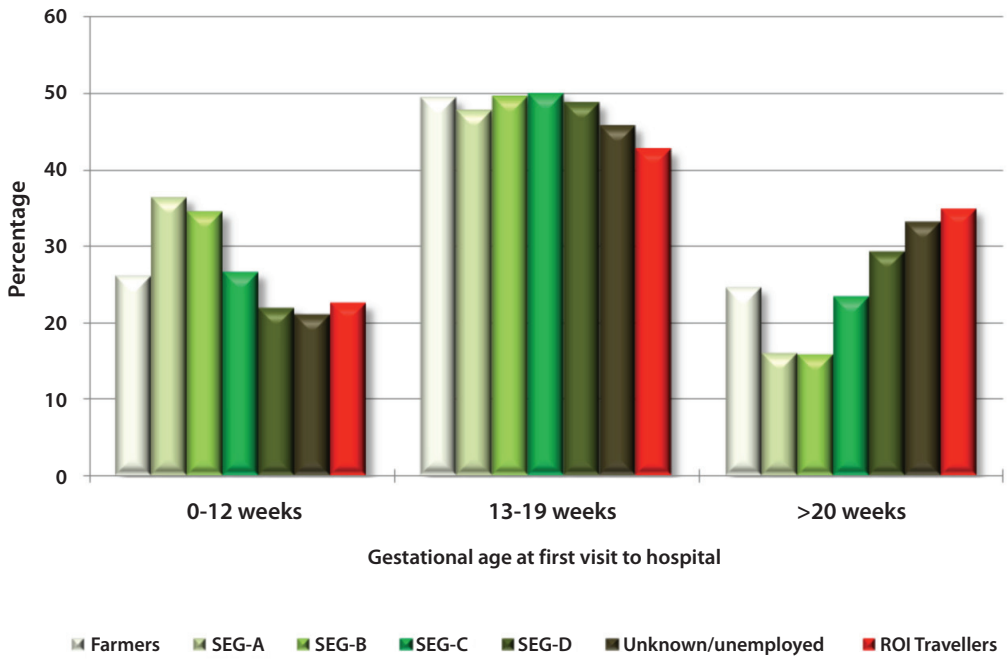


Figure 2.20: Gestational age at first visit to hospital - ROI Travellers and NPRS Irish SEG



2.3.5 Baby's characteristics

2.3.5.1 Place of birth

Virtually all Travellers in both ROI and NI are born in hospital and no domiciliary/home deliveries were documented in this study compared to 0.3% in the general population (Tables 2.42, 2.43). Births outside hospital are rare in all social categories (Table 2.44).

Table 2.42: Place of birth - ROI and NI Travellers

	ROI Travellers		NI Travellers	
	%	n	%	n
Hospital	99.8	463	100.0	35
Born before arrival	0.2	1	0.0	0
Domiciliary/home	0.0	0	0.0	0
Total	100.0	464	100.0	35

Table 2.43: Place of birth - Irish Travellers, NPRS Irish and NPRS European

	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Hospital	99.8	498	99.4	57,864	99.3	10,604
Born before arrival	0.2	1	0.3	190	0.3	31
Domiciliary/home	0.0	0	0.3	154	0.4	44
Total	100.0	499	100.0	58,208	100.0	10,679

Table 2.44: Place of birth - Irish Travellers and NPRS Irish SEG

Place of birth	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Hospital	99.3	2,074	99.2	8,290	99.5	7,396	99.5	29,206	99.7	3,720	99.2	7,153	99.8	498
Born before arrival	0.5	11	0.3	22	0.2	17	0.3	80	0.2	9	0.7	50	0.2	1
Domiciliary/home	0.2	4	0.5	43	0.3	22	0.2	71	0.1	4	0.1	10	0.0	0.0
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,213	100.0	499

2.3.5.2 Gestational age at birth

Gestational age at birth is the same for Travellers as for NPRS Irish and European women at 39.3 weeks on average (Table 2.45). Distribution of gestational age for Travellers in ROI and NI (Table 2.46) and for all Irish Travellers compared to Irish, European and according to SEG is given in Tables 2.47 and 2.48. The vast majority (91.9% in ROI and 91.4% in NI) reach a gestational age of 37-41 weeks and this is in keeping with other demographic groups.

Table 2.45: Mean gestational age at birth - ROI, NI Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

	n	mean (weeks)	range	SD	95% CI
ROI Travellers	458	39.3	20-42	2.0	39.1-39.4
NI Travellers	34	39.5	35-42	1.6	38.9-40.1
Irish Travellers	493	39.3	20-42	2.0	39.1-39.5
NPRS Irish	58,207	39.4	22-43	1.9	39.3-39.4
NPRS European	10,677	39.3	22-42	2.0	39.3-39.4
NPRS Irish SEG:					
Farmers	2,089	39.3	23-42	1.9	39.2-39.4
SEG-A	8,355	39.4	22-43	1.8	39.3-39.4
SEG-B	7,435	39.3	22-43	1.9	39.3-39.4
SEG-C	29,357	39.4	22-42	1.8	39.3-39.4
SEG-D	3,733	39.3	23-42	1.9	39.3-39.4
Unknown/unemployed	7,212	39.3	22-42	2.0	39.2-39.3

Table 2.46: Gestational age at birth - ROI and NI Travellers

Gestational age	ROI Travellers		NI Travellers	
	%	n	%	n
<28 weeks	0.4	2	0.0	0
28-31 weeks	0.4	2	0.0	0
32-36 weeks	3.9	18	5.7	2
37-41 weeks	91.9	421	91.4	31
>42 weeks	3.3	15	2.9	1
Total	100.0	458	100.0	34

Table 2.47: Gestational age at birth - Irish Travellers, NPRS Irish and NPRS European

Gestational age	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<28 weeks	0.4	2	0.4	235	0.5	55
28-31 weeks	0.4	2	0.5	315	0.5	50
32-36 weeks	4.1	20	4.9	2,833	5.2	551
37-41 weeks	91.9	453	90.5	52,676	90.1	9,619
>42 weeks	3.2	16	3.7	2,148	3.8	402
Total	100.0	493	100.0	58,207	100.0	10,677

Table 2.48: Gestational age at birth - Irish Travellers and NPRS Irish SEG

Gestational week	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
<28 weeks	0.3	7	0.3	27	0.2	18	0.4	114	0.4	15	0.7	53	0.4	2
28-31 weeks	0.6	12	0.3	26	0.6	42	0.5	154	0.5	18	0.8	61	0.4	2
32-36 weeks	4.5	95	4.6	382	5.0	369	4.8	1,404	4.9	184	5.5	398	4.1	20
37-41 weeks	92.3	1,928	90.5	7,560	90.3	6,716	90.7	26,617	90.9	3,393	89.3	6,440	91.9	453
>42 weeks	2.2	47	4.3	360	3.9	290	3.6	1,068	3.3	123	3.6	260	3.2	16
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,212	100.0	493

2.3.5.3 Birth weight

Mean or average birth weight for all births is comparable for ROI and NI Travellers and is very similar to the general population of the Irish or European women (Tables 2.49). However when the distribution is examined, a notable pattern is observed. Clinically significant low birth weight, in absolute terms, (<2500g) is the same for Travellers as for Irish and European women (Table 2.50, Figure 2.21 (a)). An expected social gradient is seen for low birth weight in the SEG groups with farmers and SEG-A least likely (4.0-4.4%) and the Unknown/unemployed group most likely (7.8%) ($p<0.001$) to be in this group (Table 2.52 and Figure 2.22 (a)). However in the next group (2500-2999g), a gradient is again observed and again the Unknown/unemployed are most likely to be in this group.

When we remove preterm (<37 weeks) and multiple pregnancies however, the pattern of lighter babies became more distinct (Tables 2.51 and 2.53, Figures 2.21 (b) and 2.22 (b)) with a greater number of Traveller babies in the <2500g categories.

Low birth weight has been associated with developmental health risks by Barker for adult chronic disease (Barker and Martyn, 1992, Barker *et al*, 1993). The overall birth weight distribution for Travellers is lighter with Traveller infants most comparable to the SEG-D and unknown/unemployed.

Table 2.49: Mean birth weight (all births) - Irish Travellers, NPRS Irish and NPRS European

	n	mean (g)	range	SD	95% CI
ROI Travellers	452	3,408	1,060-4,890	584.6	3,354-3,462
NI Travellers	34	3,372	2,300-4,600	490.8	3,203-3,540
Irish Travellers	487	3,406	1,060-4,890	578.0	3,354-3,457
NPRS Irish	58,207	3,479	500-5,720	590.5	3,474-3,484
NPRS European	10,678	3,449	510-6,090	573.9	3,438-3,460
NPRS Irish SEG:					
Farmers	2,089	3,568	520-5,620	592.8	3,542-3,594
SEG-A	8,355	3,530	500-5,360	562.2	3,517-3,542
SEG-B	7,435	3,504	500-5,610	580.3	3,490-3,517
SEG-C	29,357	3,486	510-5,720	585.5	3,480-3,493
SEG-D	3,733	3,455	700-5,440	593.6	3,436-3,474
Unknown/unemployed	7,212	3,350	570-5,660	622.3	3,336-3,364

Table 2.50: Infant birth weight (all births) - Irish Travellers, NPRS Irish and NPRS European

Birth weight: all gestational age	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<2500g	5.5	27	5.4	3,143	5.3	561
2500-2999g	15.0	73	11.1	6,432	11.7	1,252
3000-3499g	33.1	161	31.5	18,357	34.1	3,637
3500-3999g	32.6	159	35.0	20,401	34.3	3,662
4000-4499g	10.9	53	14.1	8,181	12.5	1,335
>4500g	2.9	14	2.9	1,693	2.2	231
Total	100.0	487	100.0	58,207	100.0	10,678

Table 2.51: Infant birth weight (singleton, gestational age 37 weeks and above) - Irish Travellers, NPRS Irish and NPRS European

Birth weight: >37 weeks gestation & singleton birth	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
<2500g	3.3	15	1.5	811	1.5	147
2500-2999g	13.0	59	9.4	5,032	10.1	996
3000-3499g	34.7	157	33.0	17,748	35.7	3,523
3500-3999g	34.4	156	37.8	20,298	36.9	3,645
4000-4499g	11.5	52	15.2	8,172	13.5	1,332
>4500g	3.1	14	3.1	1,688	2.3	231
Total	100.0	453	100.0	53,749	100.0	9,874

Table 2.52: Infant birth weight (all births) - Irish Travellers and NPRS Irish SEG

Birth weight category	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
<2500g	4.0	83	4.4	366	4.7	352	5.3	1,550	6.1	227	7.8	562	5.5	27
2500-2999g	8.5	178	9.1	761	10.6	790	10.7	3,132	11.6	434	15.7	1,131	15.0	73
3000-3499g	28.0	585	30.2	2,521	31.0	2,302	31.6	9,278	32.2	1,201	34.2	2,464	33.1	161
3500-3999g	38.4	802	37.8	3,159	35.7	2,658	35.3	10,364	33.8	1,263	29.8	2,149	32.6	159
4000-4499g	16.6	347	15.4	1,285	14.9	1,107	14.3	4,189	13.7	512	10.2	737	10.9	53
>4500g	4.5	94	3.1	263	3.0	226	2.9	844	2.6	96	2.3	169	2.9	14
Total	100.0	2,089	100.0	8,355	100.0	7,435	100.0	29,357	100.0	3,733	100.0	7,212	100.0	487

Table 2.53: Infant birth weight (singleton, gestational age 37 weeks and above) - Irish Travellers and NPRS Irish SEG

Birth weight: >37 weeks, singleton	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
<2500g	0.8	16	1.0	79	1.0	70	1.4	387	1.7	60	3.0	199	3.3	15
2500-2999g	6.1	117	6.9	535	8.7	598	9.0	2,454	10.3	354	14.7	970	13.0	59
3000-3499g	29.0	557	31.3	2,417	32.2	2,207	33.1	8,983	33.9	1,171	36.4	2,407	34.7	157
3500-3999g	41.3	794	40.7	3,138	38.6	2,646	38.0	10,323	36.5	1,259	32.2	2,132	34.4	156
4000-4499g	17.9	345	16.7	1,285	16.1	1,106	15.4	4,184	14.8	511	11.1	737	11.5	52
>4500g	4.9	94	3.4	263	3.3	224	3.1	842	2.8	96	2.5	168	3.1	14
Total	100.0	1,923	100.0	7,717	100.0	6,851	100.0	27,173	100.0	3,451	100.0	6,613	100.0	453

Figure 2.21: Infant birth weight ((a) all births) and ((b) singleton births, 37 weeks and above) - Irish Travellers, NPRS Irish and NPRS European

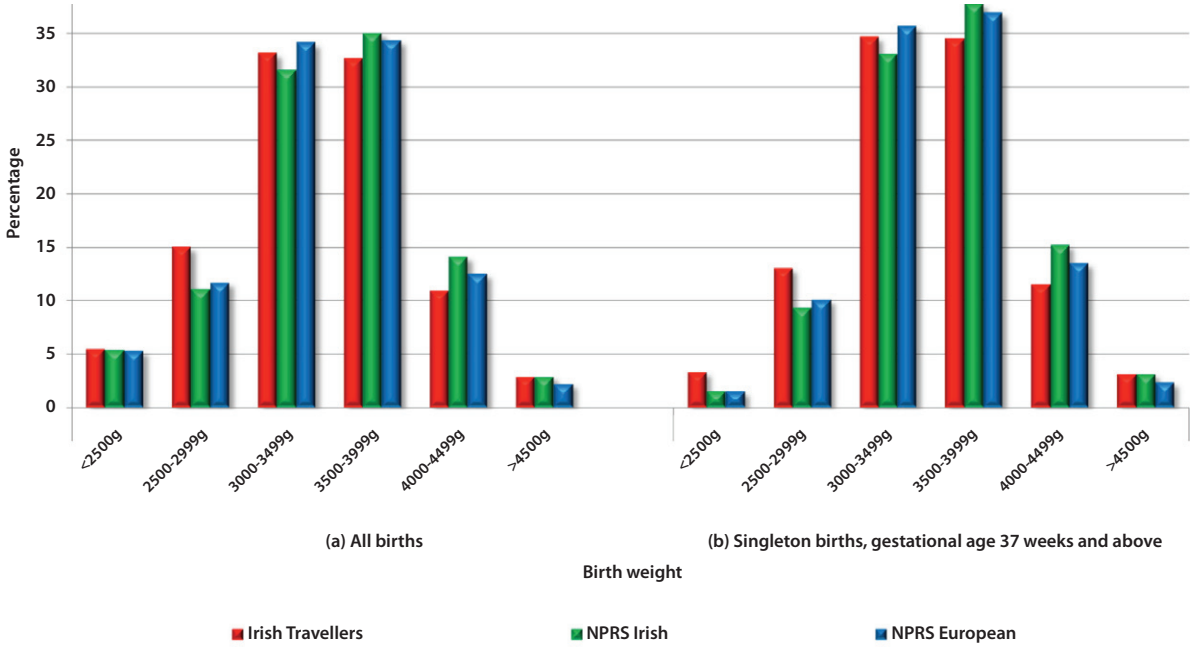
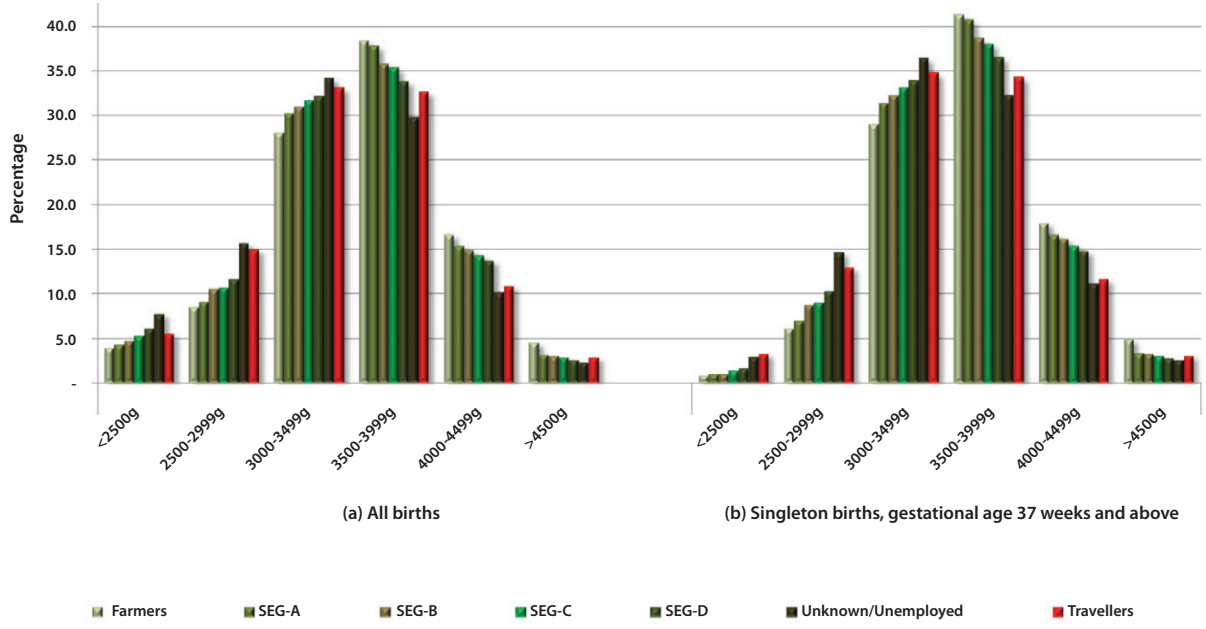


Figure 2.22: Infant birth weight ((a) all births) and ((b) singleton births, 37 weeks and above) - Irish Travellers and NPRS Irish SEG



2.3.5.4 Method of delivery

The distribution for Travellers is given in Table 2.54 and does show a different pattern to others, though with caution of smaller numbers in the observed study population. Travellers are the most likely (63.3%) of the demographic groupings to have a spontaneous vaginal delivery (Table 2.55) ($p<0.001$).

Table 2.54: Method of delivery - Irish Travellers, NPRS Irish and NPRS European

Type of delivery	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Spontaneous vaginal delivery	63.3	276	55.2	32,148	62.5	6,673
Breech + Forceps	3.0	13	0.5	295	0.5	49
Forceps	2.1	9	3.7	2,175	3.8	405
Vacuum extraction	5.0	22	12.7	7,385	13.6	1,447
Caesarean section	25.0	109	27.8	16,164	19.7	2,099
Other	1.6	7	0.06	35	0.0	5
Total	100.0	436	100.0	58,202	100.0	10,678

When method of delivery is examined according to SEG scale in the general population a gradient appears with Farmers most likely (29.7%) to have a caesarean section and SEG-A least likely to have a spontaneous delivery (54.1%). Travellers and the unknown/unemployed have the lowest caesarean section rate at 25% and 19.9% respectively ($p<0.001$).

Table 2.55: Method of delivery - Irish Travellers and NPRS Irish SEG

Delivery method	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Spontaneous vaginal delivery	56.6	1,088	54.1	4,177	54.3	3,722	56.6	15,371	56.3	1,942	65.9	4,355	63.3	276
Breech + Forceps	0.5	9	0.3	22	0.3	18	0.4	99	0.4	15	0.3	20	3.0	13
Forceps	2.3	45	4.4	343	4.5	306	3.9	1,067	3.5	119	2.8	186	2.1	9
Vacuum extraction	10.8	207	14.1	1,089	13.7	942	13.5	3,672	13.6	470	11.0	727	5.0	22
Caesarean section	29.7	572	27.0	2,083	27.1	1,860	25.6	6,952	26.1	901	19.9	1,315	25.0	109
Other	0.1	2	0.0	3	0.0	3	0.0	11	0.1	2	0.1	8	1.6	7
Total	100.0	1,923	100.0	7,717	100.0	6,851	100.0	27,172	100.0	3,449	100.0	6,611	100.0	436

2.3.5.5 Planned infant feeding

Travellers in both ROI and NI overwhelmingly opt for artificial feeding (Table 2.56). The combined rate for all Travellers is 95.9%, which compares with 57.4% of the Irish generally and just 19.9% of other Europeans (Table 2.57, Figure 2.23).

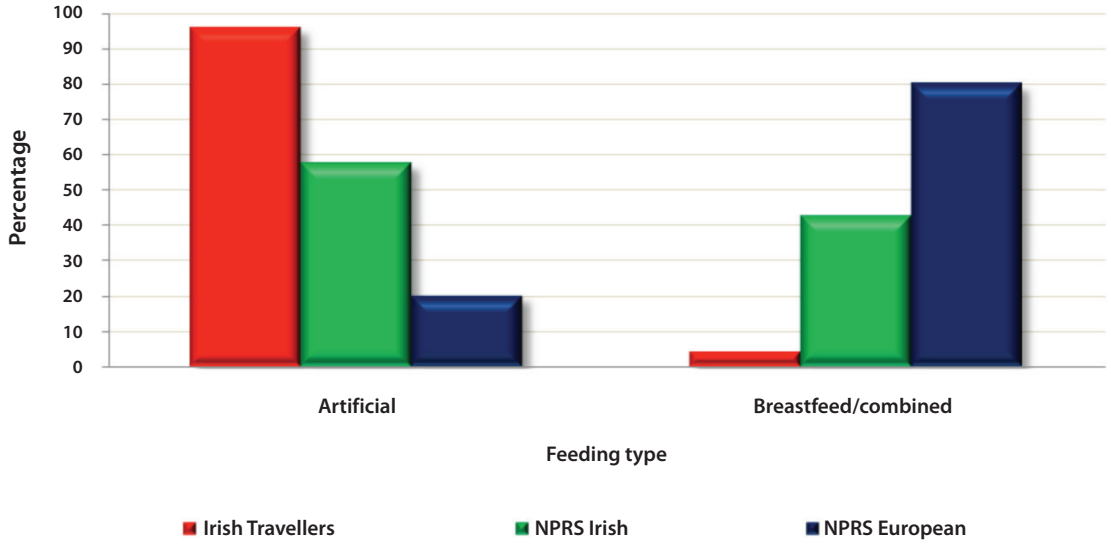
Table 2.56: Planned infant feeding - ROI and NI Travellers

	ROI Travellers		NI Travellers	
	%	n	%	n
Artificial	95.6	416	100	31
Breastfeed	3.4	15	0.0	0
Combined	0.9	4	0.0	0
not stated	0.0	0	0.0	0
Total	100.0	435	100.0	31

Table 2.57: Planned infant feeding - Irish Travellers, NPRS Irish and NPRS European

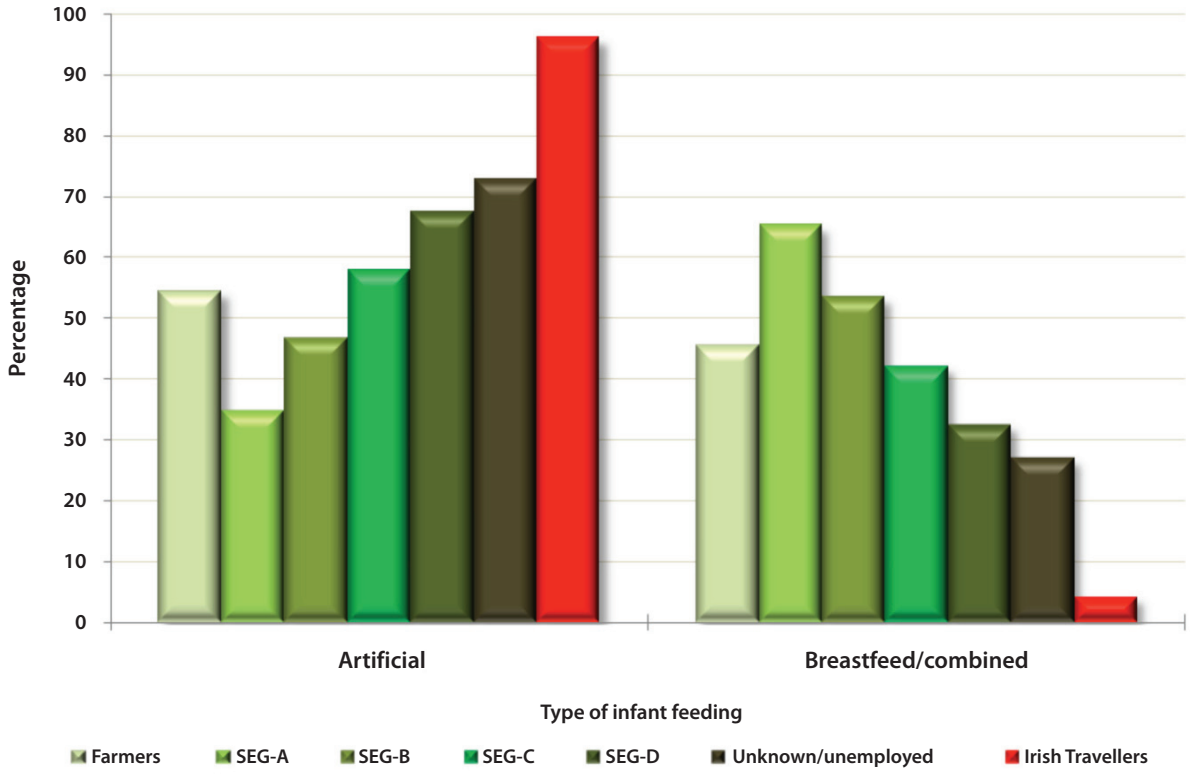
	Irish Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Artificial	95.9	447	57.4	33,349	19.9	2,122
Breastfeed	3.2	15	37.8	21,971	71.7	7,639
Combined	0.9	4	4.7	2,714	8.3	883
not stated	0.0	0	0.2	100	0.2	17
Total	100.0	466	100.0	58,134	100.0	10,661

Figure 2.23: Planned infant feeding - Irish Travellers, NPRS Irish and NPRS European



Planned feeding rates again show a class gradient, with 65.1% of SEG-A mothers planning to breastfeed compared to 26.9% of the Unknown/unemployed group of mothers. 3.2% of Travellers represent just 15 mothers (Figure 2.24).

Figure: 2.24: Planned infant feeding - Irish Travellers and NPRS Irish SEG



*p<0.001

2.3.5.6 BCG immunisation

BCG immunisation rates are 12.1% in ROI Travellers, similar to other social groups (Tables 2.58 and 2.59). Policy on BCG immunisation varies between regions in ROI and NI. Most BCG immunisation is given in the community. In some maternity hospitals, community teams give BCG immunisation to babies while they are still in hospitals. However, the community teams only visit the hospitals on a scheduled basis, and if a baby was already discharged, then the BCG immunisation is followed up in the community. BCG immunisation is recorded in the BNF01/2003 only if the immunisation was given in the hospital. This variation in policy explains the low rate of BCG immunisation uptake from the hospital data.

In Northern Ireland, BCG immunisation protocol is different in that it is based on risk assessment. Only high risk babies receive BCG immunisation.

Table 2.58: BCG immunisation - Irish Travellers, NPRS Irish and NPRS European

	ROI Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Yes	12.1	48	10.6	6,122	8.7	922
No	87.9	350	89.4	51,789	91.3	9,703
Total	100.0	398	100.0	57,911	100.0	10,625

Table 2.59: BCG immunisation - Irish Travellers and NPRS Irish SEG

	NPRS Irish SEG												ROI Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Yes	9.5	181	12.4	958	12.5	854	10.7	2,884	11.3	388	9.2	602	12.1	48
No	90.5	1,728	87.6	6,745	87.5	5,979	89.3	24,160	88.7	3,036	90.8	5,968	87.9	350
Total	100.0	1,909	100.0	7,703	100.0	6,833	100.0	27,044	100.0	3,424	100.0	6,570	100.0	398

2.3.6 Length of hospital stay

There is no real difference in length of hospital stay for mothers and infants according to demographic groupings (Table 2.60). Data are available for ROI Travellers only.

Table 2.60: Mean length of stay in hospital for mothers and infants - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG.

	n	mean (days)	range (a)	SD	95% CI
Mother's length of stay					
ROI Travellers	402	3.4	0-36	3.4	3.1-3.7
NPRS Irish	58,057	3.6	0-79	3.0	3.57-3.62
NPRS European	10,635	3.3	0-66	2.6	3.2-3.3
NPRS Irish SEG:					
Farmers	2,085	3.9	0-52	3.6	3.7-4.0
SEG-A	8,314	3.7	0-63	2.6	3.7-3.8
SEG-B	7,412	3.7	0-60	3.0	3.6-3.8
SEG-C	29,288	3.6	0-79	2.8	3.6-3.6
SEG-D	3,729	3.7	0-65	3.4	3.6-3.8
Unknown/unemployed	7,203	3.3	0-57	3.2	3.3-3.4
Infant's length of stay					
ROI Travellers	409	3.6	0-87	6.9	2.9-4.3
NPRS Total	75,587	3.4	N/A*	N/A*	N/A*

(a)The range represents total length of stay which includes mothers with pregnancy complications who may have lengthy hospital stays, but also mothers who may go home on the day of delivery

*Result as reported by Perinatal Statistics Report 2008 (NPRS, 2010). Calculation cannot be made as dates of birth of babies were withheld

2.3.6.1 Mother's total length of stay according to delivery method

Mother's total length of stay is calculated from 'date of admission' to 'date of discharge'. We did not calculate mother's post-delivery length of stay as the date of delivery (baby's date of birth) were not available for the NPRS group. The total length of stay includes length of hospital stay prior to delivery or post delivery. This includes mothers who were admitted for medical reasons pre- or post-deliveries.

Mean maternal total length of stay in the hospital is presented according to type of delivery, spontaneous, caesarean section or other in Table 2.61. Traveller mothers, on average, had a longer stay post spontaneous vaginal delivery (p=0.001).

Table 2.61: Mean total length of stay (days) by mode of delivery - Irish Travellers, NPRS Irish, NPRS European and NPRS Irish SEG

	n	Mean (days)	Range (a)	SD	95% CI
Spontaneous vaginal delivery					
Irish Travellers*	256	3	0-36	3.2	2.6-3.4
NPRS Irish*	32,001	2.6	0-67	2.0	2.6-2.7
NPRS European*	6,629	2.6	0-37	1.7	2.5-2.6
NPRS Irish SEG:					
Farmers	1,131	2.7	0-31	1.7	2.6-2.8
SEG-A	4,317	2.8	0-63	2.0	2.7-2.8
SEG-B	3,877	2.7	0-36	1.6	2.6-2.7
SEG-C	16,002	2.6	0-67	1.9	2.6-2.7
SEG-D	2,039	2.7	0-65	2.9	2.6-2.9
Unknown/ unemployed	1,077	2.6	0-18	1.5	2.6-2.7
Caesarean Section					
Irish Travellers**	86	4.8	1-35	4.2	4.0-5.7
NPRS Irish**	16,160	5.6	1-79	3.8	5.5-5.6
NPRS European**	2,099	5.5	1-66	3.8	5.3-5.7
NPRS Irish SEG:					
Farmers	672	6	1-52	5.3	5.6-6.4
SEG-A	2,459	5.5	1-51	3.2	5.4-5.6
SEG-B	2,205	5.6	1-60	4.3	5.4-5.8
SEG-C	8,186	5.5	1-79	3.7	5.5-5.6
SEG-D	1,053	5.5	1-64	4.0	5.3-5.8
Unknown/ unemployed	1,578	5.6	1-57	4.1	5.4-5.8
Breech & forceps/forceps/vacuum extractions/other					
Irish Travellers***	46	3.4	1-7	1.3	3.0-3.8
NPRS Irish***	9,890	3.4	0-64	1.9	3.4-3.4
NPRS European***	1,906	3.3	0-21	1.8	3.2-3.4
NPRS Irish SEG:					
Farmers	282	3.5	1-9	1.4	3.3-3.7
SEG-A	1,538	3.5	0-15	1.4	3.4-3.6
SEG-B	1,330	3.5	0-32	2.0	3.4-3.6
SEG-C	5,099	3.4	0-32	1.8	3.4-3.5
SEG-D	634	3.6	0-35	2.3	3.4-3.8
Unknown/ unemployed	1,005	3.4	0-11	1.4	3.1-3.4

*p=0.001, **p=0.138, ***p=0.327

(a)The range represents total length of stay which includes mothers with pregnancy complications who may have lengthy hospital stays, but also mothers who may go home on the day of delivery

Mother's total length of stay in the hospital is presented according to type of delivery, spontaneous, caesarean section, or other for the three demographic groups and according to SEG in Tables 2.62 and 2.63.

Table 2.62: Length of maternal stay in hospital according to delivery method - Irish Travellers, NPRS Irish and NPRS European

	ROI Travellers		NPRS Irish		NPRS European	
	%	n	%	n	%	n
Spontaneous vaginal delivery*						
0-1 day	14.1	36	19.0	6,071	19.4	1,283
2-3 days	65.2	167	63.1	20,194	63.6	4,213
4-5 days	15.6	40	14.5	4,651	13.7	909
6-7 days	2.7	7	2.0	647	2.1	141
8-14 days	1.2	3	1.1	351	1.1	73
>14 days	1.2	3	0.3	87	0.2	10
Total	100.0	256	100.0	32,001	100.0	6,629
Caesarean section**						
0-1 day	1.2	1	0.1	21	0.1	2
2-3 days	27.9	24	8.8	1,424	10.6	222
4-5 days	51.2	44	62.0	10,018	61.9	1,299
6-7 days	16.3	14	19.9	3,218	18.2	383
8-14 days	1.2	1	6.8	1,104	7.0	147
>14 days	2.3	2	2.3	379	2.19	46
Total	100.0	86	100.0	16,164	100.0	2,099
Breech and forceps/forceps/vacuum extractions/other***						
0-1 day	2.2	1	5.6	550	6.9	132
2-3 days	56.5	26	57.0	5,640	59.5	1,135
4-5 days	34.8	16	30.6	3,030	25.6	487
6-7 days	6.5	3	4.7	461	5.6	107
8-14 days	0.0	0	1.8	180	1.9	36
>14 days	0.0	0	0.3	29	0.5	9
Total	100.0	46	100.0	9,890	100.0	1,906

*p=0.04, **p=0.000, ***p=0.002

Table 2.63: Length of maternal stay in hospital according to delivery methods - Irish Travellers and NPRS Irish SEG

	NPRS Irish SEG												Irish Travellers	
	Farmers		SEG-A		SEG-B		SEG-C		SEG-D		Unknown/ unemployed			
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Spontaneous vaginal delivery*														
0-1 day	15.0	170	14.9	644	15.4	598	19.3	3,089	20.8	425	24.7	1,142	14.1	36
2-3 days	66.1	748	65.5	2,826	66.3	2,572	63.5	10,154	60.7	1,237	57.3	2,647	65.2	167
4-5 days	15.7	178	16.9	730	15.4	598	13.9	2,226	13.8	281	13.8	636	15.6	40
6-7 days	1.9	21	1.4	60	1.8	68	2.1	329	2.8	58	2.4	110	2.7	7
8-14 days	1.0	11	1.1	48	0.9	33	1.0	167	1.2	24	1.5	67	1.2	3
>14 days	0.3	3	0.2	9	0.2	8	0.2	37	0.7	14	0.3	16	1.2	3
Total	100.0	1,131	100.0	4,317	100.0	3,877	100.0	16,002	100.0	2,039	100.0	4,618	100.0	256
Caesarean section**														
0-1 day	0.3	2	0.2	4	0.0	1	0.1	8	0.1	1	0.3	4	1.2	1
2-3 days	4.6	31	6.4	157	7.3	161	9.1	746	10.4	110	13.8	217	27.9	24
4-5 days	63.2	425	64.0	1,573	64.1	1,415	62.1	5,081	61.4	647	55.3	873	51.2	44
6-7 days	21.7	146	21.8	536	20.7	456	19.2	1,572	18.5	195	19.8	313	16.3	14
8-14 days	7.3	49	5.7	141	5.6	124	7.1	585	7.2	76	8.2	129	1.2	1
>14 days	2.8	19	2.0	48	2.3	51	2.4	195	2.3	24	2.7	42	2.3	2
Total	100.0	672	100.0	2,208	100.0	8,187	100.0	1,053	100.0	2,039	100.0	1,578	100.0	86
Breech and forceps/forceps/vacuum/other***														
0-1 day	3.2	9	3.3	50	4.5	60	5.6	288	5.7	36	10.6	107	2.2	1
2-3 days	52.1	147	57.3	882	54.8	729	57.5	2,933	56.8	360	58.5	588	56.5	26
4-5 days	36.5	103	33.6	517	35.2	468	29.7	1,516	29.5	187	23.7	238	34.8	16
6-7 days	5.7	16	4.0	61	3.9	52	5.0	253	5.2	33	4.6	46	6.5	3
8-14 days	2.5	7	1.7	26	1.0	13	1.9	95	2.4	15	2.4	24	0.0	0
>14 days	0.0	0	0.1	2	0.6	8	0.3	14	0.5	3	0.2	2	0.0	0
Total	100.0	282	100.0	1,538	100.0	1,330	100.0	5,099	100.0	634	100.0	1,005	100.0	46

*p=0.000, **p=0.000, ***p=0.006

Table 2.63 shows mother's length of stay according to delivery method and by SEG. There is some variation seen with Travellers and mothers from SEG-A tending to stay slightly longer post spontaneous delivery when compared to other classes. In the case of Caesarean section, 29% of Traveller mothers tend to go home within 3 days compared to mothers in other SEGs ($p<0.001$).

2.3.6.2 Infant's length of stay

Infant's length of stay is calculated from the date of delivery to date of infant's discharge. Infant's date of birth for NPRS data was withheld by NPRS. Consequently, we can only compare Traveller infant's length of stay against NPRS published report (for all births). Table 2.64 shows infant length of stay for Travellers and NPRS whole population. More than half of Traveller infants stayed for less than two days while a small percentage stayed more than 29 days.

Table 2.64: Length of infant stay in hospital - ROI Travellers, NPRS Irish and NPRS European

Infant length of stay	ROI Travellers		NPRS total births*	
	%	n	%	n
0-2 days	53.9	221	48.5	36,319
3-5 days	39.5	162	45.8	34,316
6-10 days	2.9	12	3.2	2,396
11-28 days	2.0	8	1.7	1,277
>29 days	1.7	7	0.8	584
	100.0	410	100.0	74,892

*Source: Perinatal Statistics Report 2008 (NPRS, 2010, pg 70)

2.4 Discussion of findings

In this chapter, we made comparisons between Travellers and the Irish population in general and according to socioeconomic group. Where a social gradient exists, Travellers usually have the most adverse experience and in most factors are comparable with the Unknown/unemployed group, though usually somewhat worse than them.

The hospital-linkage data shows Travellers are hardy survivors, young parents, have multiple pregnancies, highest rates of spontaneous deliveries, present relatively later and the majority have a healthy baby outcome, with mean infant birth weight comparable to the Irish general population. However, Traveller mothers have higher rates of stillbirths, miscarriages, more birth mortality and lighter birth weight distribution than the general population. This may be associated with risks of multiparity (Aliyu *et al*, 2005).

Early pregnancy presentation and booking is important in detecting and providing the necessary clinical intervention in high risk pregnancy and in preparedness for potentially problematic delivery and its outcome (Confidential Enquiries into Maternal and Child Health, 2007; National Collaborating Centre For Women's And Children's Health, 2008; Alfirevic & Neilson, 2010; Bhutta *et al*, 2010; Centre for Maternal and Child Enquiries, 2010; Draycott *et al*, 2011). It is encouraging that booking rates are much better in this population, and reflect some move towards earlier presentation, to the GP at least, than was the surmised situation in the past. The percentage of Traveller women visiting a doctor at 3 months has increased when compared to that reported by McCarthy *et al* (1995) in the Task Force Report on the Travelling Community.

Rubella status is still poor or poorly documented while infant immunisation (BCG) is comparable to the general population average. Breastfeeding rates are low in comparison to other groups. Barriers to breastfeeding in Traveller mothers have been identified (All Ireland Traveller Health Study Team, 2010; McGorrian *et al*, 2010) and steps should be taken to encourage breastfeeding in this community.

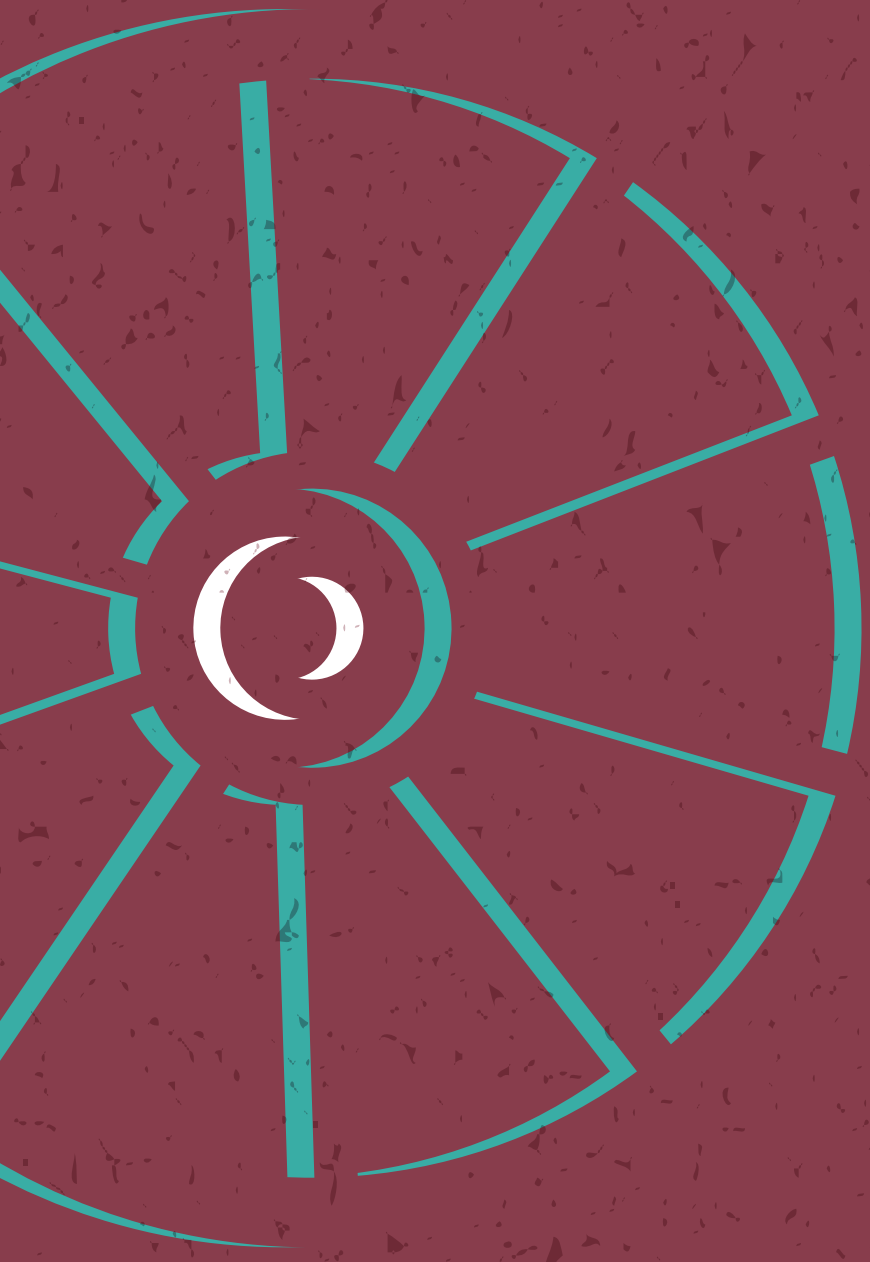
Infant birth weight is determined by two factors: duration of pregnancy and rate of foetal growth. Pre-term birth results in low birth weight (LBW) (see chapter 4 for discussion). Intra-uterine growth restriction (IUGR), or slow foetal growth, is one of the major causes of LBW babies (<2500g) and denotes a pathological process as a result of growth restriction (Divon and Barnhard, 2008). It is one of the major causes of perinatal morbidity and mortality (Ounsted *et al*, 1981, Rasmussen *et al*, 1999). The causes of IUGR can be maternal (under-nutrition, maternal low birth weight, low maternal weight gain, teenage pregnancy, low socioeconomic status, parity, and medical conditions), environmental factors (drug abuse, smoking, irradiation), foetal factors (chromosomal, genetics, congenital malformations, intrauterine infections, multiple pregnancies), and placental factors (Sankaran and Kyle, 2009). Traditionally, IUGR is inversely related with socioeconomic group (Valero de Bernabé *et al*, 2004; Kramer *et al*, 2007). Preventive strategy for IUGR aims at reducing the risks associated, including identifying risky pregnancy, abstinence from substance misuse during pregnancy (smoking, alcohol, illicit drugs) and nutritional interventions. However, these require early diagnosis thus stressing the importance of early attendance at doctor/antenatal clinic (Grivell *et al*, 2009).

More recent evidence suggests there are greater numbers of larger babies being born to obese or over-weight mothers in disadvantaged families (Sedula *et al*, 1990; Murrin *et al*, 2007; Centre for Maternal and Child Enquiries, 2010). Travellers do not appear to follow this trend as they are least likely to be in the <2500g and >4000g categories. However they do have a lighter birth weight distribution otherwise and are most likely to have infants in the <3000g category; this has been associated with increased risk of adult chronic disease (Barker, 2004b; Barker and Martyn, 1992).

'Foetal origin of adult diseases' or 'foetal programming' was developed by Barker who first described the association between infant birth weight and subsequent adult cardiovascular disease and insulin resistance/Type 2 diabetes (Barker, 2004a; Barker *et al*, 1993; Barker and Martyn, 1992; Barker, 2007; Barker *et al*, 2002). The root for cardiovascular disease, as proposed by Barker, lies in maternal poverty and its effects on under-nutrition in foetal life and early infancy. Certainly there is a body of work associating LBW with Metabolic Syndrome (a collection of diseases consisting of Hypertension, Type 2 Diabetes, insulin resistance, hypercholesterolaemia and its combinations) (Vaag, 2009; Morrison *et al*, 2010; Wells, 2010).

The data in this part of the study do not include smoking and mother's BMI which would need to be further investigated. From the AITHS census, 52.3% of Traveller households in ROI and 50.8% in NI on the island of Ireland have a smoker; 50.7% of Traveller women (of all ages) in ROI and 47.8% in NI smoked. In Traveller women of child bearing age (15-45 years old), 51.3% in ROI and 48% in NI were smokers (All Ireland Traveller Health Study Team, 2010).

Chapter 3:
Parent-held Child Record



Parent-held Child Record

3.1 Introduction

The Parent-held Child Record (PHCR) was a recording diary specially designed by the study team. Participating mothers were given these records when they were consented by the Public Health Nurses (PHNs) or the Health Visitors (HVs). The mothers were asked to present these records at every medical and nursing visit.

3.2 Methodology

3.2.1 Data recorded in Parent-held Child Record

The PHCR consisted of 4 pages. Each page recorded different aspects of child health, as illustrated in Table 3.1. All recordings had to state the date and age of the child when record was entered.

Table 3.1: Content of the Parent-held Child Record

Page	Data type
1	Type of feeding (breast, mixed, artificial), introduction of solids and complications of feeding
1	Immunisation record: date of immunisation given
2	1) Developmental measurement: weight, height and head circumference. 2) Developmental milestones, complications and interventions
3	1) Result of metabolic screening test 2) Record of medical contacts
4	Extra pages to record medical contacts

3.2.2 Record maintenance and retrieval process

The PHCR was supposed to be carried by the Traveller mothers for one whole research year.

3.2.3 PHCR retrieval process

The study team deployed several methods of PHCR record retrieval, these are:

1) **Personalised congratulatory letter upon the first birthday and repeat at 3 months**
2) **Birth cohort newsletter**
3) **Mass Short Message Service (SMS) and direct phone calls**
4) **A yellow reminder notice at 12 months & red reminder notice at 18 months to all PHNs**

1) Personalised congratulatory letter upon the first birthday and repeat at 3 months

When each child reached one year old, the study team sent out a congratulatory letter to the mother, at the same time asking the mother to send back the PHCR using the freepost envelope provided. This was the first step used to retrieve the PHCR.

This method was repeated at 3 months if the PHCR was not received by that stage.

2) Birth cohort newsletter
During the cohort maintenance period, the study team sent out newsletters on a periodic basis to all consenting mothers. This was usually done during a period of festivity, for example Easter and Christmas or during significant milestones (for example when baby Thomas, one of the first babies born on the 14th October 2008, reached his first birthday). We opportunistically requested the PHCR to be returned.

3) Mass Short Message Service (SMS) and direct phone calls
The study team also sent out mass short text-messages to all the mothers in the cohort reminding them to send back the records when babies reached their first birthdays.

If the record was not returned, then the study team made further enquiries by calling the mother on her mobile phone, asking her to return the PHCR.

4) Yellow reminder notice to PHNs at 12 months & red reminder to PHNs at 18 months
A yellow notice was also posted to the relevant link-PHN to follow up on the child and assist the mother in returning the PHCR. This was done simultaneously with the first recall letter to the mothers. This was intended to remind the PHN that a participating baby had reached his/her first birthday and for the PHN to ensure that the PHCR was returned to the study team.

This, indirectly, allowed the study team to record if the participating mother or infant had moved out of the area or experienced any major events. When a PHN informed the study team that a mother had moved out of the area, the study team then forwarded the information to the next area.

If the study team did not receive any PHCR from the mother or PHNs or correspondence from the PHNs using the yellow 12-month notice, the team then issued a red reminder notice at 18 months. This was the final recall asking the PHNs to collect the PHCR during the 18 months assessment, if it had not already been returned to the study team. A large number of the PHCRs were returned by the PHNs.

In some areas, Primary Health Care for Travellers Projects helped to encourage the participating mothers to return the PHCR. Some were retrieved directly and sent back to the study team.

3.2.4 PHCR ascertainment matrix

For PHCR return, the study team developed a 'PHCR ascertainment matrix' similar to the 'Consent ascertainment matrix' (Hamid *et al*, 2010). This was distributed monthly to all the link-PHNs to track the return rate of the PHCR.

The situation is similar in Northern Ireland. None of the PHCRs were returned directly by the mothers but by Health Visitors. In areas where there was a designated Traveller Health Visitor, all records were returned promptly. As there was no Traveller network in Northern Ireland, the study team depended solely on the HVs for this process.

3.2.5 Comparative data

The 'Lifeways Cross-Generation Cohort' (will be known as 'Lifeways' hereafter) is a cohort of babies born in two hospitals, representing an urban population and a rural population. Cohort recruitment took place in 2001 to 2003. Data for this cohort is kept in the School of Public Health, Physiotherapy and Population Science, University College Dublin (O'Mahony *et al*, 2007).

Growing Up in Ireland (GUI) is a national cohort of children of Ireland. Two cohorts of children have been recruited, an infant cohort where data were collected at nine months old and a nine years old children cohort where data collection begun at nine years. Data collection occurs at specific time points, that is, nine months or nine years old. Parents were interviewed during this period. There are over 10,000 participants in the GUI infant cohort. (Williams *et al*, 2010) For this report, we quoted the official report from the nine months infant cohort "Growing Up in Ireland: The infants and their families. Infant cohort, report 1".

3.3 Results

In this section we present the findings from the PHCR. We include comparison where there is appropriate data available.

There were 508 mothers who consented to the study. 384 (75.6%) of the PHCRs were returned to the study team (Figure 1.1). 362 (94.5%) of these were returned by the PHNs/HVs and the Primary Health Care for Travellers Projects.

PHNs/HVs sat down with the mothers to ensure the completion of the records. This was also supplemented by PHNs'/HVs' own records. 274 (71.3%) of the 384 returned records had medical contacts recorded. The PHNs/HVs took the initiative to contact the General Practitioners and local hospitals to ensure the completion of this section. Thus the quality of this section should reflect the true nature of health contacts of Irish Traveller infants during the first year of life.

3.3.1 Recorded infant feeding

3.3.1.1 Breastfeeding

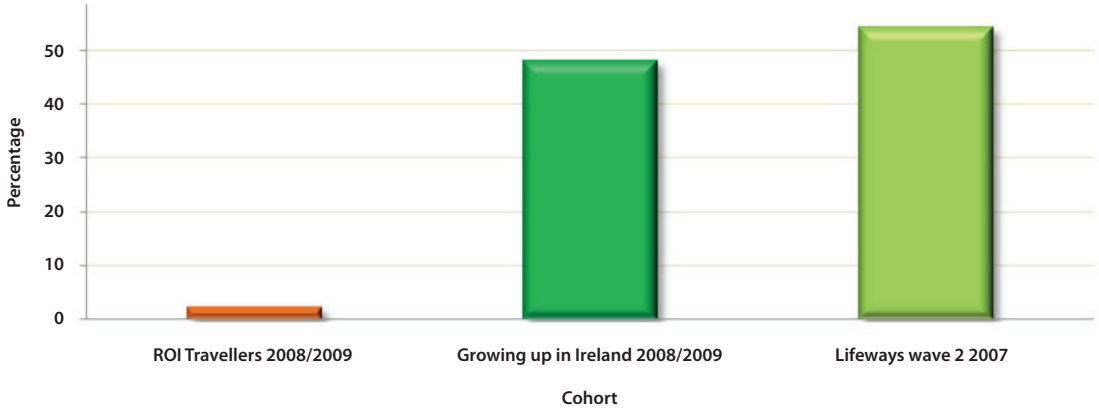
Only 2.2% of the Traveller mothers in ROI initiated breastfeeding. None of the mothers in NI initiated breastfeeding (Table 3.2). This is in keeping with the hospital linkage data (section 2.3.5.5). However, as reported in the AITHS TR1 (All Ireland Traveller Health Study Team, 2010), there is an age gradient to this with older Traveller women having a higher breastfeeding rate ever compared to younger Traveller women.

Table 3.2: Breastfeeding rate - ROI Travellers and NI Travellers.

	ROI Travellers		NI Travellers		Total	
	%	n	%	n	%	n
Yes	2.0	7	0.0	0	1.8	7
No	97.8	350	100.0	23	97.9	373
Attempted	0.2	1	0.0	0	0.3	1
Total	100.0	358	100.0	23	100.0	381

Traveller rates are low compared to the Growing Up in Ireland cohort where 48% of mothers reported initiation of breastfeeding (Williams *et al*, 2010), while 54.1% of Lifeways mothers reported initiation (McGorrian *et al*, 2010) (Figure 3.1). Of the Traveller mothers who breastfed in ROI (n=7), only one breastfed for more than three months.

Figure 3.1: Prevalence of breastfeeding by Traveller mothers and other groups



Notes:

1) NI Travellers not included as the initiation rate was 0, ROI Travellers total was 7 mothers
2) Growing up in Ireland rate is based on Irish mothers only (Williams *et al*, 2010, pg 53, section 3.6.1)
3) Data for Lifeways wave 2 was taken from "Breastfeeding is natural, but it's not the norm in Ireland": an assessment of the barriers to breastfeeding and the service needs of families and communities in Ireland with low breastfeeding rates (McGorrian *et al*, 2010, pg56)

3.3.1.2 Introduction of solids into infant's diet

The current recommendation for introduction of solids into a baby's diet is at six months (World Health Organisation, 2001; Public Health Agency, 2010; Department of Health and Children, 2003). Overall, 36% of Traveller mothers introduce solids into their infant's diet at four to five months. A small percentage introduced solids much earlier at three months. A large proportion of Traveller mothers introduce solids after nine months. However, records in the PHCR may reflect recording made during time of visits by PHNs/HVs rather than the actual introduction period. We suspect the introduction of solids, on average, may be in the 4-6 months period (Table 3.3).

Table 3.3: Introduction of solids into infant's diet by Traveller mothers

Introduction of solids into infant's diet (in months)	Irish Travellers	
	%	n
3 months or less	12.7	21
4-5 months	36.1	60
6-8 months	21.1	35
> 9 months	30.1	50
Total	100.0	166

3.3.2 Immunisation uptake

There are different protocols for immunisation according to type, and also between ROI and NI. The immunisation delivery protocols for ROI and NI are summarised in Table 3.4.

Table 3.4: Summary of immunisation schedule for ROI and NI up to 12 months

Immunisation	ROI	NI
BCG	At birth in all areas except Co Galway and Mayo where BCG immunisation is a school-based programme	No mass population based immunisation. Immunisation is based on risk-assessment
'6 in 1' (ROI) DTap/IPV/Hib/HepB	1st: 2 month 2nd: 4 month 3rd: 6 month 4th Hib only: 13 months	
'5 in 1' (NI) DTaP/IPV/Hib		1st: 2 months 2nd: 3 months 3rd: 4 months 4th Hib only: 12-13 months
MMR	12-15 months	12-13 months
PCV	1st: 2 month 2nd: 6 months 3rd: 12 months	1st: 2 months 2nd: 4 months
Meningitis C	1st: 4 months 2nd: 6 months 3rd: 13 months	1st: 3 months 2nd: 4 months 3rd: 12-13 months

Immunisation for BCG and the '6 in 1' or '5 in 1' should all have been given by the time the PHCRs were returned. When there was no entry made, then this was noted as 'not recorded'. Table 3.5 shows the immunisation uptake rates for ROI Travellers and NI Travellers. 75% of NI Traveller infants completed the three '5 in 1' doses while only 65.5% of ROI Traveller infants completed the '6 in 1'.

For BCG immunisation, the overall uptake rate was 71.8%. We adjusted the rates by removing data from areas which either do not have a neonatal BCG immunisation programme or which offer BCG immunisation based on risk assessment (NI). After adjustment, 78% of ROI Travellers infants received BCG immunisation while 0.6% did not have BCG immunisation.

The uptake rate for MMR and Hib was 50% and 23% respectively with uptake rates higher in the NI Travellers. However, the timing of the PHCR retrieval period was before the recommended vaccination period for each of these was complete; this may explain the low uptake rate seen. In the analysis of the Lifeways cohort study which used similar methodology with retrieval of PHCR at 12 months, the same findings were reported by Jessop *et al* (2011).

Table 3.5: Immunisation status of Traveller infants in ROI and NI

	ROI Travellers		NI Travellers		Irish Travellers	
	%	n	%	n	%	N
'6 in 1' (ROI)/'5 in 1' (NI)						
One dose only	9.5	34	0.0	0	8.9	34
Two doses only	11.5	41	12.5	3	11.5	44
All three doses	65.5	234	75.0	18	66.1	252
Not recorded	13.4	48	12.5	3	13.4	51
Total	100.0	357	100.0	24	100.0	381
BCG (overall)						
Yes	71.8	255	0.0	0	71.8	255
No	0.6	2	0.0	0	0.5	2
Not recorded/ due	27.6	98	100.0	24	27.6	122
Total	100.0	355	100.0	24	100.0	379
BCG (adjusted)*						
Yes	78.0	241	0.0	0	78.0	241
No	0.6	2	0.0	0	0.6	2
Not recorded/ due	21.3	66	0.0	0	21.3	66
Total	100.0	309	0.0	0	100.0	309
MMR**						
Yes	49.7	165	50.0	5	49.7	170
No	0.3	1	0.0	0	0.3	1
Not recorded/ due	50.0	166	50.0	5	50.0	171
Total	100.0	332	100.0	10	100.0	342
Hib**						
Yes	20.9	75	54.2	13	23.0	88
Not recorded/ due	79.1	283	45.8	11	77.0	294
Total	100.0	358	100.0	24	100.0	382

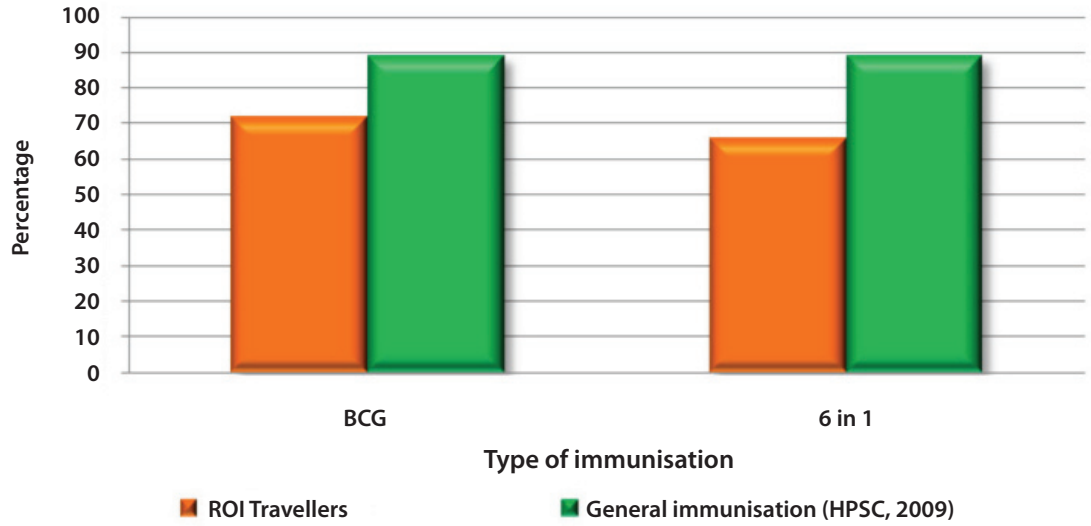
*BCG immunisation was adjusted by removing PHCR from counties which do not have a mass neonatal BCG immunisation programme (Galway, Mayo and Northern Ireland)

**MMR and Hib immunisation scheduling not yet completed when PHCRs were retrieved

3.3.2.1 Immunisation uptake: ROI

We compared the overall immunisation uptake for ROI Travellers against the national population as reported by the Health Protection Surveillance Centre Annual report (HPSC, 2009). Overall ROI Traveller infants still have a lower recorded uptake of immunisation with best records for BCG followed by the '6 in 1' (Figure 3.2).

Figure 3.2: Immunisation uptake for ROI Travellers and ROI general population

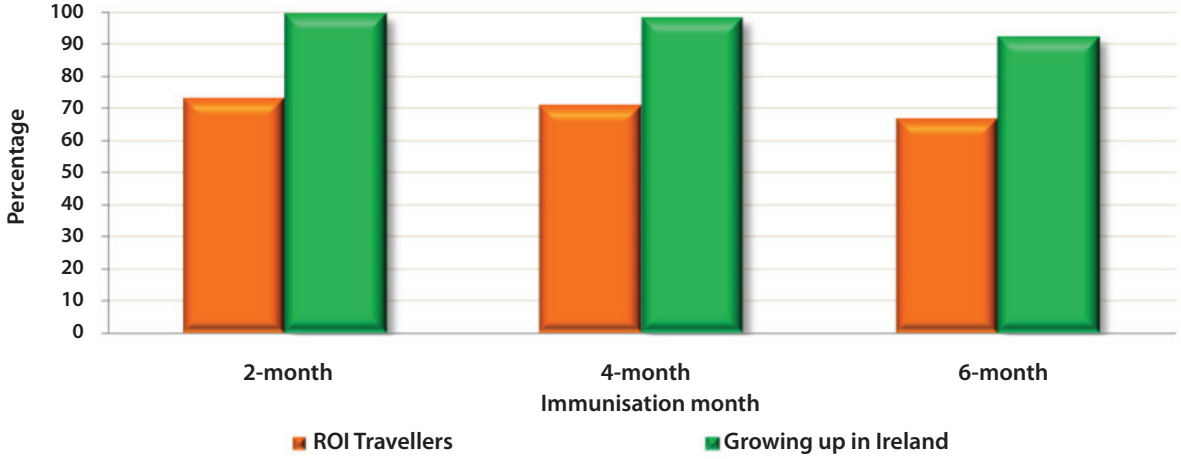


Source: HPSC Annual report 2009 (Health Protection Surveillance Centre, 2011)

*HPCS caveat: data presented are not complete data. Data based on 0-12 months immunisation schedule on babies born between 1/1/2008-31/12/2008

Figure 3.3 shows that in both Travellers and the Growing Up in Ireland cohort, there was some fall in the percentage completing the second and third doses of '6 in 1'; however for all percentages, the Growing Up in Ireland cohort have better uptake.

Figure 3.3: Percentage uptake of '6 in 1' by dosage schedule

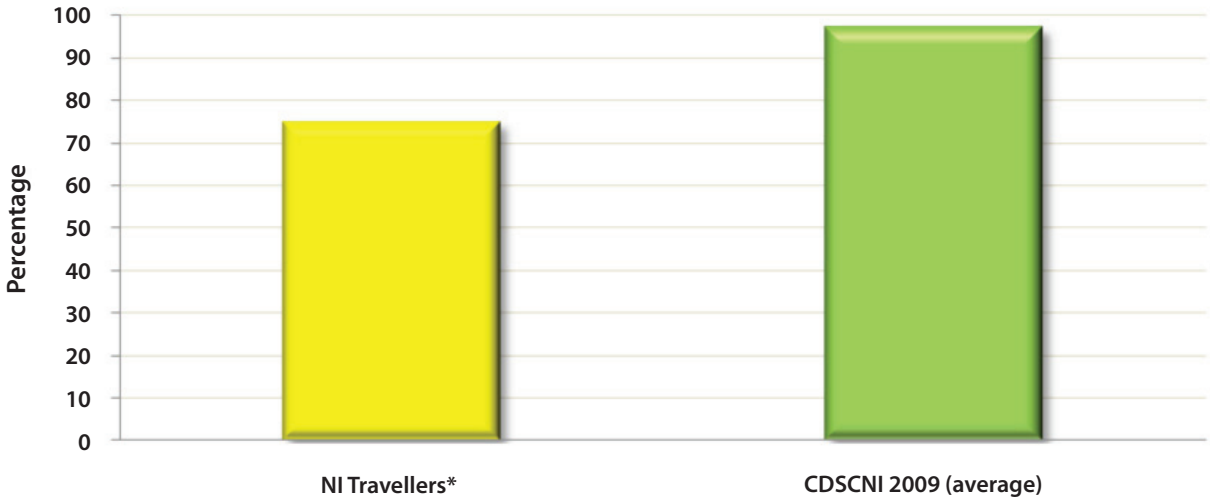


Source: Growing Up in Ireland (Williams et al, 2010)

3.3.2.2 Immunisation uptake: NI

Figure 3.4 shows the overall immunisation uptake for NI Travellers against the average for NI population as recorded by the Communicable Disease Surveillance Centre Northern Ireland (CDSCNI, 2009). 97.3% of infants in NI completed all doses of '5 in 1' as opposed to 75% of NI Travellers (recorded). Comparison was made only for '5 in 1' due to completed scheduling at 12 months. MMR is offered after 13 months while BCG immunisation is based on risk-assessment.

Figure 3.4: Immunisation uptake for NI Traveller and general population (CDSCNI, 2009)**



Source: Communicable Disease Surveillance Centre Northern Ireland (2011), available at: http://www.cdscni.org.uk/surveillance/Coveragestats/12Months.htm

*NI Travellers dataset is less than 12 participants

**CDSCNI data is based on calculated average of quarterly result for 2009

3.3.3 Infant growth and development

Infant growth and development during the first year were also recorded. For comparison purposes, we only describe the development and measurement at 9 months.

3.3.3.1 Growth measurement

An average Traveller infant at 9 months has an average weight of 9.2kg, height of 71cm and a head circumference of 46cm (Table 3.6).

Table 3.6: Mean weight, length and head circumference of Traveller babies at nine months

Irish Travellers	n	mean	range	SD	95% CI
Weight (kg)	114	9.2	6.0-12.2	1.2	9.0-9.4
Length (cm)	114	71.0	59.0-85.0	6.1	69.8-72.1
Head circumference (cm)	114	46.0	40.0-72.0	3.9	45.3-46.8

Both boys and girls Traveller infants have comparable measurements when compared to the Growing Up in Ireland infants (Table 3.7).

Table 3.7: Mean weight, height and head circumference for Traveller infants overall, for boys and girls, and compared to Growing Up in Ireland infants

		Irish Travellers	Growing Up in Ireland
Overall	Weight (kg)	9.2	9.7
	Height (cm)	71.0	72.9
	Head circumference (cm)	46.1	46.5
Boys	Weight (kg)	9.2	10.0
	Height (cm)	71.0	73.8
	Head circumference (cm)	46.9	47.0
Girls	Weight (kg)	8.9	9.3
	Height (cm)	71.3	71.9
	Head circumference (cm)	45.1	45.8

Source: Growing Up in Ireland (Williams *et al*, 2010)

3.3.3.2 Developmental milestones

We also recorded developmental problems of infants throughout the first year of life. Each condition was recorded only once and ranged from mild problems of nappy rash to suspected hearing problems needing further testing, to the more severe condition of global developmental delay. Two thirds of Traveller infants had normal development throughout the first year. This figure was 67.1% for ROI Traveller infants and 63.6% for NI Traveller infants (Table 3.8). One quarter of Traveller infants had only one recorded developmental issue, again lower in NI Traveller infants. Of note, the smaller number of infants meant that care must be taken with comparisons. The 9.3% of infants in NI and 0.3% of infants in ROI with three developmental conditions each represent a single child in each region.

Table 3.8: Number of developmental issues recorded during first year of life for Traveller Infants

	ROI Travellers		NI Travellers		Irish Travellers	
	%	n	%	n	%	n
Normal development throughout first year	67.1	210	63.6	7	67.0	217
One developmental condition noted	27.8	87	27.3	3	27.8	90
Two developmental conditions noted	4.8	15	0.0	0	4.6	15
Three developmental conditions noted	0.3	1	9.1	1	0.6	2
Total	100.0	313	100.0	11	100.0	324

3.3.4 Health services use during first year of life

Health services use and reasons for health visits, as mentioned before, need careful interpretation. Although 71.3% of the PHCR health contact section was completed, the quality varies from one single entry with little information to entries based on PHN knowledge only to entries requiring a few additional PHCRs. For a large number of the PHCR, PHNs have made an effort to include every possible detail with additional General Practitioner (GP) reports and local hospital reports. Contacts with health professionals overseas have been completed to the best effort by the PHNs.

We also broke down the data for health contact 'per unit child' as a small number of children may be the sickest and require the most health contacts. We have also removed all 'routine' contacts, for example, 6 weeks developmental checks, immunisation or PHN's first week visits, as most of these were not recorded in the health contact sections. We made the assumption that these routine contacts took place and are the average requirement for all children in Ireland, thus should not be counted as additional service use. Currently there is no comparable data on infant utilisation of health services in ROI and NI, thus exact comparison with the general population group is limited.

In Table 3.9, we show the varied health services use by Traveller infants. PHN visits and GP visits were the most common contacts by Traveller infants. These range from 3 to 30 visits by a PHN and 1 to 22 visits to/from a GP. Although the range for OPD attendance ranges from 1 to 40 visits, this represents a small number of infants who require a weekly attendance scheduled by the medical team (this includes all hospital specialties).

Table 3.9: Traveller infants' health contacts during the first year of life (based on n=274 PHCRs)

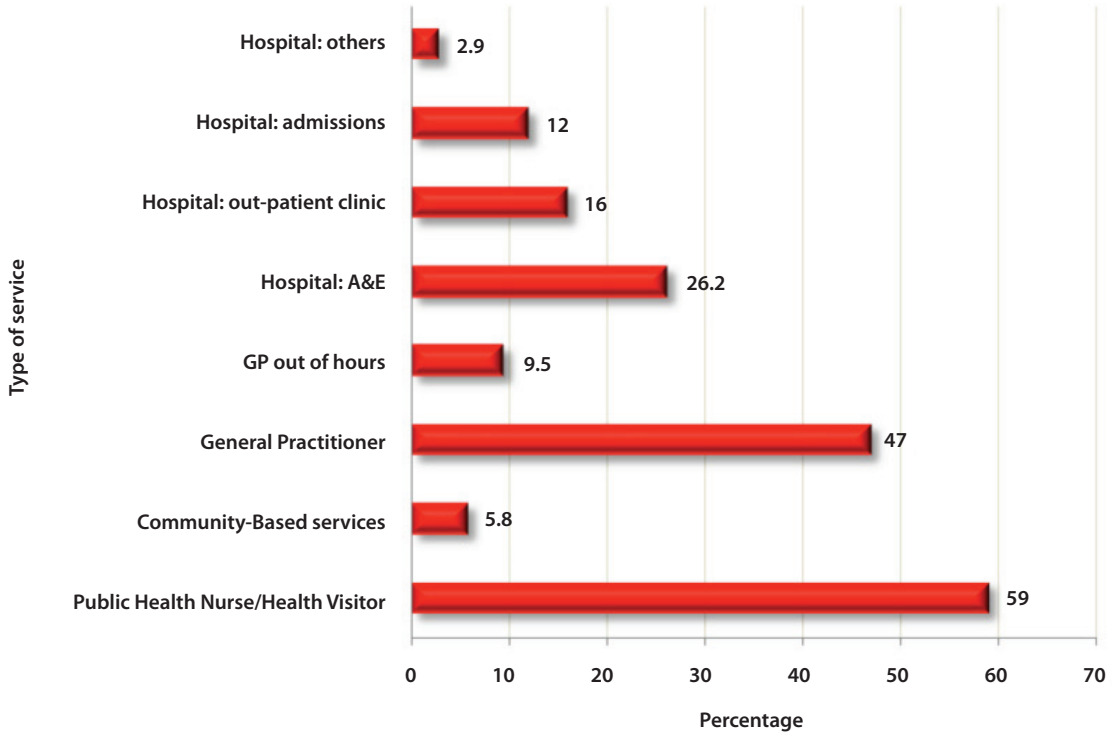
Number of visits to different health services by a Traveller infant during the first year	n	%*	mean	range	SD
General Practitioner	129	47.0	3.1	1-22	3.4
General Practitioner out of hours	26	9.5	2.8	1-8	1.9
Accident & Emergency	72	26.3	1.7	1-7	1.1
Outpatient department	44	16.0	2.7	1-40	6.1
Hospital admissions	33	12.0	1.4	1-7	1.1
Other hospital services (other than OPD medical clinics)	8	2.9	1.0	1-1	0.0
Community-based services	16	5.8	1.9	1-12	2.7
Public Health Nurse/Health Visitor	163	59.5	6.9	3-30	2.9

Note: 109 of returned PHCRs had no entry made for the health service section, analysis above is based on those who had any records made (n=274)

*% of the 274 with completed records

Figure 3.5 shows that 59% of children required additional contacts with PHNs/HVs followed by GPs at 47%. Only 26.2% of Traveller infants attended the A&E at least once, while 16% attended OPD clinics in the hospital. 12% of Traveller infants were admitted into hospital at some time during the first year of life.

Figure 3.5: Percentage of Traveller infants who had contacts with different health services during first year of life



3.3.4.1 Conditions for attending health services

Table 3.10 shows the conditions for which Traveller infants attend the health services. Respiratory related conditions (range from respiratory tract infections to breathing problems) were the most common cause of contact with 36.9% of infants having respiratory related conditions at some point in their first year of life. Fever/flu-like symptoms/viral illness/non-specific symptoms and a combination of other conditions were the second most common reason to seek health services. 13.5% of children had gastrointestinal related conditions including diarrhoea and vomiting followed by dermatology conditions at 11.3% (including eczema, rashes and fungal skin infection).

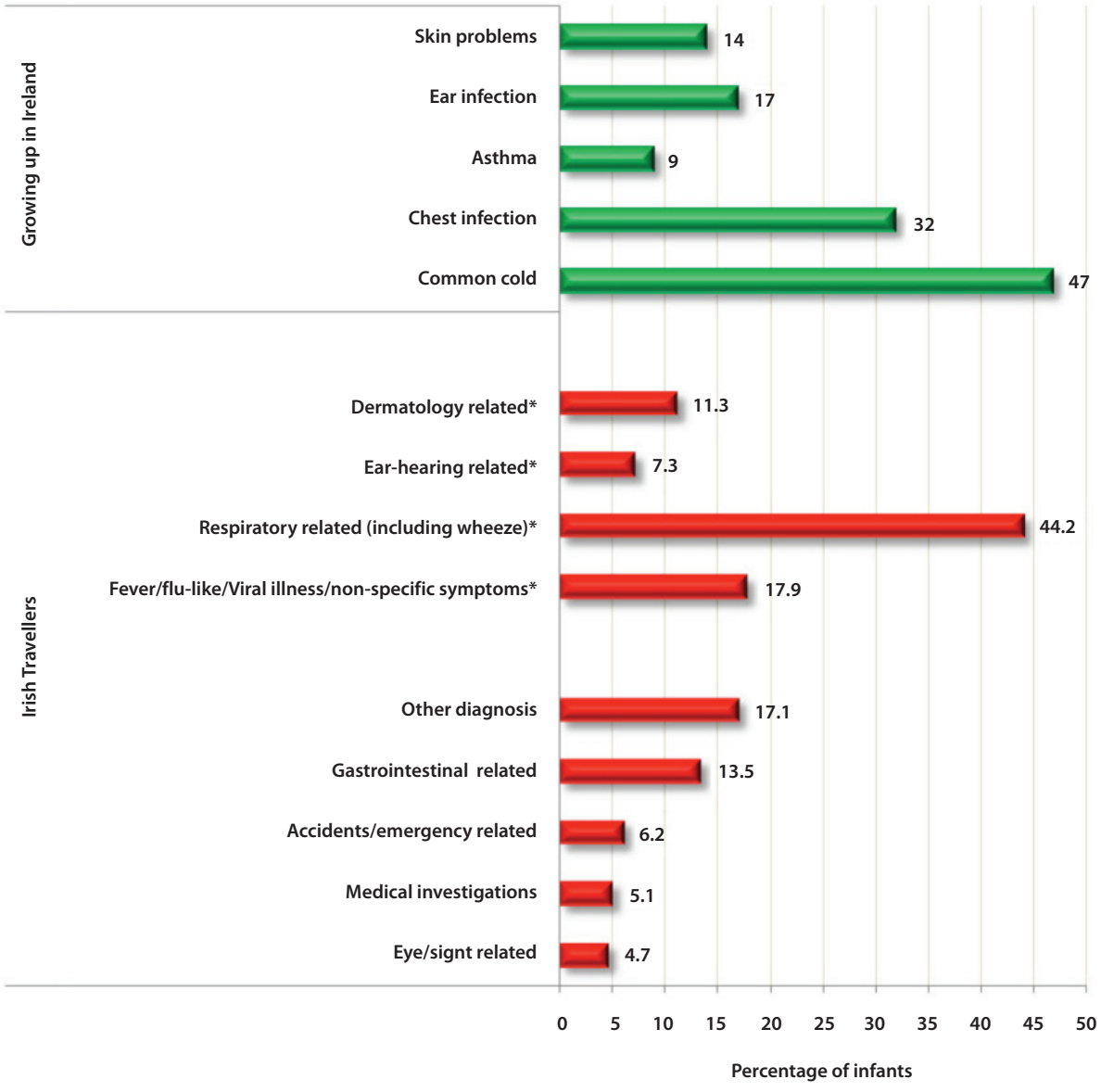
Other conditions each occurred in less than 10% of the infants, including developmental related issues, ear/hearing related, accidents/emergency related, medical investigations/interventions and eye/sight related issues.

Table 3.10: Condition requiring contact with health services

Condition	n	% of children
Respiratory related (including wheeze)	101	36.9
Fever/flu-like/viral illness/ non-specific symptoms	49	17.9
Other diagnosis	47	17.1
Gastrointestinal related	37	13.5
Dermatology related	31	11.3
Developmental issues	27	9.8
Ear/hearing related	20	7.3
Throat related (laryngitis/pharyngitis)	20	7.3
Accidents/emergency related (seizure, head injury, fracture etc)	17	6.2
Medical investigations purposes	14	5.1
Eye/sight related	13	4.7

When compared to Growing Up in Ireland infants for fever/flu-like symptoms/ viral illness/ non specific symptoms, only 17.9% of Traveller parents brought their infants to attend health professionals compared to self-reported 47% in the Growing Up in Ireland group (Figure 3.6). However, Traveller infants do suffer from more respiratory related conditions compared to the GUI infants (36.9% vs. 32%). This needs careful interpretation as the Growing Up in Ireland data was specific, for example 'respiratory infection' and 'asthma' while the Traveller categories are much broader.

Figure 3.6: Conditions for which an infant attended a medical professional since birth: Irish Traveller and Growing Up in Ireland



Source: Growing Up in Ireland (Williams *et al*, 2010)

*Growing Up in Ireland uses more specific indicators e.g. ear infection instead of ear/hearing related conditions and only 5 conditions were reported.

3.3.4.2 Frequency of health contact

Frequency of health contact by each child shows great variation (Table 3.11). Except for community services and General Practitioners, most contact took place 1-3 times by each child. 62.3% of Traveller infants had 4-6 contacts with the community services, mostly due to the contacts with PHNs/HVs. A small number of infants required more than 10 visits. Figure 3.7 shows frequency of visits to GP and/or hospital by a Traveller infant during the first year of life.

Table 3.11: Frequency of contacts with health services during first year of life for a Traveller infant

	Irish Travellers	
	%	n
General Practitioner		
No visit	20.5	33
1-3 visits	59.0	95
4-6 visits	11.2	18
7-9 visits	3.7	6
10-15 visits	4.3	7
>15 visits	1.2	2
Total	100.0	161
General Practitioner out of hours		
No visit	55.9	33
1-3 visits	32.2	19
4-6 visits	10.2	6
7-9 visits	1.7	1
Total	100.0	59
Accident & Emergency		
No visit	31.4	33
1-3 visits	65.7	69
4-6 visits	1.9	2
7-9 visits	0.9	1
Total	100.0	105
Other hospital services (excluding A&E)		
No visit	31.4	33
1-3 visits	61.9	65
4-6 visits	1.9	2
7-9 visits	4.2	3
10-15 visits	2.8	1
>15 visits	2.8	1
Total	100.0	105
Community services (Including PHNs/HVs, extra non-routine visits)		
No visit	15.9	33
1-3 visits	5.3	11
4-6 visits	62.3	129
7-9 visits	8.7	18
10-15 visits	5.8	12
>15 visits	1.9	4
Total	100.0	207

Figure 3.7: Frequency of General Practitioner and/or hospital visits by a Traveller infant during first year of life

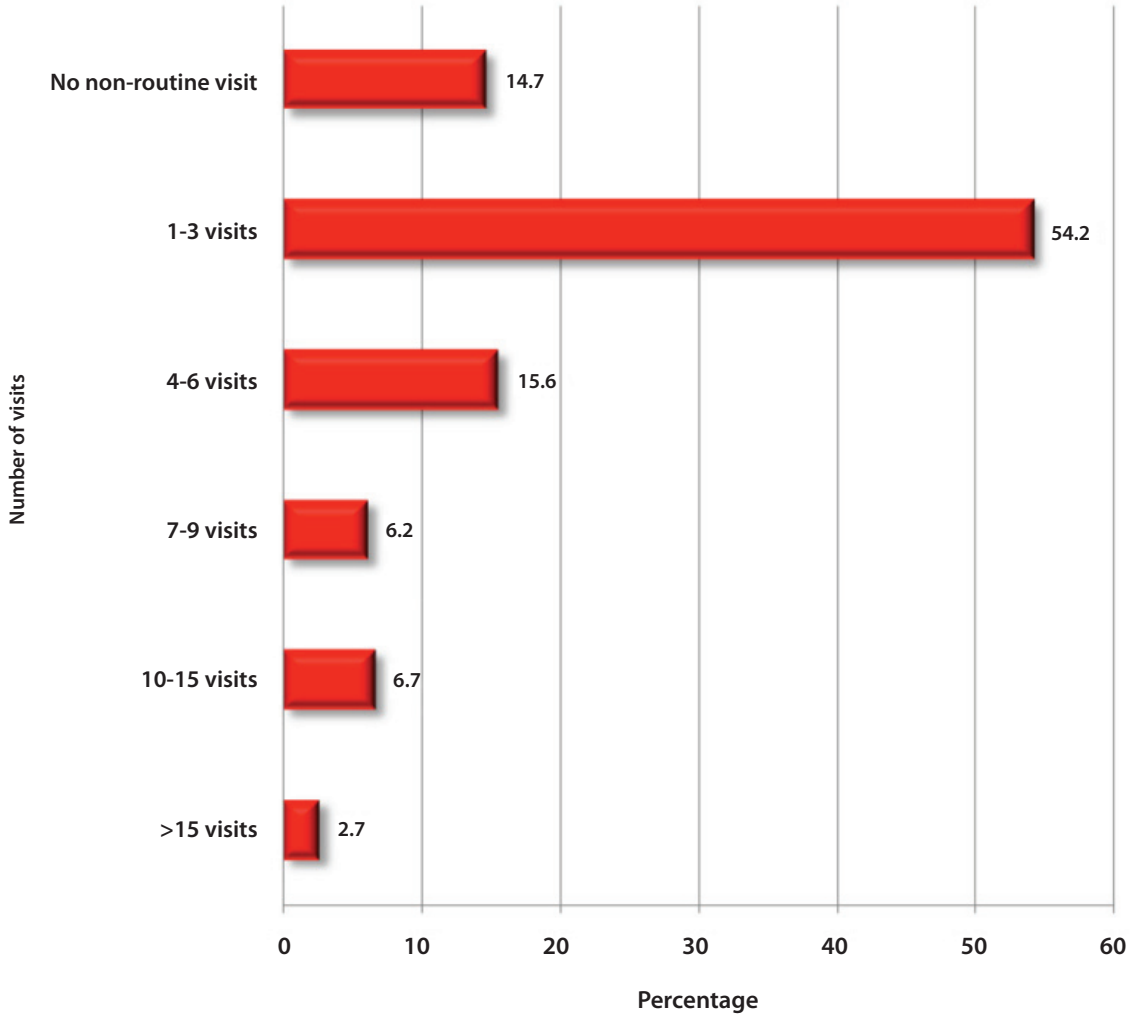


Table 3.12 shows frequency of visits to health professional by conditions. As can be seen again, most infants only require 1-2 contacts while a small number require more than 4 visits; this is true across all the conditions.

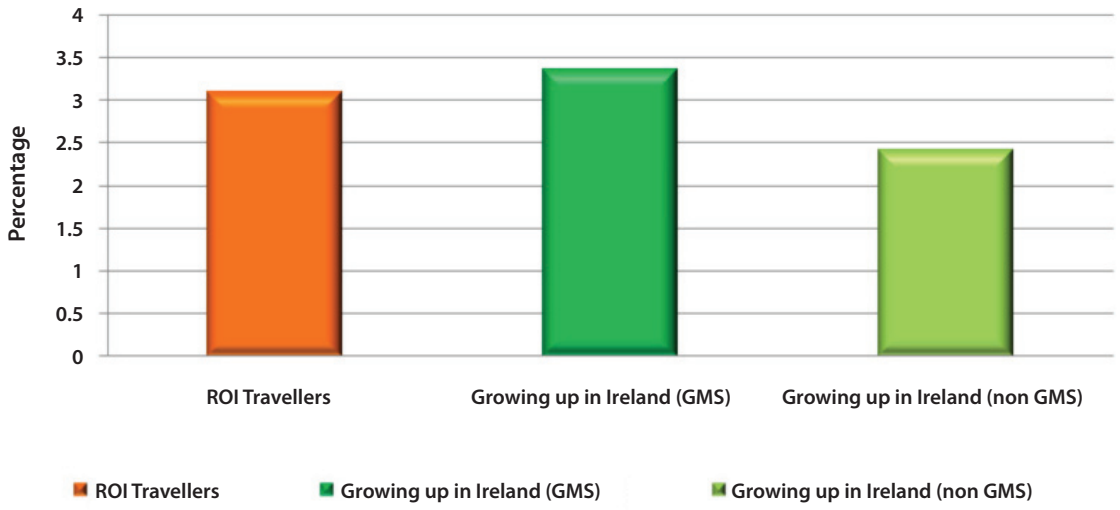
Table 3.12: Frequency of health contact according to conditions

	Irish Travellers			Irish Travellers	
Conditions & frequency	**%**	**n**	**Conditions & frequency**	**%**	**n**
Respiratory related			**Gastrointestinal related**		
No episode	24.6	33	No episode	47.1	33
1-2 episodes	55.2	74	1-2 episodes	45.7	32
3-4 episodes	12.7	17	3-4 episodes	4.3	3
5-6 episodes	3.0	4	5-6 episodes	1.4	1
7-8 episodes	2.2	3	> 9 episodes	1.4	1
> 9 episodes	2.2	3	Total	100.0	70
Total	100.0	134			
Developmental Issues			**Fever/flu-like/ viral illness/ non-specific symptoms**		
No episode	55.0	33	No episode	40.2	33
1-2 episodes	38.3	23	1-2 episodes	51.2	42
3-4 episodes	5.0	3	3-4 episodes	6.1	5
5-6 episodes	1.7	1	5-6 episodes	2.4	2
Total	100.0	60	Total	100.0	82
Ear/hearing related			**Other**		
No episode	62.3	33	No episode	41.2	33
1-2 episodes	30.2	16	1-2 episodes	56.2	45
3-4 episodes	5.7	3	7-8 episodes	1.2	1
> 9 episodes	1.9	1	> 9 episodes	1.2	1
Total	100.0	53	Total	100.0	80
Dermatology related			**Throat related (laryngitis/pharyngitis)**		
No episode	51.5	33	No episode	62.3	33
1-2 episodes	46.9	30	1-2 episodes	34.0	18
3-4 episodes	1.6	1	3-4 episodes	3.8	2
Total	100.0	64	Total	100.0	53
Eye/sight related			**Accident/emergency (seizure, head injury, suspected fracture etc)**		
No episode	71.7	33	No episode	66.0	33
1-2 episodes	28.3	13	1-2 episodes	34.0	17
Total	100.0	46	Total	100.0	50
Medical investigations					
No episode	70.2	33			
1-2 episodes	27.7	13			
3-4 episodes	2.1	1			
Total	100.0	47			

3.3.4.3 General Practitioner visits

Figure 3.8 shows the mean number of health contacts with a general practitioner for an infant in Republic of Ireland. The mean for ROI Traveller infants was similar to Growing Up in Ireland GMS infants; Growing Up in Ireland non GMS infants had a much lower mean. This may be related to real need of contact for those in the lower socioeconomic class or reluctance of the non-GMS families to attend General Practitioners due to cost issues.

Figure 3.8: Mean number of health contacts with General Practitioner



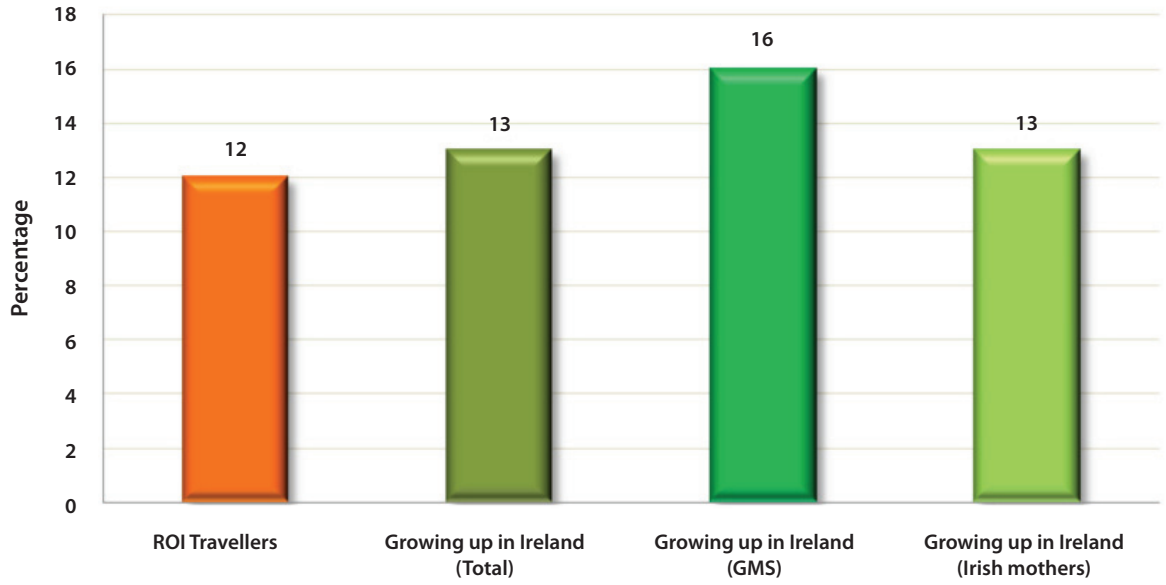
Source: Growing Up in Ireland (Williams *et al*, 2010)

Note: ROI Travellers based on PHN's record & contacting GPs for visit records and up to child's 12-month of age. Growing Up in Ireland (GUI) is based on 9 months old and parental recall. Results taken from Growing Up in Ireland report (Williams *et al*, 2010, pg64)

3.3.4.4 Hospital admissions

12% of ROI Traveller infants were admitted at least once into hospital during their first year of life compared to 16% of Growing Up in Ireland GMS infants, 13% for Growing Up in Ireland Irish mothers and 13% of Growing Up in Ireland total cohort (Figure 3.9).

Figure 3.9: Percentage of infants who were admitted into a hospital



Note: ROI Travellers based on 12 months data, Growing Up in Ireland (Williams *et al*, 2010) was based on 9 months data

3.4 Discussion of findings

The use of the Parent-held Child Record (PHCR) was a challenge in this nomadic group, but we were pleased with the response rate achieved, particularly with assistance from Public Health Nurses/ Health Visitors and Primary Health Care for Travellers Projects. PHCR is a useful method of collecting data as it is meant to assist in real-time recording instead of purely parental recall (McElligott and Darden, 2010). It also means that searching records across disparate health care delivery sites is obviated. Given the particular challenges for Travellers it was one of the recommendations of the Task Force Report previously that these should be introduced (Task Force on the Travelling Community, 1995). A similar recommendation was also made by the Welsh ASERT programme (Aspinall, 2005). Traveller mothers appear to have brought the PHCR to many GPs and hospital visits, but the majority of the information was recorded by their Public Health Nurses. The PHCR is not in general use in the general Irish population, which provided a further challenge when presenting to health professionals for completion.

The World Health Organisation recommends that breastfeeding should be the feeding method of choice and should be maintained for six months (World Health Organisation, 2001). The benefits of breastfeeding are numerous (Ip *et al*, 2007). The documented breastfeeding rate was low at 2.2% of the cohort population. Of the few Traveller mothers who initiated breastfeeding early termination of breastfeeding was the norm, with just one mother in the cohort continuing to breastfeed for more than three months. This particularly reflects the younger age of mothers in the cohort. The All Ireland Traveller Health Study (All Ireland Traveller Health Study Team, 2010) showed there was an age-gradient to history of breastfeeding with younger Traveller mothers less likely to breastfeed (4.5% in those aged under 30 years) than their older counterparts (22% and 50% of Traveller women age 45 and over in ROI and NI respectively). This suggests a fall in breastfeeding rates over time in this group. Various factors identified from our own study in the AITHS and by McGorrian *et al* (2010) on the national breastfeeding assessment report include poor support, lack of privacy and paradoxical policy recommendations between breastfeeding promotion and newborn metabolic screening. There is a national challenge to improve breastfeeding rates which may take some time to achieve, given the obstacles to its acceptability.

Introduction of solids to Traveller infants appears to occur earlier than recommended. There is a socioeconomic influence on timing of introduction of solids (Wright *et al*, 2004). This is consistent with a study by Tarrant *et al* (2010) on a population of women from Dublin West, which showed the median age of introduction of solids was at 16 weeks. 22.6% of the study population started weaning by 12 weeks postpartum which was higher than the Travellers in this cohort. The Millennium Cohort Study showed that introduction of solids was much earlier among minority ethnic groups and Northern Ireland mothers when compared to other white UK mothers. The study also noted the association of early introduction of solids with early termination of breastfeeding (Griffiths *et al*, 2007). This is something that Public Health Nurses could have a concerted impact upon, by ensuring that adequate milk supplies are available up to six months; the Primary Health Care for Travellers Projects could prioritise this also.

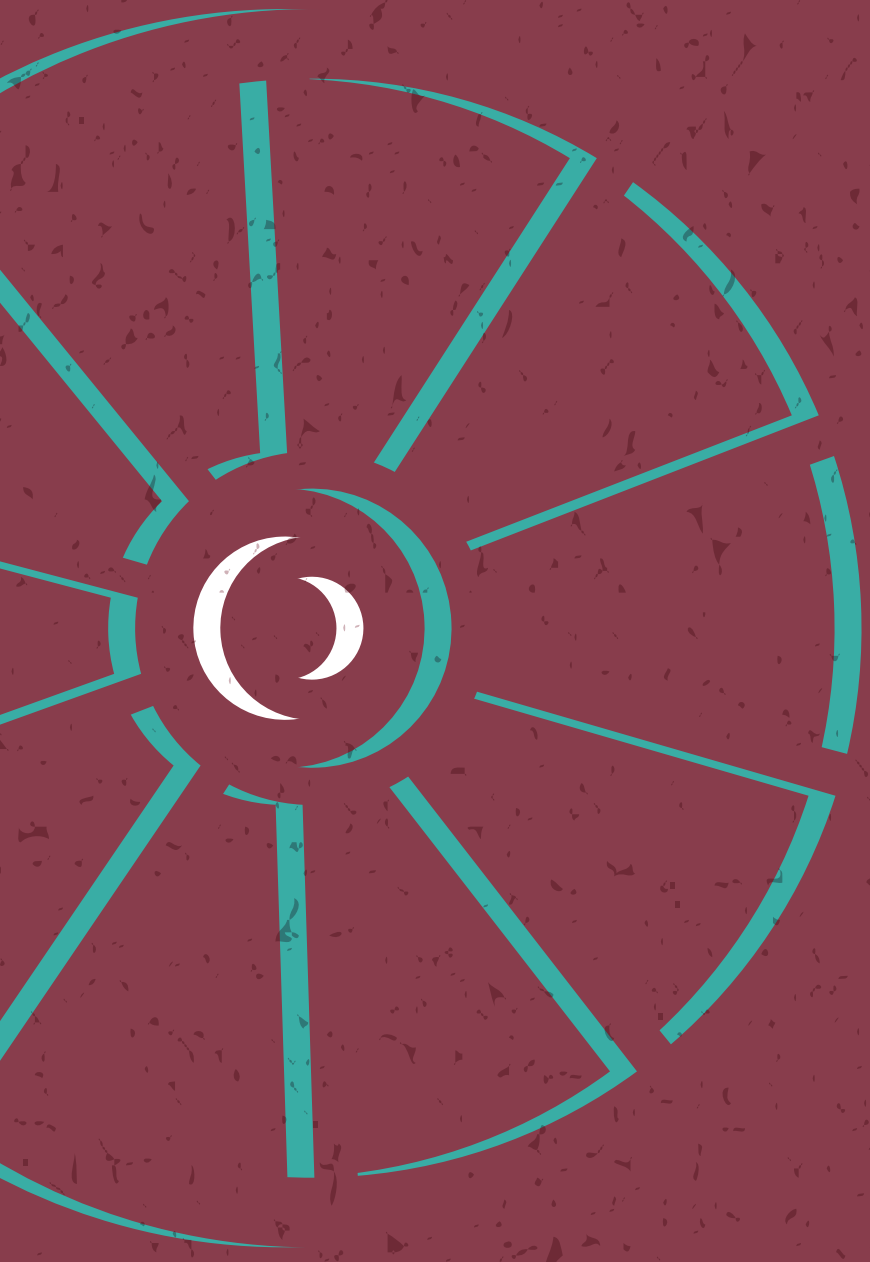
Immunisation uptake is usually lower in ethnic minorities (Menzies and Singleton, 2009; Niederhauser and Stark, 2005; Smith and Stevenson, 2008) and lower socioeconomic classes (Danis *et al*, 2010). This is also reflected in the recorded immunisation uptake from this study and true for Travellers both in ROI and NI. The pattern of attrition from the first '6 in 1' dose to the third dose is consistent with the general population, but with lower levels of immunisation at each stage of the process. There may be under-recordings of immunisation uptake depending on the accurate completion of the PHCR (Jessop *et al*, 2011; Smith and Stevenson, 2008). This is not unique to this study alone. Anecdotally, in this study a small number of Traveller infants received their immunisation while 'on the road' in the United Kingdom, showing perhaps increased commitment to immunisation in this group and the fact that nomadism should not be seen as a barrier to receiving immunisation. Clarke (2009) showed that some of the barriers to immunisation among all infants in the general population in Eastern Dublin region were the unmet need of the parents for information and poorer communication between service providers with parents. Feder *et al* (1993) suggested access to immunisation services may be contributory to completion of immunisation and the factors may include "involuntary mobility, lack of general practitioner and lack of information about community health services."

Traveller infants appear to be comparable in terms of growth to other children in the general population, with little differences noted when measurements at 9 months were compared to the Growing Up in Ireland infant cohort (Williams *et al*, 2010).

Traveller infants also appear to have good access to health services and utilise community services frequently, especially non-routine Public Health Nursing/Health Visitor services. Quantitatively, PHNs/HVs, General Practitioners and Accident & Emergency Department are the most utilised services. Comparison to other groups cannot be made as there are no detailed data within Ireland for infant utilisation of health services. However, literature has shown that health service utilisation is highest among ethnic minorities and those of lower SEGs (Flores *et al*, 1999; Moore *et al*, 2006; Fallon *et al*, 2007). As demonstrated in the AITHS TR1 (All Ireland Traveller Health Study Team, 2010), access to services does not necessarily equate with quality but this was not addressed specifically in this part of the study.

Respiratory infection, ear infection and gastrointestinal conditions are health conditions which may be related to socioeconomic deprivation (Freemantel and McAulley, 2009; Smylie, 2009). In this study, we found higher rates of respiratory and gastrointestinal conditions in Traveller infants. The lower rate of ear infections found may relate to coding of illness in different studies. 6.2% of Traveller infants sought emergency services use in the period studied, which is similar to the 6.9% reported by the 'State of the Nation's Children Report: Ireland 2010' (Office of the Minister for Children and Youth Affairs, 2010). McCarthy *et al*, (1995) identified that only 12% of Traveller children were referred to specialist services in 1995. This has increased to 16% (OPD services) in addition to the 8.7% community-based and other hospital-based allied health services.

Chapter 4:
Traveller Infant Mortality



Traveller Infant Mortality

4.1 Introduction

In this chapter we present the findings from our documentation of infant mortality of those infants who qualified for the birth cohort. We first discuss the methodology used for the birth cohort study and then present the total number of deaths and causes of Traveller infant deaths. We also make comparison to the general Irish population and other groups where data are available.

4.2 Methodology

In this section we present the methodology employed to ascertain the infant mortality rate of Traveller infants who met the criteria for the cohort.

4.2.1 Time frame and ascertainment period of mortality

The birth cohort study ascertained infant mortality prospectively from 14th October 2008 to 13th October 2010 [while the AITHS mortality study ascertained all infant mortality retrospectively starting from the AITHS census (14th October 2008)].

4.2.2 Sources of data for Traveller infant mortality

The main data sources for the birth cohort study were:

1) **Public Health Nurses/ Health Visitors and Primary Health Care for Travellers Projects**
2) **Other media sources**
3) **General Register Office**

1. Public Health Nurses/Health Visitors and Primary Healthcare for Travellers Projects

Public Health Nurses (PHNs) and Primary Health Care for Travellers Projects (PHCTPs) were asked to inform the study team of any infant deaths during recruitment and throughout the follow up period of the cohort (total of 24 months study period plus additional 4 months to final closing date of study). The study team liaised with the link-Public Health Nurses through monthly email reminders and telephone calls. The PHCTPs were reminded through the PHCTPs network meetings.

2. Other media sources

We used bereavement announcements from Traveller-specific media, namely 'The Traveller', which is a quarterly newsletter published by the Parish of the Travelling People and 'Voice of the Traveller', a Traveller-specific social magazine. However the information given in these media were limited usually giving names and common-known place of the family only. We cross-checked the information with the Public Health Nurses or Primary Health Care for Travellers Projects to confirm the eligibility of these deaths as there were limited information on these deaths. We also checked for the date of birth in the General Register Office to confirm that the deceased infant was born within the cohort period and retrieved the death certificate if available.

3. General Register Office
Access to the General Register Office (GRO) database was granted through the Office of the Registrar General. We did not approach the GRO office in Northern Ireland due to the small number of deaths and subsequent probability of an inaccurate final rate, as documented in the mortality study (Abdalla *et al*, 2010). However, we requested the details of each death from the Northern Ireland GRO.

In the remainder of the report, all references to the GRO refer to the GRO office in the Republic of Ireland.

There were specific criteria which the Office of the Registrar General specified with regard to the use of and confidentiality of the data which were adhered to.

We employed two specific methods in searching for infants deaths in the GRO database:
a) Specific names & opportunistic search of outcome list
b) Common Traveller surnames

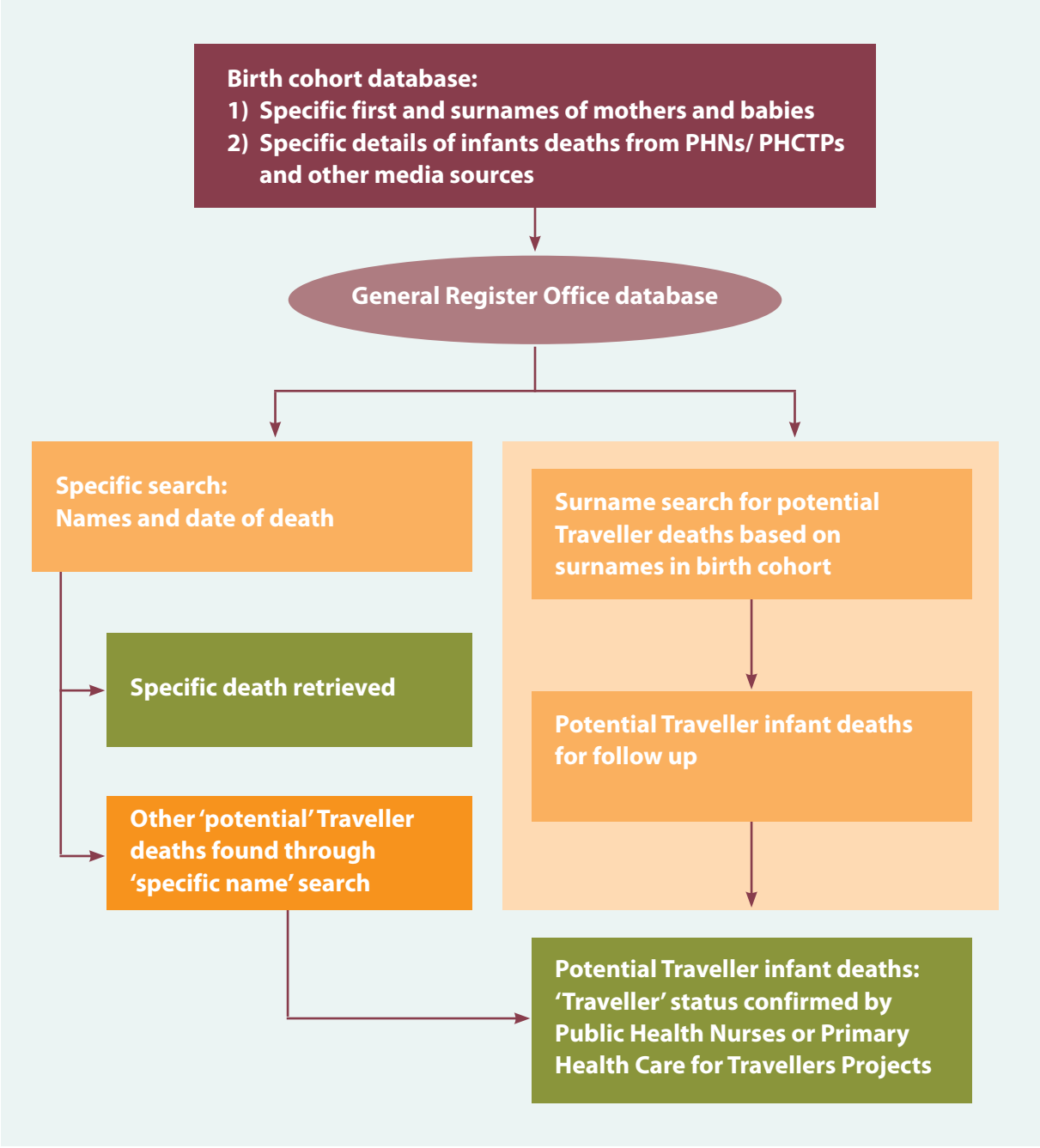
3a) Specific names & opportunistic search of outcome list
The birth cohort study had names and details of all consenting mothers and their babies. We conducted a search in the GRO database for any potential deaths arising in the cohort group by using the infants' and mothers' details. Furthermore, we also had specific names and details of infant deaths from the PHNs, PHCTPs and other media. These were searched rigorously based on available information.

The GRO database allows searches to be done using different criteria. However there are a few minimal criteria which needed to be filled (infant's surname and date of death (exact date or year of death or range of years)). It also allows the search to be narrowed down using infant's first name, age of death (specific age or range of age), registration office and place of death (by county or hospital). When a search is made using infant's surname and death under one-year during the period 2007-2009 for example, the database would create a list of names for the whole country (Republic of Ireland only). If this was narrowed down to a specific infant's first name (or initial) and date of death, the list would be further narrowed down. It is this list that the researcher examined for the death which best matched the defined case. We also opportunistically looked through this list for other potential Traveller deaths.

3b) Common Traveller surnames
A thorough search was also performed using Traveller surnames from the birth cohort database. Deaths which were likely to be of Travellers based on parental names, occupation and addresses were recorded and followed up with the PHNs and PHCTPs.

Details of this process are outlined in Figure 4.1.

Figure 4.1: Schematic representation of search strategy in GRO office by the birth cohort study team



4.2.3 Confirmation of a Traveller infant death

We made the assumption that all deaths reported by the Public Health Nurses, Primary Health Care for Travellers Projects and those found in the announcements of deaths in the Parish of the Travelling People newsletter and the 'Voice of the Traveller' were those of Travellers. For deaths which we found in the GRO through opportunistic searches, we confirmed that they were Traveller deaths by seeking corroboration from the Public Health Nurses or Primary Health Care for Travellers Projects. If these resources could not confirm it was a Traveller death or were able to confirm it was not a Traveller death, then the name was removed from our list for analysis.

4.2.4 Comparative data

Comparative data were obtained from a few sources. These were:

1) Central Statistics Office publications- Vital Statistics fourth quarter and Yearly Summary 2008 and 2009. These were the only publications available during the writing of the report.
2) 1987 Traveller Health Status Study (Barry *et al*, 1989).

Other international comparators - in keeping with the AITHS reports 2010, we make comparisons with other international minority groups where data is available. Rationale for other minority group comparison was discussed in AITHS TR1 (All Ireland Traveller Health Study Team, 2010).

4.3 Results

4.3.1 Total number of deaths

There were 12 deaths found by the study team. Only two of the 12 deaths were among babies born to consented mothers in the birth cohort and one was a baby born to a mother (non-consented) in Northern Ireland (Table 4.1).

Table 4.1: Number of Traveller infant deaths in Republic of Ireland and Northern Ireland according to cohort

Jurisdiction & total live births	Number of infant deaths in consented group	Number of infant deaths in refusal group	Total number of deaths
Republic of Ireland (n=918)	2	9	11
Northern Ireland (n=68)	0	1	1

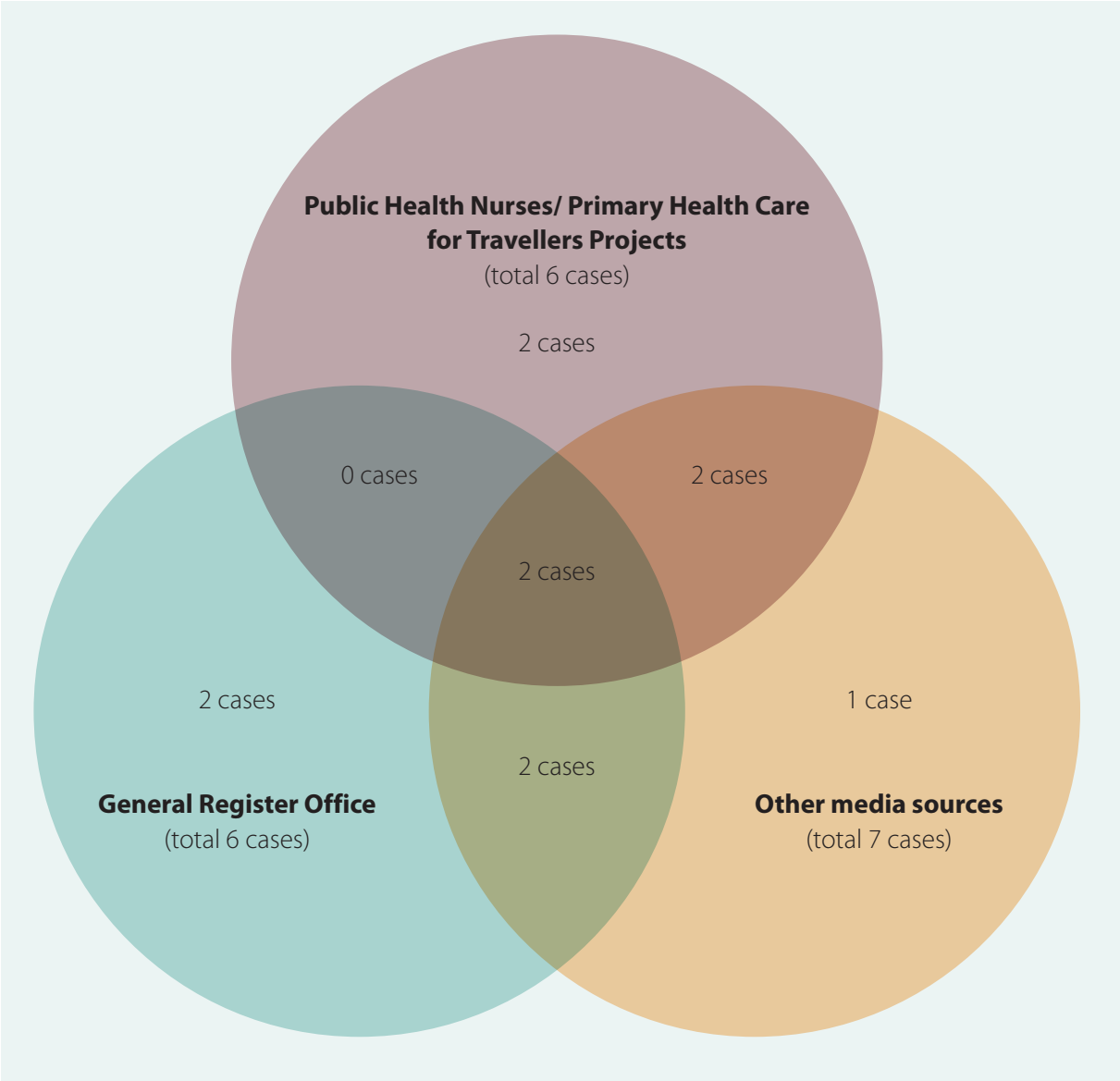
There were two further unconfirmed deaths obtained from the Parish of Travelling People newsletter. The dates of these deaths fell within the cohort period and from the entry in the newsletter it appeared that the deaths occurred soon after birth; in keeping with our other experience these births were not registered. Another possibility was that the births were registered outside the island of Ireland or deaths occurred outside the island of Ireland. However, due to lack of confirmation from any other source, these two deaths were excluded.

For the purpose of this analysis, we have not included the one infant death in Northern Ireland as there was potential for a misleading rate calculation as a result of the small numbers and the potential for the infant to be identified.

4.3.2 Source of reporting

As mentioned before, we deployed different methods to ascertain all Traveller infant deaths. Final grouping and number of cases ascertained initially from different sources is shown in Figure 4.2.
As can be seen there are a few cases where the deaths were reported initially by only one source. Some of the deaths may have been missed by the PHNs or PHCTPs which reflect the difficulties of follow-up by the PHNs. However, all deaths were subsequently confirmed (Section 4.2.3).

Figure 4.2: Initial sources of data and number of cases obtained from sources for the purpose of capture-recapture calculation (all cases were subsequently confirmed as Traveller deaths by PHNs/PHCTPs)



4.3.3 Capture-recapture technique to estimate Traveller infant deaths

Capture-recapture is a well-used technique in biology which has been adapted successfully in epidemiology (Stefanoff *et al*, 2010; Corrao *et al*, 2000; Chao *et al*, 2001; Tsay and Chao, 2001). Using this technique, based on the capture-recapture number of infant deaths from Figure 4.2, we estimated that the range for ROI Traveller infant death is between 10 and 15. Technique for this method is given in appendix B.

4.3.4 Time period and cause of death of Traveller infants

Five of the 11 infant deaths occurred within 28 days after birth (neonatal period). The rest (6 cases) occurred between 28 days and 365 days after birth (post-neonatal period).

Table 4.2 shows the cases and cause of deaths of the infants.

Table 4.2: Death period and cause of death

Case	Cause of death
1	Extreme preterm
2	
3	Congenital anomalies
4	
5	Anencephaly, Hydrocephalus, Spina Bifida
6	
7	Spinal muscular atrophy
8	Mucolipidosis type II & complications Metabolic disease & complications (no specific disease given)
9	
10	
11	Accidental injury

All the neonatal cases are caused by congenital anomalies or prematurity. This is consistent with previous causes of infant neonatal mortality in the western world before the advancement of neonatal medicine (Freemantel *et al*, 2006).

Of the six post-neonatal cases, three were due to metabolic causes, one due to congenital malformations and one due to an x-linked disorder, while there was one due to accidental cause. Aetiology of these disorders will be discussed in section 4.5.

4.3.5 Infant mortality rate

We use the definition of infant mortality rate used by the Central Statistics Office (CSO, 2010) in Ireland and the World Health Organisation (WHO, 2011). This is:

$$\text{Infant Mortality Rate} = \frac{\text{Number of infant deaths under one year}}{\text{Total number of live births}} \times 1{,}000$$

Given that we have 11 infant deaths and 918 total births (in ROI), the calculated infant mortality rate is 12.0 per 1,000 Traveller births (95% CI 5.5- 19.7).

The infant mortality rate calculated from the retrospective AITHS mortality study was 14.1 per 1,000 Traveller births (95% CI 7.3-24.7) (Abdalla *et al*, 2010).

4.3.6 Early neonatal mortality rate

The early neonatal mortality rate is defined as infant deaths under 7 days per 1,000 live births.
The early neonatal mortality rate for Travellers in 2008/2009 is 5.4 per 1,000 live births (95% CI 5.3-5.6)

Due to the methodology of the study which recruited Traveller women after they had given birth, we are not able to calculate the stillbirth rate.

4.3.7 Adjusted perinatal mortality rate

The adjusted perinatal mortality rate is calculated based on infant deaths within seven days from birth, but excluding stillbirths and early neonatal mortality deaths due to congenital anomalies. This to some extent removes perinatal events where death was unavoidable (National Perinatal Reporting System, 2010).

The adjusted perinatal mortality rate for Travellers in 2008/2009 is 2.2 per 1,000 live births (95% CI 2.1-2.3). We advise caution in interpreting this result due to the small number.

4.3.8 Neonatal infant mortality rate

The neonatal mortality rate is defined as rate of infant deaths under 28 days from birth per 1,000 live births.

The calculated neonatal mortality rate for Travellers in 2008/2009 is 5.5 per 1,000 births (95% CI 5.3-5.6).

4.3.9 Post-neonatal infant mortality rate

The post-neonatal mortality rate is defined as the rate of infant deaths after 28 days to first year of life per 1,000 live births.

The post-neonatal mortality rate for Irish Travellers in 2008/2009 is 6.5 per 1,000 live births (95% CI 6.4-6.7).

4.4 Comparison

In this section, we discuss the relevance and give context to the findings by comparing it to the general Irish population. We used data from the Irish Vital Statistics 2008 (CSO, 2009) and 2009 (CSO, 2010) published by the CSO. Where appropriate, we also include the findings from the AITHS mortality study (infant deaths only), The Traveller Health Status Study: Vital Statistics of Travelling people, 1987 (Barry *et al*, 1989), European statistics, and literature on other minority groups. Rationale for comparison to other minority groups was discussed in AITHS TR1 (All Ireland Traveller Health Study Team, 2010).

4.4.1 Number of infant deaths and causes

There were a total of 290 and 240 infant deaths recorded by the CSO in 2008 and 2009. For Republic of Ireland Travellers, there were 12 recorded cases in the mortality study and 11 cases in the birth cohort study. This resulted in similar infant mortality rates calculated for two consecutive years, 14.1 (95% CI 7.3-24.7) for 2007/2008 and 12.0 (95% CI 5.5-19.7) for 2008/2009, and similar number of deaths in the two years (12 and 11 deaths). For the corresponding years in the Irish general population, there was a difference of 50 deaths which caused the infant mortality rate to fall from 3.9 (95% CI 3.8-3.9) to 3.2 (95% CI 3.22-3.24) per 1,000 live births. In the 1986 Traveller Health Status Study, Barry *et al* (1989) found 10 infant deaths arising from 554 total live births, giving an infant mortality rate of 18.1 per 1,000 live births (95% CI 10.9-25.3).

Table 4.3 shows the cause of death among Traveller infants compared to the ROI general population.

Although we set out the cause of death by ICD 10 categories, it should be noted that care should be taken in making direct comparison, for the following reasons:

1) The CSO obtain all their causes of death through the death registry in the GRO. Some of the deaths in the Traveller group were not registered with the GRO.

2) The two databases were derived from different time frames. The Vital Statistics record deaths over a 12-month period in a calendar year while the Traveller database is based on a cohort ascertainment which ranged from October 2008 to October 2010, recording all deaths from a defined group of babies with a one-year follow up.

The table shows that Traveller infant cause of death was limited to a few conditions, notably those related to congenital malformations, metabolic diseases, prematurity and genetic-related diseases. There was one accidental death.

Table 4.4 shows the comparison in cause of deaths of Traveller infants in 1987 and 2008/2009. As can be seen, congenital abnormalities and metabolic diseases remain some of the leading causes in both cohorts. However, except for some congenital abnormalities and prematurity, some of these babies have lived longer, past the neonatal period, and died within the post-neonatal period.

A different recording system used by the Central Statistics Office in 1987 did not allow valid comparison to be made between Traveller cause of death and general population cause of death.

Table 4.3: Cause of death for ROI general Irish population infants in 2008 and 2009 versus Irish Traveller infants 2008/2009 (ROI only) and incidence of cause per 1,000 live births

		ROI 2008		ROI 2009		ROI Traveller 2008/2009	
Total deaths		290		240		11	
Cause of death	**ICD code**	**Number of cases**	**Incidence per 1,000 live births**	**Number of cases**	**Incidence per 1,000 live births**	**Number of cases**	**Incidence per 1,000 live births**
Infectious and parasitic diseases	A00-B99	2	0.03	1	0.01	0	0
Neoplasma:	C00-D48	3	0.04	3	0.04	0	0
Diseases of the blood and blood-forming organs, immunological disorders	D50-D89	0	0	1	0.01	0	0
Endocrine, nutritional and metabolic diseases	E00-E90	1	0.01	3	0.04	3	3.3
Mental and behavioural disorders	F00-F99	0	0	0	0	0	0
Diseases of the nervous system and the sense organs	G00-H95	4	0.05	8	0.12	1	1.0
Diseases of the circulatory system	I00-I99	6	0.08	0	0	0	0
Diseases of the respiratory system	J00-J99	1	0.01	0	0	0	0
Diseases of the digestive system	K00-K93	1	0.01	1	0.01	0	0
Diseases of the skin and subcutaneous tissue	L00-L99	0	0	0	0	0	0
Diseases of the musculoskeletal system/connective tissue	M00-M99	0	0	0	0	0	0
Diseases of the genitourinary system	N00-N99	0	0	0	0	0	0
Complications of pregnancy, childbirth and puerperium	O00-O99	0	0	0	0	0	0
Certain conditions originating in the perinatal period	P00-P96	120	1.6	96	1.3	2	2.0
Congenital malformations and chromosomal abnormalities	Q00-Q99	128	1.7	104	1.4	4	4.0
Symptoms, signs, abnormal findings, ill-defined causes	R00-R99	21	0.3	22	0.3	0	0
External causes of injury and poisoning	V01-Y89	3	0.04	1	0.02	1	1.0
	Total births	75,065		74,278		918	

Note: For comparison purposes, Traveller and corresponding general population rate is highlighted in red. These need careful interpretation due to the small numbers in the Traveller group

Source: Vital Statistics Fourth Quarter and Year Summary 2008 (Central Statistics Office, 2009); and Vital Statistics Fourth Quarter and Yearly Summary 2009 (Central Statistics Office, 2010)

Table 4.4: Recorded cause of death by cases (and period of death) among Irish Traveller infants in 1987 and 2008/2009

Cause of death	ROI Travellers 1987	ROI Travellers 2008/2009
Prematurity	4 cases (4 neonatal)	2 cases (2 neonatal)
Congenital anomalies	2 cases (2 neonatal)	4 cases (3 neonatal, 1 post-neonatal)
Inborn errors of metabolism	1 case (1 neonatal)	3 cases (3 post-neonatal)
Other genetic disorders	1 case (1 neonatal)	1 case (1 post-neonatal)
Infection	1 case (1 neonatal)	0 case
Accidents/unexplained	1 case (1 post-neonatal)	1 case (1 post-neonatal)
Total	10 cases	11 cases

Source: (Barry, 1996)

Table 4.5 shows causes of mortality in infants under one year old and the calculated incidence rate for ROI Travellers and other minority groups. Congenital malformations, conditions arising in the perinatal period, accidents and Sudden Infant Death Syndrome (SIDS) are the main causes for all groups.

Table 4.5: Common causes of death (under 1 year old) and incidence rates for ROI Travellers and various other minorities

ROI Travellers		Australian Aboriginal and Torres Strait Islanders (a,b)		New Zealand Maori (c)		American Indians/Alaska Natives (d,e)	
Cause of death	**Rate per 1,000 live births**	**Cause of death**	**Rate per 1,000 live births**	**Cause of death**	**Rate per 1,000 live births**	**Cause of death****	**Rate per 1,000 live births****
Congenital malformations and chromosomal abnormalities (Q00-Q99)	4.0	Certain conditions originating in the perinatal period (P00-P96)	5.7	Perinatal conditions (including premature birth)	2.8 (1.3)	Congenital malformation/ deformity/ chromosomal abnormalities	7.8
Endocrine, nutritional and metabolic diseases (E00-E90)	3.3	Symptoms, signs, and abnormal clinical findings n.e.c. (R00-R99)	2.7	Unknown causes (including SIDS)	2.4 (2)	Accidents and External causes	1.5
Certain conditions originating in the perinatal period (P00-P96)	2.0	Sudden Infant Death Syndrome (R95)	1.1	Congenital anomalies	1.2	Influenza and pneumonia	0.23
Diseases of the nervous system and the sense organs (G00-H95)	1.0	Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	1.5	Accidents (including accidental suffocation in bed)	0.7 (0.5)	Diseases of heart	0.19
External causes of injury and poisoning (V01-Y89)	1.0	Diseases of the respiratory system (J00-J99)	0.9	Respiratory diseases	0.3	Assault (homicide)	0.16
		External causes (injury & poisoning) (V01-Y99)	0.5				
		Certain infectious and parasitic diseases (A00-B99)	0.3				
		Diseases of the circulatory system (I00-I99)	0.2				
		Other conditions	0.5				

(a) Author's caveat: data are reported for Queensland, Western Australia, South Australia and the Northern Territory only. These states and territories are considered to have adequate levels of indigenous identification in mortality data. They do not represent a quasi-Australian figure.

(b) Source: AIHW analysis of National Mortality database, cited by (Freemantel and McAulley, 2009) Health of Aboriginal and Torres Strait Islander Children in Australia, (Table 6: causes of infant death by Aboriginal and Torres Strait Islander Status, Queensland, Western Australia, South Australia and the Northern Territory, 2002-2006, pg78)

(c) Source: 'Hauora: Maori standard of Health IV' cited by (Crengle, 2009).

(d) Author reported as 'per 100,000 live birth'. Study team converted to 'per 1,000 birth'.

(e) Source: Health of Indigenous Children in United States (Table 4: American Indians/Alaska Natives children mortality, pg 112)(Taualii, 2009)

4.4.2 Infant, neonatal and post-neonatal mortality rates

The infant mortality indicators for the general Irish population (2008 and 2009) and ROI Travellers are shown in Table 4.6.

Table 4.6: Number of live births, neonatal mortality, post-neonatal mortality and rates for Irish Travellers 2008/2009 and for ROI general population 2008 and 2009

Indicators	ROI 2008	ROI 2009	Travellers 2008/2009
Total live births	75,065*	74,278*	918
Number of neonatal deaths	200*	169*	5
Early neonatal mortality rate (per 1,000 live births)	2.1**	n/a	5.4 (95% CI 5.3-5.6)
Adjusted perinatal mortality rate (per 1,000 live births)	5.1**	n/a	2.2 (95% CI 2.1-2.3)
Neonatal mortality rate (per 1,000 live births)	2.7* (95% CI 2.6-2.7)	2.3* (92% CI 2.3-2.3)	5.4 (95% CI 5.3-5.6)
Number of post-neonatal deaths	90*	71*	6
Post-neonatal mortality rate (per 1,000 live births)	1.1* (95% CI 1.19-1.20)	0.96* (95% CI 0.95-0.96)	6.5 (95% CI 6.4-6.7)
Infant mortality rate (per 1,000 live births)	3.9* (95% CI 3.8-3.9)	3.2* (95% CI 3.22-3.24)	12.0 (95% CI 5.5-19.7)

Source: *CSO (2009, 2010), **NPRS (2010)

All the Traveller infant mortality indicators, except for the adjusted perinatal mortality rate, were higher than that of the general Irish population. The early neonatal mortality rate is 2.6 times greater, the neonatal mortality rate is 2.2 times greater, and the post-neonatal mortality rate and infant mortality rate are 6.7 times and 3.7 times greater respectively. The adjusted perinatal infant mortality rate was lower than the general Irish population (2008); however this needs careful interpretation due to the small numbers.

The neonatal and post-neonatal infant mortality rates for 1987 and 2008/2009 are shown in Table 4.7.

Table 4.7: Neonatal and post-neonatal infant mortality rate of Irish Travellers for 1987 and 2008/2009

Indicators	Irish Travellers 1987	Irish Travellers 2008/2009
Total live births	554	918
Number of neonatal deaths	8	5
Neonatal mortality rate (per 1,000 live births)	14.4 (95% CI 14.1-14.7)	5.4 (95% CI 5.3-5.6)
Number of Post-neonatal deaths	2	6
Post-neonatal mortality (per 1,000 live births)	3.6 (95% CI 3.4-3.8)	6.5 (95% CI 6.4-6.7)
Infant Mortality rate (per 1,000 live births)	18.1 (95% CI 10.9-25.3)	12.0 (95% CI 5.5-19.7)

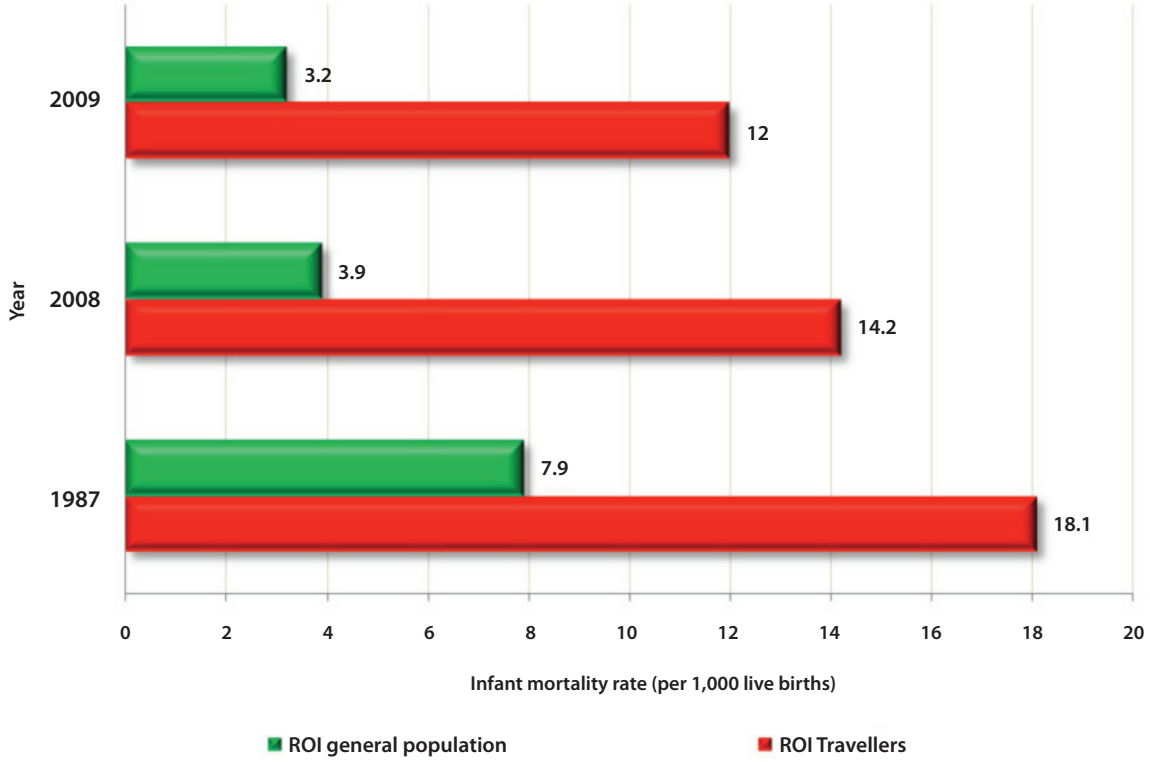
Source: Barry (1997)

There has been a sharp fall in the neonatal mortality rate since 1987 among Travellers with a rise in the post-neonatal mortality rate. This likely reflects improvements in neonatal care with resultant prolongation of life and survival. This is also seen in the general population with a steady decline of neonatal mortality rate and overall infant mortality rate.

Figure 4.3 shows ROI Traveller infant mortality in 1987, 2008 and 2009 compared to general population rates.

Although there has been a fall in infant mortality rate in both populations, the gap has actually widened due to the greater improvement seen in the ROI general population infant mortality. The Traveller infant mortality rate was 2.3 times that of the ROI general population in 1987. However by 2008 and 2009, this difference has actually widened to 3.6 and 3.7 times respectively.

Figure 4.3: Infant mortality rate for Irish Travellers and ROI general population in 1987, 2008 and 2009



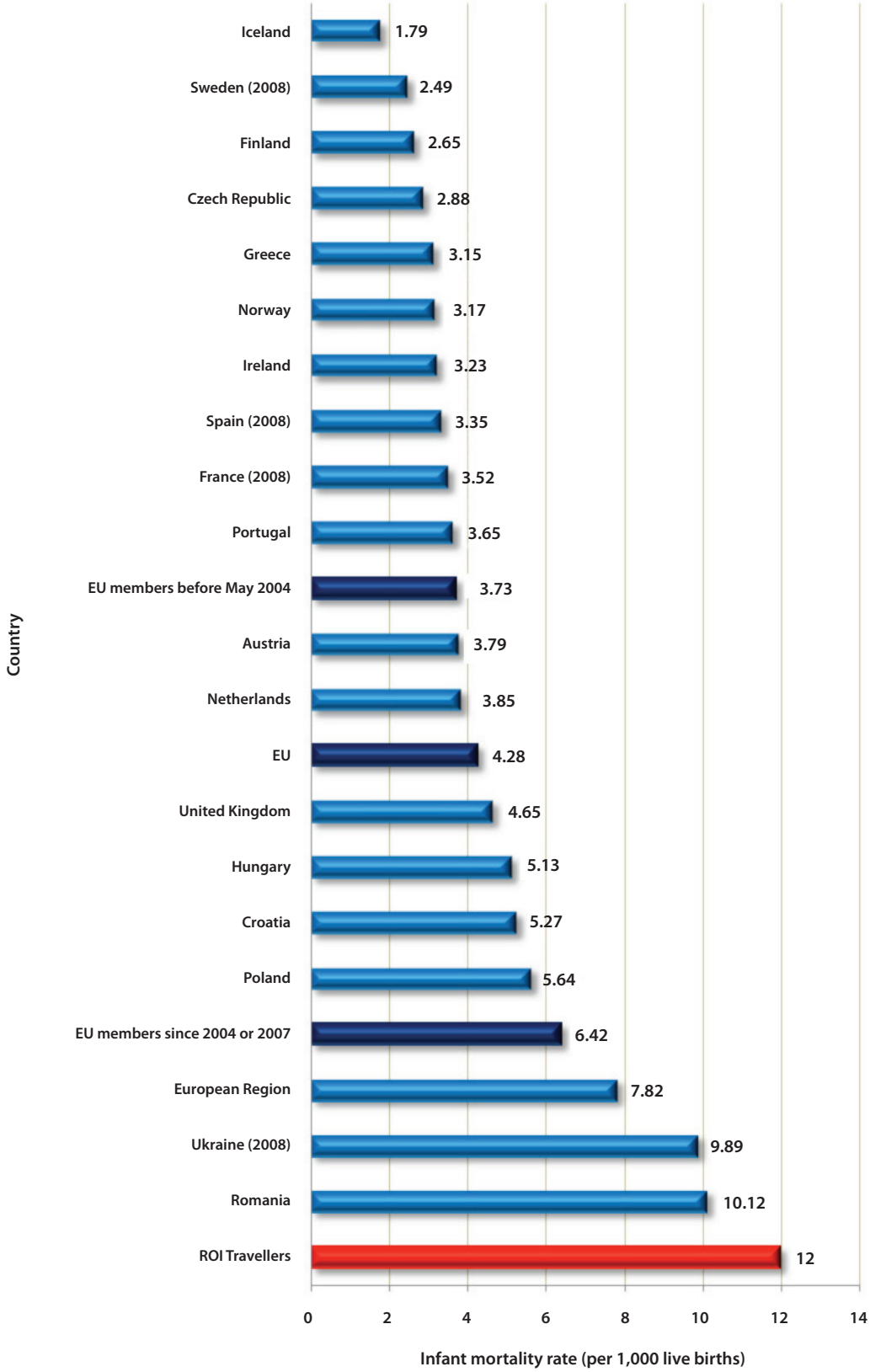
Source: Barry *et al* (1989); CSO (2009, 2010)

Figures 4.4, 4.5 and 4.6 show the infant, neonatal and post-neonatal mortality rates for Europe. These three rates for ROI Travellers are among the highest in Europe. The infant mortality rate for ROI Travellers is 2.8 times the EU average. The neonatal mortality rate is almost twice the EU average while the post-neonatal mortality rate is 4.5 times the EU average.

When compared to other minorities, ROI Travellers' IMR is one of the highest at 12 per 1,000 live births. New Zealand Maoris' IMR was 6.6 in 2010 while Australian Aboriginals and Torres Strait Islanders showed a range of 7.7 to 13.6 depending on administrative area (Figure 4.7).

However when infant mortality rate ratio between the minorities and the general populations is calculated, ROI Travellers have the largest rate ratio at 3.7 compared to other minority groups. It is similar to the Northern Territory Australian Aboriginals and Torres Strait Islanders (3.6). (Figure 4.8) The infant mortality rate for Canadian First Nations is approximately twice that of the Canadian general population (Smylie, 2010).

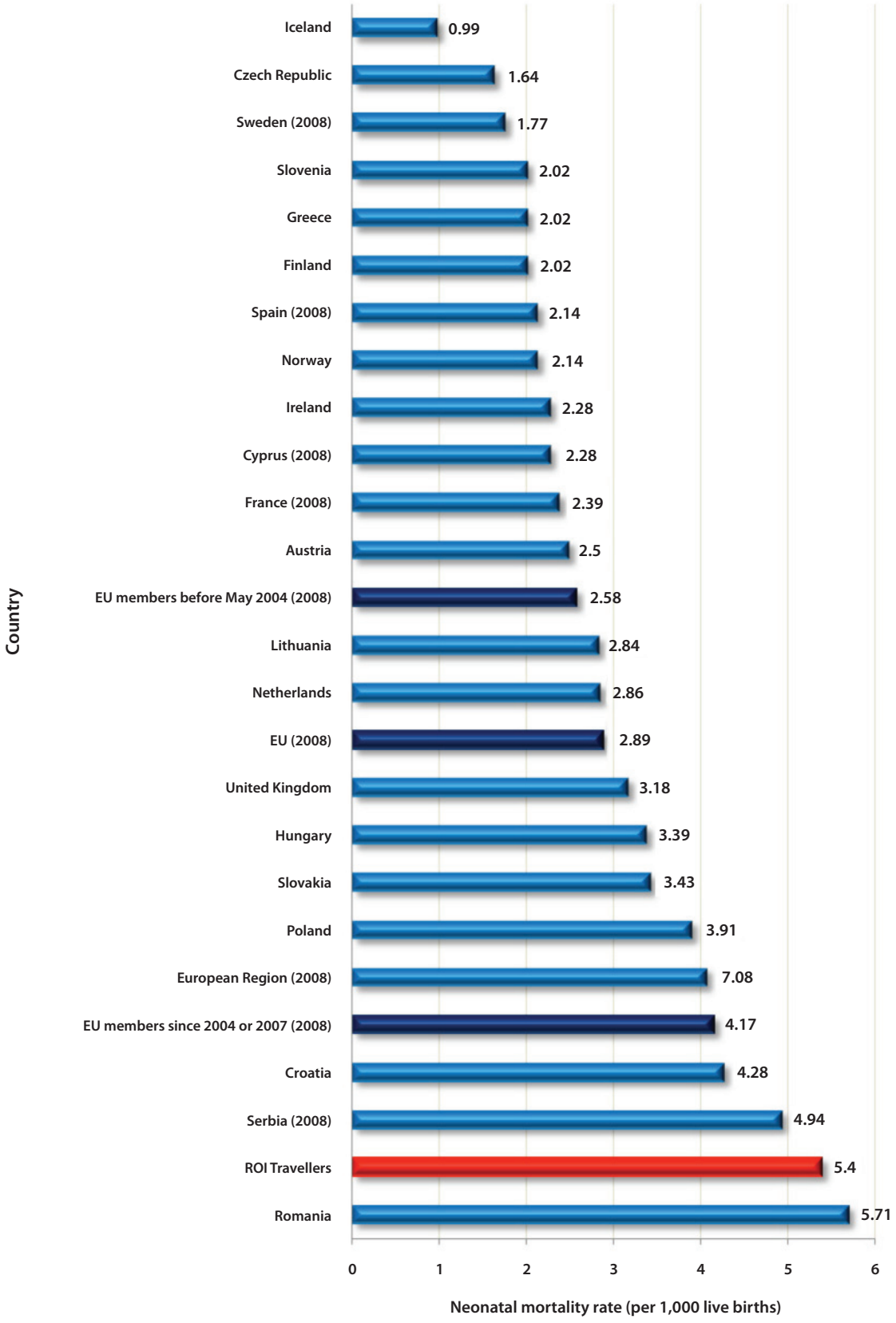
Figure 4.4: Infant mortality rate-ROI Travellers and Europe



Note: Countries selected based on availability of data and where appropriate and when 2008 data is used, it is noted in brackets after the country

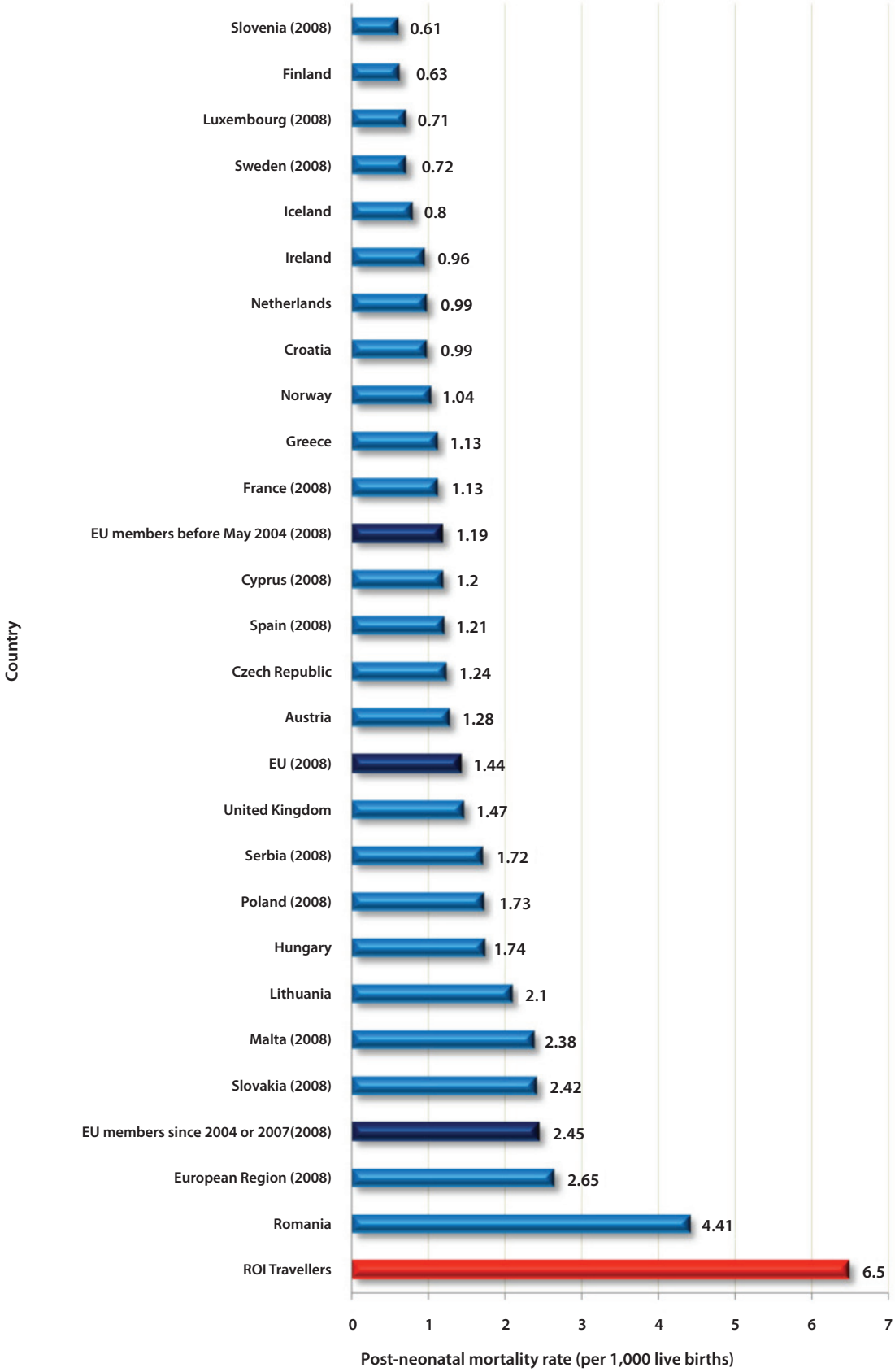
Source: World Health Organisation (2011)

Figure 4.5: Neonatal mortality rate-ROI Travellers and Europe



Note: Countries selected based on availability of data and where appropriate when 2008 data is used, it is noted in brackets after the country
Source: World Health Organisation (2011)

Figure 4.6: Post-neonatal mortality rate-ROI Travellers and Europe



Note: Countries selected based on availability of data and where appropriate when 2008 data is used, it is noted in brackets after the country

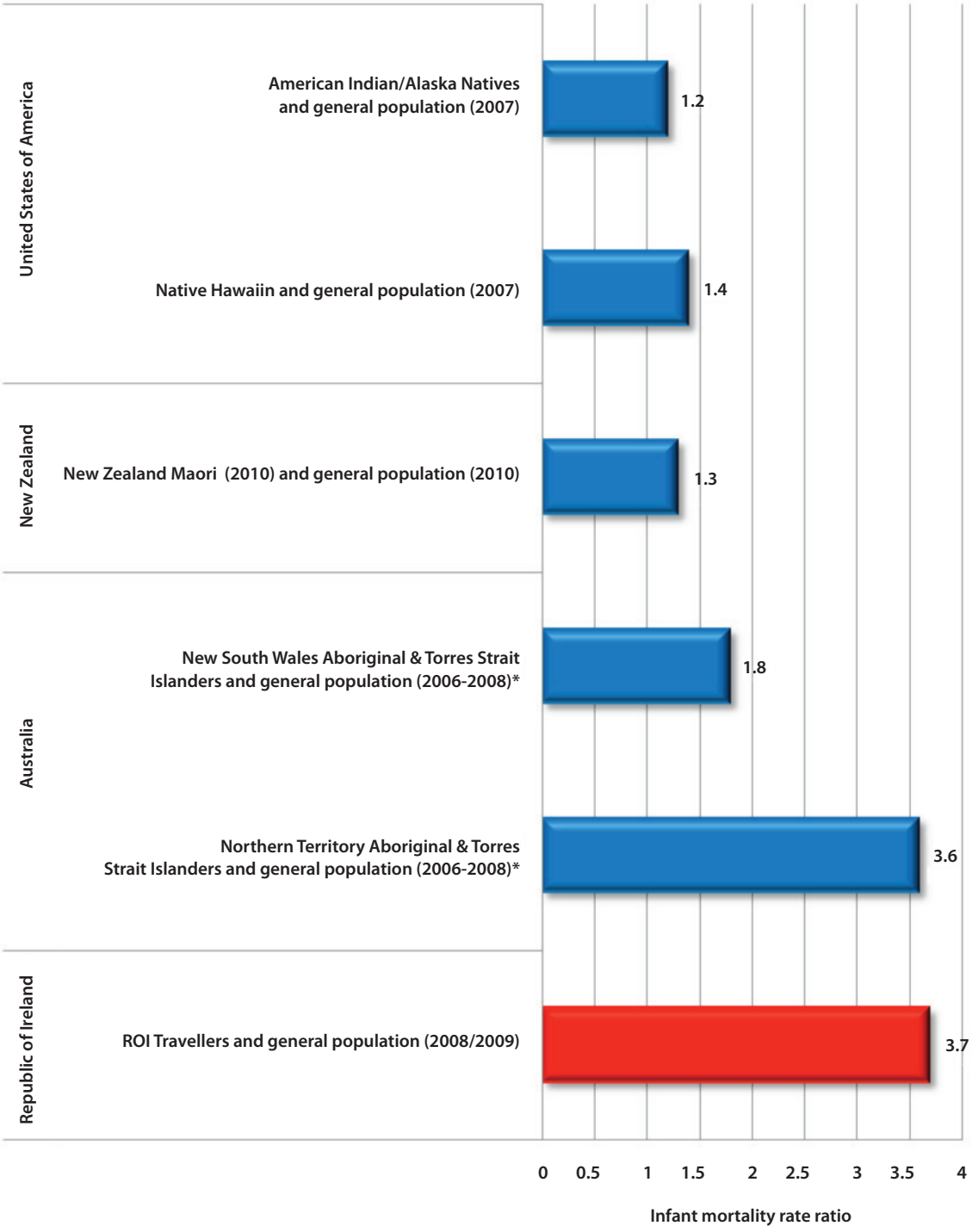
Source: World Health Organisation (2011)

Figure 4.7: Infant mortality rate- ROI Travellers, other minority groups and their respective general population

*Australian infant mortality given according to New South Wales (NSW) and Northern Territory (NT) due to the large difference in Aboriginal and Torres Strait Islanders IMR, as reported by the Australian Bureau of Statistics (2010)

Sources: Australian Bureau of Statistics (2010), Statistics New Zealand (2010), Taualii (2009)

Figure 4.8: Infant mortality rate ratio- ROI Travellers and other minorities



4.5 Discussion of findings

An infant death is a devastating event for any parent; for the Travellers it affects the whole community (Helliner, 2000). When we compare to the 1987 study (Barry *et al*, 1988) and the 2008 AITHS (Abdalla *et al*, 2010), the Travellers' infant mortality rate found in this follow up study is still high compared to the general population. Classical causes of infant death due to socioeconomic conditions such as respiratory and gastrointestinal infections (Kim *et al*, 2009; Petrou *et al*, 2006; Shaw *et al*, 2005) were not seen in this study. This may represent the effect of early access to medical services. Other common causes of infant death such as congenital conditions were noted in this study. This has been associated with socioeconomic inequalities in neonates (Smith *et al*, 2010). Major causes of death in Travellers are preterm births, congenital anomalies and inborn errors of metabolism.

Interestingly, Traveller infants' causes of death (except for metabolic diseases) are similar to other indigenous ethnic groups from Australia (Freemantel and McAulley, 2009), New Zealand (Crengle, 2009) and the United States (Taualii, 2009). Socioeconomic deprivation has been postulated as the cause of death in these populations (Australian Bureau of Statistics, 2010; Freemantel *et al*, 2006).

Preterm birth remains the leading cause of infant mortality in developed countries, accounting for 75% of perinatal deaths (Ananth and Vintzileos, 2006). There are varied causes of premature births and subsequent infant mortality; these may include spontaneous preterm labour, maternal or foetal infections and premature rupture of the membrane (Goldberg *et al*, 2008). Maternal and foetal characteristics which have been associated with preterm labour include demographic characteristics, nutritional status, pregnancy history, psychological characteristics, adverse behaviours, infection, uterine contractions, cervical length and genetic and biological markers (Goldberg and Culhane, 2005). Kramer and Hogue (2009) argue that research on the association between prematurity and socioeconomic determinants remains underdeveloped. A novel Irish study by Niedhammer *et al* (2011) showed an association between higher risk of preterm delivery in Irish-born mothers with lower socioeconomic status. The study also showed material poverty as the most important contributor to preterm delivery in the study population.

Congenital anomalies, in the more narrow specification, relates to physical anomalies which have been present since birth. In this study these include congenital heart diseases (coarctation of the aorta inclusive), anencephaly, spina bifida and hydrocephalus.

In the majority of cases, the causes of congenital anomalies are unknown. However there is a suspected interaction of multiple environmental, genetic and epigenetic factors involved. There is a socioeconomic difference in distribution of congenital anomalies which suggests environmental exposure as a possible cause (European Surveillance of Congenital Anomalies, 2009).

Folic acid deficiency in the peri-conceptional period is an established risk factor for neural tube defects (MRC Vitamin Study Research Group, 1991; Cuskelly *et al*, 1996,). Folic acid fortification and supplements pre-conception have reduced the incidence of neural tube defect (Honein *et al*, 2001). Micronutrient deficiency has been implicated in congenital anomalies (Neggers and Goldenberg, 2003; Romero *et al*, 2003).

Spinal muscular atrophy is an autosomal recessive neurodegenerative disorder caused by the homozygous deletion of Survival Motor Neuron-1 (SMN1) gene (Lefebvre *et al*, 1995) with a carrier frequency of about 1 in 40 to 1 in 60 and a prevalence rate of approximately 1 in 10,000 (Scheffer *et al*, 2001). No race or ethnic specific prevalence has been reported. It is one of the leading genetic causes of infantile mortality (Lorson *et al*, 2010). Prenatal carrier testing is available (Gitlin *et al*, 2010).

The impact of metabolic diseases on mortality and morbidity rates within the Traveller community

In this study, the specific metabolic disease that was reported as cause of death was Mucolipidosis Type II (also known as I cells). Mucolipidosis Type II has been reported in other communities worldwide (Coutinho et al, 2010). Other metabolic diseases were only recorded as 'metabolic disease' which does not allow the study team to further elaborate the specific type of metabolic disease. However, the number is small in comparison to other causes of death.

Traveller organisations such as Pavee Point Travellers Centre (2011) have shown concern that in the absence of examples or options of policy interventions to address metabolic disease the default position will be to conclude that metabolic diseases are the fault of the marriage and relationship decisions of Travellers and that little can be done. This is in part a reflection on the general lack of awareness of the advances in the treatment and management of metabolic diseases. It is important to inform public opinion more fully.

This issue requires a multifaceted response, which would include:

- Consideration of feasibility of the addition of further metabolic diseases to the newborn bloodspot screening programme to the six existing diseases that are screened for presently.
- Targeted programmes to impact on the treatment and management of metabolic diseases within the Traveller community.
- Awareness raising and education strategies with the multidisciplinary teams that treat metabolic diseases, including consultants, on the specific additional needs of Travellers.
- The amendment of existing algorithms/practice pathways to ensure the inclusion of Travellers in newborn screening and follow-up programmes in relation to metabolic diseases.
- Greater access to genetic counselling and awareness raising within the Traveller community on metabolic diseases as part of primary care programmes.

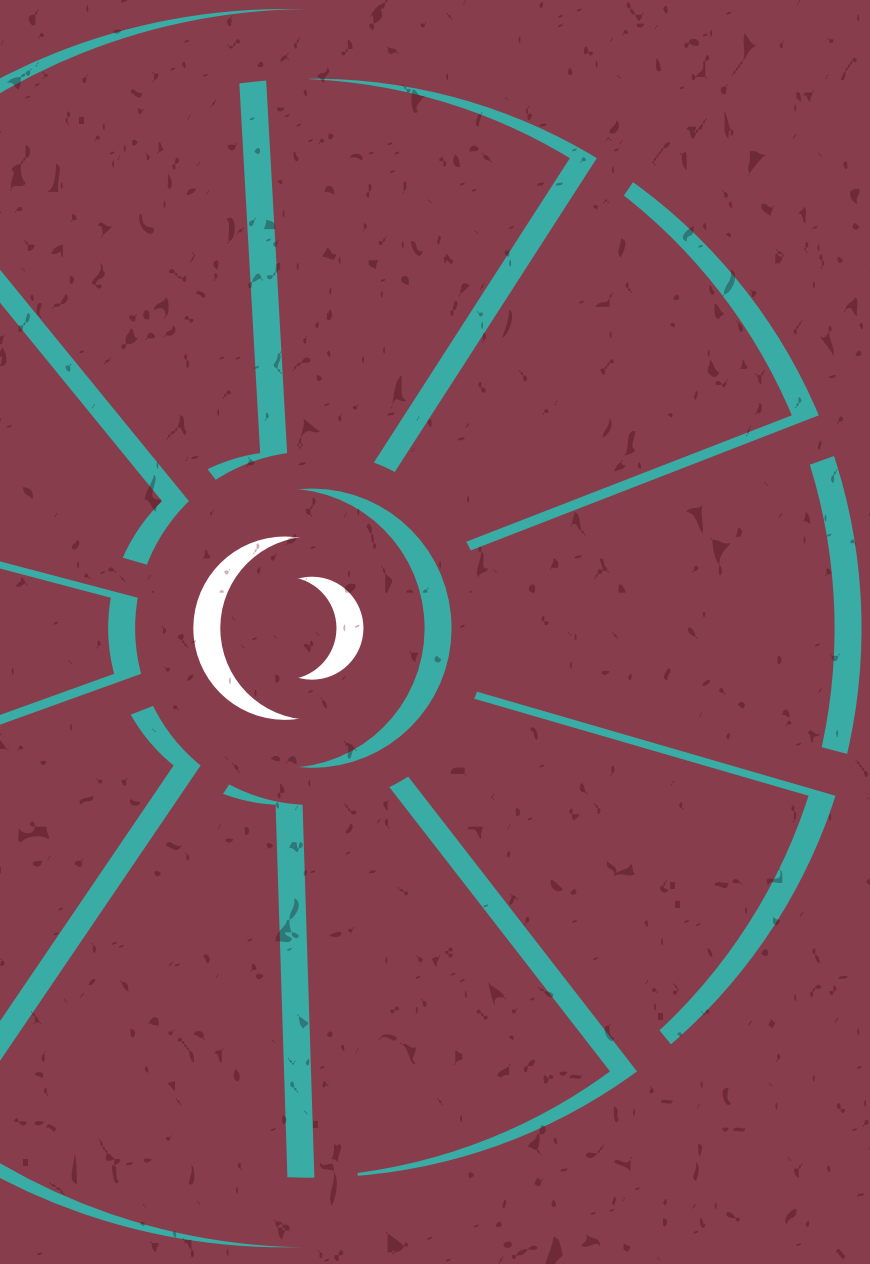
Infant mortality rate, neonatal mortality rate and post-neonatal mortality rate
Infant mortality rate is one of the most important indicators of population health. Infant mortality is not just affected by medical conditions but wider socioeconomic determinants. As such, it is also an important indicator of the social and economic health of the population (Rosicova *et al*, 2009; Fantini *et al*, 2006; Reidpath and Allotey, 2003; World Bank, 1998), and is considered an 'inverse proxy measurement of development' (Pattnayak and Shai, 1995). Thus differences in infant mortality rates between countries or groups also represent inequalities in socioeconomic and developmental potential (Gortmaker and Wise, 1997; Troe *et al*, 2006).

There has been a fall in the infant mortality rate for ROI Travellers when compared to 1987. However there remains a gap in IMR between Travellers and the general population.

ROI Traveller IMR still remains one of the highest in Europe, a position that has not changed since 1987. Other indicators such as neonatal and post-neonatal mortality rates are also high in a European context. This scenario is similar to other minority groups, including Australian Aboriginals (Freemantel and McAulley, 2009), New Zealand Maori (Crengle, 2009) and Canadian Indians (Smylie and Adomako, 2009) and their respective general populations. The Australian Institute of Health and Welfare (2006) suggested this gap may be related to socioeconomic disparities.

The standard of newborn care in Ireland has certainly improved over the past 20 years (Fleming *et al*, 2009). Shifting of infant deaths towards the post-neonatal period may also reflect the benefits of improved newborn care and access to medical services by the Travellers. However, the causes of death among Traveller infants remain those of congenital anomalies, preterm births and metabolic diseases with one case of accidental injury. These conditions, as mentioned above, may be indirectly related to socioeconomic circumstances; thus more concerted initiatives should be considered to correct these socioeconomic inequalities as was recommended in the main AITHS report (All Ireland Traveller Health Study Team, 2010).

Chapter 5:
Conclusion & Recommendations



Conclusion & Recommendations

This is the final report of the All Ireland Traveller Health Study, *Our Geels*, which addresses the longitudinal follow-up of the participant mothers and infants one year after birth of the children. As with other parts of this comprehensive study, engagement was very positive by Traveller families, Public Health Nurses, other health professionals and the maternity hospitals.

The findings will have important policy implications for the Traveller community. Just over half of new mothers agreed to the linkage follow up, though we attempted to trace all deaths occurring in the first year of life as comprehensively as possible. However, the numbers recorded are small and should be interpreted with caution. We have confirmed an infant mortality rate comparable with that calculated retrospectively for the year before in the already published vital statistics report (Abdalla *et al*, 2010). Though mortality has declined since the 1987 reported estimate, the gap between Traveller infants and the general population remains wide. Notably the causes were attributable primarily to conditions diagnosable at birth with little evidence of purely environmentally attributable causes. As we discussed in chapter 4, the Traveller community has already engaged with the issue of detecting and preventing heritable conditions and this should receive careful consultative consideration now for the future (Bittles and Black, 2009; Traveller Consanguinity Working Group, 2003). There are precedents for this in communities such as the Ashkenazi Jews in New York which might apply usefully here in Ireland (Jones, 1996). Furthermore, there are Irish researchers in this area whose work has shown promising results (Casey *et al*, 2010a; Casey *et al*, 2010b; Casey *et al*, 2011).

However, it is important to put this issue in context. It should be noted by readers that Travellers experience higher morbidity and mortality at all ages and that the predominant causes are the same as for the general population. These include cardiovascular disease, respiratory-related diseases and cancers, as has been discussed comprehensively in TR2a. The focus for intervention should ensure these common issues are tackled.

The demographic profile, compared to mothers of both Irish and European origin giving birth in this country, and also across social classes, gives us a clear picture of current Traveller families. Both parents are younger on average than other groups, have more pregnancies and children and most experience positive outcomes. As we discuss in chapters 2 and 3, booking rates are now high, though still not at the level of the general population and factors such as immunisation completion need to be improved to reach the general population rates.

Travellers are more likely to have spontaneous vaginal deliveries, but also go home earlier if they have had a caesarean section. Breastfeeding rates are confirmed as very low as previously found (All Ireland Traveller Health Study Team, 2010; McGorrian *et al*, 2010). There is also evidence that Traveller babies are lighter on average than other population groups with the causes likely to be similar to the general literature on low birth weight. Utilisation rates of health services in the first year of life are higher than expected generally.

It is now well established that low birth weight is associated with higher risk of adult chronic disease, particularly of cardiovascular conditions (Barker *et al*, 1989; Barker and Martyn, 1992; Barker, 1995; Barker *et al*, 2002; Gillman and Rich Edwards, 2000; Drake and Walker, 2004; Gluckman and Hanson, 2006; Morrison *et al*, 2010). We have already established in the main surveys that there is a higher level of cardiovascular morbidity and mortality in adult Travellers and these findings are consistent with that observation.

It should be noted that in general non-participating mothers are likely to be more vulnerable both to adverse social outcome and poorer health (Walker *et al*, 1987; Drivsholm *et al*, 2006; Fitzsimon *et al*, 2007; Bergman *et al*, 2010) than those who did participate; this is likely to be the same in Travellers and so we may be underestimating the prevalence of some of these factors.

In the main AITHS report (All Ireland Traveller Health Study Team, 2010) we made a number of recommendations around prioritising maternal and child health services and educational opportunities for young Traveller parents. This longitudinal follow-up serves to reinforce those recommendations. A summary of the AITHS recommendations is given in Table 5.1 and available in the AITHS main report (All Ireland Traveller Health Study Team, 2010, pg 156-174). The introduction of a unique identifier for Travellers would facilitate attentive support to Traveller mothers when they present for health care as discussed in the AITHS Summary of Findings (All Ireland Traveller Health Study Team, 2010, pg 171). The Primary Health Care for Travellers Projects present a strong opportunity for peer-led health promotion initiatives for Traveller mothers. We hope these recommendations will be acted upon for the families who put their trust in this study.

Table 5.1: Summary of recommendations from the AITHS Summary of Findings (All Ireland Traveller Health Study Team, 2010, pg156-174)

• A strategic action plan should be set out, with a firm commitment to implementation, targets and timeframes
• Adequacy of accommodation is essential to ensure health improvement for Travellers
• Every Traveller child should obtain the minimum equivalent of the Junior Certificate and a similar percentage should go on through secondary school to professional or higher level education as the general population within 10 years
• Strong attention should be given to adult education, especially for those under 30 years old
• A national multi-level education campaign is required to help break down stereotypes many people in the general population have about Travellers and produce a more rounded understanding
• A national exhibition of Traveller crafts and traditions could be mounted, in the National Museum, as a mainstream event
• Employment policy must be to treat the community like a small or medium enterprise and take a bottom-up strategy
• The current undergraduate and graduate curricula for health and education professionals should explicitly include a module on Traveller health status and customs
• Hospitals with a significant Traveller catchment population should include a section on Travellers as part of routine staff inductions. General practices with a Traveller list should offer similar induction to staff and there should be a set of guidelines on how Traveller families are managed from frontline to discharge
There are four priority health care needs which require a unique identifier to implement: • All sectoral aspects of mother and child services merit top priority to reduce infant mortality, support positive parenting outcome and break the cycle of lifelong disadvantage that starts so early for Traveller families • A gendered strategy needs to be adopted and men's health issues need to be addressed, specifically with an emphasis on empowerment and promotion of self-esteem for young Travellers of both sexes to improve mental health and well-being • There is a concerted need to address cause-specific issues for respiratory and cardiovascular disease. This necessitates supportive and culturally appropriate strategies for all aspects of positive lifestyle as well as risk factor detection and management • Priority should be given to a new model of primary care delivery for Travellers dovetailed in the Republic of Ireland with emergence of Primary, Continuing and Community Care services, and in partnership with Primary Health Care for Travellers Projects Networks

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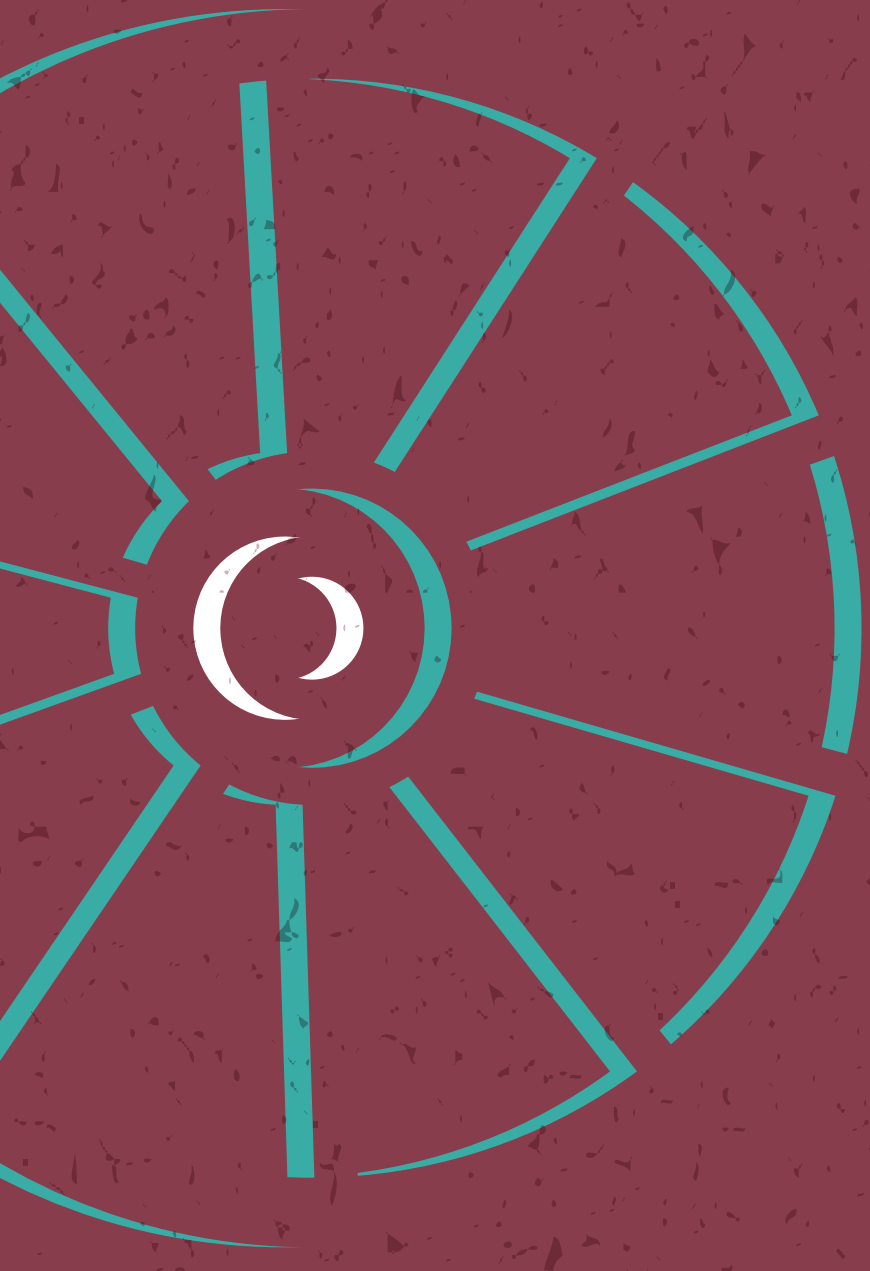

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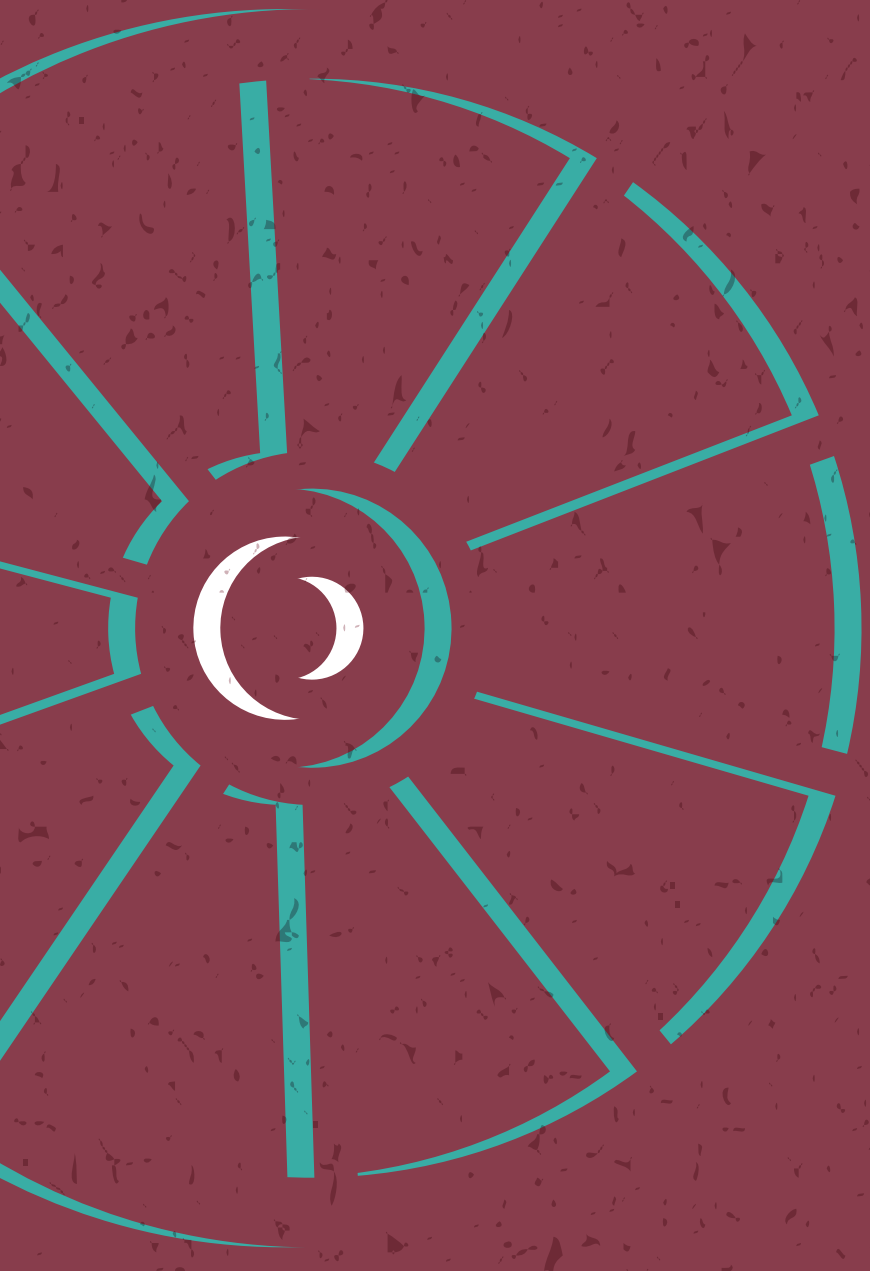
Appendices



Appendices

Appendix A: Birth Notification Form (BNF01/2003): Copy number 3, NPRS copy

Notification of Birth - To: National Perinatal Reporting System, The Economic & Social Research Institute, Whitaker Square, Sir John Rogerson's Quay, Dublin 2

TYPE OF BIRTH (Live = 1, Still = 2) 1 | PLACE OF BIRTH (Hospital = 1, BBA = 2, Domiciliary = 3) 2 | NAME AND ADDRESS OF HOSPITAL

[redacted] HOSPITAL NO. 3 | CASE NO. 6 Y Y Y Y

INFANT'S DETAILS

DATE OF BIRTH (DD/MM/YYYY) 14

TIME OF BIRTH

IF MULTIPLE BIRTH | ORDER OF BIRTH No. 22 of 23

[redacted]

SEX (Male = 1, Female = 2, Indeterminate = 3) 24

BIRTHWEIGHT 25 GRAMMES

PERIOD OF GESTATION 29 WEEKS

FATHER'S DETAILS

[redacted]

COUNTY 31

COUNTRY 34

NATIONALITY 38

OCCUPATION 42

DATE OF BIRTH (DDMMYYYY) 44

[redacted]

MOTHER'S DETAILS

[redacted]

COUNTY 52

COUNTRY 55

NATIONALITY 59

OCCUPATION 63

DATE OF BIRTH (DDMMYYYY) 65

[redacted]

MARITAL STATUS (Married = 1, Never Married = 2, Widowed = 3, Married but Separated = 4, Divorced, = 5) 73

DATE OF PRESENT MARRIAGE (DDMMYYYY) 74

DATE OF LAST BIRTH (live or still) (DDMMYYYY) 82

NO. OF PREVIOUS LIVE BIRTHS 90

CHILDREN STILL LIVING 92

STILLBIRTHS 94

SPONTANEOUS ABORTIONS 96

PERINATAL DEATH

TYPE OF DEATH (Early Neonatal = 1, Stillbirth = 2) 98

WAS AUTOPSY PERFORMED (Yes = 1, No = 2) 99

AGE AT DEATH 100 DAYS 101 HOURS

PLACE OF DEATH 103

IF STILLBIRTH, DID DEATH OCCUR BEFORE LABOUR (1) DURING LABOUR (2) NOT KNOWN (3) 106

CAUSE OF DEATH

MAIN DISEASE OR CONDITION IN FOETUS OR INFANT 107

OTHER DISEASES OR CONDITIONS IN FOETUS OR INFANT 112

MOTHER'S HEALTH

ANTENATAL CARE THIS PREGNANCY (Hospital / Obstetrician = 1, G.P. Only = 2, Combined = 3, None = 4, Midwife Only=5) 117

DATE OF FIRST VISIT TO DOCTOR DURING PREGNANCY (DDMMYYYY) 118

DATE OF FIRST VISIT TO HOSPITAL DURING PREGNANCY (DDMMYYYY) 126

WAS MOTHER IMMUNE TO RUBELLA (Yes = 1, No = 2, Not Known = 3) 134

METHOD OF DELIVERY (Spontaneous = 1, Breech = Forceps = 2, Forceps = 3, Vac. Extraction = 4, Caesarean Sec. = 5, Other = 6) 135

MAIN MATERNAL DISEASE OR CONDITION AFFECTING FOETUS OR INFANT

136

OTHER MATERNAL DISEASES OR CONDITIONS AFFECTING FOETUS OR INFANT

141

INFANT'S HEALTH

TYPE OF FEEDING (Artificial = 1, Breast = 2, Combined = 3) 146

WAS BCG ADMINISTERED (Yes = 1, No = 2) 147

MAIN DISEASE OR CONGENITAL MALFORMATION AFFECTING INFANT

148

OTHER DISEASES OR CONGENITAL MALFORMATIONS AFFECTING INFANT

153

HOSPITAL

WAS ADMISSION BOOKED (Yes = 1, No = 2) 158

DATE OF MOTHER'S ADMISSION (DDMMYYYY) 159

DATE OF MOTHER'S DISCHARGE (DDMMYYYY) 167

DATE OF INFANT'S DISCHARGE (DDMMYYYY) 175

WAS INFANT TRANSFERRED TO OTHER HOSPITAL FOR MEDICAL REASONS (Yes = 1, No = 2) 183

IF 'YES', NAME OF HOSPITAL

184

GENERAL PRACTITIONER ATTENDED BY MOTHER

[redacted]

Signature Date **BNF01/2003**

Note: The blanked-out sections shown on this copy of the form were available to the study team.

Appendix B: Capture-recapture technique

Capture-recapture is a well-used technique in biology which has been adapted successfully in epidemiology (Carrao *et al*, 2000; Chao et al, 2001; Van Hest 2007). This technique allows estimation of a 'true' population using different independent sources by eliminating duplicates from both sources when it is not possible to perform a complete census of the population. Stefanoff *et al* (2010) used this technique to estimate the Roma population and measles immunisation uptake in Poland.

There are three criteria for capture-recapture technique, which are:

1) Independence between sources
2) A closed population
3) Independence between individuals

For large numbers sources, there are at least three different statistical methods to calculate the estimates. These are ecological models, log-linear models and the sample coverage approach (Chao *et al*, 2001a). However, due to the small size of our sample (12 deaths in total), these could not be employed. Instead, we referred back to the original technique used in biology and derived an average of the estimated Traveller infant deaths. The original formula, Lincoln-Petersen method, tends to over-estimate the true population. A more practical method which corrects for over-estimation, the Schnabel method or Chapman estimator, was used for this analysis. The formula for the Schnabel method is given below.

$$N = \frac{(M+1)(C+1)}{R+1} - 1$$

Where:
N= estimate of total population size
M= Total number counted on first cohort
C= Total number counted on second visit
R= Number of individuals counted in first cohort followed by recaptured in second cohort


Our
Geels
All Ireland
Traveller
Health Study


DEPARTMENT
OF HEALTH & CHILDREN
AN ROINN SLÁINTE
AGUS LEANAÍ


Department of
Health, Social Services
and Public Safety


Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive


UCD
DUBLIN


DCU