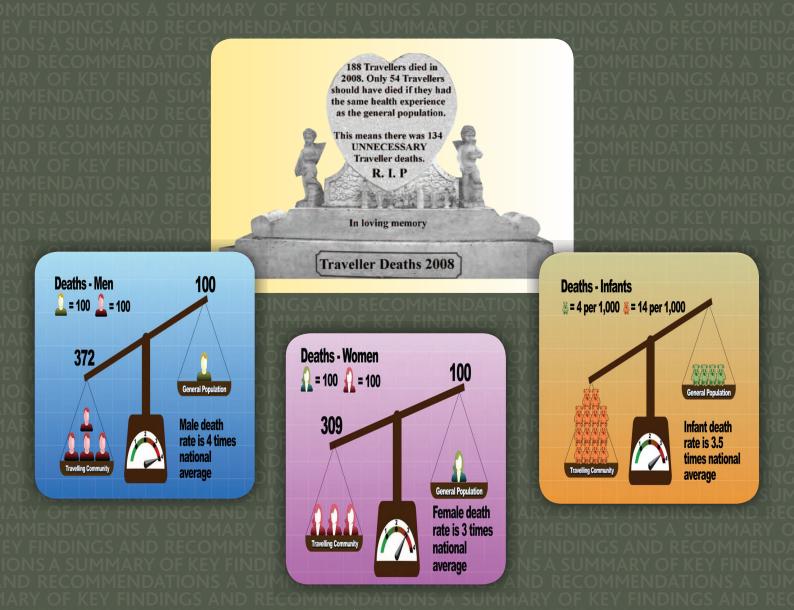
# Selected Key Findings and Recommendations from the All-Ireland Traveller Health Study – Our Geels 2010



The All Ireland Traveller Health Study (AITHS) is the first study of Traveller health status and health needs that involves all Travellers living on the island of Ireland, North and South. It was conducted 'With, For and About Travellers'.

It arose From recommendation in the Department of Health and Children's National Traveller Health Strategy - 2002- 2005 (Department of Health and Children, 2002).

80 study coordinators from Traveller projects trained as trainers by UCD. The study coordinators trained 400 Traveller peer researchers from over 50 Traveller organisations and Primary Health Care for Traveller projects around the country.



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Reports available on www.dohc.ie/publications/traveller\_health\_study.html

Final section on priorities is based on reports from National Traveller Health Network meetings.

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# **FORWORD**

One of the consequences of the deepening inequality in Irish society is that a large cohort of the population die prematurely. That is they die at ages lower than the average age at which the rest of the population die. It is literally true that government policy is killing people, killing people in that category that repeatedly we are assured it is government policy to protect, the so-called "vulnerable".

A government funded report "Inequalities in Mortalities" was published almost 10 years ago now by the Institute of Public health (governments have refused to fund updates of that report) and it showed:

- Between 1989 and 1998, the rates for all causes of premature death were over three times higher in the lowest occupational class than in the highest.
- The death rates for all cancers among the lowest occupational class was over twice as high
  for the highest class; it was nearly three times higher for strokes, four times higher for lung
  cancer, and six times higher for accidents.
- Perinatal mortality was three times higher in poorer families than in richer families.
- Women in the unemployed socio-economic group were more than twice as likely to give birth to low-birth-weight children as women in the higher professional group.
- The incidence of chronic physical illness was found to be 2½ times higher for poor people than for the wealthy.
- Men in unskilled jobs were four times more likely to be admitted to hospital for schizophrenia than higher professional workers.
- The rate of hospitalisation for mental illness was more than six times higher for people in the lower socio-economic groups as compared with those in the higher groups.
- The incidence of male suicide was far higher in the lower socio-economic groups.

Unsurprisingly, the mortality rate for Travellers is worst of all and this report, based on five pieces of research conducted between 2007 and 2010 at UCD, shows, not just that Travellers die younger, but that the health and longevity of Travellers is worsening. The gap in the life expectancy of Traveller men, as compared with men generally in the population, has increased from 10 years to 15 years since 1987. It shows that the suicide rate for Traveller men was seven times that of the rate for men generally, the research found there were only 8 Travellers aged over 85 found in the census study in 2008..

This All Ireland Traveller Health Study(AITHS), conducted by UCD in partnership with Traveller groups and the HSE, had a response rate of over 80 per cent, confirming the concern there is within the Traveller community about Traveller health. It was jointly commissioned by the Departments of Health in the Northern Ireland and the Republic of Ireland and conducted over a three year period from 2007 -2010 at a cost of approximately 1.5 million. The document was launched by the then Minister of Health, Mary Harney, in September 2010 with a commitment that it would inform future Traveller health policy. She specifically acknowledged the positive outcomes of Primary Health care for Traveller Projects.

However, the findings of the research seem to have had no impact at all on the agencies and Ministers that funded it, as indicated by the progressive reductions in the Traveller health budget of 5 per cent annually, which, with the other reductions in the level of health service provision

due to loss of designated personnel and resources, have resulted in less availability of critical services for Travellers.

In addition, other austerity measures appear to be disproportionally affecting Travellers, with a loss of all Traveller visiting teachers; reduction in after school support programmes; cuts to social welfare and increase in rent allowance and utility bills. All are contributing to a further deterioration in the health status of Travellers.

We have the stark evidence of deteriorating Traveller health and longevity and we have specific recommendations to address this worsening condition of the most disadvantaged section of our community. It would be unconscionable, if, along with the multiple disadvantages, discriminations and belittlements Travellers are subjected to, the worsening progression towards early death and, very often, suicide, went ignored any longer.

Vincent Brown June 2012

# Background to Our Geels-All Ireland Traveller Health Study

In Travellers own language, Cant, Our Geels means our community/our family. This was the title given to the All-Ireland Traveller Health Study (AITHS). Our Geels was the first Study of Travellers Health Status and Health Needs that involved all Travellers living on the island of Ireland, North and South. It arose from a recommendation in the National Traveller Health Strategy (2002-2005) to "carry out a Traveller Needs Assessment and Health Status Study to update and extend the indicators used in the last survey of Travellers' Health Status and to inform appropriate actions required in the area of Travellers' Health".

### 1.1 Overview

The Our Geels-AITHS, is the first Study of Travellers Health Status and Health Needs that involved all Travellers living on the island of Ireland, North and South, and it was jointly funded by the Department of Health and Children and the Department of Health, Social Services and Public Safety (NI). It was undertaken by the School of Public Health, Physiotherapy and Population Science, University College Dublin. The Study ran for a three year period from 2007 to 2010.

### 1.2 Our Geels AITHS

### Aim:

The purpose of the Study was to:

- examine the health status of Travellers,
- to assess the impact of the health services currently being provided
- to identify the factors which influence mortality and health status.
- It also provides a framework for policy development and practice in relation to Travellers.

# **Principles:**

The Our Geels-AITHS was informed by the principles of equality, human rights, social inclusion and respect for Traveller values, beliefs, culture and perceptions. This Study was "With, For and About Travellers". Ongoing training and support was available to ensure that Travellers and Traveller organisations built their capacity to participate fully in all stages of the Study.

### Methodologies:

The Study used methodologies which were culturally appropriate and innovative in that it used an audio, visual computer programme, focus groups and creative youth workshops which facilitated the participation of Travellers with all levels of literacy in the research.

### **Process:**

The UCD Project Team worked closely with Pavee Point and other Traveller organisations to ensure that Travellers could participate fully. Traveller peer researchers who were drawn from the Traveller community played a key role in data collection for the Study. **80 Study coordinators** from Traveller projects were trained as trainers by UCD. The Study coordinators in turn trained **400 Traveller peer researchers** from over **50 Traveller organisations and Primary Health Care for Traveller Projects (PHCTP's)** around the country.

Because of the engagement of Travellers themselves in conducting the research, **the response rate was 80% which is unprecedented for a Study of this kind**. The Traveller organisations and Primary Heath Care for Traveller Projects were fully engaged in the process and they collected the mapping information on the numbers and location of Traveller families around the country, which provide the denominator information for the Study.

# 1.3 Study Reports

A series of Study reports with detailed findings were launched in September 2010. The Summary Report which contains background information and key findings from each of the three technical reports was the only report published. The other Technical Reports as outlined below are available as PDF's for download from the following websites: http://www.dohc.ie/publications/traveller\_health\_Study.html and www.pavee.ie/ourgeels

**Technical Report 1** features the findings of the Census of Traveller Population and a Quantitative Study of Health Status and Health Utilisation.

**Technical Report 2** reports on Demography and Vital Statistics including mortality and life expectancy data, a preliminary report of the Birth Cohort Study and a report on Travellers in Institutions.

**Technical Report 3** reports on Consultative Studies including qualitative studies based on focus groups and semi-structured interviews with Travellers and key stakeholders, and a survey of Health Service Providers.

The final part of the Study – **the Birth Cohort Follow Up Report** – was published in 2011. This report presents the one year follow up of Traveller infants born on the island of Ireland between October 2008 and October 2009. The research informing the report consisted of a detailed longitudinal study investigating health-related issues of maternal and infant health status and the health services utilisation experience of 508 Traveller families and their infants.

This summary report is based on data and information which has been extracted from all of the above reports. It is focusing on the data findings from the Republic of Ireland and does not include data from the North of Ireland, unless otherwise stated.

# Selected Findings from Our Geels – All Ireland Traveller Health Study (AITHS)

# 2.1 Population and Demographic Information from the Census

Table 1: Estimated Traveller Population Enumerated for the AITHS

	ROI	NI	All- island
Number of Traveller families enumerated	9,056	1,562	10,618
Average family size	4.0	2.5	3.8
Estimated Traveller Population	36,224	3,905	40,129

9,056 Traveller families were enumerated/mapped

- Estimated total Traveller population 36,224
- Average Family Size: 4

Table 2: Number of Traveller Families Enumerated and Response Rate Per HSE, Traveller Health Unit (THU) Region.

THU Region	Traveller families enumerated	Percentage response
South Eastern	1,043	70%
North Eastern	904	80%
Western	1,431	83%
Mid Western	997	63%
Midlands	1,049	79%
North Western	428	94%
Southern	1,439	73%
Eastern	1,763	84%
Total	9,056	78%

# 2.2 Age Structure

- 42% of Travellers under 15 years of age compared with 21% of the general population
- 63% of Travellers under 25 years of age compared with 35% of the general population
- 3% of Travellers are aged 65 years and over compared with 13% of the general population.
- Only 8 Travellers were found over 85 years of age

# 2.3 Comparative Population Pyramids for Travellers in the AITHS 2008 and the General Population from CSO 2006

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

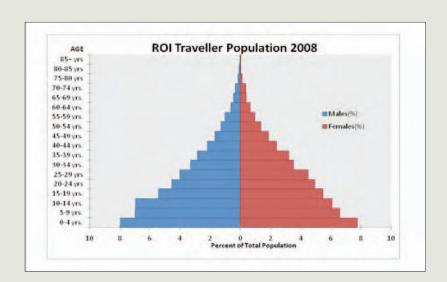
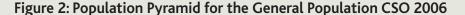
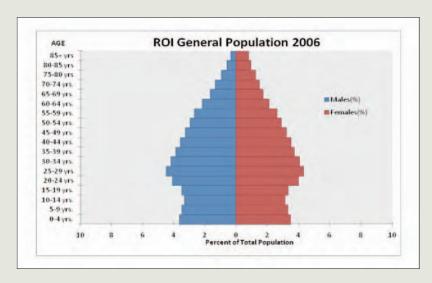


Figure 1: Population Pyramid for Travellers in the AITHS 2008





These population pyramids illustrate a very different profile for the Traveller population than the general Irish population. Whilst the general population pyramid is increasingly typical of developed countries from the West, with relatively large numbers of middle-aged people and increasing numbers of old people, the Traveller population pyramid is more reminiscent of a developing country, characterised by high fertility and premature mortality.

# Life Expectancy and Mortality

The findings are very alarming. They indicate that the gap in the health status and life expectancy between Travellers and the general population has widened since the last Study on Traveller's health was conducted in 1987.

# 3.1 Life Expectancy

- The life expectancy at birth for Traveller women is now 70.1 years, which is 11.5 years less than women in the general population, and is equivalent to the life expectancy of the general population in the 1960's. In 1987, the life expectancy of Traveller women was 65 years and the gap in life expectancy between Traveller women and women from the general population was 12 years.
- Life expectancy at birth for Traveller men has remained at the 1987 level of **61.7** years which is **15.1** years less than men in the general population. In 1987 the gap in life expectancy between Traveller men and men from the general population was **10** years, representing a widening of the gap by **5.2** years. This is equivalent to the life expectancy of the general population in the **1940's**.

# 3.2 Mortality/Deaths

There has been a slight improvement in Traveller's heath but the gap has widened since 1987 as there has been a marked improvement in the health status of the general population.

- Traveller men have four times the mortality rate of the general population
- Traveller women have three times the mortality rate of the general population.
- Suicide among Travellers is 6 times the rate of general population and accounts for approx 11% of all Traveller deaths.
- The infant mortality rate for Travellers is 3.6 times the rate of the general population (4 infant deaths per 1,000 live births in the general population compared to 14 infant deaths per 1,000 live births in the Traveller population)
- If Travellers had the same mortality experience as the general population, the number of **deaths expected in the year would be 54, but the actual number of deaths was 188**, which means an **excess of 134** Traveller deaths (91 in males and 43 in females).

Compared to the general population, Travellers are dying younger. In the general population 60% of deaths occur in those aged 75 years or over. In the Traveller population only 17.6% of deaths occur above that age. Age specific death rates are higher for Travellers in each and every age group in both males and females. In every age group Travellers die at a greater rate than those in the general population. The excess mortality experienced by Travellers is not confined to a particular age group but is an endemic problem across all ages. Male Travellers especially continue to have higher mortality rates for all causes of death.

Figure 3: Main Causes of Death



Table 3: Comparison of Traveller Mortality Rates With That of the General Population

	Traveller population 2008	General population value or expected value.
Infant mortality rate (per 1,000 live births)	14.10%	3.9%
Number of Traveller deaths	188	54
Excess deaths	134	0
All-cause SMR, (Males) (Females)	372 309	100 100
Life expectancy at birth, (Males) (Females)	61.7 70.1	76.8 81.6
Change in life expectancy since 1987, (Males) (Females)	0 +4.8	+ 5.2 +4.4
External cause SMR, (Males) (Females)	548 393	100 100
Respiratory disease SMR, (Males) (Females)	746 536	100 100
Heart disease and Stroke SMR (Males) (Females)	337 489	100 100
Suicide SMR (Males) (Females)	660 489	100 100

Over 30% of excess deaths were due to external causes. In both male and females deaths due to respiratory conditions and heart disease were higher than expected.

# Morbidity/ Illness

- Over 52% of Travellers aged 40 60 years, who were interviewed, had been diagnosed with high blood pressure in the last year, compared to 35% of the general population.
- Over **42% Travellers diagnosed with high cholesterol** in last year, compared to 30% of the general population.
- 31.3% of Travellers are on some form of prescribed medication.

The Traveller groups appear to have a greater burden of chronic diseases than the general population, with conditions such as back conditions, diabetes, and heart attack, which was increased by a factor of 2 in the Traveller group, and respiratory conditions such as asthma and chronic bronchitis, increased by a factor of 2 to 4, in comparison with the general SLAN population.

Table 4: Doctor-diagnosed Illnesses, within the Last 12 Months, by Comparative Group

Illness	Traveller ROI	SLAN 2007 general population	SLAN 2007 SC 5-6 (n=3,445)
Back condition	30.4%	16%	22.1%
Asthma	12.5%	6%	8.9%
Chronic bronchitis	12%	3%	5.9%
Cancer	1%	1%	2.8%
Arthritis	13.8%	11%	28.1%
Diabetes	6.1%	3%	6.5%
Angina	4.3%	2%	5.6%
Heart attack	2.3%	<1%	2.3%
Stroke	1.1%	<1%	2.2%

The most common health complaint reported as being diagnosed by a GP in ROI, was a back condition (30.4%). Reported diagnosis of angina was 4.3% overall. The highest rates of heart attack (11.1%), angina (24.2%) and stroke (3.3%) were seen amongst those respondents aged 65 years and older.

Most respondents of both sexes had not been screened for cardiovascular risk factors in the last 12 months.

# 4.1 Reasons for High Morbidity and Mortality

Travellers experience higher mortality than the general population and have not benefited from the decrease in mortality experienced by the general population in the last twenty years, when Traveller data was last examined in 1987. The reality is the mortality gap has widened.

Age-specific mortality rates suggest excess rates at all ages for both Traveller men and women. We also know from the census count, that there are negligible numbers of Travellers over fifty years of age. This is not explained by migration, is not explained by integration into the general population, and not explained by denial of Traveller identity. The only realistic explanation is of premature death.

In early to late middle-age, the main causes of death are respiratory and cardiovascular diseases. In the census survey, self-reported morbidity was higher than in the general population also for respiratory conditions including chronic bronchitis and for cardiovascular disease. Travellers reported high levels of typical lifestyle risk factors, such as smoking, excessive salt and saturated fat intake and physical inactivity. They also report higher rates of diagnosed diabetes, and have high rates of risk factors such as hypertension and raised cholesterol.

### Child Health:

In children, asthma was the most common ailment reported. The child asthma rate was estimated at 70% in children reporting a current health problem.

Traveller children also have higher reported prevalence of hearing, eyesight and speech problems than children in the general population.

# **Social Determinants**

# Causes of Gap in Levels of Morbidity and Mortality Among Travellers:

Both Travellers and health service providers interviewed acknowledged that Social
 Determinants were the main cause of the poor health status of Travellers, this includes
 accommodation, education, employment, poverty, discrimination, lifestyle and access and
 utilisation of services.

The Study adopted a social determinants approach in line with the government National Health Strategy and the National Traveller Health Strategy. It explored the causes of the inequalities evident in Traveller health status. Headline data related to some key determinants are highlighted below:

The main determinants of health

Living and working conditions

Living and working conditions

Living and working conditions

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Figure 4: Social Determinants of Health

### 5.1 Accommodation

- The majority of respondents, (75.9%) lived in family units of 5 or less.
- 73% of respondents most frequently lived in a house
- 18.2% lived in a trailer/mobile home or caravan.
- Flush toilets were reported in 60.2% of trailer/mobile home or caravan sites

The Study found that most Travellers are living in houses, but there is a wide range of accommodation experience and the most destitute of Travellers are living in very poor conditions. During the recruitment phase of the survey these were the families hardest to access and yet most in need of support. The evidence from this Study suggests that it is appropriate amenities, rather than type of accommodation that are important factors. .... the recommendation should be to ensure existing policy is comprehensively implemented so that there are for instance adequate amenities on halting sites, with the basic principle that the children particularly in such situations have rights to a secure childhood and that need should be the primary driver of policy.

Service Providers recognised, both in interviews and as part of the survey, that accommodation adequacy is a key health determinant. (Service Provider).

There is a worrying trend developing which is the movement of young Travellers into standard housing and apartments as a solution to the accommodation problem, but there are concerns that this can further isolate young Travellers with no extended family for support.

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

# 5.2 Education/Literacy

- 38.5% of 30-44 year olds and 25.8% of 45-64 year olds had primary education only
- More than 90% of 14 year olds are currently in school or training centres.
- 28.8% had difficulty in reading.
- 50% of Travellers had difficulty reading the instruction for medication.

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

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

- "...the more confident the parent, the more confident the child" (SSI: Service Provider).
- "...Slow learners, like I got put into a room with the teacher fixing jigsaws and I got put into the slowest class in school. 'Slow Learners' everyone used to call it and I got put into that like automatically, without even doing a test. And just putting me down like" (Education 1).
- "...In trailers like it is hard for a child to do their homework...A lot of schools now has homework clubs where the children can wait and do their homework, that's good"

# 5.3 Employment

# • 4.8% in RoI were either employed or self-employed

Discriminatory practices and social exclusion leading to low self esteem and poor performance in education and training sessions were named by Travellers as contributing to there low levels of employment.

"If you experience racism, if you are relegated to a thing rather than a person and you find yourself with no work and you are completely excluded, marginalised from society, I think that has an effect" (Men 1).

Unemployment and reduced social circumstances also combine producing feelings of negativity, fatality, depression and low self worth. Travellers feel bullied by mainstream culture.

There is little history of Travellers staying in education or working outside the Traveller economy.

Many of the young people indicated that there was very little point in staying on at school because there was no chance of gaining paid employment afterwards because of discrimination. The only way to get on and get jobs was to integrate, become like them and deny your identity.

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

# 5.4 Lifestyle

"... it is well understood in the general literature that unhealthy lifestyle choices are not so much a wilful ignoring by people of a paternalistic health promotion message as a signal of a coping strategy in the face of difficult circumstances...What this means is that those most empowered are most likely to make life changes that promote their health. It is not that lifestyle is unimportant as a health determinant, but rather that it is the first thing to change if you are in control of your life and the last if you are not. In this context knowledge about lifestyle is power, rather than an undermining of the dignity of one's social position."

- 31% Travellers said price is a factor which prevents them to eat healthy.
- 4 in 10 Travellers (40.3%) reported eating fried food less than once per week. Traveller men were more likely to consume fried food.
- 56.2% use butter as the most popular spread and was consumed most days.
- 38% added salt to food at table.
- 45% eat fruit or vegetables daily.

### Alcohol:

• The reported frequency of alcohol consumption by Travellers is comparable to that of the medical card holders in SLAN 2007. However. 66.1% of male Travellers and 42.3% of female Travellers drink six or more alcoholic drinks on days when they are drinking alcohol, compared with 35.8% of male and 17.0% of female SLAN 2007 GMS medical card holders.

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

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

### **Smoking:**

• 52% of Travellers were current smokers, compared to 37% of the general population. (SLAN 2007). There was little difference in the smoking rates between men and women and most smokers smoked 20 or more cigarettes a day.

### Addiction:

• 66.3% of Travellers said that illicit drug use is a problem in the community

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

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

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

There was agreement that addiction and drug use is related to social and environmental circumstances. These include feelings of alienation, discrimination and pressure on Traveller identity, culture and expression.

Women thought that depression was never properly assessed and counselling was usually never offered. Overmedication was said by many women to be a major concern. Men and women said that prescription sleeping tablets were not monitored, particularly for women. Travellers reported that they often did not see the GP but were prescribed drugs on the basis of earlier assessments.

The data showed thematic prevalence of prescription drugs as a major concern for Travellers, particularly women (Addiction2).

# 5.5 Social Capital and Cultural Considerations

# **Social Capital:**

The concept of Travellers as a community is integral to our understanding of their health status. Travellers self identify, share a culture and value systems, choose to socialise and congregate together and value immediate and wider family networks.

What came across clearly in the research was the importance and pride Travellers have in their religion/faith (83%) Traveller identity (74%) culture (73%), and membership of the Traveller community (71%), followed by nomadism (54%)

- What became clear in the qualitative discussion is the importance of the extended family network and the support they get from within family and community.
- Travellers also have a strong sense of the value of community and there is a high level of trust within the Traveller community.
- They are also a community in transition and they are open to adapting to change, one of the changes taking place is the empowerment of Traveller women

# 5.6 Trust and Quality of Service

Travellers at all points of engagement with services, reported higher levels of discrimination than expected and Travellers were much less likely than the general population to trust health professionals and to feel respected in such encounters. In the qualitative datasets many negative accounts were recounted about treatment received and a general sense of not being understood and catered for by the system. (TR1)

- 48% of Travellers don't feel "most people can be trusted"
- The level of complete trust by Travellers in health professionals was only 41%. This
  compares with a trust level of 83% by the general population in health professionals.

- Over 50% of Travellers had concerns of the quality of care they received when they engaged with services.
- 53% of Travellers "worried about experiencing unfair treatment"
- Over 40% of Travellers had a concern that they were not always treated with respect and dignity.

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

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

### 5.7 Discrimination

40% of Travellers have experienced discrimination in accessing health services, compared to 17% of Black Americans and 14% of Latino Americans (Krieger et. al. 2005)

The discriminatory practices and challenges from some service providers in care delivery were discussed in the qualitative process.

- It does exist... there is that sentiment that Travellers are less deserving, hence give them substandard services (SSI: Service Provider).
- Racism as one of factors, but won't be said officially as they (institution) will be in trouble (SSI: Service Provider).
- Service Provider Y: "It is not as simple as that. It is not all the same. The reason that there are named category... like Travellers, is that there are special requirements and special needs and where you have an attitude like "we treat everyone the same" then that doesn't recognise that everyone is different..."

"We have to integrate, but not assimilate. Now, that's the difference there is that yes we want to integrate, but not assimilate. Travellers are always going to be Travellers, even if we experience discrimination in our daily lives for that choice." (SSI Traveller)

Table 5: Experience of Discrimination (assessed in the Study using a comparative question from the US, (Krieger et. al.2005)

Once or more than once	Traveller ROI	Black US	Latino US	White US
At school	62%	21%	9%	10%
Getting work	55%	28%	20%	14%
In shop/pub/restaurant	61%	41%	20%	10%
In public settings	50%	38%	24%	15%
With guards/courts	52%	22%	18%	6%

# **Access and Use of Services**

# 6.1 Services Used in Last 12 Months

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

Table 6: Services Travellers Used in the Previous 12 Months

	Not Used	Once	More than once	N
Hospital inpatient	74.00%	15.40%	10.60%	1,939
Hospital day patient	77.30%	12.80%	9.90%	1,927
Hospital out patient	67.20%	15.40%	17.40%	1,934
Hospital A&E	70.30%	16.60%	13.10%	1,941
GP	24.40%	15.40%	60.20%	1,968
Mental Health Services	90.10%	4.40%	5.50%	1,817
Community Health Services	74.90%	11.30%	13.80%	1,884

# **6.2 Service Provider Study**

As part of the Study, front line, middle managers and senior managers were also interviewed to illicit their understanding of the issues affecting Traveller's health.

Overall, respondents considered Travellers less likely than other patients to access and use their services.

- Just under half of respondents rated Travellers as about as likely to understand as others (43.8%) and just over a quarter (27.3%) as less likely.
- Travellers were considered less likely (51.0%) or much less likely (15.3%) than others to keep appointments.
- Respondents considered Travellers to be less likely (41.6%) or much less likely (10.7%) than other patients to be on time for appointments.
- Compliance with instructions about treatments was again rated as less likely or much less likely by appreciable numbers of respondents, 52.7% overall.

- Attendance for service follow-up was rated as less likely (47.7%) or much less likely (9.0%) by a majority of respondents.
- A majority (56.4%) of respondents thought Travellers less likely or much less likely to attend referral appointments from their service.
- Travellers were considered as being less likely (53.3%) or much less likely (22.4%) than others in similar circumstances to avail of preventive services.

When service providers were asked to list the three most important factors impacting on the health status of Traveller's Education was selected as the key determinant, followed by socio-economic factors in general, accommodation adequacy and cultural factors. They also selected education as the key solution to addressing the health status of Travellers.

66.7% of service providers thought that Travellers experience discrimination in their use of health services in general.

54.7% of service providers said they had never received cultural awareness training.

45.3% of service providers said that information on how to use their service was no disseminated in a way that would ensure that Travellers receive it.

18.7% of health service providers said it was difficult/very difficult to establish a relationship of trust with their Traveller patients.

73.6% of service providers said it was difficult for Travellers to carry out written instructions, for example from information leaflets or prescriptions.

49.9% thought it was difficult for Travellers to understand factors concerning their health and well-being.

The majority of service providers do show an understanding of the wider health determinants and clearly recognise the importance of socio-economic, environmental and cultural factors, as well as individual lifestyle and access issues. They also acknowledge discrimination as a possible factor in service delivery. Education was recognized as critically important by service providers, both as a contributory factor for ill-health and the principal means of improving it.

Trust, dignity and respect were important to Travellers in the census survey and the qualitative accounts amplify the importance of this.

So, in relation to Travellers and the All-Ireland Traveller Health Study for example and the health of Travellers — there was — and there is quite a bit of evidence in terms of how generally the population's health is affected by not just Health Services but by the whole determinants of health (SSI: Service Provider).

Education, education is important, and poverty... (SSI: Service Provider).

... we have a responsibility to work on education, accommodation and employability.... this also includes early family support...and children, early years intervention is very important, it is important that we do it for the Travellers are their families and that we do it in a sensitive way that they feel it is respectful... (SSI: Service Provider).

Overall respondents reported significant difficulties for Travellers in using their services. The data suggests that there is insufficient training for key frontline providers on cultural aspects of Traveller healthcare.

# 6.3 Travellers Identified the Following as Barriers to Accessing Services

- Waiting list (62.7%)
- Embarrassment (47.8%)
- Lack of information (37.3%)
- Cost (31%)
- Difficult to get to (25%)
- Health settings (22%)
- Refused service(15%)

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

"I would say that if you go in, a man tries to explain himself, doesn't get it quite across to the Dr, or the Dr does not pick up on it, how embarrassed is he coming away from that then being embarrassed mean his experience of that means it was a negative experience....He is talking in big words' People are embarrassed to say they don't understand them" (Men2).

Travellers were much less likely than the general population to trust health professionals and to feel respected when using services, based on the census data. In the qualitative datasets many stories were recounted about treatment received and a general sense of not being understood and catered for by the system.

Taken together, the three sources of information, from the census, the qualitative consultation and the service providers' survey suggest that there is considerable and feasible room for improvement in the quality of the health care encounter.

# **6.4** Value of Primary Health Care for Traveller Projects

Significant sources of information trusted by Travellers (particularly for those with literacy problems) were health care teams and Traveller health workers (ROI). Travellers who were in contact with these organisations and projects indicated that in addition to information, they crucially provided informal support and a network for information exchange and were more tuned in to the specific health issues that Travellers faced.

Traveller women thought that outreach services like the PHCTP facilitated Traveller trust. This was reported to enhance the uptake and use of services such as screening as borne out in the census data when Traveller health community workers were able to mediate between the services and individual Travellers in the community.

Traveller projects were also said to have positive psychosocial benefits for those involved in the projects and for particularly vulnerable individuals. Concern about the closure of projects was also frequently expressed in Traveller narratives.

"We find is lots of Travellers get their information from Traveller organizations and health care projects" (Women 1).

### **Health Information:**

• 83% of the Travellers interviewed said they got their health information and advise from Primary Health Care for Traveller Projects (PHCTP) and the Travellers organisations.

"The primary health care projects go out on site and the Travellers are more aware of them and that works... they trust them more now.... They know what's happening to Travellers out there." (Women1).

### Women's Health:

- 25% of Traveller women compared to 13% of general population had a breast screening.
- 23% of the Travellers had smear test compared to 12% of general population.

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

# **Healers:**

"A majority of respondents (60.6% in ROI) had some experience of consulting with healers or a curing person for ailments. Common indications for such consultation included eczema, aches and pains, burns and depression or worries."

# Other Key Findings

# 7.1 Mental Health

- 62.7% of Traveller women said their mental health was not good for one or more days in the last 30 days compared to 19.9% of GMS female card holders
- **59.4% of Traveller men said** that their mental health was not good for one or more days in the last 30 days **compared to 21.8% of GMS male card holders**
- **56% of Travellers** said that poor physical and mental health restricted their normal daily activities **compared to 24% of the GMS population**

The data showed that while mental health services were available they were often perceived as inadequate. Travellers and Traveller advocates reported that Travellers tended not to use available counselling services. They were perceived to be inappropriate and Travellers and no provision said to be made for the specific needs of Travellers. Travellers said that using these services would be difficult because of social stigma.

Provision is not developed as a specific response to Travellers (SSI: Service Provider).

As reported perceived discrimination was a major problem for all Travellers and there were significant accounts of this directly influencing mental health leading to feelings of depression, anxiety and suicide. Men agreed that discrimination causes stress and said that stress was one of the biggest things in the Travelling community. Personal experiences differed, but social stigma and discrimination were viewed as being present, constant and underlying in virtually all the qualitative data. Traveller men stated that the sense of difference and of shame begins early in a child's life and was interpreted as impacting on mental health.

Women, including young women reported feeling isolated and with periods of depression.

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

One Service Provider noted what he perceived to be:

"...an under diagnosis of severe depression and psychosis amongst Travellers. Many providers who do not work regularly with Travellers do not know what the norm represents or understands their culture in the same way they do the general population...."

"The provision of mental health was patchy depending upon region. Where you live makes a difference."
(SSI: Service Provider).

"... and again if you extend that to people who are already socially excluded, before they get into a mental health problem there is a sort of a double social exclusion. So you are excluded because you are a Traveller or an ethnic minority and then you are excluded further because you have a mental health problem" (SSI: Service Provider).

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

Traveller living conditions also has an impact on their mental health and wellbeing; "This extends from exposure to physical hazards in the poorer quality accommodation to impact on mental health and wellbeing of living in stressful situation."

# 7.2 Men's Health

The suicide rate is 7 times higher among Traveller men compared to men in the general population.

"We are all liars at this table, and I will tell you why. An awful of the men are hanging themselves, taking over doses, buying the rope the whole lot..." (Men2).

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

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

"Men felt more comfortable attending for check-ups in sessions specifically aimed at them" (Men2).

"We did groups like, where a nurse came in. A load of us came in to it. I thought that was very good... they would be more comfortable doing that than going to the doctor. I think if you were pulled into a certain area, and they do a health check now you would get more screening... You come in and you know that when you go there, they are going to be very sympathetic towards what you are saying because they are already Traveller friendly you know what I mean" (Men2).

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

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

Traveller men were highly pessimistic and fatalistic in outlook. Many men also agreed that only felt truly comfortable around other Travellers. "... We have lost our thick skin" (Men 1).

### 7.3 Travellers in Prision

### 7.3.1 Prison census findings

This study confirms that Travellers are over-represented in prison compared to the non-Traveller population, and according to Traveller families' responses to the AITHS census, Travellers comprised 4.6% of the prison population during the census as compared to 0.9% of the ROI population. When calculated using the Traveller-reported prisoner population (AITHS Census data), the risk of a Traveller being imprisoned was more than 5 times that of a non-Traveller (RR 5.5, 95% CI 4.7–6.4), and for Traveller women the risk was 18 times that of non-Traveller women (RR 18.3, 95% CI 11.1-30.1) and Traveller men were 8 times more likely to be imprisoned than Traveller women (RR 8.6, 95% CI 5.27 to 14.01).

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

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

# 7.4 BirthCohort Study

# Key Findings from the Birth Cohort Study Included the Following:

- Traveller parents are younger in comparison to the general Irish population with an average age of 27.5 years for Traveller fathers and 25.9 for Traveller mothers. This is a difference of 7.1 years for fathers and 5.7 years for mothers when compared to the general population.
- Traveller mothers have a shorter birth gap between pregnancies and higher parity and stillbirth rates compared to the general population. On average, 5.0% of Traveller mothers have had at least one stillbirth compared to the 1.6% average of the general population.
- The breastfeeding rate for Travellers was still very low. Only 2.2% of Traveller mothers initiated breastfeeding compared to around 50% in the general population.
- The commonest complaint that Traveller infants attended health services for was for respiratory-related conditions. This was also the case in the general population.

# 7.5 Traveller Ethnicity

The qualitative data indicated that the concept of Traveller ethnicity remains a central issue to Travellers and one that they believe has consequences for them not only in terms of cultural survival but also in terms of health and life chances. They also recognise that definitions of Traveller identity have important policy implications

Identity and ethnicity strongly emerged as a central theme of concern throughout all the various qualitative data. Traveller identity therefore needs to be addressed head-on because the perceived distinction between Travellers and the settled community, and the relationships between them are significant, socially, politically and economically.

"Traveller ethnicity is a key factor that has to be taken into account in identifying and responding to the needs of the Traveller community. Culture and identity shape the needs of a group. Policies and programmes that respond to needs will only be effective to the extent that they take into account the culture and identity of the group concerned" (Equality Authority 2006:9).

# 7.5.1 Ethnic Identifier

One issue that recurred in this Study is the paucity of standard surveillance information. If all health service documentation contained a unique identifier then routine monitoring of trends would be facilitated and appropriate care provided. The registration process would have been much more straightforward if the equivalent of the census question on cultural and ethnic background, which includes a Traveller category, were available.

"Unless we have got robust data sure how can you plan services, it is ridiculous, it is just ridiculous" (SSI: Service Provider).

# **Recommended Actions**

There has been no shortage of policy production in the last two decades of relevance to Travellers nor is there a shortage of International literature and policies of direct relevance, what is required is translation of evidence into action. The Traveller community put its trust in this Study and other stakeholders at all levels engaged with it to the credit of all parties. The results suggest an obligation on all stakeholders to translate the evidence of its findings into action. The Study has uncovered a life or death reality and it is as serious as that.

- An action plan informed by the still valid recommendations of the Traveller Health Strategy should be set out, with a firm commitment to implementation, targets and timeframes, this will require cross-sectoral engagement and a lead player or champion to deliver. We have shown that Travellers have distinct health needs and the challenge remains to close the gap between their health and that of the general population. Traveller public policy to date has not delivered and a clean sheet cross-sectoral strategy is required. Initiatives and exemplars of good practice should be mainstreamed.
- The establishment of mutual trust between Travellers and the rest of Irish society, on both sides of the border. A national education campaign is required to help break down the stereotypes many people in the general population have about Travellers and produce a more rounded understanding. The policy the media and other agencies have is contributing to this, implicitly or explicitly, in that many news stories are about a negative event and it is often mentioned after the fact that the incident is Traveller-related.
- A national exhibition of Traveller crafts and traditions could be mounted, in the National Museum, as a mainstream event. Travellers do not lack positive role models, there are many well known artists and sportspeople with a Traveller background, these should be engaged in supporting this process.
- The cornerstone remains education, whether in acquiring basic literacy, learning about one's culture and that of others, or acquiring lifeskills to get a job, negotiate the public service bureaucracy, achieving successful parenting or accessing health information. The first line objective is that every Traveller child should obtain the minimum equivalent of the Junior Certificate and that a similar percentage should go on from secondary school to professional or higher level education as the general population within 10 years.
- Strong attention should be given also to adult education, for three reasons; firstly, the population is still very young, most people are under thirty. Secondly, these are the parents and breadwinners of the immediate future. Thirdly, education is the rate limiting step to empowerment.
- The appropriate employment policy must be to treat the community like a small or medium enterprise and take a bottom-up strategy. Traditional skills need to be re-created as their contemporary equivalent as well as more innovative strategies in line with the Knowledge Economy. Cultural identity is key, not as a health determinant in itself but as a practical means of empowering and engagement.

- Adequacy of accommodation is a given to ensure health improvement for Travellers. There should be no official halting site without basic amenities and a sufficient number of them to accommodate the travelling Travellers on the island. A Charter negotiated between Travellers and the local authorities, overseen by the Minister for the Environment or its equivalent in both jurisdictions, should be drawn up and agreed as acceptable.
- The current undergraduate and graduate curricula for health and education professionals should explicitly include a module on Traveller health status and customs, so that all are trained in the basics from first stages.
- Hospitals with a significant Traveller catchment population should include a section on Travellers as part of routine staff inductions, general practices with a Traveller list should offer similar induction to staff and there should be a set of guidelines on how Traveller families are managed from frontline to discharge, which are regularly reviewed.

# 8.1 Priority Health Care Areas

There is no systematic primary care detection system for CVD risk factors in general and Travellers are no different from anyone else in this respect. However, relative to the risk they run, they are not having risk factors detected or treated. Given their high mortality, likely high incidence, and low appreciation of the risk factors in the community, it is appropriate to mount an opportunistic CVD Risk Factor Detection Programme for Travellers.

There are four priority health care needs, based on the combined evidence from across the report, but most particularly the mortality data, which require a unique identifier to implement in practice.

- Firstly, all sectoral aspects of mother and child services merit top priority to reduce infant mortality, support positive parenting and break the cycle of lifelong disadvantage that starts so early for Traveller families. Travellers value their children and service providers agree that children are their first priority.
- Secondly, 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 to improve mental health and well-being. This needs a comprehensive crosssectoral approach to facilitate work opportunity, break down the substance misuse problems
  and engage men in health service participation.
- Thirdly, there is a concerted need to address cause-specific issues for respiratory and CVD. This necessitates supportive and culturally appropriate strategies for all aspects of positive lifestyle as well as risk factor detection and management and the women peer leaders, particularly the Traveller community health workers in the Primary Health Care for Travellers Projects, are the agents for positive change here.

Fourthly, Priority should be given to a new model of primary care delivery for Travellers. One way to improve the situation is to concentrate Traveller services into new primary care units with a sufficient mass of staff with specialist training and as necessary, run specialist clinics for Travellers. The mapping and scoping exercise gives us a clear geographical picture of where to start. This could be dovetailed with the emergence of Primary, Continuing and Community Care services, and in partnership with the Primary Care for Travellers Project networks, and the National Traveller Health Network.

# Priorities for Action Identified by the National Traveller Health Network to Support the Implementation of the Findings of the All Ireland Traveller Health Study.

# 9.1 Context of the Selected Priority Actions

The National Traveller Health Advisory Committee instructed in the absence of a new Traveller Health Strategy being developed in the short term, and as an immediate response to the finding of the AITHS, that five key priority areas for action were to be selected which would inform the work of the HSE in relation to Traveller Health in 2011.

As part of this process the National Traveller Health network (NTHN), Coordinated by Pavee Point, held two meeting at the end of 2010 to present and discuss the main findings of the AITHS, and to identify five key priorities for action to inform the work of the Traveller projects working in health for 2011. Network members highlighted the importance that all actions had to be informed by a social determinants of health approach (as used in the AITHS), e.g. if we look at developing initiatives to address the mental health of Travellers we have to look at causality and not just the consequences, so discrimination and racism have to be addressed; lack of recognition of ethnic status for Travellers; lack of inclusion of Travellers history and culture in the education curriculum; inadequate accommodation provision; low levels of participation of Travellers in education and employment etc. so a more holistic approach has to be taken if we want to effectively address the mental health status of Travellers.

The NTHN felt that they did not want to lose the existing analysis, values, principles and relevant actions from the National Traveller Health Strategy 2002 which they feel together with the findings of the AITHS should inform any national actions plan developed for Traveller Health.

The network also felt before priorities were developed or implemented the first step should be to increasing awareness of the health status of Travellers (now that we have evidence based data from the AITHS) with policy makers, relevant government departments, service providers, Travellers and Traveller organisations. This can be done through the Department of Health working with the National Traveller Monitoring and Advisory committee to make presentation to other Government Departments and policy makers. Information can be disseminated to Travellers and Traveller organisation via the Our Geels website developed and resourced by Pavee Point, which has PDF files on the detailed study reports, power presentations on the key findings and the DVD on study results.

# 9.2 Five key prioties for action selected

1st Priority: Social Determinants - Discrimination/ Employment/ Education Health and Accommodation

Proposed actions:

- Ethnic identifier to be included on all health data sets
- Traveller Proofing of public policies

- Equality proofing of access, participation and outcome to all health services for Travellers.
- Affirmative actions as required to address the ongoing inequality in health outcome experienced by Travellers.
- Representation of Travellers on all relevant national foras including the High Level Officials Group (HLOG)
- Implementation of the actions in the Traveller Education Strategy
- Implementation of the Local Traveller Accommodation plans
- Anti-racism training for all service providers and development of codes of practice
- HSE to act as advocates for Traveller Health.

# 2nd Priority: Access, Participation and Outcome to Services for Travellers

### Proposed actions:

- Linkage with HSE Primary Care Teams, build on the learning emerging from the pilot in Wicklow with the PHCTP and role out with other Primary Care Teams.
- Development of Good Practise Guidelines for Traveller inclusion in Primary Care Teams (being developed by Pavee Point and the NTHN)
- Mapping of services in areas where there is a population of Travellers
- Patient journeys on access, participation and outcome to Health Services for Travellers
- Pilot ethnic identifier with Primary Care Teams
- Traveller Proofing of all services and policies than inform them
- Development of Codes of Practise and Training on Traveller Health and culturally appropriate provision for service providers
- Identification of models of good practice in relation to health initiatives with Travellers

### 3rd Priority: Mental Health, Addiction and Suicide

### Proposed actions:

- Patient journeys on access, participation and outcome from mental health services for Travellers to identify gaps.
- Counselling support for siblings and family members
- Bereavement/Console training and support
- Training and support on suicide
- Traveller proofing of mental health services to make them more accessible for Travellers

- Explore appropriate linkages and engagement between PHCTP's and local mental health teams
- Identification and dissemination of learning from existing models of good practise in relation to Traveller's mental health, addiction and suicide.
- Training on Traveller Health and Cultural appropriate provision for service providers
- Development of modules and training materials on mental health and addiction for Traveller Projects.

# 4th Priority: Men's Health

Proposed actions:

- Development new programmes to engage Traveller men
- Identification and dissemination of learning from existing models of good practise in relation to Traveller men's health
- Link with Traveller youth projects to target young men's health.
- Development of appropriate modules and materials
- Address barriers to access to screening services for Traveller men

# 5th Priority: Lifestyle and screening

Proposed actions:

### Lifestyle

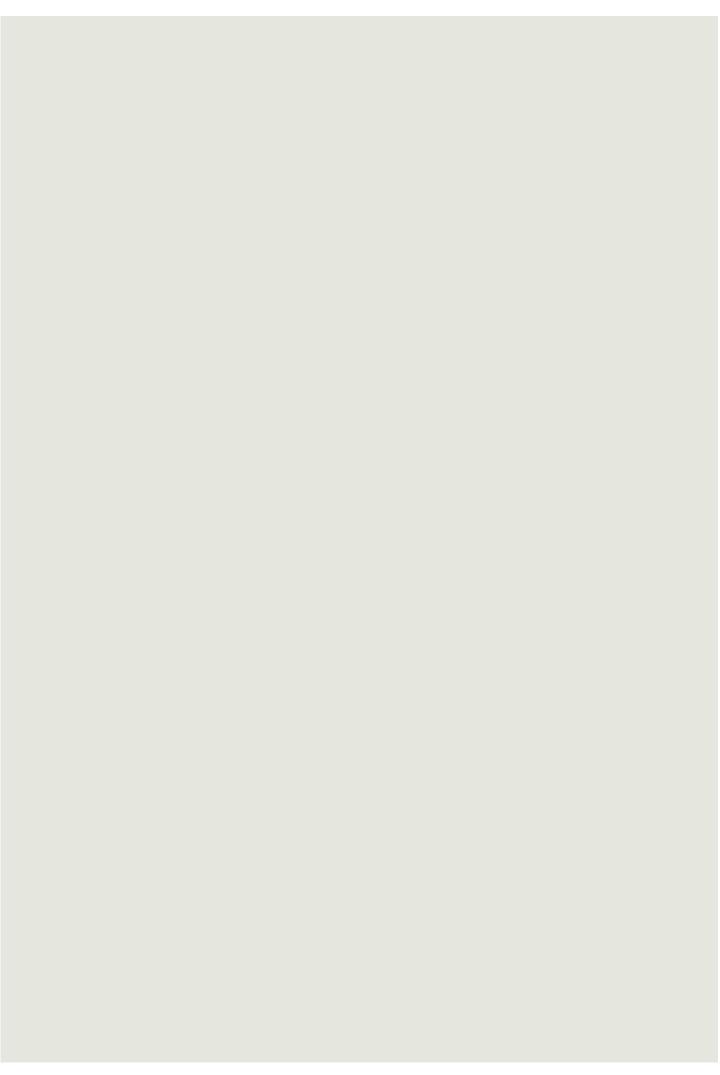
- Training modules and materials on nutrition, exercise, smoking and alcohol.
- Identification and dissemination of learning from models of good practise on diet, exercise, smoking and alcohol.
- Adaptation of 'smoke busters' programme for Travellers
- Encouragment of Travellers to engage with local sports and exercise initiatives

### Screening

- Cardiovascular
- Cancer
- Respiratory disease
- Diabetes

Table 7: Traveller Families Enumerated by County in the AITHS 2008.

County	No Of Families	%
Carlow	144	2%
Cavan	175	2%
Clare	213	2%
Cork	1,061	12%
Donegal	236	3%
Dublin	1,344	15%
Galway	1,030	11%
Kerry	378	4%
Kildare	214	2%
Kilkenny	114	1%
Laois	133	1%
Leitrim	60	1%
Limerick	626	7%
Longford	222	3%
Louth	344	4%
Mayo	316	4%
Meath	251	3%
Monaghan	134	1%
Offaly	308	3%
Roscommon	85	1%
Sligo	132	2%
Tipperary	288	3%
Waterford	154	2%
Westmeath	386	4%
Wexford	502	5%
Wicklow	206	2%
Total	9,056	100%



# To access copies of the Summary Report and the four detailed AITHS reports shown below:

http://www.dohc.ie/publications/traveller\_health\_study.html. www.pavee.ie/ourgeels



Missy Collins called on the Department of Health and the HSE to ensure that money allocated to Travellers health gets spent in that area of work.

"I'm very frustrated when I hear some of the findings from this Study and I know of the health needs of my people, and that many of us are dying too young. We all need to work together to improve Travellers' situation in Ireland. This study shows that there has been much done in addressing Travellers health but that there is much more to do and the funding that should be there is made available to address the new issues emerging from the study as well as the important work we have already been doing."

# According to Martin Collins:

"The study clearly shows that health is too important an issue to be left to the medical profession, neither can Primary Health Care for Travellers Projects be seen as a panacea for addressing all Traveller health needs.

We urgently need a time limited action plan to prioritise the findings of this study. Traveller organisations are ready, willing and able to do our part, and we have already established trust and good working relationships with the HSE; we look forward to working in collaboration with all other stakeholders."

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