

# Dying fifteen years early – what can Traveller men and relevant agencies do?

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Application of Research Methods in Social
Work

**Submitted October 2012** 

The dissertation is being submitted to fulfil a NI Leadership & Strategic Award under the Northern Ireland Post Qualifying Education and Training Framework in Social Work and for the MSc Professional Development in Social Work of the University of Ulster.

Final Version: November 2012

"It has never been done. It needs to be done, but if it isn't done Traveller men will die of ignorance. They wouldn't answer it to a woman or have the confidence to go to a professional. This survey will give them the confidence. When they voice it - they know they can talk about it. Men believe they have to be strongthis survey is the help they need."

(Ellen McDonagh [Traveller Advisor], 31 October 2011)

### **ACKNOWLEDGEMENTS**

### **Traveller Advisors**

Special thanks to the Traveller Advisors without whom, this research would not have been possible;

Michael Purcell

**Ned Doherty** 

Martin Ward

Martin McDonagh

Michael McDonagh

Kathleen Sheridan

Ellen McDonagh

**Bernard Ward** 

Martin Maughan

Charles Maughan

(And two people who wished to remain anonymous)

## **Traveller Participants**

Thanks to everyone who gave so generously of their time so that others might learn!

## **University of Ulster**

Dr Anne Campbell - for moving research ideas into action and steady support as my tutor

Dr Brian Taylor- for enthusiastic teaching and good leadership Dr Roger Manketlow- for working over his Christmas holidays to help me meet deadline for ORECNI application! Dr Anne McGlade- for inspirational teaching

Nick Curry University of Ulster – for ethical assistance

Elaine McCormick University of Ulster- for ethical assistance

#### **Southern Health and Social Care Trust**

Mark Irwin - for supervision and positive encouragement in his role as Practice Assessor to me

Maureen Devlin - for finance and solid support

Valerie Hamilton - for unwavering support and attention to ethical detail

Irene Knox - for constant encouragement

Dr Peter Sharpe - for early advice on ethical issues

Gerard Rocks - for management support

Melanie McClements - for support in accessing Trust Focus group and help with morale

Other participants in Trust focus group including: Declan Larkin, Lynda Gordon, Carolyn Agnew Angela Corr, Jacqueline Connolly (Co-operation and Working Together) and John McGrath (HSCB) Promoting Wellbeing Team for support throughout Special thanks to Karen Faloon PWBT secretary

## Southern Area Action with Travellers (SAAT)

Jim Maye - chairman of SAAT, Southern Education and Library Board

Martin O'Neill – Health and Social Care Board

Mary Black – Public Health Agency

Teresa Moley – Equality Commission N.I.

Caroline Coleman – Southern Regional College

Louise Gregory- Wade Training

Lisa Moore, Safe and Well Stella McLoughlin - PWBT

Staff in Traveller Support Groups including:

Trevor McMahon Safe and Well (one of the first to assist with literature and support)

Fidelma McCoy, Armagh Traveller Support Group;

Geraldine Donnelly, An Tearmann;

Lisa Hogg, Craigavon Traveller Support Group;

#### Clerical

Valerie Maxwell and Yvonne Neill– for skilful analysis and presentation of results

#### **ORECNI**

Special thanks to Jan Daley for helping to meet an impossible deadline of January 3<sup>rd</sup> 2012 for submission to ORECNI!

All members of the ORECNI committee for their constructive feedback

### **Professional advice**

Special thanks to a range of people who provided invaluable literature or advice during the research including:

Dr Patrice van Cleemput

Dr Philip Brown

Dr Noel Richardson

Nick Clarke

Richard O'Neil

Colin Fowler

**Dolores Atkinson** 

Dr Mick Adams

### **Dissemination**

Thanks to the staff and management committee of Safe and Well for financial assistance for the accompanying DVD to disseminate findings, and in running a seminar to launch this research (courtesy of the Big Lottery Fund)

Special thanks to Vivienne Reid, Safe and Well for invaluable help with launch of results.

### And finally last but definitely not least...

Joan, Annie, Dervla, and Eoghan for patience in putting up with my absence from family life! Special thanks to my wife Joan for painstakingly working with me on the final, final version!!

## **TABLE OF CONTENTS**

Contents		Page
Acknowledgeme	ents	(i)
Table of Conter	nts	(v)
List of Tables		(viii)
List of Figures		(viii)
Abstract		(ix)
CHAPTER 1	INTRODUCTION AND CONTEXT	1
1.1.	Employment history and	0
1.2. 1.3. 1.4.	qualifications Professional interest Rationale Aims and objectives	2 2 3 3
CHAPTER 2	LITERATURE REVIEW	5
<ul><li>2.1.</li><li>2.2.</li><li>2.3.</li><li>2.4.</li><li>2.5.</li></ul>	Introduction Men's Health: General Indigenous/ Nomadic men Racism and health The All Ireland Traveller Health	6 10 12 16
2.6.	Study Summary	17 19
CHAPTER 3	METHODOLOGY	21
3.1. 3.2. 3.3. 3.4. 3.5. 3.6.	Overall design and methodology Traveller Advisors Traveller Support Groups Design of structured interviews Validity and dependability Focus groups with key informants from strategy meetings	22 25 26 26 27
3.7.	Sampling	26 28

3.8. 3.9.	Ethical approval  Method of Analysis	29 32
CHAPTER 4	FINDINGS	34
Section 1	Demographic profile	36
4.1.1.	Participating families	38
4.1.2.	Age	39
4.1.3.	Area of residence	40
4.1.4.	Accommodation	41
4.1.5.	Employment	43
4.1.6.	Experience of trades	44
4.1.7	Father's trade	46
4.1.8.	Age joining and leaving school	46
4.1.9.	Qualifications attained	49
4.1.10.	Literacy by area and barriers	50
Section 2	Lifestyle	53
4.2.1.	Fitness	55
4.2.2.	Blood pressure, cholesterol and diet	57
4.2.3.	Drugs and alcohol	59
4.2.4.	Smoking	61
4.2.5.	Protection against hazardous	
	substances	62
Section 3	Mental health	66
4.3.1.	Culture	68
4.3.2.	Discrimination	75
4.3.3.	Domestic violence	86
4.3.4.	Stress	88
0	B.B 4 . 124	00
Section 4	Mortality	90
4.4.1.	Reasons for dying early	92
4.4.2.	Main causes of death	94
4.4.3.	Suicide	98
Section 5	Access to services	100
4.5.1.	Access to primary care	101
4.5.2.	Rating for doctors and nurses	102
4.5.3.	Reasons underlying rating of GPs	103
4.5.4.	When to see a doctor	104

4.5.5. 4.5.6.	Who do you mention pain to? Belief in people with cures	105 107
<b>Section 6</b> 4.6.1. 4.6.2.	Health information Sources of health information Rate sources of health information	<b>112</b> 113 116
<b>Section 7</b> 4.7.1. 4.7.2.	Groups that would interest men Groups that would interest men Cross cutting themes	<b>120</b> 121 126
CHAPTER 5	DISCUSSION	131
5.1.0 5.1.1	Limitations of methodology Action research and ethical	132
	considerations	132
5.1.2.	Sample	133
5.1.3.	Objectivity and bias	134
5.1.4.	Piloting and recording and instruction errors	135
5.2.	Social determinants of health	135
5.3.	Male engagement, masculinity and	420
5.4.	gender  Region sectorionism and	138
5.4.	Racism, sectarianism and discrimination	142
5.5.	Community development, community	142
J.J.	infrastructure and empowerment	152
5.6.	Adopting a health promotion/	
	preventative approach	158
5.7.	Primary Care	159
CHAPTER 6	CONCLUSION	164
CHAPTER 7	RECOMMENDATIONS	167
REFERENCES		180
APPENDICES		198
Glossary		344

List of Tables		Page
Table 1	Knowledge of domestic violence services by area	86
Table 2	Who do you mention the pain to?'	105
Table 3	Sources of health information	115
Table 4	Rate sources of information	119
List of Figure	es	
Figure 1	Population pyramid of Traveller community in Northern Ireland 2008	8
Figure 2	Population pyramid of the general	
	Northern Ireland population	8
Figure 3	Comparisons of life expectancy for Indigenous peoples in Australia, Canada, New Zealand and the United	
	States of America	13
Figure 4	Overview of the overall design	. •
1.90.0	and methodology	22
Figure 5	The embedded design	24
Figure 6	Thematic map of demographic	
· ·	Profile	37
Figure 7	Profile of participating families	38
Figure 8	Age profile	39
Figure 9	Area of residence	41
Figure 10	Accommodation Type	42
Figure 11	Experience of trades	45
Figure 12	Literacy by area of residence	50
Figure 13	Thematic map of lifestyle	54
Figure 14	Protection against hazardous	
	substances	63
Figure 15	Thematic map on factors affecting mental health	67
Figure 16	Thematic map on causes of	07
	mortality	91
Figure 17	Access to GP Surgery	101
Figure 18	'How do you rate doctors and	
-	nurses'?	103
Figure 19	Belief in people with cures	109
Figure 20	What would make the biggest	
	difference to health?'	156

### **ABSTRACT**

The All Ireland Traveller Health Study (2010) highlighted Irish Traveller men were dying 15.1 years earlier than Irish men in general.

This two stage qualitative study, using action research methodology and a cross sectional design, explored Traveller men's views as to why this might be, and what they and relevant agencies should do.

Structured interviews co-designed by Traveller Advisors elicited qualitative and quantitative data.

Findings were presented to two focus groups internal and external to the health sector, and recommendations made on health improvement.

A literature review covers worldwide inequalities in men's health which deepen for indigenous and nomadic men. Studies only rarely engage Traveller men in health research.

Information was covered on *demography:* accommodation, age, education, unemployment, and experience of trades; *lifestyle*: exercise, nutrition, cholesterol, blood pressure, drugs and alcohol, smoking and protection against hazardous substances; *mental health:* discrimination, impact of culture on health, stress and domestic violence; *mortality:* causes including suicide and *access to services:* primary care and belief in people with cures, *health information*, sources and rating and *groups that would interest men.* 

This information highlighted the complexity of the problem and that no single reason existed for dying 15 years early, but many interrelated factors requiring multi-faceted solutions.

The research concurs with Richardson & Carroll (2008) that the men's health movement is comparatively modern and approaches which combine health promotion/ prevention with holistic health and a social determinants/ community development approach are best practice. However action is also required to tackle racism and discrimination including a refreshed Racial Equality Strategy and a cultural shift in attitudes by the general population.

A robust community/ voluntary/ statutory sector partnership infrastructure critically enabled implementation of action research principles with the Traveller men and promoted high levels of engagement.

## **CHAPTER 1 INTRODUCTION AND CONTEXT**

### 1.1. Employment history and qualifications

I qualified as a social worker in 1986. My early employment included community arts and youth and community work in the voluntary sector, and adolescent social work and community work in legacy health trusts. As a community worker in the Craigavon and Banbridge Trust I completed Practice Teaching and Post Qualifying Awards in Social Work in 1996 and 1997. I moved to a Community Development Manager post in the Newry and Mourne Trust in 2001.

The Promoting Well Being Department (PWBD) in the Southern Health and Social Care Trust (SHSCT) was established following the merger of four legacy Trusts and brought Health Promotion resources at area and locality levels together with Community Development Teams from legacy Trusts.

Since 2008 I have worked as a Promoting Wellbeing Manager (PWBM) in the SHSCT. In 2011 I obtained a Postgraduate Diploma in HSC Management.

The SHSCT Promoting Well Being Strategy (2010) outlines a number of key settings, priority groups, (including Black and Minority Ethnic [BME] groups), issues and approaches. Key approaches include personal and public involvement, community development and health improvement.

#### 1.2. Professional interest

My professional interest in this research stems from past experience as a Youth and Community Worker (1988-1992) with Newry Travellers and my current role as the PWBD Black and Minority Ethnic (BME) lead. I represent the Trust on partnerships with part or full focus on Travellers' needs including the Southern Area Action with Travellers group (SAAT), Safe and Well (SAW) and Belong. I also manage a Traveller Family Support Worker.

#### 1.3. Rationale

The impetus for this research came from the All Ireland Traveller Health Study (AITHS, 2010). According to this study:

- In 1987 the gap in life expectancy between Traveller men and settled men was 9.9 years (AITHS, 2010, p. 94);
- A male Traveller now can expect to die 15.1 years before
  his general population counterpart aged 61.7 (AITHS, 2010,
  p. 95).

These statistics represent a significant health inequality and provide the rationale for this study.

## 1.4. Aims and objectives

#### **Aims**

 To explore adult male Traveller health in the Southern Trust area through Traveller men's own viewpoint to inform the development of services aimed at improving their health and wellbeing.

### **Objectives**

To explore Traveller men's attitudes to findings in the All
 Ireland Traveller Health Study about inequalities in their

- health and what actions they, and relevant agencies, need to take to improve their health status.
- To identify responses from relevant community, voluntary, and statutory sector groups to Traveller men's expressed views on the factors that would make a difference to their health.
- To conduct an international literature review on male nomadic health in order to explore cultural and service barriers to accessing services and identify models of best practice.
- To fulfil requirements for the author's NI Leadership &
  Strategic Award under the Northern Ireland Post Qualifying
  Education and Training Framework in Social Work
  (Appendix 1) and for the MSc Professional Development in
  Social Work of the University of Ulster.

## **CHAPTER 2 LITERATURE REVIEW**

### 2.1. Introduction

This literature review will begin with a definition of the term "Travellers" set within a legal and cultural context, followed by definitions of key concepts. The study is then set within the wider context of generic men's health at European, Republic of Ireland and Southern Trust levels.

Inequalities in health experienced by indigenous / nomadic communities across the world including the Aboriginal and Torres Straits Islanders, Canadian First Nations and Māori communities are highlighted. Communities living within developed nations have been chosen to enable more suitable comparison.

Inequalities faced by Gypsy, Traveller and Roma Communities in the UK and Ireland are noted, before concluding that although aspects of Traveller men's health are covered in the literature addressing health status and inequalities, racism, access to services, lifestyle, health promotion, ethnicity/ culture, mental health, equality and social determinants of health, studies focused exclusively on Traveller men's health are rare.

A strategy for gathering information was adopted as described below. First, computer and manual searches were undertaken, using online and catalogue resource, at the University of Ulster at Jordanstown. Searches were conducted using online databases including Medline, Proquest, Cinahl, Psychinfo, ASSIA and Ovid. Additional information was sourced from the Men's Health Forum websites in Ireland and Europe. Follow up searches to literature cited in Van Cleemput (2010) and in the AITHS (2010) were undertaken. Key words used to refine the search strategy

included 'Traveller's Health', 'Traveller men's health', 'Ethnology', 'Aboriginal men's health', 'Gypsy', 'Romany men's health', 'men's health', 'inequalities in health', 'social determinants of health' with 'social work', 'health promotion' and 'nursing' added. The literature included books, journals, professional magazines and policy documents.

The SMR tells us how much worse or better any particular group is compared to the general population.

SMR = Observed Deaths divided by Expected Deaths x 100.

The Standard Mortality Ratio for Traveller men is 3.7 times that of the general population (AITHS, 2010, p. 90).

The AITHS estimates that -

There is a population of 3,905 Travellers in Northern Ireland living in 1,562 families (AITHS, 2010, p.85).

43% of Northern Irish Travellers were living in the Southern Trust area in Newry, Armagh, Dungannon, Coalisland and Craigavon in March 2011 (SAAT, 2011 p. 11). There were 251 adult Traveller males in the SHSCT area in March 2012 (SAAT, 2012, advanced viewing - estimate for Dungannon unavailable).

The age profile of the Traveller Community in Northern Ireland is markedly different from that of the general population as a comparison of *Figure 1* and *Figure 2* demonstrates. 75% of Travellers are under thirty and only 1% over sixty-five. The variation is particularly stark in older age groups. This reflects in part a higher birth rate, higher mortality rates and inward migration from the Republic of Ireland.

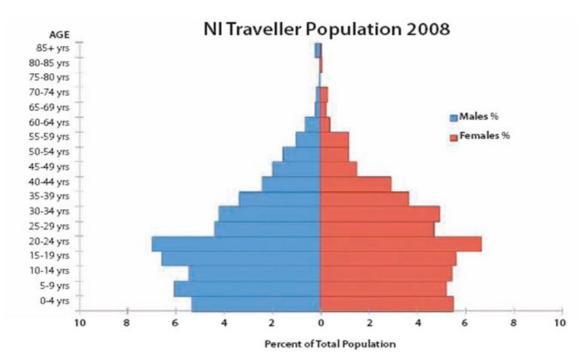


Figure 1 Population pyramid of Traveller community in Northern Ireland 2008 (courtesy of Gossrau-Breen D 2010, PHA)

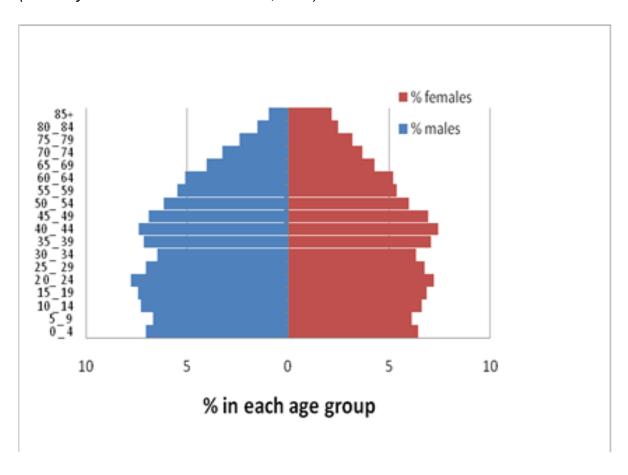


Figure 2 Population pyramid of the general Northern Ireland population (courtesy of Gossrau-Breen D 2010, PHA

### 2.1.1. Ethnicity

The Race Relations (Northern Ireland) Order 1997 recognises Irish Travellers as a racial group within the meaning of the law. It defines the Irish Traveller community as

"a community of people commonly so called who are identified (by themselves and others) as people with a shared history, culture and traditions, including, historically, a nomadic way of life on the island of Ireland" (Part 1, Article 5, 2a).

For this reason many practitioners would concur with Van Cleemput (2010) who pleads that a capital T is used when writing the word 'Travellers', as they are a recognised ethnic group and should be afforded this respect. However the literature is replete with lower case references.

#### 2.1.2. Culture

In the 1960s and 1970s, Traveller culture came under scrutiny from policy makers and academics from anthropological, historical, and sociological backgrounds.

According to Rozelle (2008) there is now a general consensus from this literature that Travellers base their lives around their extended families and are a collectivist society, following a "gemeinschaft" community model rather than the individualistic, competitive "geselleschaft" one in which most contemporary Irish persons live. This means that Travellers do not define themselves by what they do for a living or where they live, but by their genealogies and the names of their relatives.

### 2.1.3. Definitions of key terms and concepts

Appendix 2 contains definitions of key terms including 'relevant agencies' and 'men's health' and key concepts relevant to this research, including 'health inequality' and 'inequity', 'social determinants of health', 'primary care', 'community development', 'asset based approaches', 'health promotion', 'racism', 'sectarianism' and 'discrimination'.

### 2.2.0. Men's Health: General

### 2.2.1. Men's Health - Europe

The State of Men's Health in Europe (EC, 2011) highlights the range of mortality and morbidity data arising from different health conditions that affect European men, and does so through the perspective of men's lives.

Patterns emerge that show marked differences between the health of men and women in Europe (life expectancy for men is 76.1 as compared to 82.2 years for women) and at the same time large disparities in health outcomes between men in different countries, and within male populations in each Member State.

The main message is that there is a high level of preventable premature morbidity and mortality in men, which will only be addressed by targeted activity across the lifespan.

## 2.2.2. The Republic of Ireland (ROI)

In recent years, there has been a growing concern about the burden of ill-health experienced by men in Ireland (Richardson, 2004; McEvoy & Richardson, 2004). Male life expectancy is

almost 5 years lower than female life expectancy (CSO, 2006) and men in Ireland have higher death rates for most of the leading causes of death across the lifespan (CSO, 2003; CSO, 2005). The National Men's Health Policy (Richardson & Carroll, 2008) is an example of a national gender proofed policy and builds on key principles through adopting approaches which consider: gender mainstreaming, social determinants (Courtenay, 2000), community development, health promotion/ prevention, intersectoral and interdepartmental work, tackling men's health from a strengths perspective and supporting men to become more active agents and advocates for their own health.

### 2.2.3. Northern Ireland

In 2006-08 male life expectancy in Northern Ireland reached 76.4 years which represented a 0.8 year increase from 2001-03. Female life expectancy also increased by 0.8 years to reach 81.3 years in 2006-08 (Rodgers & Stewart, 2011)

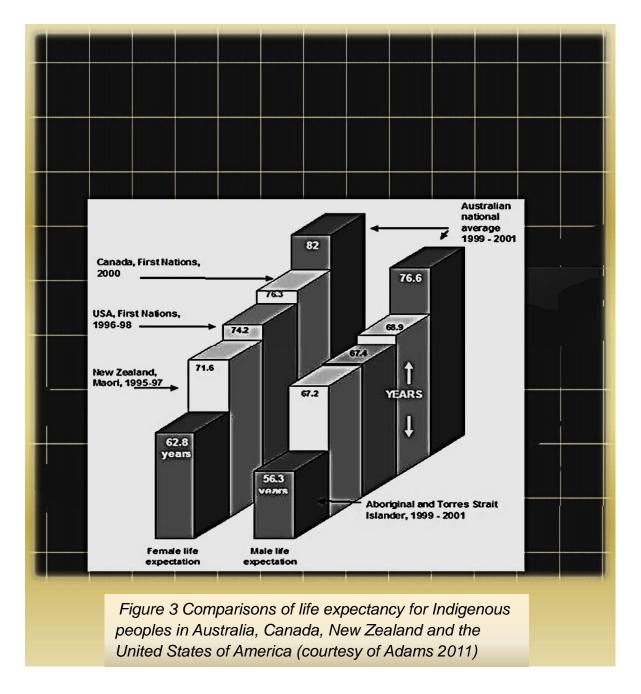
Cushnahan (2008) puts forward reasons for inequalities between men and women including: poorer use of health services (Institute of Cancer Research, 2009; Southern Investing for Health, 2007); a lack of political will to tackle men's health on the one hand, but problems with men not effectively campaigning for improvement on the other; ineffective gender biased health promotion campaigns; and lifestyle choices including smoking, drinking (Marques - Vidal et al, 2000) and taking illegal drugs.

## 2.3.0. Indigenous/ nomadic men

### 2.3.1. Indigenous men- international

Literature from indigenous communities provide useful comparisons for Travellers, as studies show comparable inequalities in life expectancy and levels of economic, social and educational disadvantage contributing to poor health outcomes.

According to Adams (2011) Aboriginal and Torres Straits Islander men have by far the worse health outcomes of any sub-population in Australia with a life expectancy of 56.3 (20.3 less than non - indigenous men). Adams presents evidence of Māori men living to 67.3, USA First Nations, 67.4 and Canada First Nations, 68.9 (*Figure 3*) although more recently Māori life expectancy has risen to 69 years (Cormac 2007).



In 1999, New South Wales became the first Australian state or territory to adopt a men's health policy (NSW Health Department, 2000).

Brown & Macdonald (2009, p.16) contend that-

"Despite the commitment to the social determinants of men's and boys' health, there appears to be a growing emphasis on behaviourism: a 'men behaving badly' approach to men's health. Current government priorities of reducing smoking, unhealthy drinking and obesity risk overshadowing the social determinants of health."

In Canada First Nation men living on reserves die an average of 5 years younger than those living off reserve and 8.9 years younger than Canadian men in general (Frohlich et al, 2006).

In a review of 254 citations on aboriginal populations in Canada, Young (2003) concluded researchers had not adequately examined several important health needs of the aboriginal population. The proportion of papers did not reflect the demographic composition of aboriginal people in Canada.

Robertson et al (2009) contend that although Canada is internationally renowned for its health promotion policies, men's health has remained neglected nationally and recommends the establishment of a Men's Health Forum/Network.

## 2.3.2. Research into Traveller, Gypsy and Roma men

Research on health outcomes indicates that Gypsies and Travellers have the worst physical health outcomes of any ethnic group in the UK (Parry et al, 2007). There are extremely high rates of morbidity associated with cardiac problems, diabetes, asthma and arthritis, and high rates of hereditary conditions associated with intra community marriage (Matthews, 2008).

Although there are extensive studies of Gypsy, Roma and Traveller (GRT) communities documented by Van Cleemput (2010) and in the AITHS (2010), scant attention has been paid to the issue of men's health.

In a literature review of 78 studies by Van Cleemput there are no studies cited which deal exclusively with GRT men's health.

Of the 489 studies cited in the AITHS there are only limited references to GRT men's health, although aspects of men's health and wellbeing are covered under: health status:- (Barry et al, 1989; Ginnety, 1993; Hajioff & McKee, 2000; Parry et al, 2004; Parry et al, 2007); inequalities:- (Battel-Kirk & Purdy, 2007; Balanda & Wilde, 2003; Blaxter, 1997; Cemlyn et al, 2009; Hawes, 1997; Marmot &McDowell, 1986); racism: - (Connolly & Keenan, 2002; Helleiner, 2000; MacLaughlin, 1996; McVeigh, 2007; O'Connell, 2002); access to services:- (Ginnety, 2006; Betancourt et al, 2002; Brach & Fraserirector, 2000); lifestyle:-(Fountain, 2006; Van Hout, 2009); health promotion: - (Smart et al, 2003); ethnicity / culture: - (Gmelch & Gmelch, 1976; Irwin & Dunn, 1996; Jenkins, 1997; Kirk & O'Baoill, 2002; Liegeois, 1987; Anter, 2008; McCann et al, 1994; Ni Shuinear, 1994); *mental* health: - (Kennedy et al, 2005; Linehan et al, 2002; Treise & Shepperd, 2006; Walker, 2008); equality: (Equality Authority, 2006; Equalities Review, 2007 Commission for Racial Equality, 2006); and social determinants literature (Farrell et al, 2008; Marmot et al, 2008; Wilkinson & Marmot, 2003).

The DHSSPS (2008) recommended carrying out a needs assessment into Traveller men's health and providing culturally appropriate material on men's health due to a lack of information on their needs.

There are some exceptions to the scant literature on Traveller men's health in the Republic of Ireland and United Kingdom.

O'Neill et al, (2008) identified a number of barriers to Traveller men engaging with health, including disconnection, fear of scrutiny, hierarchy and challenge of engagement, the need to be convinced, feeling left behind by Traveller women, machismo (The Men's Development Network, 2008), rigid paths to learning, previous experience of agencies, historical and economic suspicions.

Clarke (2010) reviewed activities in a Traveller men's group in Spring Lane Halting Site, Cork. Issues ranged from horses, land and facilities, training and education in trades to mental health, depression and the impact of suicides.

In relation to access to services, 63 per cent of Traveller attendees at a clinic in Ireland were women and 37 per cent were men (Clohessy- McGinley, 2002).

Men generally find it harder to access health services and it is particularly common for Traveller men to be stoical about their health (Parry et al., 2004; Van Cleemput et al., 2007).

Van Hout (2009) found high incidences of Traveller men presenting with increasingly problematic alcohol use, because of dissipation of their culture and their experiences of marginalisation, discrimination, depression, illiteracy and poverty.

### 2.4. Racism and health

According to Krieger (2000; 2003) research on racism as a determinant of poor health is a recent development. Krieger highlights three issues – the links between racism, biology and health; methodological controversies on how to study the impact

of racism on health; and debates over whether racism or class underlies racial and ethnic disparities in health. She argues race is a social rather than a biological category, with one group benefiting from dominating others. She describes direct and indirect methods to test the hypothesis 'does racism harm health?' and questions validity and recall in investigations relying on self- report.

### 2.5. The All Ireland Traveller Health Study

The All Ireland Traveller Health Study (AITHS, 2010) is the most comprehensive study of Travellers in Irish history and contains research activity from 2007 to 2010. Researchers employed a mix of quantitative and qualitative methods to conduct seven substudies: census of Travellers; quantitative study of health status and health service utilisation; mortality study; birth cohort study; qualitative consultation; service provider study; and Travellers in institutions study. Of the estimated 10,618 Traveller families on the island of Ireland 8,492 were interviewed for the study (78% ROI and 93% N.I.).

The study employed a 'social determinants' model (Dahlgren and Whitehead, 1991) which acknowledges educational, cultural, engagement (Mackenbach et al, 2008), and psycho-social issues (including the effects of discrimination [Krieger et al, 2005]). It supports the contention of Marmot et al, 2008) that health policies overly dominated by disease-focused and reductionist solutions at the level of the individual, without a wider appreciation of social determinants, are unlikely to be successful.

The most common causes of death included heart diseases and strokes (25%), cancer (19%), respiratory diseases (13%), and deaths from external causes (e.g. accidents, poisonings, drug overdoses, suicides.) Male Travellers had a suicide rate which was 6.6 times that of men in the general population and accounted for 11% of all Traveller deaths (AITHS, 2010, p. 91-94).

In NI 44.3% were diagnosed with high blood pressure and 36.8% with high cholesterol in the previous twelve months (AITHS, 2010, p.61).

As regards the social determinants of health, research into the economic activities of Traveller culture identifies an emphasis on income generation rather than waged employment. However with increasing regulation and enforcement in work areas associated with Travellers (e.g. recycling, waste disposal, horse trading) opportunities for self- employment have become more difficult to find (AITHS, 2010, p14).

Data from Connolly and Keenan (2002) cited in the AITHS (2010, p14) indicates that 59% of Travellers aged 16-24 left school with no qualifications compared to 17% of the general NI population. 92% of Travellers had no GCSEs or higher qualifications.

Literacy difficulties (reading and filling out forms) was reported by 28.8% of ROI families and 35.3% of those in NI, but 95.5% of ROI and 89.8% of NI family respondents could calculate change from a Euro or Pound Sterling as relevant (AITHS, 2010, p.46).

A majority of respondents (66.3% in ROI and 64.6% in NI) considered illicit drugs to be a problem in their community and this

was a consistent pattern for both men and women and across age groups. 53.9% of Traveller men in N.I. were smokers (AITHS, 2010, p67).

Four in ten Traveller respondents in ROI (40.3%) and 31.3% in NI reported eating fried food less than once per week, with just 11.8% in ROI and 12.9% in NI reporting daily consumption. Men were more likely to consume fried food frequently than women. 30.9% of Travellers said price was a factor that prevents them eating healthily (AITHS, 2010, pp. 71-72).

In ROI 41.0% had complete trust in health professionals treating them, compared to 34.6% in NI. Women reported more trust than men but there was no consistent age pattern.

83% of Travellers interviewed obtained their health information and advice from Primary Health Care for Travellers Projects (AITHS, 2010, p. 76).

However a limitation of the AITHS was that of the 88 research coordinators, 5 (6%) were male and of the 302 peer researchers, 6 (2%) were male, although the study did engage with males at preconsultation stage and in the survey.

## 2.6. Summary

Traveller men's life expectancy is 15.1 years less than the general population.

Traveller health inequalities are reflected in nomadic and indigenous groups across the world.

Studies of Traveller men's health, which engage men in the research design, are rare with Traveller women historically taking the lead.

Racism can have a detrimental effect on health.

The men's health movement is comparatively new and approaches which combine health promotion/ prevention with holistic health and a social determinants/ community development approach are considered best practice.

## **CHAPTER 3 METHODOLOGY**

## 3.1. Overall Design and Methodology

Figure 4 provides an overview of the overall design and methodology and is broken into three parts. Stages 1 – 9 addressed the question 'Dying fifteen years early- what can Travellers do?' Stages 10-12 answered the question 'what can relevant agencies do?' Stages 13-14 focused on the final report and dissemination.

Stage 1	Literature review	
Stage 2	Establish Traveller Advisors	
Stage 3	Structured interview design	
Stage 4	Submit research proposal	
Stage 5	Ethical approval	
Stage 6	Sampling	
Stage 7	20 structured interviews	
Stage 8	Analyse Stage 1 results	
Stage 9	Prepare Stage 1 results	
Stage 10	Focus Group 1 (Trust: n=6)	
Stage 11	Focus group 2 ( SAAT: n=8)	
Stage 12	Thematic analysis	

Stage 13	Complete report	
Stage 14	Dissemination	

Figure 4 Overview of the overall design and methodology

#### 3.1.1. Action research

This was primarily a qualitative study employing an action research methodology (Gilmore et al, 1986). A cross sectional survey (Sarantakos, 2005) was used to gather data from the Traveller participants:

"Action research...aims to contribute both to the practical concerns of people in an immediate problematic situation and to further the goals of social science simultaneously. Accomplishing this twin goal requires the active collaboration of researcher and client, and thus it stresses the importance of co-learning" (Gilmore et al, 1986, p.161).

According to Dick B (1993) action research lends itself to use in work or community situations. Practitioners can use it as part of their normal activities. Mainstream research paradigms in some field situations can be more difficult to use. This is especially the case with a group which has been traditionally hard to reach and is suspicious of statutory authorities.

Other researchers are using action research methods to ensure that their research instigates a process of empowerment for Gypsy- Travellers and enlightenment for researchers and commissioners (Greenfields & Home, 2006; Brown et al, 2007; Lomax, 2008).

#### 3.1.2. Mixed methods

Structured Interviews designed by Traveller Advisors utilised open and closed questions to elicit qualitative and quantitative data to interrogate biomedical, lifestyle and social determinant factors in Traveller men's health. Creswell & Clarke (2007) describe this kind of a mixed method design as the "Embedded Design" in which one data set provides a supportive secondary role in a study based primarily on the other data type (*Figure 5*).

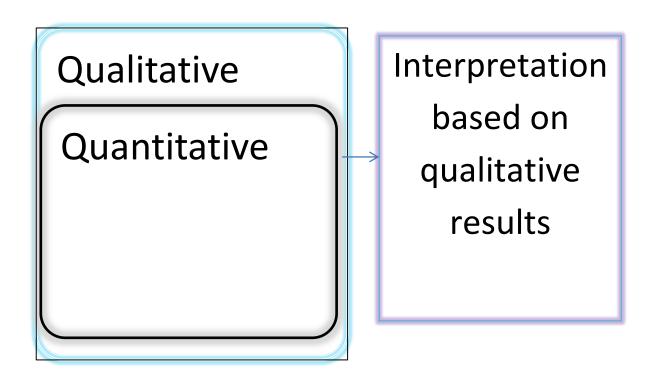


Figure 5 The Embedded Design (Creswell and Piano Clarke (2007, p68)

### 3.1.3. Focus groups

Flick et al (1991) advocate use of qualitative methodology when there is a need to study reality from the point of view of the subject and the standard of knowledge in the area of the research subject is inadequate. Flick (1998) also advocates the use of focus groups to test group strategies in solving problems.

Focus groups were held with key informants from 2 existing strategy groups; a multi-disciplinary Trust Traveller Action Group (n=6) and an Interagency Group comprising of representatives from health, housing, education, voluntary/ community sector and local government (Southern Area Action with Travellers, n=8). The purpose of these groups was to explore emerging themes in the primary research and answer the question 'what can relevant agencies do?'

#### 3.2. Traveller Advisors

To overcome mistrust, introductions to Traveller Advisors were obtained through Traveller Support Groups and personal contacts.

According to Brown & Scullion (2010) involving members of the community who are the focus of the study helps ensure the questions being asked are appropriate, methods of consultation are unobtrusive, insight is gained into the cultural 'do's and don'ts', and contact is made with people who are suspicious of participating, hidden, or difficult to engage.

The Advisors (8 male and 4 female, n=12) drawn from 5 areas, agreed the terms of reference and ensured that questions were culturally appropriate. They designed the structured interview and helped with access to men in each area using a "key informants" approach (Bloor & Wood, 2006). Although in some studies trained peer researchers conduct research, considerations around confidentiality and time led this author not to pursue this route.

Advisors were aware of the potential need to supplement the sample with additional recommendations from Traveller Support Groups, due to family dynamics.

### 3.3. Traveller Support Groups

Traveller Support Groups are community groups which employ staff to assist Travellers with health, accommodation, education and community development issues. In the Southern Trust area there are groups in Craigavon, Armagh, Coalisland and Dungannon. There is a Traveller Family Support Worker in Newry. In this study another area wide initiative 'Safe and Well', focusing on Traveller support, was included.

### 3.4. Design of structured interviews

Key findings relevant to men from the AITHS were discussed with the first Traveller advisor, and questions developed. The structured interview was refined through five subsequent meetings.

Considerations around sequencing of questions and analysis of the structured interview, as discussed on the Social Work Methods course, influenced the final version (Appendix 3).

Prompts and probes were used to encourage participants responses (Sarantakos, 2005, p. 278). Although Sarantakos (2005, p. 290) lists disadvantages of face to face surveys compared to telephone or mail surveys (high inconvenience, unsuitability for sensitive questions, and high cost), this is outweighed by advantages (a high response rate, more

opportunity to probe, the ability to conduct a long survey with high complexity, and opportunity to overcome literacy issues).

### 3.5. Validity and dependability

Research rigour and validity are perhaps more difficult to establish in qualitative, typically using a small number of participants, rather than in quantitative research (Bryman, 2004). However, over 8000 Travellers were surveyed in the AITHS which influenced the design of the structured interview in this study, contributing to its validity.

Participatory research approaches have emerged from studies that involved working with oppressed or powerless people and groups in developing countries (Fals-Borda &Anishur Rahman, 1991; Hall, 1993). According to Brown et al, (2012, p.4), researchers interested in enhancing marginalised people's voices, and ensuring their research has validity, have increasingly opted to involve community members in the research process (Temple and Edwards, 2006; Jacobs, 2007; Lomax, 2008). Furthermore it has been argued that research, without the involvement of the community being researched, cannot be entirely valid (Temple & Steele, 2006).

In this study validity has been increased by the participation of key informants (Traveller Advisors) in the compilation of all questions.

To ensure validity of the qualitative data gathered from interviews (Sarantankos, 2005, p. 268), an independent researcher analysed a sample of survey transcript data. Subsequently, she also

completed thematic analysis and compared her results with those of the primary researcher.

In promoting dependability (Guba & Lincoln, 1994) complete and accessible records at all stages of the research process were kept to facilitate independent audit.

# 3.6. Focus groups with key informants from strategy meetings

Results and preliminary recommendations were considered by two focus groups: a Trust Traveller Action group and Southern Area Action with Travellers (SAAT), an interagency strategy group co-ordinating Traveller work in the Southern Area. The AITHS was already known to these groups. The aim of the focus groups was to consider appropriate responses to the research findings from Stage 1 and to answer the question- what can relevant agencies do? (See Appendix11 and 12). Consent was sought from focus group participants for attribution of their comments to their department/ agency/ group (Appendix 14).

Findings were disseminated, using a DVD, to Travellers in partnership with Safe and Well and Traveller Support Groups, and to stakeholders in education, training, health, accommodation, councils and the community sector.

## 3.7. Sampling

Structured interviews were conducted with 20 Traveller men using a combination of key informants (Bloor & Wood, 2006) and purposive sampling approaches (Sarantakos, 2005, p.164).

In a key informants approach research subjects in ethnographic studies have a disproportionate weight and role in the conduct and outcome of the research and are 'key' in that they facilitate access through social networks. Without the help of Traveller Advisors the high response rate would have been harder to achieve, and the opportunity for real engagement and empowerment missed.

Purposive sampling produced subjects relevant to the project i.e. Travellers from a range of families, accommodation types, ages and locations. Purposive sampling was also used to choose two strategic focus groups: an area wide SHSCT multi-disciplinary group implementing recommendations from the AITHS (n=6) and an area wide inter-agency group promoting Traveller health and wellbeing (SAAT, n=8).

### 3.8.0. Ethical approval

### 3.8.1. Guidelines/ principles/ ethical approval

The research was conducted as advocated by 'Good clinical practice for investigators' guidelines' (ICH, 1996) issued by the Southern Trust's Research and Development Office. The researcher attended Trust training in relation to both this issue and the Application of Research Methods in Social Work. The Code of Practice for Research (2009) issued by the UK Research Integrity Office also informed practice.

Following review by the University of Ulster Research Ethics
Committee filtering system, ethical approval was sought and
obtained via the Office of Research Ethics Committees Northern
Ireland (ORECNI) and the Southern Trust's Research

Governance Committee. Permission to commence was subject to submission of amended documents (Appendices 15-17). Subsequent to the finding that 35% of the sample had problems with literacy, a substantial amendment was submitted for the production of a DVD to disseminate research findings. This obtained ORECNI and Trust approval (Appendices 18-19).

#### 3.8.2. Payment of expenses

According to Brown & Scullion (2010, p.178) in their review of Gypsy - Traveller research;

"It is becoming increasingly common for researchers to offer something to research participants to compensate for their participation".

Arguments favouring this approach include valuing participants' time, and affording a mark of respect to people experiencing financial deprivation. Reimbursement for participants' and advisors' meals were offered together with a thank you letter to acknowledge participants' time (Appendices 9 and 10).

### 3.8.3. Literacy/Culture

Traveller Advisors eliminated any potential problems arising from culturally inappropriate questions. Literacy difficulties were overcome by the researcher manually recoding structured interview responses, when required (Appendix 3).

# 3.8.4. Information needs arising from interview/ distress protocol

Following an introductory letter read by the researcher (Appendix 4) or Traveller Support Worker (Appendix 5) an information pack (Appendix 6) was made available to Traveller participants.

Backup copies of both were accessible through TSGs.

The pack detailed support services should men feel upset or distressed by anything discussed during the interview.

# 3.8.5. Legal issues including confidentiality and data management

The research was carried out in compliance with the Data Protection Act (1998) and Freedom of information Act (2000).

Confidentiality was addressed, as recommended by Babbie (1999), by making data anonymous through allocation of a unique identifier and by changing dates, place names and recorded personal information that might lead to the eventual identification of the participants. Interview codes and participant identification were kept in separate locations. Personal data was stored in a locked filing cabinet. A secure master identification file was created that linked the identifier to names to permit the later correction of missing or incorrect information.

A Participant Information Sheet (Appendix 7) and Consent Form (Appendix 8) ensured that participants gave informed consent and were aware of the implications of taking part.

Regarding unexpected disclosures, participants were informed both verbally and in writing (through the Participant Information Sheet) regarding the limitations of confidentiality, should professional misconduct or child protection issues become evident.

Written consent was gained prior to each interview. A consent form was presented to the Research Governance Committee as part of ethical approval. All participants were given a copy of their consent form. A written copy of their responses was available on request.

Information will be destroyed after 5 years, in line with Trust data retention policies.

Analysis of data was on a secure encrypted, password - protected laptop to comply with the Data Protection Act (OPSI 1998).

### 3.9. Method of Analysis

Responses from the interviews and focus groups were analysed using manual thematic data analysis to produce qualitative information (Burnard, 1991).

In stage 8 of the research, transcriptions from open questions in the structured interviews with 20 Traveller men were analysed using this method. This included reading and re-reading transcriptions to formulate, initially broad then refined headings. To aid validity an independent researcher repeated this process with 3 scripts. (Glaser & Strauss, 1967).

With categories agreed, each script was coded against each heading and the categories or themes were collated and written up.

The Statistical Package for Social Sciences (SPSS) was used to analyse the data gathered from the remaining closed or Likert - style questions within the interview. A code book was prepared for all closed questions in advance of the survey (Appendix 20).

In Stages 10-11 findings from this initial analysis were brought to two focus groups (N= 14). The transcriptions of these meetings underwent further analysis in order to inform the final recommendations of the report.

# **CHAPTER 4 FINDINGS**

In this chapter the findings from qualitative and quantitative analyses of the interviews are followed by focus group member's response analysis. Additional cross cutting themes raised by the focus group members are then presented.

Focus group members were provided with -

- Printed slides from a power-point presentation addressing an overview of the study aims, rationale and methodology, and summary responses to the structured interviews (Appendix 21) which they were invited to annotate
- Templates for the 7 sections of the findings. Each person was asked to complete the mortality section, due to its centrality to the research question, plus one additional section.

Group discussion in each of the focus groups (Trust Traveller Action Group, n=6 and Southern Area Action with Travellers, n=8) followed, which was taped and transcribed. Notes from the annotated power-point slides, response templates and group discussion were collected and subjected to thematic content analysis.

# **Section 1 Demographic profile**

This section will cover demographic profile including family, age, area, accommodation, employment, trades, and education. *Figure 6* provides an overview, using themes derived from the structured interview responses.

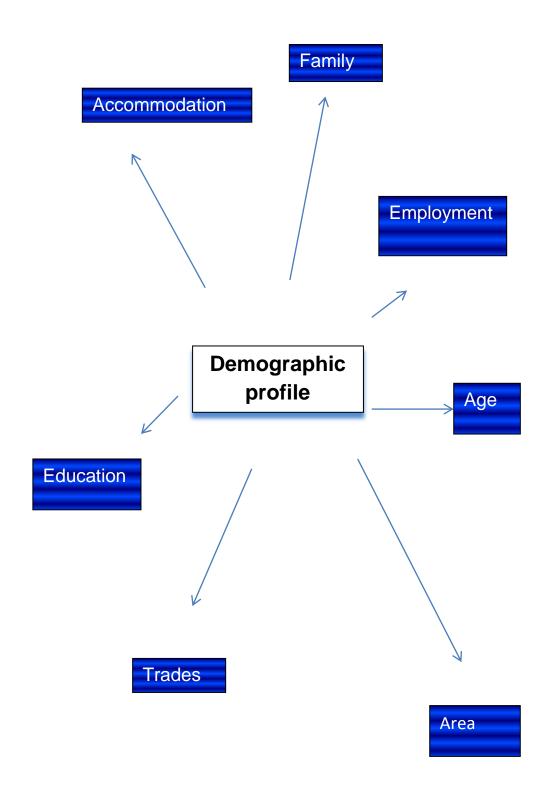


Figure 6 Thematic map of demographic profile

## 4.1.1. Participating families

Twenty Traveller men, from 6 family groups, were interviewed (*Figure 7*). Two family groups were predominant with 8 participants (40%)<sup>1</sup> from Family C and 5 (25%) from Family D.

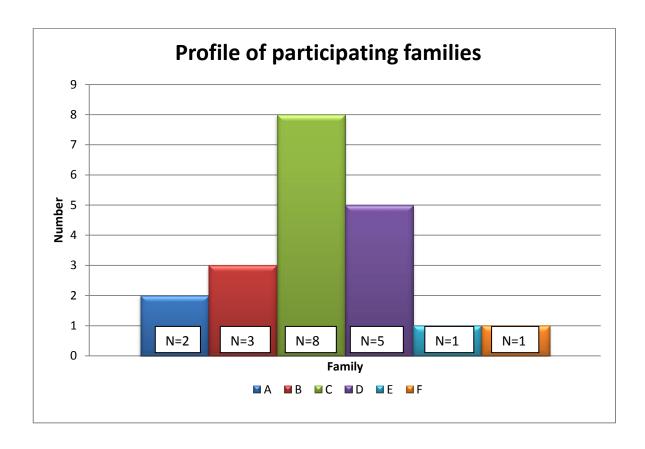


Figure 7 Profile of participating families

<sup>1</sup> The researcher used this style of reporting results using a number followed by a percentage on advice from Professor Brian Taylor

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(38)

### 4.1.2. Age

Age bands were based on the AITHS (2010, p86) with the lowest band being modified to 18 instead of 15 years to reflect the adult sample (*Figure 8*). There was a good spread across the life span with the highest number in the 25-39 age group; 7 (35%) followed by 6(30%) in the 40-64 age group and 5 (25%) in the 18-24 agegroup. Two people were interviewed in the 65 + age-group.

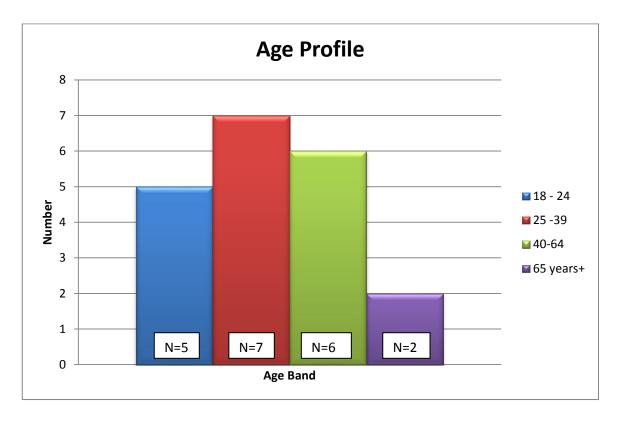


Figure 8 Age profile

### Response from focus group members

Seven respondents reacted to the slide on Traveller age with six focusing on their shortened life expectancy compared with settled people and one on how:

<sup>&</sup>quot;Travellers see themselves older beyond time".

#### Comments included:

"A 15 year gap - needs to be addressed as a priority".

"This is totally unacceptable and requires a new long term properly resourced initiative across the region".

Another was surprised that 2 men in the study were over 65 years old. This was perceived as a:

"Higher % of 65+ than demographic norm of 65+ Travellers".

### 4.1.3. Area of Residence

Four people (20%) were interviewed in Craigavon, Dungannon and Armagh (Figure 9).

A decision was made to interview a fifth person from Newry when the opportunity arose to interview two men from an un-serviced site in Newry, to improve representation in respect of accommodation type (see below).

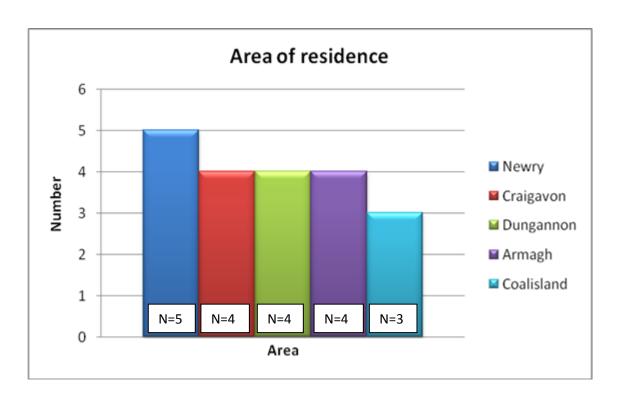


Figure 9 Area of residence

### 4.1.4. Accommodation

# Response from Travellers

12 (60%) of the sample resided in NIHE accommodation; 5(25%) on a serviced site; 2(10%) on an un-serviced site) and 1 (5%) in a Housing Association house (see Figure 10).

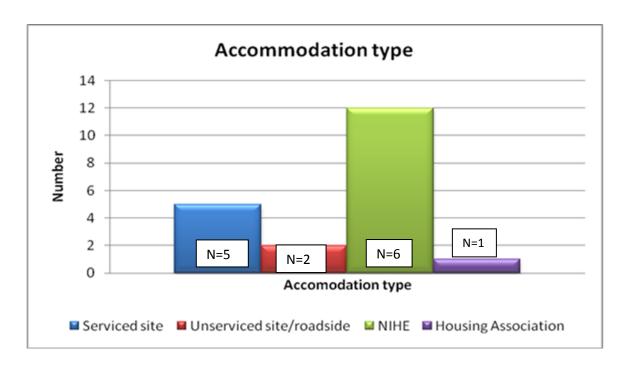


Figure 10 Accommodation type

### Response from focus group members

Seven members responded to the accommodation findings.

Two made a direct link between accommodation and Traveller health and wellbeing:

"Travellers moving into houses have had no impact on health improvement";

"Housing facilities have impacted on culture and the feeling of Travellers feeling hemmed in"

### Another suggested:

"Lifestyle programmes need to be tailored to the circumstances of housed Travellers recognising the negative impact housing has had on mental health".

Two highlighted the impact of accommodation type on ability to make generalisations from this study:

"12/20 NIHE- cautious with statistics".

### 4.1.5. Employment

### Response from Travellers

Overall 9 (45%) respondents indicated that they would normally be self -employed (usually casual employment). 15 (75%) indicated that they are currently out of work; 2 (10%) are of retirement age and 3 (15%) are currently self- employed. No-one was working for an employer.

### Response from focus group members

Eight respondents reacted to information about employment.

Three commented on high levels of unemployment:

"Significant levels of unemployment vs. settled community"

Three noted the importance of self- employment in Traveller culture. One felt this was a direct result of discrimination:

"Travellers don't seem to be able to access employment in 'normal society' at all- with a few exceptions they are treated as outcasts"

Another believed self- employment was a strong cultural value.

One respondent noted that Extern and Southern Regional College are currently developing Pathways to Employment for Traveller men.

One person believed that Travellers felt that working for someone else was a sign of weakness:

"Will not identify this as Traveller men do not want to look silly in front of other Travellers".

Two considered the implications for training, employment and education.

### 4.1.6. Experience of trades

# Response from Travellers

Figure 11 details the number of men with experience of various trades. The most frequently reported trades were scrap dealing 17 (85%), power-washing 16 (80%), market trading 14 (70%) and door to door sales 11 (55%).

No major differences in experience of trades across geographical areas were found.

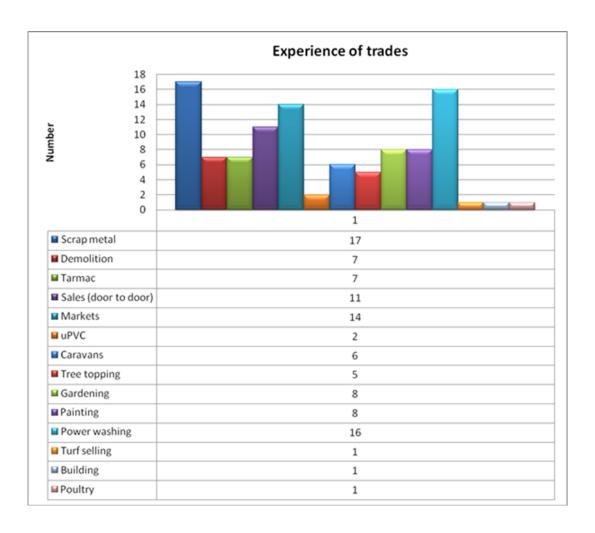


Figure 11 Experience of trades

### Response from focus group members

Focus group members commented on the prevalence of manual labour; the predominant trades; the failing nature of the traditional trades; and the barriers to training which included economic pressures, duration, entry requirements and perceived relevance:

"Prevalence of manual labour";

"Scrap, power-washing, UPVC, markets and sales";

"Old trades failing";

"Not seeing the benefit of general education and training as they all still provide for their families and don't believe that formal training will enhance that- rather it is seen as too time consuming";

"The duration of courses was a barrier, the minimum requirements are too high (GSCE English and Maths)".

Some focus group members suggested a change in mind set from Traveller men would be required

### 4.1.7. Father's trade

### Response from Travellers

In response to the question: 'Did your father also do any of this work or did he do something different?' 18 (90%) said yes, commenting that their father worked on the same or similar trades as themselves:

" Much the same – scrap and power-washing";

"Same power-washing and painting".

2(10%) said their fathers were tinsmiths, with one man stating
"Since Travellers moved into houses there's an issue with
making noise – hammering. You can still buy tin, but there is

no-one to keep the tradition going. Plastics also affected this".

### 4.1.8. Age of joining and leaving school

### Response from Travellers

In relation to leaving school early 13(65%) respondents gave no answer.

4(20%) stated they joined and left school to engage in religious milestones (sacraments of First Communion and Confirmation) as

school based preparation was their main reason for going to school, 1 (5%) completed school aged 16, 1 (5%) never attended. 1 (5%) made the following comment:

"School will chase Travellers up who leave school early, but live in houses. They won't follow you up if you're in a trailer because you are not part of their culture".

#### Another commented:

"I didn't attend full time as I was moving around a lot".

I (5%) attended night-school to learn to read and write.

### Response from focus group members

Ten respondents provided comments in relation to age of joining and leaving school. One person noted the importance for Travellers of accessing sacraments through school:

"To access sacraments of Holy Communion and Confirmation".

Three commented on 75% having left school by 14 and one person said:

"None 16+ in education".

One person noted the disadvantage of leaving school early as it was:

"likely to lead to limited literacy and qualifications – linkages with unemployment/ sense of wellbeing".

Two suggested the need for a link with policy:

"Education; we need a new strategy with new ideas.

Empowerment, confidence building etc. from early years";

"75% are out of school by age of 14 – why retention in post primary needs to be addressed – exemplars needed."

Others referenced the work of the Taskforce on Traveller Education, highlighted economic pressures, the duration, entry requirements and perceived relevance of education as challenges.

"Not seeing the benefit of general education and training as they all still provide for their families and don't believe that formal training will enhance that- rather it is seen as too time consuming".

#### She went on to note that:

"Traveller men are less interested in recreational courses and more interested in trades"

She suggested a change in mind set from Traveller men as a way forward:

"Travellers need to be able to see the tangible benefits of remaining in Further Education and Training"

#### She added that:

"Children should be encouraged and supported to remain in further education"

The issue of length of courses as a barrier was further elaborated:

"Lack of understanding that it can take up to three years full time including work experience to qualify for a trade- an impossible time commitment for Southern Regional College (SRC) courses- these requirements are not set by the SRC but by awarding bodies...The minimum requirements are too high (GSCE English and Maths)".

### 4.1.9. Qualifications attained

### Response from Travellers

In response to a question on whether any exams had been passed, 1 person reported attaining 8 GCSES, NVQ 3 in joinery and computer qualifications, 2 (10%) obtained Junior Certs, 1 (5%) obtained maths, science and sports qualifications and 1 reported grade C in first year exams.

9(45%) participants in Armagh and Newry reported no qualifications.

## Response from focus group members

Three people noted that there were no qualifications reported in Newry or Armagh and three noted that one person had obtained 8 GCSEs. One person remarked on problem reporting on such a low sample:

"Difficulty in using percentages in qualitative research (nos. are so small)".

### 4.1.10. Literacy by area and barriers

### Response from Travellers

Figure 12 provides details on literacy levels by area. Newry had the lowest levels of literacy with 4 (80%) out of the 5 reporting they couldn't read and write. In Coalisland all 4 (100%) respondents were literate. 3(75%) out of 4 in Craigavon were literate and similarly 3(75%) in Dungannon said they could read and write with the fourth person saying he could "a small bit".

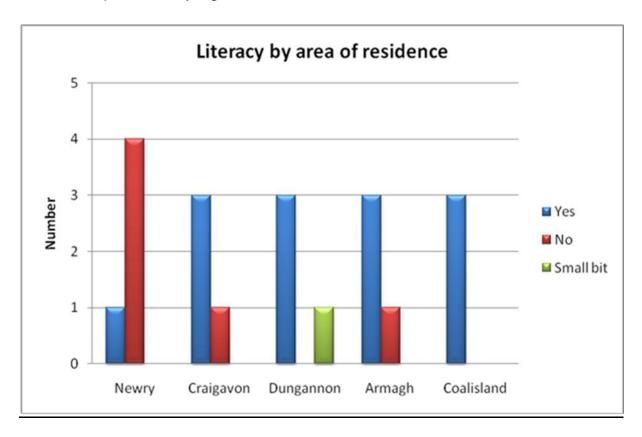


Figure 12 Literacy by area of residence

Of the 7 (35%) respondents with literacy problems all said they would like to read and write.

Barriers to reading and writing included negative school experience and a perception that it was now too late to learn.

### Response from focus group members

Six respondents noted that 35% had literacy issues and two advised comparison with other disadvantaged groups. Another noted impact of illiteracy:

"Implications – means to engage in relevant issues".

Five reacted to the statement that one man would like to learn how to order on e-bay, seeing this as a culturally relevant opportunity to introduce computer training:

"Opportunity for education to use the computer as a hook to wider education";

"Influences of IT – logical for Travellers;

Buying/selling important and reflects on culture";

"How to use e-bay- entrepreneurial spirit".

Three reacted to the comment that it was too late to learn:

"At 43 years of age man felt it wasn't worth learning"

One person remarked on the men's learning style:

"Learning styles- activist/ pragmatic"

One person stated she:

"Tried to run various courses and the level of literacy was a problem".

Literacy was viewed by her as an essential skill:

"Lack of literacy impacts on every course and it's the course SRC have found the lowest uptake. They would prefer oneto one classes - however they are not cost effective".

This respondent highlighted the CAWT (Co-operation and Working Together) Employment and Skills training as a model of success, but only for females:

"This was the first time a class of Travellers have gone to the SRC to take up IT and Literacy and Maths-however the classes are all female".

She suggested building numeracy and literacy into every training programme and training a:

"Traveller man to deliver training and pay him to deliver training to others".

She also favoured men only groups with proper commitment and suggested:

"Travellers themselves need to engage when something has been set up. We have set these up several times for men and they didn't turn up which is why I would stress that this has to be a two-way approach"

# **Section 2 Lifestyle**

This section covers fitness, blood pressure, cholesterol, diet, drugs and alcohol, smoking and protection against hazardous substances.

Figure 13 provides an overview using a thematic map.

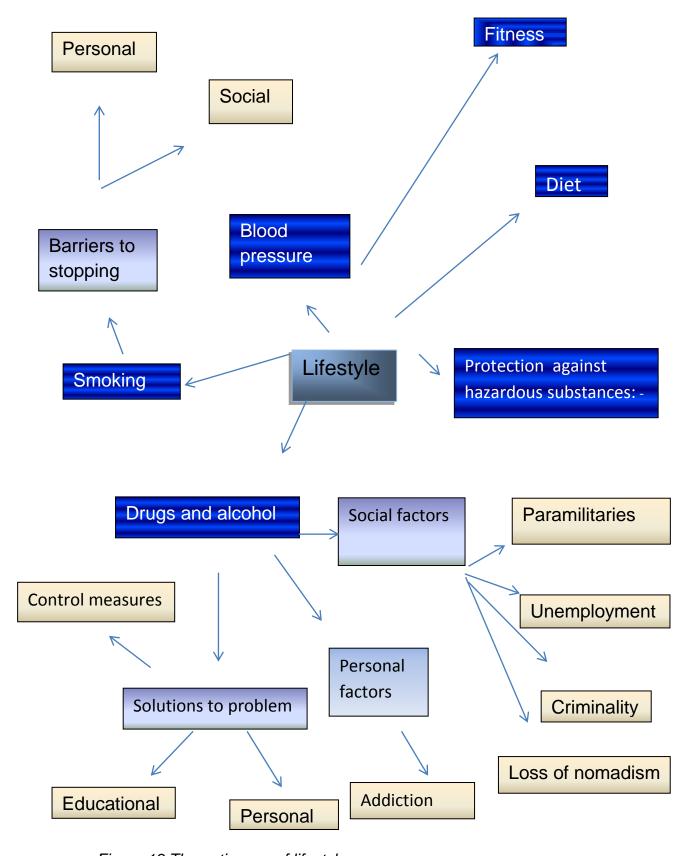


Figure 13 Thematic map of lifestyle

#### 4.2.1. <u>Fitness</u>

### Response from Travellers

When asked about fitness, 7 (35%) reported walking, of whom 2 also hunted, and 1 played golf. 7 (35%) said they don't keep fit:

"I don't- I'd be interested in joining a gym, but I have arthritis in the lower spine and in left knee cap, sciatica, and I am blind in one eye".

2 (10%) were interested in horses, 1 (5%) ran a half marathon, and 1 played handball in Cookstown but wanted a facility in Coalisland.

5 (25%) showed high levels of fitness and attended the gym:

"I am an All - Ireland Champion Boxer";

"I am a member of the certified Training Academy and Leisure Centre".

### Response from focus group members

Seven respondents reacted to the finding on fitness. Two commented on current activity and three made suggestions. Five reacted to the interest in handball. One queried the practicalities of handball in Coalisland:

"Is handball practical in Coalisland?"

Another spotted an opportunity to use it to incentivise a group:

"Use handball to retain a group".

Others suggested further exploration of handball with the Gaelic Athletic Association (GAA) and local councils.

One respondent reacted strongly to the finding on boxing, feeling that professionals and community groups were too quick to offer boxing at the expense of other activities:

"Travellers are stereotyped and offered boxing – is domestic violence more of an issue in Travellers?"

He went on to suggest an alternative:

"Thinking about Traveller men as personal trainers for lifestyle coaching etc."

One expressed surprise at the levels of walking:

"Wasn't expecting levels of walking".

She went on to suggest a:

"Focus on walking development and its benefits for mental health".

This respondent felt that Travellers in the study showed a higher percentage of physical activity than the settled community and this demonstrated individuals taking responsibility for their own fitness. Fitness was viewed as a social norm.

One person highlighted that duration of course and literacy were barriers to participation in a fitness course.

### 4.2.2. Blood pressure, cholesterol and diet

### Response from Travellers

In response to the question 'do you have high blood pressure and cholesterol?' 8 people (40%) reported high blood pressure and 7 (35%) high cholesterol. All respondents recognised healthy and unhealthy foods and could give examples of each.

### Response from focus group members

8 people reacted to the findings in relation to blood pressure and cholesterol. Reactions varied between:

Prevalence:

"High prevalence:"

Awareness:

"Improving awareness"

Primary care implications:

"Means they've been to have a test, usually age-related - opportunity for outreach service";

"Referred to Pharmacist and GP outreach initiatives";

Others suggested:

"Need to take health checks to Travellers wherever they are".

As regards diet, there was a mixed response from six members. One person highlighted the role Traveller women play in healthy living:

"The way to everyman's heart condition is through his stomach- educate Traveller women in relation to healthy living".

Another person suggested including Cook It Programmes in the PWBD with young women's groups:

"Could have an impact on the type of food that they cook for their families".

There were conflicting views about healthy eating with two people commenting about good awareness of healthy and unhealthy food:

"Good awareness of healthy eating"

This contrasted with:

"Traveller men have fries every day".

Responses are perhaps best summed up by one respondent:

"Good awareness of right and wrong foods but unhealthy choices".

### 4.2.3. Drugs and Alcohol

### Response from Travellers

When presented with 6 pictures of drugs, each respondent was asked if they could recognise and name the drug in the picture. Respondents were also asked if they knew anyone who had taken drugs, and whether the issue of drugs and alcohol had got better or worse within the last five years.

15 (75%) correctly identified cocaine; 11 (55%) correctly identified cannabis; 13 (65%) correctly identified heroin; 11 (55%) correctly identified diazepam. By contrast, 14 (70%) either incorrectly identified mephedrone or didn't recognise it. 15 (75%) knew someone who had taken drugs. 15 (75%) said issue of drugs and alcohol had got worse in last 5 years.

When Travellers were asked, 'how do you think this could be made better if it's got worse?' themes identified included:

- Control measures- including reduced availability of drugs, stiffer penalties and legalizing drugs
- Educational/ awareness measures- including awareness and counselling and use of media
- Personal action- including direct action and disassociation with drug dealers
- Underlying social factors- including unemployment, paramilitaries, criminality and loss of nomadism
- Personal factors- such as addiction.

One person expressed how loss of nomadism impacted on their drinking:

"Reason for drinking - I ended up badly depressed and drinking. When you are out and about you have your freedom moving from place to place - you're too much confined in a house".

## Response from focus group members

## Recognition

Five respondents commented on the high numbers of Travellers positively able to identify drugs:

"Overall findings were reinforcing the AITHS re high drug and alcohol issues. And initial reaction was shock at the high levels of Travellers able to positively identify drugs".

It was noted however that the two people living in an un-serviced site had less awareness of drugs.

#### How could the situation be made better?

Five respondents reacted to Travellers' answers to this question holistically by underlining or restating words like: availability, penalties, legalise, awareness, schools, counselling and media. One person felt the responses mirrored those of the wider community:

"Views on legal, educational, social personal factors mirror the views of the wider community",

whilst another felt they were in line with official policy:

"Sound - in line with official policy and the issues associated with use".

# 4.2.4. **Smoking**

# Response from Travellers

#### Prevalence

60% (n=12) smoked.

# Age of first cigarette

5 (25%) respondents reported taking their first smoke aged 8-12; 4 (20%) aged 13-15 and 2 (10%) aged 18-19.

## Smoking cessation

Of the 12 who smoked, 10 (83%) had tried giving it up and 2 (1) had not. 6(30%) said they would like to stop and 5(25%) wanted to know about services available.

Asked 'what's stopping you smoking?' Personal, social and medical themes were identified.

# Response from focus group members

#### Prevalence

Three respondents commented on the early age five men took their first smoke:

"25% in 8-12 category is frightening".

Three commented on the high rate of prevalence in general:

"Prevalence x 2 of the settled community".

#### Gender

One person felt there were gender differences:

"Traveller boys are allowed to smoke at any age whereas the girls have to wait until they are married".

## Smoking Cessation Service Uptake

Two did not feel Travellers were accessing Trust services:

"Travellers are not making contact with services within the Trust".

They queried motivation to stop and the need to consider targeting services. One person stated that Travellers had similar reasons for not stopping as settled people.

# 4.2.5. <u>Protection against hazardous substances</u> Response from Travellers

Figure 14 highlights the number of men who took protective action when dealing with hazardous substances.

10 (50%) reported experiences of working with burning plastic, 10 (50%) with paint fumes; 6 (30%) asbestos and 3 (15%) with copper wire.

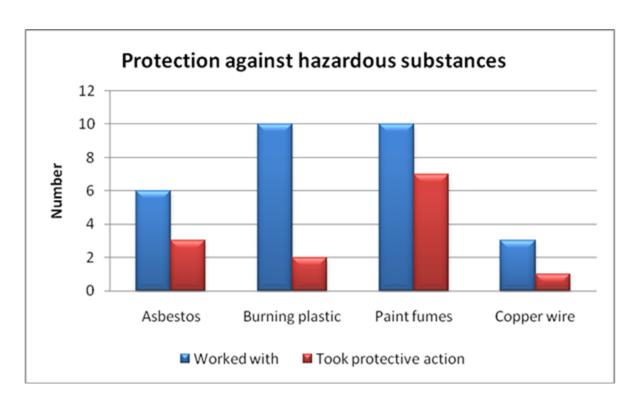


Figure 14 Protection against hazardous substances

7 out of 10 wore masks when painting. 2 out of 10 took protective action when burning plastic. 3 out of 6 either walked away, threw away or avoided asbestos, and 1 out of 3 took protective action whilst burning copper wire. One man reported:

"I keep my hands on my mouth and wear a mask in a caravan if cutting asbestos".

#### Other comments included:

"I breathed in hypo chloride - also known as red label (farmers use it and its used for cleaning the streets) – I wore a mask sometimes and sometimes I didn't."

"I wore old gloves for tinsmithing".

Of 16 (80%) men power-washing, 7(35%) used protection which included wearing a mask and using goggles.

# Response from focus group members

There was a high response rate to this issue with 8 reactions, 6 suggestions and 2 comments on current activity.

Reactions highlighted this as a gap:

"Risk we normally don't address-how?"

"Gap in protection because self -employed?";

"Costs too high for equipment";

"Not sufficient protection".

There were implications for awareness campaigns and training:

"Male health promotion- importance in the use of photos for campaign work";

"Need to do training for young men on hazardous substances".

One person from the Education Board stated:

"Some information available to wider community through a range of media publications".

He went on to suggest ways of tackling the issue through mapping existing information on hazardous substances and considering:

"production of culturally specific information".

He highlighted the K54 element of the curriculum at post primary within the Southern Education Library Board (SELB) which:

"focuses on vocational opportunities for students/ schools to consider this issue"

He suggested influencing the Council for the Curriculum Examinations and Assessment (CCEA):

"through revisions in wording in the curriculum- more focus on health and safety issues".

Another person from Wade Training highlighted opportunities through the Steps to Work option:

"for courses re hazardous substances and HGV license fee to be funded pending a job offer".

She also noted that self- employment courses may include provision of personal and protective equipment, paid for by employers.

The role of women in encouraging men to wear safety gear was raised:

"Women can encourage their men to wear safety gear. The Southern Regional College's upcoming course is very relevant and should be rolled over the area".

The Southern Regional College highlighted their accredited programme *Working Safely* as the beginning of a series of Traveller specific health and safety courses, to be provided on a time limited basis over the next two years.

# **Section 3 Mental health**

This section will cover the impact of culture on health, discrimination, domestic violence and stress.

Figure 15 provides an overview of factors affecting mental health from thematic analysis including discrimination, stress, culture, access to services and domestic violence.

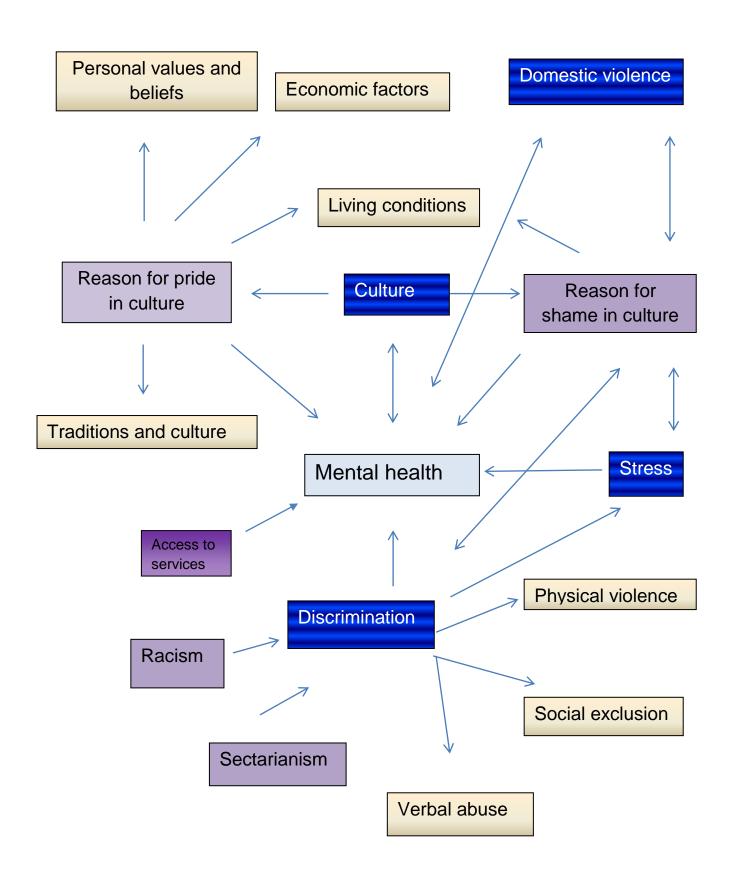


Figure 15 Thematic map: factors affecting mental health

## Summary and overview of Traveller responses

Economic factors, personal values, beliefs and traditions were factors reported as contributing to pride in Traveller culture and positive mental health, whereas stress, domestic violence and discrimination were reasons for shame. (Travellers understand 'shame' to mean embarrassment).

Discrimination arising from perceived sectarian or racist motives manifested itself in physical violence, social exclusion or verbal abuse. This was evident in both early life and recent experiences.

# 4.3.1. <u>Culture</u>

## Response from Travellers

Q1'If you were to meet a stranger from America who knew nothing about Travellers how would you describe Traveller culture which makes you different from an Irish person?'

Thematic analysis identified 4 themes:

- 1. Personal values and beliefs
- Social factors
- 3. Economic factors
- 4. Living conditions

These themes and associated sub-headings are expanded below.

## 1. Personal values and beliefs

## Separation from settled community

"We don't let our daughters go to discos or hang round locals – they'd pick up too many bad habits. We don't let them into houses – just stick to our own clan";

"We'd welcome the American but we wouldn't be taking them home".

## Family values

"Parents are stricter than country people – going smoking and drinking with girls before you're married. They'd have more self -respect than country people. You wouldn't be allowed. When you come to a certain age you take on your own responsibilities – the opposite of country people".

# Marriage

"Marrying the one woman and being truly faithful".

# Equality

"We're a proud tradition as good as anyone. We don't have to rob people to be any good. There will come a time when there is no discrimination".

#### Education

"Making sure the children are well educated- education is important in our culture and it wasn't always that way".

## Language/accent

"Our cant";

"Our accent is different".

# Identity

#### Born into culture

"I'm an Irish Traveller – I was born and raised in a caravan".

## Hiding identity

"I wouldn't describe a Traveller to an American if he didn't know."

#### Nomadism

"Buffers stay in the one spot – Travellers move from place to place".

## 2. Social Factors

#### Traditions and culture

"Traditions and beliefs are a big issue – the fact they're still holding on to their culture. I'm proud of my culture. I cannot change it nor wouldn't change it";

"Different Travellers have different cultures".

## Dealing with conflict

"Travellers do a lot of fighting among each other".

#### Discrimination

- Jobs

"One of the differences is I can't get a job except one in a hundred".

#### - Bars

"How you're treated getting into a bar".

## 3. Economic Factors

## **Tinsmithing**

"We made tin and sold it to farmers – tin pots, buckets, mugs etc. Travellers invented a penny tinker – a yoke with a clip and two washers at the side of a kettle".

## Horse-trading

"We have different ways of getting on - horse-dealing".

## 4. Living conditions

"How we lived in caravans – how tough they had it years ago. We lived up here when there was no running water or toilets. We brought creamery cans of water. My mother hand washed the clothes. We had a wooden hut with a range and a caravan to sleep in".

# Q2 'What makes you proud of being a Traveller?'

Although answers contained similar themes to the question on defining Traveller culture, this question elicited aspects of culture promoting positive mental health. These were classified as:

- 1. Values and beliefs
- 2. Culture
- 3. Fighting discrimination

## 1. Value and beliefs

## Family values

"Our family never do drugs or going around fighting and arguing";

"My father makes me proud";

"Some Travellers wouldn't let young girls out after 7-8pm".

## Marriage

"Good marriages".

#### **Beliefs**

"My beliefs".

# Equality

"I don't count myself worse than anyone".

## 2. Culture

# Language

"We have our own language".

# Identity

"We didn't have to go take GCSEs- we know our own trades";

"It's being part of that ethnic group".

#### **Traditions**

"It's the fact of having our own ways and traditions".

#### Culture

"Although I was reared in a house...... I still kept the culture".

#### Nomadism

"You can move where you want to be. If you don't like it you can move on".

## 3. Fighting discrimination

"We like doing our own thing. We don't like people telling us what to do. We don't like being discriminated against".

# Q3 'What kind of things makes you ashamed or feel bad about Travellers?'

Answers focused on aspects of discrimination in bars, schools and shops:

"Getting refused from pubs and clubs" (15 comments);

"Refused from shops – getting followed round shops, being treated different for being a Traveller" (5 comments);

"Discrimination and hate crime and kids getting bullied" (1 comment).

#### Sectarianism also arose:

"We helped Protestants build bonfires and paint flagstones...We still left because we knew that Protestants didn't want the Catholics around during the 12th.... You weren't just a 'Fenian'; - you were a 'Gypsy Fenian (1 comment).

The negative impact of the media was raised:

"My Big Fat Gypsy Wedding" – the caravan I have is all I need – for settled people to see fancy weddings, cars, glamour and I ask for 50 euros to wash a driveway they'd say 'what do you want 50 euro for?' You'd be struggling to make ends meet." (1comment).

## Q4 'Do you think your culture affects your health?'

Three themes from Traveller culture were identified as having an impact on health:

- 1. Racism
- Access to services
- 3. Culture

#### 1. Racism

"It does stress you out that they're judging you for no reason. It absolutely frustrates you - you feel 'what's the point talking if they're putting you down?';

"Being bullied causes depression and isolation";

"People looking at you coming into a bar - there'd be 20 there. All the people looking at you make you feel embarrassed. We're not asking for nothing";

"You haven't the same facilities as settled people. You haven't the same equal rights – you would have more pressure. A local man would get in and you wouldn't - you'd have a lot of worry".

### 2. Access to services

Access to primary care and education were highlighted:

"Before St Christopher's Park we had.... no doctors";

"Travellers don't like going to doctors";

"You're more educated than you were 25 years ago. Now there are classes for learning - years ago there was nothing".

## 3. Culture

Physical activity and environmental aspects of the culture had an impact on health:

"Travellers are exercising all the time. As some Travellers do the hunting their health is good. They're also walking";

"Back years ago we were out in the rain camped out in caravans and tents, sleeping and eating rough. We never got fair play- the police had us round from place to place".

# 4.3.2. Discrimination

# Response from Travellers

Early and recent discrimination were examined, whether incidents experienced were reported, and their outcomes.

20(100%) experienced discrimination with 12(60%) experiencing it before the age of 10 years. In total 39 incidences were described, 19 from early childhood and 20 which were more recent. 17(85%) did not report early discrimination and 15 (75%) did not report recent discrimination.

As regards outcomes of discrimination when reported, one person pursued a successful court case concerning recent discrimination with the assistance of the Equality Commission, and two people described outcomes from early discrimination.

Three types of discrimination in early childhood were described:

- 1. Verbal abuse
- 2. Exclusion/ social isolation
- 3. Physical violence

## 1. Verbal Abuse

This included racist name-calling such as:

```
"Gypsy" (9 comments); "smelly" (3 comments); "tramp" (2 comments); "knacker"; (3 comments); "bastard"(1 comment).
```

#### Other comments included:

"I don't like being called an itinerant which is a higher word than a dog";

"Vile comments about my family".

There was sectarian name-calling:

"We weren't just 'Fenians' – we were classed as 'Gypsy tinkers' "

#### 2. Exclusion/ social isolation

This was evident in school, at the shops and in leisure facilities:

"You are out-casted in primary class. The children wouldn't involve you in groups."

"I got put out of the shopping centre"

"The football field beside us was denied to us".

## 3. Physical violence

Physical violence varied from insults to physical aggression and included very severe incidents:

```
"Spitting";

"They tried to bully you";

"Burning clothes off line";

"Thrown through window of school";

"Burning house";
```

"When we used to stand waiting for the bus the Protestants kicked the crap out of my four oldest brothers".

# Reporting early discrimination

17(85%) did not report early discrimination.

Two serious incidents of early discrimination were reported, resulting in allocation of a new house and expulsion of offenders.

One person who reported being burnt out of his house said:

"My father would have had to report this. We got a different house with no electricity, no windows, facing the graveyard".

Another person who was thrown through a school window stated:

"Yes, I reported it to the teacher. Five were expelled. One stared me in the eye and said "don't tell on me". Ever since that fellow looked after me because I didn't report him".

Two incidents of school bullying weren't reported for fear of teacher and pupil reactions:

"No, I was a child at school. The Master gave you slaps too, so you couldn't report it to anyone";

"No, pointless you'd be bullied again for reporting it after school. He's a tout."

Recent discrimination included social exclusion from bars 17 (75%), shops 5(25%), and leisure facilities 2(10%):

"Barred and refused from pubs and restaurants for being a Traveller. Got told they had a bit of trouble with me and my mates the week before and it was my first time in the bar!";

"Got followed around shopping centres by security - I felt very intimidated";

"We went to golf course in Dungannon to play a game of golf - five Travellers and six settled people. The following

week, five Travellers went out for golf and were refused entry three weeks in a row".

## Reporting recent discrimination

15 (75%) did not report recent discrimination, despite experiencing it:

"No, a waste of time".

Those who did take action went to solicitor or court, the bar manager or took action themselves:

"No, we're more likely to floor somebody than report it".

One person did take a successful case against a golf club:

"Took a case to the Equality Commission. They had to issue a public apology and offer compensation to each of the five of us. Told us we could play anytime. When we won - the course didn't refuse us since".

# Response from focus group members

#### Overview

One respondent provided an overview of the impact of social determinants on mental health:

"Clearly discrimination, poor health status, low education attainment, lack of government support, accommodation, access to services, income etc. will have a massive impact on Travellers experience of mental health".

Another set the issue within the wider NI context:

"How to place the wider context of discrimination that settled people will also have experienced due to conflict in N.I and additional impact on Travellers – level of risk very high".

#### Culture

There was a variety of reaction to information presented on Traveller culture. Two people saw potential educational value for settled people, especially regarding Traveller values:

"Something to make settled population to be aware of";

"Positive values to be supported and help other settled people to understand".

5 others noted positive values including self- respect, family values, cultural pride, integration and respect for Protestant culture and education:

"High values and family values";

"Pride in culture- aspiration for no discrimination"

"Two things. There is a level of integration and respect for Protestant culture"

"Education value noted in some localities – very valued".

Another person picked up on the conflicting view expressed by a Traveller about GCSES:

"We know our own trades-don't see the value of education".

However one person reacted against the comment from a Traveller about not letting daughters go to discos or hang around locals:

"Control of children has an influence on their mental healththis goes down through generations".

Another highlighted gender differences in attitudes to drinking:

"When women become mothers, they traditionally drink on special occasions, whereas it is acceptable for men to drink more freely".

One person noted the impact of family values on education stating that they:

"had to ask Dad's permission for daughters to take to take their courses involving intensive negotiations and providing guarantees relating to location of classes, nature of delivery, content of courses, tutor etc.".

#### She added:

"Happy to do so if it reassures parents and increases uptake of course".

In relation to the slide on economic elements of Traveller culture, one person noted the impact on mental health of the decline of traditional trades and compared this with other disadvantaged communities:

"Historical trade/tradition now largely defunct – similarities with mental health on other communities e.g. East Belfast Shipyard Workers – decline of manufacturing".

This respondent went on to suggest that more Travellers should be employed by the Health Trust.

In response to the Traveller who defined culture as "fighting" one respondent stated:

"How Travellers deal with conflict - violence and culture".

As regards reactions to responses from Travellers about how culture affects health 6 respondents highlighted the effects of exclusion and bullying on mental health:

"Fundamental issues of exclusion can impact on health";

"Bullying lowers self- esteem";

One person underlined a comment:

"All Traveller children bullied in school, made to feel different-being bullied causes stress and depression".

Two noted issues in relation to accessing primary care:

"Men's health issue- don't like going to doctors";

"Travellers still facing barriers from front line staff- GPs may not be aware of staff's attitudes unless they contact GP through Traveller Support Worker/ Group".

Four respondents noted down the observation from the researcher that the word "ashamed" meant "embarrassed "within Traveller culture.

One respondent reacted to the Traveller's comment concerning hidden identity:

"I wouldn't describe a Traveller to an American if he didn't know" asking was this a form of protection against discrimination:

"?? Travellers hiding their identity for fear of discrimination".

Another respondent gave an example of children trying to fit in with settled children by changing their accent:

"I am aware of Traveller children who 'speak like country people' so as not to be recognised as Travellers".

#### Racism

Six members reacted to the complaint from the Traveller about the impact of TV programmes such as 'My Big Fat Gypsy Wedding' on public perception of Travellers wealth. They viewed this as fuelling stereotypes and public ignorance of Travellers:

"Perpetuation of prejudice – inaccurate representation of Travellers";

"Media through Big Fat Gypsy Wedding has given a distorted view of the culture":

"Media – hurt and dilemma of mismatch - all of us to challenge negative stereotypes".

#### Sectarianism

Four respondents commented on the slide highlighting how one Traveller had helped Protestants build a bonfire but left before the 12<sup>th</sup> as he perceived himself to be viewed as a 'Gypsy Fenian', by noting public attitudes were both racist and sectarian:

"Double whammy- sectarianism and racism";

"Both impacts – southern accent into Northern area";

"Perceived threat and actual evidence – <u>racism and</u> <u>sectarianism".</u>

Experience of discrimination

Seven respondents reacted to the finding that 100% of the sample experienced discrimination.

This finding evoked strong feelings from focus group members who noted the widespread prevalence of discrimination and its serious impact on mental health:

"It's such an everyday occurrence, most don't even recognise it anymore- it comes from all sources and never seems to have been addressed – legislation is clearly not enough".

Respondents from the Trust's Equality Unit and the Equality Commission N.I (ECNI) detailed a wide range of policy and practice initiatives and suggestions to reduce discrimination. The Equality Commission representative discussed the research with agency colleagues, culminating in a comprehensive response (Appendix 22).

The Trust's Equality Department outlined training initiatives and resources for staff including Traveller cultural awareness training, "E-learning on diversity", a Traveller awareness leaflet, and a multi-cultural handbook for frontline staff.

One respondent highlighted the potential under the Community Development Strategy for Health and Wellbeing (2012) for 'citizenship building' and 'asset based approaches' as a way of counteracting discrimination and negativity.

14 respondents expressed concern about reports of childhood discrimination including the levels of harassment, the very early age of first experience of discrimination (including direct verbal discrimination), and its nature.

## Reporting discrimination

Eight respondents commented on Travellers failure to report early or recent discrimination with one specifically querying whether the Traveller Education Task Force Action Plan address the issue of bullying through anti-racist school initiatives:

"Has this been picked up in the Education Task Force?".

Another person suggested the need for capacity building:

"Travellers need capacity development to enable them to feel confidence in making a complaint regarding discrimination".

Another respondent expressed disappointment that Travellers do not report discrimination to the Equality Commission:

"Travellers are reporting discrimination to Traveller Support Groups, Northern Ireland Housing Executive, or teachers but not to the Equality Commission".

## 4.3.3. <u>Domestic violence</u>

# Response from Travellers

When asked if they thought that domestic violence was high amongst Travellers 12(60%) said yes, 7(45%) no, and 1(5%) don't know. On further questioning if they knew a man or woman who had suffered domestic violence 11 (55%) replied yes and 9(45%) no.

Table 1 outlines men's knowledge on where to get help for domestic violence. There was a higher lack of knowledge of services in the Armagh and Dungannon areas than in Newry, Coalisland or Craigavon.

Table 1 Knowledge of domestic violence services by area

		Area				
Question	Reply	Newry	Craigavon	Dungannon	Coalisland	Armagh
Know where to	Yes	4	3	1	3	3
get help for someone if they	No	1	1	3	0	3
needed it?						

# Response from focus group members

Five respondents commented on the sample's belief or actual knowledge of domestic violence levels:

"Significantly perceived to be higher than settled community- associations with mental health";

"Violence within the community seems to be an issue";

"Very high".

In relation to findings about Travellers knowing where to access services related to domestic violence, one person stated in relation to the Armagh Travellers:

"At least knew where to get help".

Another person reacted against what she perceived as oppression of Traveller women:

"Traveller women suppressed by men: not allowed to work, form groups etc."

A third person sought reasons behind domestic violence and linked it to wider issues:

"Related to other pressures that men have reported".

Another asked if Traveller women are more likely to have knowledge of domestic violence services than these male respondents.

# 4.3.4. Stress

# Response from Travellers

In response to a question 'how do you cope with stress?' Traveller men reported a range of positive and negative coping strategies.

Positive strategies included taking exercise, leaving the house, seeing the doctor, watching TV, seeking a friend, sleeping or working:

"Go for a game of football":

"Get out of the house and get over it - everyone worries";

"Go see a doctor";

"You come home in evening - let wife out and watch a video and then go to sleep";

"If someone hurts/excludes you go for a different friend";

"Sleep it off - relax";

"Go get a bag of scrap".

Negative strategies included turning to drink, drugs or smoking, bottling it up or becoming depressed:

"Very bad – smoke... took a cocktail of drugs - odd joint."

"I would bottle it up - tell my wife".

"I would suffer from depression and I have a suicidal number on my phone. There are days I feel so depressed I say not another day - tablets only last for so long. Everything is stress"

# Response from focus group members

Seven respondents reacted to findings about how Travellers coped with stress. There was a divergence of opinion with one person stating that Travellers employed a wide range of strategies and another felt limited coping strategies were used.

A few commented on negative coping strategies, including the substance misuse and impact of bullying and access to leisure facilities:

"Substance use/ misuse";

"Being bullied causes stress and depression".

In relation to the exercise strategy, one person highlighted potential difficulties:

"Where there are services that Travellers can access".

# **Section 4 Mortality**

This section will cover Traveller men's perceptions of why they are dying earlier than the general male population, what they perceive as the main causes of death, and suicide.

Figure 16 provides an overview of the reasons for early mortality as perceived by the men including ill-health, environment, lifestyle, mental health and access to services.

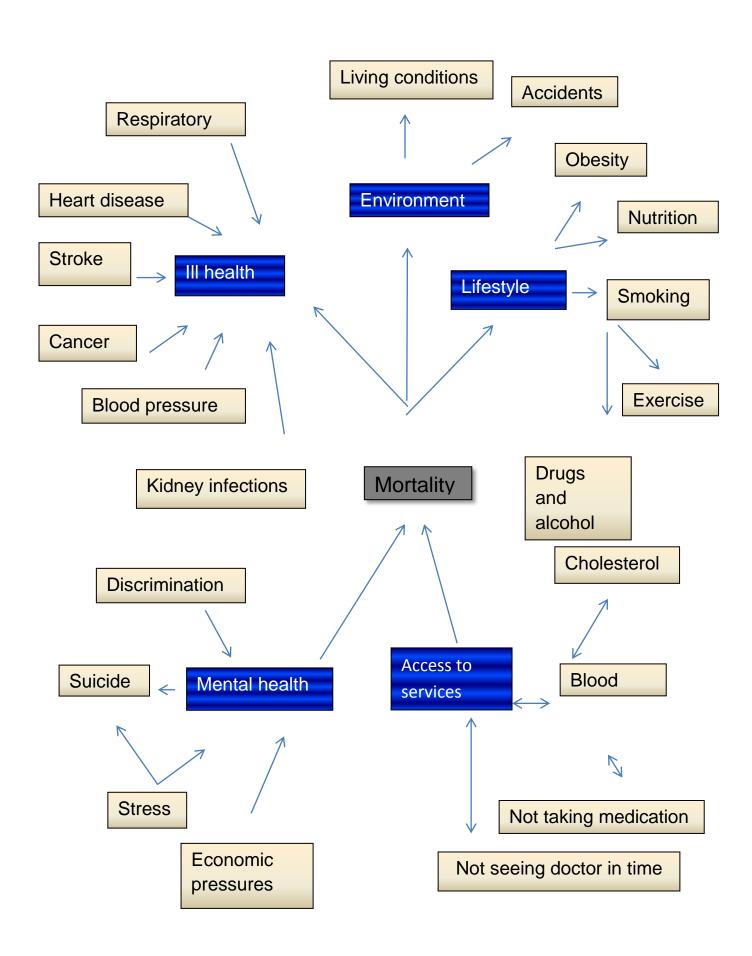


Figure 16 Thematic map on causes of mortality

# 4.4.1. Reasons for dying early

# Response from Travellers

Respondents were asked for reasons why Traveller men were dying earlier than men in the general population. Answers focused on lifestyle, access to services, mental health, physical health and living conditions.

## Lifestyle

Answers included drugs and alcohol, nutrition/ obesity, smoking, exercise and sleep:

"Alcohol- drugs will have an effect in next 12 years";

"An average Traveller man is eating too much salt and small portion of food, cheap brand of butter (hard block)";

"They put on a lot of weight over 40";

"Smoking";

"No exercise, no football, hurling, running - mostly driving a car/van and taking no exercise";

"Not sleeping right".

# Access to primary care services

Answers focused on awareness of blood pressure, cholesterol, timely access to doctors and taking medication:

"They don't have an awareness of blood pressure, cholesterol":

"Not seeing a doctor when you should";

"Not taking medication".

#### Mental health

Respondents highlighted discrimination, gender, stress, economic pressure and suicide -

"Discrimination";

"Traveller men do not talk about their problems/they are not open about seeking help/think it is a macho thing. I went to a pub and they didn't serve me and the man was at school with me - very hurtful";

"Stress, hardship, providing for family";

"having no work would affect life expectancy";

"There's a lot of Travelling men commit suicide".

# Physical health

Respondents noted family history of cancer and heart disease and kidney infections:

"They could have a family history of cancer or heart disease";

"Don't get kidney infections treated".

# Living conditions

The impact of adverse environmental conditions was also highlighted:

"Years ago all they had were wagons - they were out in the cold":

"Hard life growing up".

# 4.4.2. Main causes of death

# Response from Travellers

When Travellers were asked' what were the main causes of death within the last two years?', answers covered chronic diseases, suicide, accidents, lifestyle, and non-attributable causes.

In order of frequency cancer received the most comments (13) followed by strokes (7), mental health (including suicide) (5) and drugs/ alcohol (5), heart disease and blood pressure (3 each), non- attributable comments such as bad health or no particular reason (2) and respiratory infections or accidents (1 each).

The issue of gender arose again in the context of mental health and suicide and emphasized that young male drivers are at risk of accidents:

"Men are afraid to speak out/ more ashamed to discuss their problems. Should be encouraged to take problems to a doctor/he listens. There's help there if people wants it. If you can get one man to come forward & get help you'll feel good";

"Suicide (it's depression, everything builds up and they don't talk to anyone)";

"Car crashes - especially young fellow driving hard".

# Response from focus group members

As there is overlap in responses to the two questions 'Why do you think Traveller men are dying so young?' and "What do you think are the main causes of death amongst Traveller men in last two years?- responses will be grouped together under common themes. Figure 16 provides an overall framework for analysis.

## Mortality

Seven respondents made general comments about the widening gap in mortality, social and genetic determinants of health, loss of nomadism and impact of discrimination.

#### One commented:

"Why has mortality got worse since last study (9:1 v 15:1) what has changed? Feedback says things are better Prevention and mental health promotion needs higher profile- support group potential".

One went on to highlight local and regional interagency initiatives which employ a social determinants perspective.

Another noted impact of loss of nomadism:

"Traveller mortality has got worse because of the change to a more settled sedentary life".

Discrimination and depression were raised:

"Discrimination, depression, mental and emotional wellbeing, racist attacks and attitudes at schools – we need to do more".

#### He suggested:

"Action plans joined up with Travellers, awareness of support groups and help lines, better PR, Commissioning plans and Voluntary and Community Sector Fora".

The Office of the First Minister and Deputy First Minister (OFMDFM) was named as the preferred lead.

Another person expressed concern about how information on mortality is communicated to Travellers:

"The manner in which information re health is communicated to Travellers needs to be looked at".

One highlighted a discrepancy between knowledge and action:

"Traveller men appear to know why but seem to ignore health facts".

Cancer screening and engaging men were suggested as ways forward:

"Cancer screening – all screening needs to be highlighted with the men and trust built up with them".

## Lifestyle

Five highlighted specific aspects of lifestyle including drugs and alcohol, smoking, exercise, diet, sleep pattern and unemployment. The Trust's Smoking Cessation Service and

Drugs and Alcohol Programmes were noted with a suggestion for Traveller male role models to be encouraged to come forward:

"Explore ways of encouraging Traveller male role models who come forward to seek help and influence others".

One person acknowledged the work of the Promoting Wellbeing Department and asked if more could be done by other Programmes of Care:

"A lot is being done in the Promoting Wellbeing Department. How much is being done by other programmes of care?"

One respondent raised the importance of training for health promotion staff in Traveller cultural awareness:

"Need staff trained in Traveller culture before delivering health promotion programmes".

#### Mental health

Seven commented on mental health issues including stress, gender, empowerment and employment:

"Traveller men don't talk about their problems, stress and hardship";

"Barriers – different approaches needed to empower group";

"Have Travellers work in our health departments".

## Access to primary care services

Issues highlighted in relation to primary care included the need for more pharmacy programmes and the importance of literacy: "More pharmacy programmes for men":

"Taking wrong prescription".

#### 4.4.3. **Suicide**

#### Response from Travellers

Respondents were given a choice to answer a question on suicide with18 (90%) agreeing to answer it. 13 (65%) said their family had not been affected; 5 (25%) stated their family had been affected by suicide; 15 (75%) knew of other Travellers that have lost their life by suicide. 13 respondents (65%) did not know of suicide support groups.

Two men described personal experiences:

"I was drinking with a Belfast lad on Christmas Day and 3 weeks later I went to his funeral. Travellers wouldn't really go to things like that there";

"I have suicidal thoughts - after Christmas I was bawling my eyes out I'd bad thoughts about it. I know of 3 chaps that hurt themselves".

## Response from focus group members

Suicide evoked the largest response within this section with 13 comments. Four commented on the fact that 75% of respondents knew of a Traveller who had lost his/her life by suicide:

"Quite high-big awareness";

"Suicide (6 times more likely)".

The majority highlighted issues about men's lack of knowledge of suicide support groups whilst also querying likely uptake if the knowledge was provided; gender differences; seasonal influences on suicide; and the need for better promotion of services:

"Traveller women would be aware of PIPS- but men don't.

Travellers do not understand the process of counselling from my experience";

"Would they uptake on support groups?";

"Is Christmas linked to celebration/ drink?";

"Better promotion of services already on offer and sign posting".

# **Section 5 Access to services**

This section covers access to and rating of primary care services. It also covers traditional beliefs, namely people with cures, and the reported outcomes.

## 4.5.1. Access to Primary Care

# Response from Travellers

In relation to Traveller men's access to their GP, *Figure 17* shows that 13 (65%) had visited their GP within the last month, 18 (90%) had seen them in their GP surgery, 19 (95%) had made an appointment and 17 (85%) did not feel they were treated differently by staff and other patients, compared with the general population.

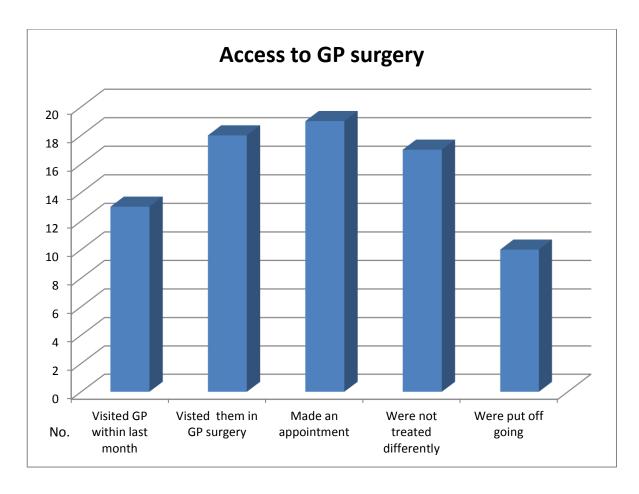


Figure 17 Access to GP surgery

One, who did feel treated differently, commented:

"They came up with excuses - you were seen as only temporary".

10 (50%) were put off going to the GP at some time.

Asked for the reasons why,' if they had ever been sick and been put off from going to the doctor and not gone', respondents cited fear, time, self - healing, low motivation and shyness:

"Afraid of what's wrong with you";

"You could be waiting 4 or 5 hours in Craigavon Hospital, so I went home despite the pain in my head";

"I would be too shy";

"Just never bothered";

"The kids could be sicker than you - you'd get the kids seen first".

## 4.5.2. Rating for doctors and nurses

# Response from Travellers

Respondents were asked to rate doctors and nurses on a scale of 1-5 where 1 was 'don't trust at all' and 5 was 'trust a lot' (*Figure 18*). 18(90%) 'generally trust',' trust' or 'trust doctors and nurses a lot'.

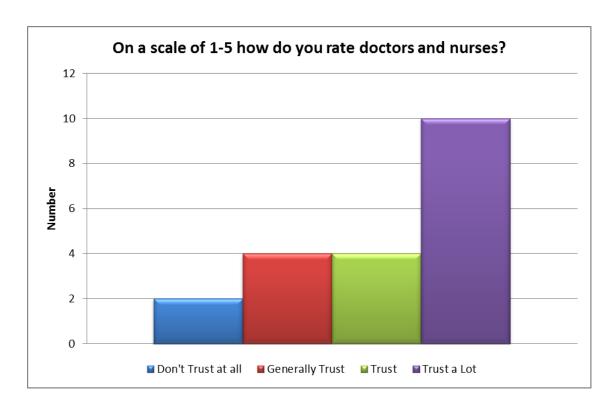


Figure 18 'How do you rate doctors and nurses?'

## 4.5.3. Reasons underlying rating of GPs

# Response from Travellers

The main reasons for a positive rating included: professional values and non- racist attitudes, respect for a family doctor and their knowledge:

"Most of the doctors are a fair judge. If I walked in I'd know a man was racist - this hasn't been my experience of doctors";

"A doctor is only there to think of your wellbeing";

"My doctor in Dungannon is brilliant";

"They're doing a good job. They went through all the qualifications";

"There's doctors that are 100% and nurses too".

Reasons for negative rating included incompetence or a lack of trust:

"I ended up in hospital over him. I took a stroke and he gave me painkillers";

"No-reason-just don't fully trust them";

"Some doctors give you medicine for kids and they don't cure you- others do cure you".

## 4.5.4. When to see a doctor

# Response from Travellers

When asked 'how do you know it's serious enough to see a doctor?' the reasons were pain, dizziness, sickness, unable to cure oneself or to appease one's wife:

"If you were suffering the way I was you'd go to see the doctor":

"If it was unbearable- before I got my appendix out";

"If you take a dizzy spell";

"You'd nearly know- you'd be sick";

"When you realise you can't cure yourself";

"When you start complaining too much she would make sure you see a doctor".

## 4.5.5. Who do men mention the pain to?

## Response from Travellers

Table 2 'Who do you mention the pain to?'

Who do you mention pain to?	N	Who makes appointments and gets medication?	N
Doctor	20		
Wife	15	Wife	14
Mother	9	Myself	7
Friends	7	Mother	1
Son	6	Daughter in law	1
Daughter	6		
Father	1		

20(100%) mentioned pain to doctor and 15(75%) mentioned pain to their wives, mothers 9 (45%), and daughters 6 (30%). Friends and sons also played a part 7(35%) and 6(30%) respectively. Strong gender roles were evident in the family with the wife 14(70%) playing an important role in arranging appointments and getting medication, although the men themselves also played a role in this 7(35%).

## Response from focus group members

Seven respondents noted surprise and/or encouragement at the high levels of attendance at the GP within the last month:

"Surprised at % accessing primary care in previous month – especially for males, given historical perception that accessing services is challenging".

However seasonal factors, a skewed NIHE sample (with high GP registration) and possible hidden discrimination were highlighted:

"February more inclined to contact GP re colds, flus, not travelling";

"Figures may be skewed by number of sample being resident in NIHE accommodation-therefore more likely to be registered with GPs for a number of years. This would correlate with % being seen in GP surgery and level of satisfaction as to how they were treated";

"Men may not be aware that wives may have faced discrimination while making appointment".

Three people highlighted the important role of women in influencing male health appointments:

"Women have a key role in all communities in influencing how, when and where males access health services.

Four people referred to the potential of a primary care initiative known as the Traveller Local Enhanced Service (LES) currently under review:

"LES is being provided by 8 GP practices in the Southern Area. This offers a potential for more specialised services to Travellers registered within these practices. Another person suggested that the success in this scheme needs to be replicated regionally:

"LES in Southern area – success needs to be built upon regionally"

This was tempered with a comment about needing more local support:

"To develop potential of LES in Primary Care and tackle poor uptake amongst GPs".

Nine respondents reacted positively to the high rating given to GPs. One person noted how trust had grown over time, affording good future potential:

"Primary care providers trusted and a great opportunity – shift over time and this level of trust is an important opportunity";

"Good to see this- a lot of faith";

"Surprised"

# 4.5.6. Belief in people with cures

## Response from Travellers

18 (90%) believed in people with cures (Figure 19):

"My father has a cure for ringworm - children and adults come to him".

13 (65%) had been to a person for a cure:

"I saw them in Tyrone for murmur in the heart. She got oatmeal, poured it into cork, wrapped hanky round top and went round body 3 times praying - took hanky off and it was empty. 2nd time cork half full and 3rd time I went up murmur was gone and cork was full".

12 (60%) said they helped or cured the problem:

"I was poisoned with an arrow in the back of my leg - aged 15. When I was in Intensive Care parents went to a man who travelled to Waterford and he cured me".

8 (40%) did not trust people with cures more than doctors:

"No, a lot of the curer people are looking for a hand-out - I don't class them as real ones".

6 (30%) trusted them the same as doctors:

"I would believe in traditional healing because of God - for tablets I'd trust the doctor".

4 (20%) did trust people with cures more than doctors.

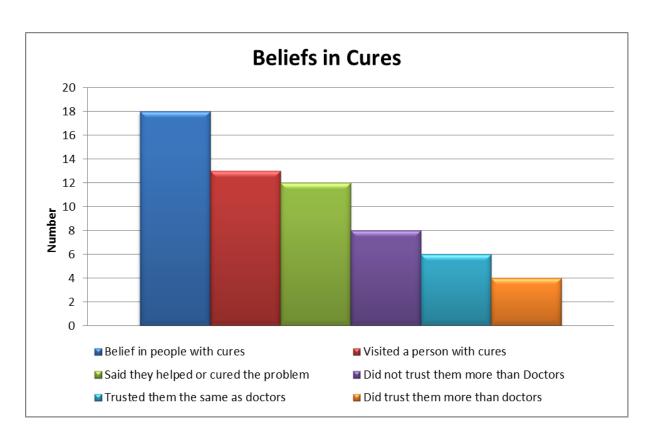


Figure 19 Belief in people with cures

Other comments on traditional cures included:

"I'm the 7th son and I've the cure for ringworm. 1 Sign of cross on affected area 2 Blow 3 times 3 Put right hand on the affected area 4.Prayers 5. Sign of Cross 6. Blow 3 times cure finished";

"My sister and grandfather were in a car crash on Monaghan Road - my father went to Dublin and left sister with my grandfather. My grandfather wasn't so bad. My parents went to a priest who'd said tomorrow you'd have good news - meant to have brain damage - doctors had no hope. Now she's 3 kids and married. My sister got confirmed with same priest who cured me";

"You have to believe - you never thank them you say God bless. She never asked for money. I gave her a fiver and boiled sweets for the telephone bill";

"Went to Lourdes - there's a cure for clot in the heart, pains, and bleeding. Some cures are done over the phone or at their house";

"There's another woman in 'Blaney' for cure for rash in the head. There's somebody out there for sore mouths".

## Response from focus group members

Seven people reacted to the information that Travellers believe in people with cures. The importance of understanding health beliefs set within a wider debate around alternative therapies was highlighted:

"Important to understand culture and health beliefs model";

"There has always been debate about a holistic approach to health and wellbeing, encompassing alternative therapies. The role of the faith healer, through culturally significant, is no different in this respect".

Two noted that 90% believed in cures and one person stated (in relation to primary care and traditional cures):

"Travellers in our care would use both".

One person suggested further exploration of the model to identify underlying risks:

"to explore folk medicine and its uses identifying health and safety risks".

## **Section 6 Health Information**

This section covers a range of sources and rating for health information including health professionals, family sources, type of health information and methods of delivery.

#### 4.6.1. Sources of health information

## Response from Travellers

Table 3 shows that health professionals 19(95%) and family members 15(75%), followed by TV 13 (65%), friends 12(60%) and posters 9(45%) were the most used sources of health information. Internet; 2(10%) and leaflets; 6(30%) were amongst the least used.

## Response from focus group members

Six respondents noted the importance of family members as sources of health information. One person underlined the 75% statistic for family as a source stating:

"Value of lay health programme".

She referred to the Belfast Trust's employment of 2 female Traveller Lay Health Workers. This was echoed by another person:

"Need for peer support workers- male and female".

Another comment highlighted the importance of building Traveller women's knowledge:

"As it appears women are at the forefront of giving information they should be educated so they can disseminate information to the men".

Five noted the influence of TV. One referred to the programme-'Citizen Traveller' which she believed raised issues successfully: "Citizen Traveller was very successful in the Republic of Ireland in raising issues".

Four commented on leaflets, with particular reference to a specially designed safety leaflet within the Promoting Wellbeing Department:

"Specific leaflets have been designed in relation to safety issues".

One referred to a regional CAWT newsletter:

"A newsletter is being developed by NI Traveller Forum to inform Travellers about work of the Forum under CAWT Access to Services Programme".

Three respondents reacted to low internet usage highlighting literacy issues, lack of access and knowledge of IT:

"Level of access to internet is much poorer for Travellers compared to settled community";

"Reflects literacy need";

"No access to computers or unable to use one".

One respondent asked if the slide on sources of information differed from the general population.

Table 3 Sources of health information

Source of health	n	%	
information			
Health professional	19	95	
Family member	15	75	
TV	13	65	
Friend	12	60	
Poster	9	45	
Leaflet	6	30	
Internet	2	10	
Conversations	2	10	
Cousin	1	5	
Locals	1	5	

#### 4.6.2. Rate sources of health information

## Response from Travellers

Table 4 shows results from a question asking people to rate sources of health information from 1-5, with 1= not good, 3 = good, 5 = very good.

19(95%) rated health professionals between 'good' and 'very good'; 18 (90%) rated one to one methods, and 12 (60%) rated group education methods within the same range.

14(70%) rated TV between 'good' and 'very good' although15 (75%) rated videos as 'not good' to 'fairly good'.

Leaflets received mixed response with 12(60%) rating them between 'good' and 'very good' and 8(40%) responding 'not good' to 'fairly good'. 16 (80%) rated internet as 'not good'.

A cross tabulation of health information rating by levels of literacy (*Table 21*) revealed, that of the 7 respondents who could not read, 6(85%) gave the Internet, 5(71%) leaflets and 4(57%) posters low ratings. Of this group 6(85%) rated health professionals, 6(85%) one to one and 5(71%) rated word of mouth, group education and TV as 'fairly good' to 'very good'.

Conversely of the 13 who could read 13(100%) rated health professionals, 12(92%) rated TV, word of mouth, one to one and leaflets as 'fairly good' to 'very good'. 9(69%) of those who were literate did not rate video or internet highly.

## Response from focus group members

Two respondents commented on one to one methods receiving higher rating than group methods. Others offered contrasting views on the merits of this method with one questioning its practicality and the other offering a one to one service:

"Low level for group education vs. one to one";

"One to one method – is it practical?"

"PWBT Traveller Family Support Worker can promote health information on one to one basis to each family".

As regards group methods one person highlighted the need for single sex groups and training programmes addressing men's needs designed by men:

"Traveller men won't attend mixed training groups with males and females-more training programmes addressing Traveller men's specific health needs designed by Traveller men".

General comments about health information focused on the need for plain English, a description of existing targeted health promotion initiatives including 'Reach' (a Community Lifestyle Programme funded by the Lottery), 'Man Alive' (a cancer prevention programme targeting male Travellers), and Safe and Well (offering health, community development and youth programmes to Travellers). Consideration was also given to the venue for information provision:

"More health information could be given in sporting venues".

One person highlighted the need for information sharing in Neighbourhood Renewal areas (areas of highest deprivation within NI funded by the Department of Social Development):

"Neighbourhood Renewal areas need to be sure that Travellers are aware of what's happening in their areasthey may not be able to read leaflets or read ads in local papers – Traveller Support Workers should be informed of up and coming events so they can inform Travellers".

Table 4 Rate sources of information

	Not	Fairly		Quite	Very
Source	good	good	Good	good	good
Health professional	1	0	4	4	11
TV	3	3	10	2	2
Poster	9	4	4	2	0
Leaflet	7	1	6	4	2
Video	13	2	2	2	1
Internet	16	0	0	0	3
One to one	1	0	5	7	6
Group education	6	1	7	1	4
Word of mouth	3	0	7	6	4

# **Section 7 Groups that would interest men**

This section focused on men's views about social, recreational, educational and other opportunities that might be of interest to them.

Groups that would interest men included educational, trades, Traveller culture, citizenship, health, social, and recreational.

## 4.7.1. Groups that would interest men

## Response from Travellers

Respondents were interested in educational, trades, Traveller culture, citizenship, health, social, and recreational groups for fitness and arts activities.15 (75%) requested at least a weekly meeting if not more frequently.13 (65%) preferred it either in their own locality. The highest number 8 (40%) preferred evening meetings, although 4 (20%) would consider any time .17 (85%) suggested promoting a group through word of mouth.

## Response from focus group members

#### Education and trades

The focus group responded to the potential additional benefits of ICT training (8 comments), venue (5 comments), school curriculum, (4 comments) timing (2 comments) and trades (1 comment):

"Could ICT be a driver for the desire to improve literacy?

E.g. e-bay and the increased use of internet technology -this in turn could improve access to information";

"To extend IT training to groups outside the Trust";

"To train one young Traveller man in ICT OCN level 2 by October" (CAWT);

"To train Travellers to teach IT as role models";

"To further develop ICT skills for drug and alcohol awareness, driving theory; build literacy into other training";

"Look at these groups and link into health, numeracy and literacy".

"Mostly practical – implications for school curriculum on offer. Greater emphasis needed to reflect the world of work of Travellers and their culture";

"Programmes developed specifically for schools to provide vocational and recreational- interests to be met as well as literacy and numeracy- PHA could assist/lead with others to progress issue and has already influenced the commissioning of some social care";

"Offer opportunities at school on these issues i.e. trades, driving, sport, horses"; implications for education to create a programme which addresses their career and lifestyle issues".

Focus group members also had ideas about innovative methods of engaging men, either on a one to one basis or in small groups e.g. men's sheds. There were conflicting ideas about whether services should be offered on an outreach basis or whether mainstream venues should be made more welcoming to Travellers:

"Explore the idea of men's sheds";

"Provide small structure directed training sessions in various locations throughout the region tailored to their needs – areas of interest e.g. topic of interest like hunting, fishing, handball. Could play a part in focused topic for a portfolio";

"Overall outcomes in SRC to break down the barriers faced by Travellers in accessing SRC provision and 2.5 years into the project 7 classes have moved from community venues to SRC at the request of Travellers"; "CAWT Employment and Skills training: first time a class of Travellers have gone to the SRC to take up IT and Maths Classes previously done in the Community";

"Campuses should be open to Travellers as to everybody else – Navan Fort for a Travellers venue - the feedback from Travellers was never been here before".

Barriers to gaining qualifications in trades were highlighted. They felt Travellers were more interested in trades than recreational activities and recommended peer training and incentives:

"Barriers – may take up to 3 years for trades. They will also need literacy and numeracy for forklift, HGV, and Driving Licence":

"Trades and practical issues";

"Limited work areas in training, trades and recreation -peer training and incentives to small business".

The Safe and Well representative highlighted a Towing Licence course which they offer and suggested developing a HGV training opportunity. Another respondent saw training for trades as a natural progression from demographic information on experience of trades:

"Training for trades – natural progression from manual work referred to in employment statistics".

#### Timing

One person underlined the highest number preferring evenings which was a barrier for her agency but acknowledged potential for development:

"Low uptake by Travellers of Wade courses – potential for development".

SRC noted that they do provide evening provision.

#### **Training**

One respondent referred to a Safe and Well capacity building course with Travellers:

"Train the trainers being carried out by Safe and Well".

#### Recreation

Four respondents reacted to information on recreation with three addressing fitness and one arts. In relation to fitness one person queried the appropriateness of voluntary sector Traveller specific groups taking the lead indicating that the Council and GAA should be proactive:

"Is this something that the voluntary sector should be providing? What about the Council Sports Development Workers and GAA involvement?"

This issue was prompted by the interest in handball with another person suggesting that the GAA should develop handball clubs and other activities:

"Development of Handball Clubs and sporting activities with the general population".

She went on to acknowledge the psychological benefits of sport:

"Use sport to promote self-worth and self-belief".

Walking groups were also suggested. Another respondent reacted to the interest in boxing by drawing attention to an after schools boxing/drugs and alcohol programme instigated by a Health Promotion student with the PWBT:

"In Newry a male student health promotion worker has just completed a very successful programme in partnership with a school".

She went on to suggest the need for male workers.

One respondent suggested a link with Arts-Care (a Voluntary organisation dedicated to arts provision in the health sector) to meet artistic interests also suggesting a celebration of Traveller culture:

"More links with Arts-Care to promote history, storytelling, and music to capture and celebrate culture and pass on to the next generation".

#### Health

Drugs and Alcohol and cancer screening elicited two comments.

The CAWT worker highlighted a Hidden Harm Drugs and Alcohol project which she suggested should be rolled out in Monaghan:

"Needs to be more widespread. Pilot Hidden Harm Project in Monaghan".

Another person noted the Man Alive Cancer screening programme run by Ulster Cancer Foundation.

#### Citizenship:

Four commented on the interest in Traveller rights highlighting the success of the 'Citizen Traveller' TV programme in the Republic of Ireland and the limited success of Traveller rights initiatives in N.I.:

"Initiatives to inform Travellers of their own rights have had limited success with events cancelled at the last minute",

although more work was being planned by the Equality

Commission. Another person from Safe and Well suggested:

"More work with the Equality Commission".

## 4.7.2. Cross cutting themes

In the final section cross cutting themes and new issues introduced by focus group members are explored. These include the social determinants of health, male engagement, gender, community development, community infrastructure, and ethnic monitoring.

#### Social Determinants of Health

Although this was mentioned under mental health there were four comments throughout the research indicating its centrality:

"Action on the wider determinants of health will underpin any positive changes in mortality";

"Need action on wider social determinants of health including poverty, education, jobs, inclusion agenda mixing with others in discos, bars";

"To move on health and social agenda" (with reference to the Southern Area Action with Travellers).

In reference to the study title one person commented:

"Two pronged approach important".

A fifth person reacted to the slide on the literature review, recommending approaches that combine health promotion with holistic health:

"Our Integrated Promoting Wellbeing Department".

Male engagement and gender

Six additional comments were made on the issues of male engagement and gender:

"Need for more engagement with men – men need to be given confidence to express themselves";

"To engage men where they are at";

"When giving research results from AITHS- men didn't want to know".

"Gender issue pervades all work for change";

"Common male issues – women to the fore- need to build on women".

In relation to opening quotation from Ellen McDonagh:

"Interesting to start with a female perspective";

"Need to empower Traveller women to play a major part in improving their men's health".

#### Community Development

In addition to the reference to 'asset based approaches' in the mental health section there is also a suggestion that Travellers should be offered training as volunteers:

"The need to engage Travellers in the new Volunteering plan in the HSC. Travellers need to be offered training as Volunteers".

Another respondent highlighted the Community Development and Neighbourhood Renewal Programmes. Another suggested:

"Citizenship", 'asset based approach', Community Development strategy";

"HSCB/PHA commissioning securing Traveller work at Grassroots and Atlantic Philanthropy";

(with OFMDFM taking the lead).

#### Community Infrastructure

There were two comments about the role community infrastructure played in enabling engagement for this research:

"Infrastructure has to be there for Fergal to engage with";
"Infrastructure in area facilitated the engagement".

One commented on the need for continuing investment in TSGs:

"Need to invest in the infrastructure of the existing Traveller Support groups and relevant staff".

She observed that too much time was spent chasing funding. Another respondent suggested the establishment of a CAWT Cross Border Health Advisory Group.

#### Ethnic Monitoring

Ethnic monitoring was raised in the demography and health information sections as key to monitoring service uptake with the OFMDFM identified as the lead body:

"Many key information systems have the capability to record ethnic status but this is not seen as a priority and in many cases is not recorded. Priority is placed on religion, sex, disability, with these areas covered by legislation";

"Ethnic monitoring will require a TOP DOWN organisational wide drive to ensure it takes place".

## Suggestions included:

"Improve Ethnic Monitoring in order to assess the take up and use of agency services"; "Improve data quality and target services from obvious areas of weakness/ shortfall";

"A Racial/ Equality Ethnic Monitoring Strategy from OFMDFM across all professional groups".

# **CHAPTER 5 DISCUSSION**

#### **Preamble**

To address the central question "Dying fifteen years early – what can Traveller men and relevant agencies do?" this section will use themes from the National Men's Health Policy 2008 – 2013 (Richardson & Carroll, 2008) due to their relevance, international applicability and future potential. Issues identified by men and focus group members in the mortality section will be woven through these themes. Limitations in methodology will be addressed first.

## 5.1. Limitations of methodology

#### 5.1.1. Action research and ethical consideration

Sarantakos (2005, p.337) lists the weaknesses of action research as:

- allows no replication
- biased towards interests of certain groups
- cannot assure representativeness, objectivity, nor generalizability.

However weaknesses need to be weighed against strengths. It has been evident that Traveller men's health has been neglected in Ireland with a concomitant shocking mortality rate.

Action research methodology enabled exploratory research, innovative and in depth engagement and an opportunity to influence relevant agency policy and practice. Traveller Advisors played a key role in facilitating engagement in a group traditionally suspicious of statutory involvement and subjected to on-going racism and discrimination. The study fulfilled action research

principles: it was applied, situational, topical, collaborative, participatory and political (Sarantakos, 2005, p.333).

In accordance with action research principles the researcher consulted with Traveller advisors about terms of reference and the content of structured interviews prior to ethical consent. This caused nervousness among academic advisors in case it would be perceived by OREC that the research had commenced prior to approval. The researcher presented evidence to OREC that in Canada, the Tripartite Council of Policy on Ethics had established the principles of ownership, control, access, and possession (OCAP) when doing research with Aboriginal communities and within this context prior consultation was considered best practice. This was referenced by OREC when granting approval (Appendix 13).

However measured against these standards the research fell short of full action research methods in which peer researchers have been trained to conduct work within their own community (AITHS, 2010; Etowa et al, 2011; Brown & Scullion, 2010) although it did overcome issues concerning confidentiality and reliability highlighted in a recent paper (Brown et al, 2012).

### 5.1.2. Sample

Due to the small sample size temptations to generalise should be resisted especially when so little health research has been done specifically engaging Traveller men. Even within the small sample differences of opinion existed. However Sarantakos (2005, p.171) observes that

"the more intense and in depth the method of data collection, the smaller the sample size".

Weight is also added to the findings of this study through similar findings identified in the international literature.

Purposive sampling was employed to ensure a representative spread of ages, accommodation types, family groups and area but again caution is required in making generalizations with such a small sample. However, it is acknowledged that a limitation of the study was that despite these efforts the sample was skewed towards Housing Executive tenants, which may have affected findings in relation to primary care.

#### 5.1.3. Objectivity and bias

Action research challenges positivist assertions that the methods of physical sciences are applicable in social science, truth is absolute, reality objective and the influence of the researcher neutralized (Sarantakos, 2005, p.34). Truth is viewed in action research as a social construct (Guba & Lincoln, 1994). Some feminist researchers do not accept the neutral distant role and assumption that the interviewer is the 'expert' while the interviewee is the 'ignorant party'. They argue the relationship must be more egalitarian (Reinharz, 1992; Westkott, 1990 in Sarantakos, 2005, p.278). This research was not value free and the researcher took the side of respondents to help them understand their real situation, in terms of discrimination, and set out from the onset to bring findings to relevant agencies in order to affect change. This does leave the researcher open to challenges about objectivity.

### 5.1.4. Piloting, recording and instruction errors

Some responses from focus group members could not be included due to illegibility. Time pressure to interview the Traveller participants before they departed for seasonal travel meant that there was insufficient time to pilot the structured interview. A two part question on domestic violence needed to be reworded for the second interview.

Conversely the process of amending the structured interview tool whilst consulting twelve Advisors counterbalanced the absence of the formal pilot. It provided an opportunity to develop a tool which was culturally relevant and easy to understand.

Questions about discrimination more closely aligned to the format developed by Krieger et al, (2005) and employed by the AITHS, would have allowed standardised comparisons. However the principles of action research questions emerging from Advisors.

#### 5.2. Social determinants of health

From the onset this study adopted a social determinants of health perspective advocated by the AITHS (2010), and other health studies of indigenous men and men in the general population (McCalman et al, 2006; Brown & Macdonald, 2009; Smart el al, 2003; Cushnahan, 2008; European Communities, 2011; Richardson & Carroll, 2010).

Focus group members recognised the need for action on wider determinants to underpin positive changes in mortality and mental health:

"Clearly discrimination, poor health status, low education attainment, lack of government support, accommodation, access to services, income etc. will have a massive impact on Travellers experience of mental health"

#### as did Travellers:

"One of the differences is I can't get a job except one in a hundred".

An integrated multiagency long term strategy to tackle inequalities in partnership with Travellers was suggested:

"Action plans joined up with Travellers, [led by OFMDFM]"

One focus group member observed:

"Travellers moving into houses has had no impact on health improvement".

Disconnecting Travellers from their extended families leads to social isolation which can result in depression (Van Hout, 2011; AITHS, 2010).

In Donegal 50% of Travellers living on sites stated that the accommodation situation was cause for stress, with more Travellers who lived on sites reporting depression than those resident in houses (Leonard & O'Leary, 2006).

Contemporary indigenous health literature reinforces this message.

"The health disadvantages experienced by Indigenous people ...are specifically manifest in measures such as education, employment, income, housing, access to services, social

networks, connection with land, racism, and incarceration" (Thompson et al, 2011).

Some Travellers commented on links between mental health issues like stress, unemployment, depression and suicide:

"suicide: it is depression, everything builds up and they don't talk to anyone";

"I would suffer from depression and I have a suicidal number on my phone. There are days I feel so depressed I say not another day - tablets only last for so long. Everything is stress";

"Stress, hardship, providing for family";

"having no work would affect life expectancy".

According to the AITHS (2010, p.94) Traveller men have a 6.6 times higher suicide risk than settled men. However according to Gossrau- Breen (2012) statistical information on suicide among Travellers is available for ROI via two recent studies but not for N.I. In the present study 13 (65%) said their family had not been affected and 5 (25%) stated their family had been affected by suicide; 15 (75%) knew of other Travellers that have lost their life by suicide and13 (65%) did not know of support groups. Evidence indicated a need for suicide support groups to be better promoted amongst Traveller men across the area. However focus group member queried if such services would be used due to existing cultural norms.

The need for a long term integrated strategy, based on the social determinants model of health to tackle Traveller inequality emerged as a clear way forward:

"A 15 year gap - needs to be addressed as a priority";

"This is totally unacceptable and requires a new long term properly resourced initiative across the region".

## 5.3. Male engagement, masculinity and gender

Gender is one of the major organising structures of social life. It is related to broad divisions of labour, social authority and control over resources, patterns of sexuality and emotional attachment, and identities. Groups of men and groups of women have differences in exposure to health risks, behaviour, interest and learning (Connell, 2000). Traveller culture is marked by patriarchy and strong gender demarcations (AITHS, 2010; Allen, 2011; Walker, 2008). Traditionally, women have been responsible for childcare and the home and have been financially dependent on their husbands, who make the decisions.

Masculinity, gender and male engagement issues permeated the study. For example 'macho' attitudes were evident in the discussion about suicide:

"Men are afraid to speak out/ more ashamed to discuss their problems - should be encouraged to take problems to a doctor- he listens".

Cultural ideas around conflict were noted:

"Travellers do a lot of fighting among each other" as were methods to deal with discrimination;

"No, we're more likely to floor somebody than report it".

The extent of the anecdotally high levels of depression and bereavement in GRT families (Greenfields, 2008; Cemlyn et al, 2009) is not widely known, nor has the importance of the extended family as a source of strength and resilience been fully explored. The cultural competency gap needs to be bridged through cultural awareness training for professionals, in order that mainstream services are perceived as more accessible by these communities.

Gender issues emerged when making appointments for services, (70% said their wives made appointments) obtaining health information, (75% obtaining information from family members) choosing trades and recreational activities, addressing nutrition strategies and in taking action to report discrimination with high demarcation in roles.

"When you start complaining too much she would make sure you see a doctor"

The Belfast Trust recently employed two female Traveller lay health workers and reference was made by a focus group member to justification from evidence around Traveller women's roles in health and the need to employ more Travellers in other workforces.

According to Etowa et al (2011) significant under-representation of Aboriginal peoples in the health professions is problematic in Canada. Increasing representation is a promising strategy to narrow the gap in access to appropriate health care for Aboriginal peoples. Etowa used Community Based Participatory Research to actively engage team members in all aspects of the research to address the three goals of CBPR; research, education and action.

Traveller men may feel traditional Traveller male roles are threatened as their traditional nomadic economy and bonding forms of social capital are depleted and undermined, whilst Traveller women may be more successful at developing bridging forms of social capital (Ryder & Greenfields, 2010).

Focus group members highlighted gender differences throughout:

"Gender issue pervades all work for change"

e.g. in lifestyle issues like drinking and smoking:

"Traveller boys are allowed to smoke at any age whereas the girls have to wait until they are married"

education and training:

"Not seeing the benefit of general education and training as they all still provide for their families and don't believe that formal training will enhance that- rather it is seen as too time consuming";

domestic violence, stress and the role of women in accessing primary care:

"Women have a key role in all communities in influencing how, when and where males access health services".

Male engagement was present from the design stage (although not exclusively as the quotation at the beginning of this research and the gender ratio of the Traveller Advisors testifies) and the themes of male engagement and the need for a gender strategy re-occurred in various parts of the research.

90% of the sample followed the trades of their fathers. A Traveller man was suggested as a paid role model to be trained to deliver numeracy and literacy to other Traveller men. The Equality Commission for Northern Ireland (ECNI) recognised the need for further work to increase the number of Traveller men taking discrimination cases. Other focus group members highlighted the 'Man Alive' cancer screening programme, a successful boxing/ alcohol and drugs programme delivered by a male health promotion student, and the need for more training programmes like the SAW towing programme.

According to the AITHS,

"a gendered strategy needs to be adopted and men's health issues need to be addressed specifically, with an emphasis on empowerment and promotion of self-esteem for young Travellers of both sexes to improve mental health and wellbeing, but particularly drawing in the engagement of men. This requires a comprehensive cross-sectoral approach to facilitate work opportunity, break down the substance misuse problems and engage men in health service participation" (AITHS, 2010, p174).

However gender politics is complex. According to Connell (2000) it is commonly assumed that a progressive politics of masculinity must take the form of a social movement such as the gay movement, labour movement or civil rights movement.

But he argues Australian men as a group and heterosexual men in particular are not oppressed or disadvantaged, and attempts by men to address sexism have been subverted towards a concern about being 'positive' about men and 'masculinity therapy' (Connell, 2000).

Paradoxically, Connell reasons, to fight for justice in gender relations often means doing the opposite of the things that would create a "men's movement". That is, tackling issues that inevitably divide men rather than unite them, such as homophobia, affirmative action for women, equal pay, sexual harassment and violence. These pose challenges for more traditional gender roles within Traveller culture and in the wider community.

One idea which has gained momentum is the growth of men's sheds as a safe space for men to meet (<a href="www.mensheds.org">www.mensheds.org</a>) and this was referenced by a focus group member as worth exploring.

## 5.4. Racism, sectarianism and discrimination

15(75%) reported current unemployment compared with the N.I. unemployment rate for the period of 6.9% (March - May 2012, DETI 2012). In the 2006 census in the Republic of Ireland (Central Statistics Office, 2007) the unemployment rate for Travellers was 75% compared to 9% for the general population. Traveller statistics from the NI 2011 Census are unpublished but

unemployment in NI for Travellers in 2001 was 89% (AITHS, 2010, p.14).

Ryder & Greenfield (2010) have discussed how bonding social capital within the Traveller communities may have emerged as a defensive mechanism as a result of centuries of racism and exclusion from mainstream society, including mainstream employment opportunities. It's no surprise then that 45% reported being normally self - employed. Reference was made by Travellers to the impact of unemployment on stress, depression and suicide:

"Stress, hardship, providing for family";

"having no work would affect life expectancy";

"Suicide -it's depression, everything builds up and they don't talk to anyone)".

20(100%) of Travellers in the sample experienced discrimination (both early and recent with only one person not reporting experiences of early discrimination). 39 incidences were documented. Findings elicited a comprehensive reaction from the Equality Commission N.I. (ECNI) who suggested a strengthening of the racial discrimination laws to bring them into line with the Equality Act 2010 (21/3/2012) and a refreshed racial equality strategy (**Appendix 22**).

Widespread discrimination and racism against Travellers is already well documented (AITHS, 2010; NICEM, 2011; Walker, 2008; Helleiner, 2000; Connolly & Keenan, 2002). Traveller

Advisors prioritised questions on racism and discrimination over others. In answer to questions about what made them proud or embarrassed about their culture the issue featured:

"We're a proud tradition as good as anyone. We don't have to rob people to be any good. There will come a time when there is no discrimination";

"Discrimination and hate crime and kids getting bullied".

15 people reported experiencing recent discrimination in bars/ clubs, 5 in shops and 2 in leisure facilities. Childhood discrimination focused on name calling, school bullying and physical violence with additional examples of social exclusion. One focus group member described Traveller comments about experiencing racism and sectarianism as:

'a double whammy'.

Racist attitudes were exacerbated by media stereotyping in 'My Big Fat Gypsy Wedding' which impacted directly on one man's livelihood. This programme offended Travellers and Gypsies across the UK and a related Channel 4 advert was referred to the Advertising Standards Authority after 370 complaints (Sweney, 2012).

According to ECNI (2012) 35% of respondents would mind having a Traveller as a work colleague, 54% as a neighbour and 55% as an in law. ECNI calls for the Executive to address these attitudes through the Cohesion and Social Integration (CSI) Strategy.

The impact of discrimination on stress and mental health was clearly articulated:

"It does stress you out that they're judging you for no reason. It absolutely frustrates you - you feel 'what's the point talking if they're putting you down?'

Findings around the impact of racism and discrimination elicited strong reaction from focus group members:

"It's such an everyday occurrence, most don't even recognise it anymore- it comes from all sources and never seems to have been addressed – legislation is clearly not enough".

According to Krieger (2000; 2003) research on racism as a harmful determinant on poor health is recent. Krieger highlights three issues – the links between racism, biology and health; methodological controversies on how to study the impact of racism on health; and debates over whether racism or class underlies racial and ethnic disparities in health. She argues race is a social rather than a biological category with one group benefiting from dominating others. She describes direct and indirect methods to test the hypothesis 'does racism harm health?' and asks a question around validity and memory recall in investigations relying on self- report. On reflection this research would have benefited from the instrument Krieger et al (2005) used to measure discrimination, and which was used by the AITHS to allow direct national and international comparisons (AITHS, p.74). However findings from this study resonated with the AITHS. Finally she raises debate over whether racism or

social class explains racial/ ethnic disparities in health and which is causally prior (Krieger, 2000; Krieger et al, 1993; Williams, 1999).

According to the AITHS (2010) Travellers' experience of discrimination was widespread and affected every area of their life. Discrimination was reported by 3 out of 4 Travellers in accommodation requests; 7 out of 10 at school, being served in a shop or pub, and on the street/in a public place; 6 out of 10 when seeking work of from the police or in the courts. Experience of discrimination was more keenly felt in Northern Ireland than in ROI. Ethnic discrimination was higher among Travellers in the AITHS than in low income mixed race groups in US studies on the listed issues.

Sectarianism may account for the higher levels of discrimination experienced in NI according to the AITHS. The contribution of sectarianism to the findings in this study requires further research as caution is required in drawing conclusions due to the small sample size. Focus group members commented:

"Both impacts – southern accent into Northern area";

"Perceived threat and actual evidence – <u>racism and</u> sectarianism".

Krieger outlines five pathways through which racism can harm health:

- 1. economic and social deprivation
- 2. toxic substances and hazardous conditions

- socially inflicted trauma (mental, physical, sexual, directly experienced and witnessed, from verbal acts to violent acts)
- targeted marketing of commodities that can harm health
   junk food and psychoactive substances
- inadequate or degrading medical care.

The effect of these 5 factors is evident in this study to varying degrees as is variation in the individual's response to discrimination. Examples of internalised oppression are manifest in the number of Travellers who did not report either early or recent discrimination:

"No, I was a child at school. The Master gave you slaps too, so you couldn't report it to anyone";

"No, a waste of time - the same pub discriminated against us a load of times".

Socially inflicted trauma was experienced and witnessed. 12(60%) of the sample felt domestic violence was high and 11(55%) knew someone who has experienced it. One focus group member queried whether domestic violence was related to other pressures. EHRC (2007), on the health of Gypsies and Travellers in Wrexham, reported that 61 per cent of married English Gypsy women and 81 per cent of married Irish Traveller women interviewed for the study had experienced direct domestic abuse. However no further information is available on whether the methods of identifying or recruiting women may have influenced these figures. A subsequent EHRC report makes the point that Gypsy and Traveller women who have suffered domestic violence

will have suffered it more severely, and over a longer period of time than other women (EHRC Report, 2009). Domestic violence is not specific to Travellers and it has been contested whether it is more prevalent within the Traveller Community (Pavee Point, 2005). Yet, it has been suggested by Traveller women and service providers that domestic violence is more acceptable within the Traveller Community (AITHS, 2010; Allen, 2011; SAAT, 2011; Watson & Parsons, 2005).

Three graphic incidents were recalled in relation to early discrimination in this study - being thrown through a school window, burned out of a house and physically attacked while waiting for a bus.

Incidences of childhood verbal abuse and bullying were among other examples of socially inflicted trauma:

"You are out-casted in primary class. The children wouldn't involve you in groups".

Some focus group members offered praise for Belong, (<a href="www.belongni.org">www.belongni.org</a>) an evidence based programme in the Southern Trust area for 7-12 year BME children employing antibullying, cultural competence and educational support programmes. Belong arose out of the work of Biggart et al (2009) which documented racism and discrimination amongst BME children (including Travellers). Some focus group members were keen that the Traveller Education Task force addresses the issue of bullying in is forthcoming strategy.

Another response documented harmful use of psychoactive substances like alcohol, drugs and tobacco in response to stress and depression:

"Reason for drinking - I ended up badly depressed and ended up drinking. When you are out and about you have your freedom moving from place to place - this is one of the biggest factors - you're too much confined in a house... they're losing a lot of traditions over housing"

The AITHS (2010) reported that 38.1 % of respondents in ROI and 39.3% in NI indicated they never drank alcohol, although rates of non-drinking were considerably higher in women than men. According to Hurcombe et al (2010) the most important barrier to help-seeking for problem drinking is failure to address the stigma attached to alcohol problems and the experience of discrimination. To address racism and systems within organisations that support it, a comprehensive framework that assesses cultural competence has been developed (Fountain, 2009).

60% of the sample smoked tobacco compared with the European male average of 32% (European Commission, 2009) and N.I. male average of 25% (DHSSPS, 2011). The AITHS reported 52.5% of Travellers in ROI and 50.8% in NI were current smokers with 53.9% of male Travellers in N.I smoking. According to Robinson et al (2009, p.13) the highest prevalence rates were among economically inactive people aged 16-59 whose last job was a routine or manual one (50%).

15 (75%) knew someone who had taken drugs; 15 (75%) said the issue of drugs and alcohol had worsened in the last 5 years. In the AITHS a majority of respondents (66.3% in ROI and 64.6% in NI) considered illicit drugs to be a problem in their community and this was a consistent pattern for both men and women and across age groups. Traditional anti-drug Traveller culture is diminishing in potency, as families become fragmented and Traveller youth assimilate within educational settings, and over time one would question if drug use among Travellers will replicate or even exceed that of the 'settled' population, given the marginalisation and discrimination they experience (Van Hout, 2011).

This study presents evidence of Travellers taking limited protection against hazardous substances like asbestos, copper wire, burning plastic, paint and power-washing and focus group members responded with suggestions to tackle this (see recommendations section).

Responses to discrimination varied from inaction to active resistance. Those who did take action went to a solicitor or court, the bar manager or took action themselves:

"No, we're more likely to floor somebody than report it".

The family who won their case against discrimination on the golf course through the ECNI were proud of this and saw it as a landmark event for Traveller rights and equality, although the ECNI acknowledges much more work is required to encourage male complainants to come forward (Appendix 22).

In relation to marketing of commodities many men although able to distinguish between healthy and unhealthy food admitted to eating fries and junk food. Some focus group members were keen to promote healthy eating through young women's groups.

One Traveller stating how he would describe Traveller culture to an American said:

"I wouldn't describe a Traveller to an American if he didn't know".

A focus group member added:

"I am aware of Traveller children who 'speak like country people' so as not to be recognised as Travellers".

Connolly (2011) provides evidence of ethnic awareness and attitudes among three to four-year-old children in Northern Ireland. Many GRT people choose to hide their identity, or they identify as another ethnic group in order to avoid racism (Cemlyn et al, 2009; AITHS, 2010).

In summary, racism, sectarianism and discrimination have had an adverse impact on male Traveller's mental health and employment chances leading to increased stress, depression and suicide. Action is required across statutory, voluntary and community agencies, in partnership with Traveller men, to tackle this.

# 5.5. Community development, community infrastructure and empowerment

An 'asset-based' approach to community development has gained ground in recent years as a corrective to the more familiar 'deficit' approach, which focuses on the problems, needs and deficiencies in a community such as deprivation, exclusion, crime, anti-social behaviour, illness and health-damaging behaviours. Focusing entirely on deficits can create a sense of hopelessness amongst communities and resignation amongst professionals. As a result, a community can feel disempowered and dependent. People can become passive recipients of services rather than active in their own and their families' lives. Clearly it remains important to be aware of needs and disadvantage and to narrow inequalities, but emphasising assets gives a better balance and generates confidence and aspiration.

Tackling men's health from a strengths perspective is also emphasized in the National Men's Health Policy (Richardson et al, 2008).

Travellers demonstrated initiative and resilience in the areas of finding occasional labour, beliefs, changing attitudes to education, fitness, accessing primary care and a willingness both to advise and engage in this study.

"Community development emphasises the community's perspective, because this is usually less visible and less powerful than that of the public agencies, especially in disadvantaged areas or situations. Community development will also show that

even very disadvantaged communities have abundant assets as well as needs" (O'Neill, 2012, p.4).

Overall 9 (45%) replied that they would normally be self-employed, but not within a steady business and usually in occasional labour. The most common experience of trades were scrap dealing 17 (85%), power-washing 16 (80%), market trading 14 (70%) and door to door sales 11 (55%). It is interesting to note Travellers have adapted to today's economic climate with traditional trades like tinsmithing substituted by power-washing, although buying and selling has remained. One man was proud of his ability to survive despite poor educational outcomes:

"We didn't have to go take GCSEs- we know our own trades".

Although there was evidence of this changing:

"Making sure the children are well educated- education is important in our culture and it wasn't always that way".

Travellers remain strongly connected to traditional beliefs and values. The men interviewed had strongly held family values. The information on 18(90%) believing in traditional cures, 13 (65%) having sought a cure and 12(60%) reporting improved health as a result is interesting, even if one focus group member advised caution in terms of potential risk. Parry et al (2001) viewed Travellers' health beliefs as cultural pride in self-reliance.

As regards fitness, 7 (35%) walked, of whom 2 also hunted, and 1 played golf. 5 (25%) showed high levels of fitness and attended the gym:

"I am an All-Ireland Champion Boxer";

"I am a member of the certified Training Academy and Leisure Centre".

Focus group members picked up on the interest in handball, asking if the GAA or Council could take this forward. One person remarked:

"Examples of Travellers in Coalisland doing marathons for charities. They aren't members of running groups and decided to do it themselves."

The boxing/ alcohol drugs initiative set up by a male health promotion student for a disengaged youth group was successful. However comments from one focus group member about not stereotyping opportunities offered is noted, and underlined by the golfer.

Community Infrastructure was viewed by focus group members (and acknowledged by Traveller Advisors) as an essential pre-requisite for engagement in this research, provision of essential front line support to Travellers and future development of services including provision of one to one health information, promotion of additional activities for men and facilitation of access to services. Without TSGs, integrated interagency locality planning across education, health, accommodation and the community/ voluntary sector would not be possible nor would there be the means to take holistic health action.

Empowerment is at the centre of community development, action research and health promotion. 32 Travellers, of whom 28 were

men, engaged at the advisory and implementation stages of this research despite literature on lack of engagement in health services by nomadic/ indigenous people and men in general (Westerman, 2004; Vicary & Andrews, 2001; McLennan & Khavarpour, 2004, Parry et al, 2001).

Reconstructing male empowerment and self-determination are key building blocks in the Australian National Framework to improve the health of Aboriginal and Torres Islander males (Adams, 2011) who have early mortality rates comparable to Irish Traveller men (*Figure 1*).

From a deficit perspective the 35% illiteracy rate, similar to that reported in the AITHS, would be viewed as high:

"As a key outcome of education and an instrument for further learning, literacy is part of the right to education and it facilitates the achievement of other rights. Equitable opportunities to acquire and use literacy are not available to certain groups, such as indigenous populations and nomadic communities" (Richmond et al, 2008, p.7).

However, it is easy to overlook the 65% literacy rate, experienced by the researcher when some respondents completed structured interviews unaided, and the qualifications attained by a small number. The young man who expressed an interest in learning ICT skills to aid buying and selling on e-bay provoked responses from 5 focus group members who asked could 'ICT be a driver for change?' Two saw this as a culturally relevant opportunity to introduce ICT:

"Opportunity for education to use the computer as a hook to wider education";

"Influences of IT – logical for Travellers. Buying/selling important and reflects on culture".

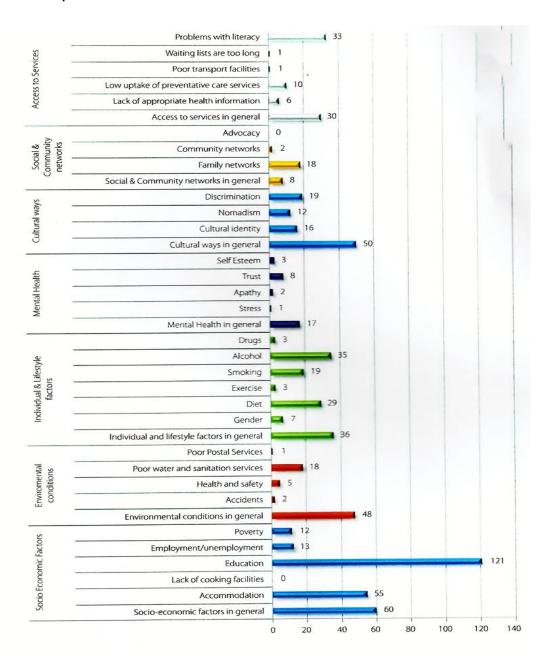


Figure 20 'What would make the biggest different to health?' (AITHS 2010, p151)

In the AITHS respondents were asked what 3 factors would most improve the health and wellbeing of the Traveller community (Figure 20). Frequency of mention was presented in rank order. Better education was ranked by far the highest, followed by better accommodation, better uptake of preventive services, better provision for those with literacy problems and more culturally appropriate services (AITHS, p.151), although it would be interesting to see the gender breakdown of these respondents.

The success of the SAW towing course attended by 17 men demonstrates the appetite for attending relevant courses addressing self-identified need.

Employment of more Traveller men and women across agencies, the development of new Traveller role models like those envisaged by CAWT, SRC and Safe and Well to train other Travellers in literacy and numeracy skills, and the acquisition of new skills like ICT and HGV licences, which may be possible through training courses offered by WADE training, will all play important roles in future 'asset building'.

However very real barriers have been highlighted by the SRC in relation to time commitment, literacy and economic imperatives that prevent Traveller men undertaking a 3 year course to gain a trade qualification, with shorter courses like towing, driving and security proving more feasible.

Empowerment was demonstrated by four Traveller Advisors and three Traveller musicians who came forward to make a DVD to disseminate findings in this research. Other opportunities need to be created by agencies and taken up by Traveller men in the future.

Few Traveller men are involved in championing Travellers issues at a policy level, with some exceptions in the Traveller Education Task Force. Travellers will need to become directly involved in the refreshed Racial Equality Strategy, if the issue of discrimination is to be effectively tackled.

Some focus group members referred to the need for a long term integrated strategy to address the early mortality rate with the Equality Commission recommending OFMDFM to take the lead.

# 5.6. Adopting a health promotion/preventative approach

The growth in recent years in the fields of preventative medicine and health promotion bears testimony to the contention that health behaviours are critically important in terms of influencing health outcomes.

Epidemiological studies implicate particular lifestyle patterns as a major factor in premature death rates among men (WHO, 2002; White & Holmes, 2006).

This has been confirmed by a growing shift in healthcare policy, both internationally (U.S. Preventive Services Task Force, 1996) and nationally (Department of Health and Children, 2001) towards the importance of individual health behaviours, disease prevention and lifestyle in determining health outcomes.

Policy statements clearly implicate cigarette smoking, excessive alcohol consumption, physical inactivity, raised total cholesterol,

hypertension and poor diet in the aetiology of many of the principal causes of mortality and morbidity, including cardiovascular and respiratory diseases, and some cancers.

Although some of these health behaviours have already been examined within the context of racism and discrimination, Travellers and agencies acknowledged their importance in reducing mortality. Lifestyle factors including drugs and alcohol, nutrition and obesity, smoking, exercise and sleep deprivation were all cited by Travellers amongst the reasons for dying early.

The Promoting Wellbeing Department in the SHSCT provides an interesting model of service delivery employing community development and health promotion specialists enabling both engagement, volunteering, capacity building, partnership approaches and empowerment and also preventative mental health work, carers work, sexual health, drugs and alcohol and smoking cessation. This prompted one focus group member to proclaim:

"Our integrated Promoting Wellbeing Department"

in response to a slide advocating health improvement and community development as ways forward for men's health.

## 5.7. Primary care

The most surprising findings related to primary care usage. In relation to Traveller men's access to their GP, 13 (65%) visited their GP within the last month, 18 (90%) had seen them in their GP surgery, 19 (95%) made an appointment and 17 (85%) did not feel they were treated differently by staff and patients.

It has been consistently shown that men of different ages, ethnicities and social backgrounds access health services less frequently than do women for both physical and mental health problems (Addis et al, 2003; Cohen et al, 1995; Tudiver & Talbot, 1999; Parslow et al, 2004).

When men do avail of primary care services, their consultation times tend to be shorter than those of women and they ask fewer questions (Courtenay, 2000). Men's underutilisation of the health services is likely to be associated with their higher levels of potentially preventable health problems and, on average, lower life expectancies at any point throughout the lifespan (White & Johnson, 2000). Some of the responses from Travellers to the question 'why do you think Traveller men are dying so young?' supported this contention.

"They don't have an awareness of blood pressure, cholesterol";

"Not seeing a doctor when you should."; "not taking medication".

Respondents were asked to rate doctors and nurses on a scale of 1-5 where 1 was 'don't trust at all' and 5 was 'trust a lot'. 18(90%) 'generally trusted', 'trusted' or trusted doctors and nurses 'a lot'. Reasons included their professional values and non- racist attitudes, respect for family doctor, and expertise. Those who did not trust their doctor cited poor diagnosis or just lack of trust. This result was further backed up by findings in the rating for sources of health information. 19(95%) rated health professionals 'good' to 'very good';18 (90%) rated one to one methods 'good' to 'very

good' as opposed to 12 (60%) for group education methods. One focus group member highlighted that TSGs/ workers also provide one to one support and health information.

Focus group members felt this was a positive finding although caution was advised in relation to a winter survey, a potentially skewed sample (60%, NIHE) with access to family doctors and the possibility that their wives had faced problems at reception/appointment stage. Nonetheless the finding that 90% of respondents generally trusted doctors and nurses is encouraging.

The most important characteristics valued by men during a medical encounter are a professional attitude and approach on the part of the physician; a relationship built on trust, confidentiality and respect; courtesy during a physical examination; time for meaningful information exchange; and the opportunity to discuss health-related concerns with a non-judgemental, competent and respectful healthcare provider (Dubé et al, 2005).

In response to the question 'do you have high blood pressure and cholesterol?' 8 (40%) reported high blood pressure and 7 (35%) high cholesterol. Focus group members reacted to the high prevalence, awareness levels and primary care implications:

"Means they've been to have a test, usually age-related - opportunity for outreach service";

"Referred to Pharmacist and GP outreach initiatives";

"Health checks for men in the evenings (for those who work on sites or wherever".

It is well established that men also tend not to use pharmacies despite their potential as a source of advice, information and self-treatment (Baker, 2004). Therefore the responses by Travellers and focus group members in relation to GP and pharmacy outreach programmes indicate excellent practice in the Southern Trust area. Four focus group members referred to the current and future potential of a primary care initiative known as the Traveller Local Enhanced Service (LES):

"LES is being provided by 8 GP practices in the Southern Area. This offers a potential for specialised services to Travellers e.g. longer appointment times, walk in appointments, greater integration with Trust to ensure screening...provision of health information, cultural awareness training and provision of outreach with Trust staff".

Focus group members recommended this is rolled out to more practices locally and regionally.

With on-going improvements in cancer treatment, procedures and screening technologies, secondary prevention and prompt presentation to health services are increasingly playing a key role in reducing mortality from the disease (Evans et al, 2005). One initiative targeting male Travellers, referred to by focus group members, was the Man Alive programme, provided by Cancer Focus N.I. and delivered by community nurses. McKinlay (2005) stresses the important role that community nurses can serve in delivering outreach services to men and in supporting community-based men's health initiatives.

Ethnic monitoring (also referred to in the AITHS as a unique identifier) was recommended by focus group members as essential to track improvements in services for Travellers and other groups. There are some initiatives currently underway in three areas of the Southern Trust and within other agencies but the need was acknowledged for it to be higher on the political agenda and driven from the OFMDFM as a cross cutting interdepartmental initiative. The AITHS (2010, p.171) identified potential drawbacks to ethnic monitoring as a result of Traveller fears that disclosing one's identity might lead to discrimination, compounded by a fear of written information which many, for literacy reasons, cannot verify. The study recommends providing reassurance to Travellers that the overall result will be positive and raising healthcare professionals' awareness of the issue.

The Australian Royal College of General Practitioners (2006) recommended that practices routinely record ethnic identification of Aboriginal and Torres Straight Islanders to improve patient care.

## **Chapter 6 CONCLUSION**

#### Conclusion

This study began with a literature review that uncovered worldwide inequalities in men's health. These deepen considerably for indigenous and nomadic men. It also explored cultural and service barriers to accessing services and identified models of best practice.

The All Ireland Traveller Health Study (2010) highlighted Irish Traveller men were dying (aged 61.7) 15.1 years earlier than Irish men in general. This life expectancy is better than Aboriginal men who are dying 20.3 years earlier (aged 56.3 years) than non - indigenous men, but worse than Māori and First Nations men in the USA and Canada (Adams 2011).

It has been evident that Traveller men's health has been neglected in Ireland with a concomitant striking shortened life expectancy. Health studies which have engaged Traveller men have been rare.

Action research methodology enabled exploratory intensive research, innovative engagement and an opportunity to influence relevant agency policy and practice.

Structured interviews co-designed by Traveller Advisors elicited qualitative and quantitative data on demography, lifestyle, mental health, mortality, access to services, health information and groups that would interest men.

Findings were presented to two focus groups, internal and external to the health sector, to explore actions relevant agencies could take to improve the men's health status.

Findings highlighted the complexity of the problem with no single reason emerging for dying 15 years early, but many interrelated factors requiring multi-faceted solutions.

This study concludes that a multi-agency long term strategy will be required to tackle the issue of Traveller men's life expectancy, with Traveller male engagement at its heart. The National Men's Health Policy (2008-2013) (Richardson and Carroll, 2008) contains a useful framework for future development with its focus on social determinants of health, male engagement, masculinity and gender, community development, health promotion/prevention, primary care, interagency work, tackling men's health from a strengths perspective, and supporting men to become more active citizens and advocates. However the policy needs to be adapted to a Northern Ireland context, as issues of sectarianism, racism and discrimination need to be tackled within the context of NI legislation and governmental structures. A shift in attitudes is also required by the general population.

## **CHAPTER 7 RECOMMENDATIONS**

#### Recommendations

- 1. Policies to tackle 15 year gap in life expectancy (including racism and discrimination)
- 1.1. DHSSPS should resource a long term interagency Traveller men's health strategy to tackle the shortened Traveller male life expectancy and other health findings from the AITHS, building on the principles of social determinants of health, male engagement, masculinity and gender, community development, health promotion/ prevention, primary care, interagency work, tackling men's health from a strengths perspective, and supporting men to become more active agents and advocates. This could be incorporated into a wider men's health strategy incorporating specific elements to tackle racism and discrimination. A Traveller champion is needed in the Assembly.
- 1.2. The researcher endorses ECNI's recommendations to strengthen racial discrimination laws to bring them into line with the Equality Act 2010, a refreshed racial equality strategy led by OFMDFM and the Executive to address negative public attitudes through the Cohesion and Social Integration (CSI) Strategy. Travellers have also raised concerns about their community portrayal in programmes like 'My Big Fat Gypsy Wedding' and there is a need for alternative programmes to represent diversity within Traveller culture.

- 1.3. The Department of Justice (DOJ) needs to finalise its strategy on hate crime. This should include capacity building of vulnerable groups such as Travellers so that they are aware of their rights and the supports available, and know how to report hate crime.
- 1.4. ECNI should increase the capacity of Traveller men to tackle discrimination through Citizenship training with TSGs and increase the number of Traveller men taking discrimination cases to the courts, through increased opportunities for engagement.
- 1.5. Local statutory and voluntary agencies should use the PHA/ HSCB Community Development Strategy (2012) to encourage Traveller men to come forward and become more involved in their own community and engage with agencies who work to improve Traveller's quality of life.
- 1.6. The Traveller Education Task Force needs to address bullying in its forthcoming action plan.
- 1.7. More support is needed for the integration of Travellers into communities, jobs and agencies by statutory, voluntary and community agencies. Employers should be encouraged to use the equality laws to increase the employment of Travellers.
- 1.8. Young Traveller males need to be supported to report alleged discrimination in schools, colleges or workplaces

and to attend capacity building courses on citizenship, when available.

## 2. Community infrastructure

2.1. Integrated planning across agencies and government departments at area and regional level is critical. Continued financial support for the existing community infrastructure is a pre-requisite for future work with Travellers due to these groups' knowledge of the local Traveller community and their trusted relationships.

## 3. Male Engagement

- 3.1. Employment of male workers (preferably Traveller) by statutory or voluntary organisations to work with Traveller men on the social determinants of health including education, employment, training, lifestyle, discrimination, recreation and access to services is recommended.
- 3.2 Volunteering opportunities should be explored for Traveller men to increase their employment prospects.
- 3.3 Developing projects such as Men's Sheds as a method of increasing male engagement should be actively explored by TSGs and other relevant agencies.

## 4. Education and Training

- 4.1. Travellers need to be able to see the tangible benefits of remaining in Further Education and Training and to recognise that qualifications in trades can take up to 3 years to complete. The existing trend in short term courses leading to qualifications is welcomed and should be built on.
- 4.2. The All Ireland Traveller Health Study identified education as the single biggest factor that Travellers felt would improve their health. Literacy and IT are essential skills which some Travellers would prefer to be delivered on a one to one basis. IT training would also help men with entrepreneurial skills of buying and selling e.g. learning about e-bay. It is also relevant for many other areas e.g. driving theory exam.
- 4.3. Educational and training providers should work with TSGs and local Travellers to develop new courses at times and in venues which would suit Traveller men. Small group training sessions at various locations throughout the region, tailored to men's needs, should be provided where possible, preferably during the winter to maximize Traveller participation acknowledging seasonal work/ travel patterns.
- 4.4 Ultimately Traveller men should be trained and employed to deliver courses as there is a need to develop role models.

- 4.5 The TETF in partnership with DE has a key role in developing an agreed action plan to improve educational outcomes for Traveller children.
- 4.6 Belong should continue to be resourced to provide support for 7-12 year old children in order to tackle anti-bullying, cultural competence and educational support.

### 5. Hazardous substances.

- 5.1. Health and Safety courses relevant to Travellers should continue to be delivered by the Southern Regional College.
- 5.2. Travellers should be encouraged to take part in the 'Steps to Work Programme' organized by agencies like Wade Training. One of the benefits of participation is that expenses can be paid towards health and safety equipment. Another benefit is to gain a route to HGV training.
- 5.3 It is recommended that CCEA examines its health and safety programmes to explore opportunities to address Traveller cultural needs.

#### 6. Fitness

- 6.1. It is recognised that some Traveller men already engage in activities which increase their fitness including walking, hunting and training horses.
- 6.2. Work is needed with local Councils and GAA clubs to improve Traveller men's access to facilities, including handball.
- 6.3 Sports clubs need to be more proactive in welcoming Traveller men into a wider range of facilities.

# 7. Blood pressure and cholesterol checks

- 7.1. Doctors, nurses and pharmacists should continue to offer blood pressure and cholesterol checks to Traveller men in locations and at times that suit them. Strokes and heart disease were cited as the cause of 25% of Traveller deaths in the AITHS.
- 7.2. There will be other opportunities in 2012-2013 for male health screening utilising a British Heart Foundation Programme. This will be delivered by Craigavon Traveller Support Committee.

#### 8. Diet

8.1. Despite the fact that most Traveller men had good awareness of healthy and unhealthy food, some still chose unhealthy options such as fries and carry outs. Traveller women have an important role in selecting food for the family meal. It is recommended that more training is offered such as 'Cook It' Programmes.

# 9. Drugs and Alcohol

- 9.1. It is recommended that more Drugs and Alcohol awareness programmes be offered to Travellers in school and in the community.
- 9.2. Action is needed by the justice system to enforce stiffer penalties and reduce availability of drugs.

## 10. Smoking

10.1. Reducing the high smoking rates could prevent respiratory infections and lung cancer (the second highest cause of death in the AITHS). Smoking Cessation Services should work more closely with TSGs and Travellers to promote their services, with more outreach to be considered.

- 10.2. Targets to reduce smoking amongst Travellers need to be included in Tobacco Action plans.
- 10.3. Opportunities for the Man Alive Programme to provide cancer screening should be maximised by TSWs.

#### 11. Traveller culture

11.1. TSGs and training providers should offer cultural awareness training to the public and relevant agencies. This should include information about Traveller family values, nomadism, religion, trades, equality and discrimination.

# 12. Stress and depression

- 12.1. In common with men in general, some Traveller men don't talk about their personal problems, stress and hardship and need encouragement to do so. Travellers expressed a preference to do this on a one to one or small group basis.
- 12.2. Revision of the HSCB's LES and TSG work should take this into consideration.

#### 13. Domestic violence

13.1. Domestic violence was perceived as being high amongst Travellers and has a negative impact on mental health. Support services are sometimes needed and should be better promoted and easy to access when required.

#### 14. Suicide

14.1. Suicide support services are not well known amongst Travellers across the southern area and awareness needs to be better promoted.

# 15. Access to primary care and people with cures

15.1. The positive regard in which 90% of the men held their GPs and nurses was seen by focus group members as one of the most encouraging results of the research. 95% turned to health professionals for information. Focus group members were also surprised by the high number who had been to the GP surgery within the last month. At the moment there are 8 GP Practices taking part in a "Locally Enhanced Scheme" which encourages GPs to pay special attention to the health needs of the Traveller Community.

It is recommended that this scheme be reviewed and disseminated to more GP practices in the Southern area and regionally.

15.2 It is recommended by the agencies that folk medicine is acknowledged and further explored. Benefits and risks for health and safety should be identified.

#### 16 Health Information

### 16.1. Family members

Given that 75% said that they received health information from family members it is recommended that more Lay Health workers, male and female, are employed.

### 16.2. Ethnic monitoring (Unique identifiers)

Ethnic monitoring within the health service needs to be improved and extended in order to assess the take-up and use of agency services.

Given Traveller fears in the AITHS that disclosing identity might lead to discrimination, the study recommends providing reassurance to Travellers that ethnic monitoring is a positive step in improving health outcomes. Healthcare professionals need awareness of Traveller fears.

#### 16.3. TV

Given that 70% received health information from TV it is recommended that agencies use TV when possible to convey health messages.

### 16.4. Culturally relevant information

More Traveller friendly literature needs to be developed in partnership with Travellers. Alternative methods such as DVDs may also be considered.

## 17 Groups that would interest men

### 17.1. Enterprises

Given the history of Traveller men's preference for self employment, social enterprises should be explored.

#### 17.2. Venue

There was a mixed response from relevant agencies. Some recommended more outreach services to Travellers. On the other hand, Southern Regional College classes have now moved from community venues to the college campus. A pragmatic approach, based on availability of venue and suitable times for Traveller men, is recommended.

#### 18 Future research

- 18.1. Future research should continue to employ action research principles to engage Traveller men.
- 18.2. Employing Traveller men to conduct research with adequate training to overcome issues of confidentiality and validity should be considered.
- 18.3. Research into the impact of sectarianism on attitudes towards Travellers within NI is recommended.
- 18.4. More research on the prevalence of suicide amongst NI Traveller men is required.
- 18.5. The benefits and risks of folk medicine should be explored.
- 18.6. There is a need for further research into Traveller male engagement, exploring models of intervention such as Men's Sheds.

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Pavee Point Travellers' Centre (<a href="www.paveepoint.ie">www.paveepoint.ie</a>, accessed 29th October 2011)

# Southern Area Action with Travellers

(<a href="http://www.southernareacsp.ni.nhs.uk/Southern%20Area%20Action%20with%20Travellers.htm">http://www.southernareacsp.ni.nhs.uk/Southern%20Area%20Action%20with%20Travellers.htm</a>, accessed 12 November 2011)

#### **APPENDICES**

Appendix 1 **Professional Requirements** Appendix 2 Key terms and concepts Appendix 3 Structured interview Appendix 4 Introductory letter (Researcher) Appendix 5 Introductory letter (Traveller Support Worker) Appendix 6 Information pack Appendix 7 Participant information pack Appendix 8 Consent form (Structured interview) Appendix 9 Thank you letter Traveller Advisor Appendix 10 Thank you letter participant Appendix 11 Programme for Trust Traveller **Action Focus Group** Appendix 12 Programme for Southern Area Action with Travellers Focus group Appendix 13 Participant Information Sheet Focus group Appendix 14 Consent Form Focus Group Appendix 15 Conditional Ethical Approval OREC

Appendix 16 Response to OREC Appendix 17 Ethical approval from Southern Health and Social Care Trust Research and Governance Committee Appendix 18 Approval from OREC to proceed with DVD Appendix 19 Ethical approval from Southern Health and Social Care Trust Research and Governance Committee to proceed with DVD Appendix 20 Code book Appendix 21 Power-point presentation (notes version) used with Focus Groups Appendix 22 Response from Equality

Commission N.I. to findings

### **Appendix 1 Professional Requirements**

This dissertation fulfils the following PQ requirements of the NI Leadership and Strategic Award in Social Work:

2. Demonstrate a substantially enhanced and sustained level of competence in a defined area of work, taking a leading role in developing and promoting good practice, drawing on international perspectives to inform this

This was achieved through a literature review comparing adult Irish Traveller males with nomadic/ indigenous males including Gypsy, Roma, Aboriginal, and First Nations from Canada and USA, and generic men's health literature from Canada, Australia, Europe, Republic of Ireland and the Southern Trust area. The author took a lead role in developing good practice in the area with minimal qualitative N.I. research available and traditionally very low levels of Traveller male engagement. The All Ireland Traveller Health Study (2010, p.174) recommended -

"adoption of a gendered strategy" with "men's health issues ... addressed specifically", and

"An emphasis on empowerment and promotion of selfesteem for young Travellers of both sexes to improve mental health and wellbeing, but particularly drawing in the engagement of men- this requires a comprehensive crosssectorial approach to facilitate work opportunity, break down the substance misuse problems and engage men in health service participation". Utilising action research methodology, 12 Traveller Advisors (n= 8 male, 4 female) and 20 Traveller men participated at advisory and implementation stages. A further 14 focus group members represented a cross section of agencies including the Public Health Agency, Health and Social Care Board, Southern Health and Social Care Trust, Southern Regional College, Equality Commission NI, Wade Training, Cooperation and Working Together and Safe and Well. The research covered an extensive range of topics including demography, lifestyle, mental health and mortality, access to services, health information and groups that would interest men.

5. Work creatively, innovatively and effectively, taking a leading role in the context of risk, uncertainty, conflict and contradiction, or where there are complex challenges and a need to make informed, independent and balanced judgements

Literature on adult Irish Traveller male health is scant and, as female Travellers take traditional roles within the family with health matters, this research was complex and challenging from the onset.

Innovative, creative methods of engagement were required, attention paid to low levels of literacy, family dynamics and a high risk that the target group would not choose to engage.

In relation to risk, Traveller men have a suicide rate that is 6.6 times higher than the general population (AITHS, 2010) and with a mortality rate 15.1 years earlier than Irish men, they are a clearly a group with significant risk factors.

Following action research principles the researcher consulted with Traveller advisors about terms of reference and content of structured interviews prior to ethical consent. This caused nervousness from one academic in case it would be perceived by OREC that the research had commenced prior to approval. The researcher presented evidence to ORECNI that the Tripartite Council of Policy on Ethics in Canada established the principles of ownership, control, access, and possession (OCAP) when doing research with Aboriginal communities and within this context prior consultation was considered best practice. This was referenced by OREC when granting approval.

The researcher was advised by Traveller Advisors not to use focus groups with Travellers if he wished to achieve maximum honesty and to conduct the research before the brighter evenings in March to avoid potential loss of interviewees due to patterns of travelling and seasonal work. He had to work flexibly and efficiently to meet his target of 20 men from 5 towns, different family groups and different ages.

He also secured resources from Safe and Well for the production of a DVD and launch of research to disseminate results and overcome the 35% illiteracy rate in the sample. 7 Travellers including 4 Advisors and 3 musicians took part in the DVD along with 5 Agency representatives.

9. Use critical knowledge and comprehensive understanding of service users and carers' issues to actively promote, develop and implement service – user and where appropriate, carers rights

and participation, in line with the goals of choice, independence and empowerment

An action research approach was used which involved Traveller men from the beginning in designing all research questions and advising on the direction of this research. A summary of the All Ireland Traveller Health Study results relevant to Traveller men was taken to the first Traveller advisor and questions formulated. These were subsequently refined through input from an additional 11 Travellers. Input on content ensured cultural relevance, participation, choice and empowerment and helped to overcome literacy issues. This was evidenced through the researcher's subsequent ability to access the research sample, which were mostly obtained through Advisors, with additional men recommended from Traveller Support Groups.

Critical knowledge of service users' issues was gained from a comprehensive literature review. This ensured that from the onset a social determinants/ community development perspective incorporating social justice, anti-discriminatory and anti-racist values combined with health promotion/ prevention approaches was employed. These principles proved critical in achieving maximum engagement.

## **Appendix 2 Key terms and concepts**

### Key terms

Definition of "relevant agencies"

"Relevant agencies" will be defined in this study as statutory, voluntary and community sector agencies that provide services to Travellers in the Southern Trust area of Northern Ireland.

Definition of Men's Health

The World Health Organization (1946, p.2) defines a healthy man as one who is empowered to experience optimum "physical, mental and social well-being and not merely the absence of illness" and who experiences health as a resource for everyday living.

## Key concepts

Health inequality and inequity

Health inequalities can be defined as "differences in health status or in the distribution of health determinants between different population groups" (WHO, 2012, p.2). It is important to distinguish between inequality in health and inequity. Some health inequalities are attributable to biological variations or free choice and others are attributable to the external environment and conditions mainly outside the control of the individuals, concerned (leading to health inequities). Both concepts are relevant to this research as it will deal with lifestyle and social determinants perspectives.

### Social determinants of health

Social determinants of health are the economic and social conditions under which people live which determine their health. They are societal risk conditions, rather than individual risk factors that either increase or decrease the risk for a disease, for example for cardiovascular disease and type II diabetes.

According to Wilkinson and Marmot (2003, p.7) health policy was once thought to be about little more than the provision and funding of medical care: the social determinants of health were discussed only among academics. This is now changing. While medical care can prolong survival and improve prognosis after some serious diseases, more important for the health of the population as a whole are the social and economic conditions that make people ill and in need of medical care in the first place. Nevertheless, universal access to medical care is clearly one of the social determinants of health.

## Primary care

The concept of Primary Health Care was established at the joint WHO / UNICEF conference in Alma Ata in 1975. Primary Care "is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process (WHO, 1975: VI). Primary Health Care has been identified and used as an innovative approach to health care in the developing world. According to The Department of Health and Children (2002) there has been a growing interest and demand for such a service in the

developed world as evidence from studies indicates that marginalised populations are suffering disproportionately from poor health and have less access to health care services.

## Community development

Community development is defined as:

"Enabling people to organise and work together to identify their own needs and aspirations; take action to exert influence on the decisions which affect their lives; improve the quality of their own lives, the communities in which they live, and societies of which they are a part. It is a long term value based process which aims to address imbalances in power and bring about change founded on social justice, equality and inclusion" (O'Neill, 2012, p.8).

Community development practitioners work alongside people in communities to help build relationships with key people and organisations and to identify common concerns. They create opportunities for the community to learn new skills and, by enabling people to act together, community development practitioners help to foster social inclusion and equality. As Action Research is founded on community development principles this concept is relevant to the research methodology.

## Asset based approaches

An 'asset-based' approach to community development has gained ground in recent years as a corrective to the more familiar 'deficit' approach, which focuses on the problems, needs and deficiencies in a community such as deprivation, exclusion, crime, anti-social behaviour, illness and health-damaging behaviours.

(O'Neill, 2012, p.5). Focusing entirely on deficits can create a sense of hopelessness amongst communities and resignation amongst professionals. As a result, a community can feel disempowered and dependent; people can become passive recipients of services rather than active in their own and their families' lives. Clearly it remains important to be aware of needs and disadvantage and to narrow inequalities, but emphasising assets gives a better balance and generates confidence and aspiration. In the context of health and social care, an asset is any factor or resource which enhances the ability of individuals, communities and populations to maintain and sustain health and wellbeing and meet identified needs. These assets can operate at the level of the individual, family or community as protective and promoting factors to buffer against life's stresses.

#### Health Promotion

Health promotion has been defined as "the process of enabling people to increase control over their health and its determinants, and thereby improve their health" (Health Promotion International, 2006, p.10). Health promotion and community development approaches have many common threads and The Promoting Wellbeing Department within which this research has taken place has amalgamated staff from both traditions.

### Racism, sectarianism and discrimination

Racism refers to the institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict by judgement and action, the lives of those against whom they discriminate (Berkman et al, 2000, pp.36-75).

Discrimination refers to "the process by which a member, or members, of a socially defined group is, or are, treated differently (especially unfairly) because of his/her/their membership of that group" (Jary &Jary, 1995 p. 169). This unfair treatment arises from "socially derived beliefs each [group] holds about the other" and "patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege" (Marshall G, 1994, pp.125-6).

Sectarianism is "bigotry, discrimination or hatred arising from attaching importance to perceived differences between subdivisions within a group, such as between different denominations of a religion, class, regional or factions of a political movement" (Wikipedia 2012).





# **Appendix 3 Structured Interview**

Structured Interview			
Unique Code:			
You will notice from this form your name is not on it and I have given you a number.			
Questionnaire for:			
Dying fifteen years early- what can Traveller men and relevant agencies do?			

Section 1: About you		
1. <u>Age</u>		
What age are you?		
2. <u>Area</u>		
Newry		
Craigavon		
Dungannon		
Armagh		
Coalisland		
3. Accommodation		
Serviced site		
Un-serviced site/		

Roadside

Group housing	
NIHE	
Private	
Other	
4. Employment	
The majority of Traveller me yourself?	n are self- employed. Do you work for
Yes No No	N/A
If participant answers N/A as	sk
Are you currently unemploye	ed? Yes No No
or do you work for someone	else?
Yes No No	N/A 🔲

Travellers work in a large number of trades. Do any of the following trades currently apply to you or have they applied to you in the past?

Scrap Metal			
Yes 🔲	No 🔲		
Demolition			
Yes	No 🔲		
Tarmac			
Yes	No 🔲		
Sales (door to	door)		
Yes	No 🔲		
Markets			
Yes 🔲	No 🔲		
PVC			
Yes 🔲	No 🔲		
Caravans			
Yes	No 🔲		

Tree topping			
Yes	No .		
Gardening			
Yes	No .		
Painting			
Yes	No .		
Power-washing			
Yes	No .		
Other (please sp	pecify)		
Did your father a different?	also do any of this work or did he do something		
Prompt			
	on of scrap, demolition, or painting, ask further		
question: Have you ever worked with:			

Asbestos	Yes	No 🔲		
Burning plastic	Yes	No 🔲		
or paint fumes?	Yes	No 🔲		
How do you prot	ect yourself?			
	on of power-washin s from stone chips	•	er question - do you es?	
Yes N	lo 🔲			
or wear a mask to protect yourself from fumes from chloride?				
Yes N	lo 🔲			
5. Education				
What age did yo	u first go to schoo	l at?		
What age did yo	u leave?			
(If answer is 15/16 did you pass any exams?)				

Yes No No			
What were they?			
Have you attended night school? Yes No			
If yes what were you doing?			
(If man has left at 13-14) I notice from your answer that you left			
school early. Can you read and write?			
Yes No No			
If not, if you get a letter who reads it for you?			
Would you like to read and write?			
Yes No Don't know			

What's stopping you from learning to read and write?
If there was a course in your area for learning to read and write would you go?  Yes  No
What time should this be at?
Where?
Section 2: Lifestyle
6. Exercise
How do you keep yourself fit?

Are you member of the gym or sports centre?			
Yes No No			
7. Blood Pressure			
Do you have high blood pressure?			
Yes No Don't know			
8. Nutrition			
What do you eat during the day?			
Do you have this every day? Yes No			
Can you tell me what you think is healthy food?			
Can you give me examples of bad food?			

# 9. Cholesterol

Do you have high cholesterol?			
Yes No Don't know			
Prompt with certain kinds of cholesterol Greater Chance of Heart Disease – get a check at GP			
10. <u>Drugs and Alcohol</u>			
I will ask you a question about drugs and alcohol.			
(Show 6 photos of drugs chosen by Alcohol and Drugs Specialist advisor)			
Would you recognise any of the following drugs that you might have seen on television?			
Photo one: Yes No Don't know			
Name chosen			
Provide correct answer: Cannabis			

Photo two:			
Yes 🔲	No		Don't know
Name chosen.			
Provide correc	t answe	r:	Alcohol
Photo three:			
Yes 🔲	No		Don't know
Name chosen.			
Provide correc	t answe	r:	Mephendrone
Photo four:			
Yes 🔲	No		Don't know
Name chosen.			
Provide correc			Diazepam
Photo five:			
Yes 🔲	No		Don't know
Name chosen.			
Provide correc	t answe	r:	Heroin

Photo six:				
Yes 🔲	No	Don't	know	
Name chose	n			
Provide corre	ect answer:		Cocaine	
Do you know any names.			gs? I don't want to know	
In the past 5 years do you think the issue as regards drugs and alcohol has got better or worse?				
Better	Yes	No 🔲	Don't know	
Worse	Yes	No 🔲	Don't know	
How do you think this could be made better if it's got worse?				

Would you be interested in gaining a qualification about drug and alcohol awareness?				
Yes No Don't know				
Are you aware of services available to help you or someone else you know who might need help? Yes No				
(Provide information if requested)				
11. <u>Smoking</u>				
Have you ever smoked?				
Yes No No				
If yes, what age can you remember taking the first smoke?				
Why did you smoke?				
Did you ever try giving it up? Yes No				

What's stopping you?
Would you like to give it up? Yes No No
Would you like to know about services available?
Yes No No
(If yes- give contact telephone numbers for Smoking Cessation Service.)
Section Three: Mental Health
12. Traveller Culture
If you were to meet a stranger from America who knew nothing about Travellers how would you describe Traveller culture which makes you different from an Irish person?

(Prompt Travellers have a long history in Ireland and in the UK, musical, tinsmithing etc.)

What makes you proud of being a Traveller? (e. g. sense of community)
What kinds of things make you ashamed or feel bad about Travellers? (Newspaper references etc.)
Do you think your culture affects your health?
Yes No Don't know
Can you explain why?

# 13. Discrimination

Have you ever been discriminated against?				
Yes No No				
If yes, what was the earliest age you can remember someone				
discriminating against you?				
What happened?				
Did you report it to anybody?				

Did anything happen about it?
(Provide information on Equality Commission if relevant to enable Traveller to take further action and to advise them on their rights)
Do you know someone or have you faced any discrimination within the past 5 years?
Yes No No
What happened?
Did you report it to anybody?

15. Stress
How do you cope with stress?
(Provide service information from the useful contacts sheet if requested)
Section 4: Life Expectancy
16. Life expectancy
What age do you think most men live to in Ireland?
Comment on answer compared with correct answer for Irish average
Within your uncles, cousins, brothers or grandfathers, what was the age of the oldest man that you can remember?
The average life expectancy is 61 for Traveller men and 76 for "country- men" <sup>2</sup> . The All Ireland Traveller Health Study has shown

<sup>2</sup> Country- men is term often used by Travellers to describe "Settled people"

that Traveller men's health has worsened since 1987 when they

were dying 10 years younger. In 2008 they were dying 15 years younger. Why do you think Travelling men are dying so young? 17. Suicide In the general population suicide has proven to be on the increase. I have a question about suicide. You can choose if you want to answer this question yes or no? Yes No \_\_\_ If yes: Has anyone in your family been affected by this? No  $\square$ Yes \_\_\_\_ Do you know of any other Travellers that have lost their life through suicide? Yes No Have you heard tell of any support groups for families affected by suicide? No 🗀 Yes \_\_\_\_ (If appropriate give name of local contact)

# 18. Causes of Death

What do you think are the main causes of death amongst Traveller men in last 2 years?			
(prompts suicides, disease, lung disease)	_	accidents, cancer, heart	
(Provide information	if requested from	m AITHS)	
Section 5: Access t	o Services		
19. <u>Accessing Health Services</u> When was the last time you were at the doctor?			
When was the last th	ne you were at t	ne doctor:	
Did you see the doct	or at:		
a. GP surgery	Yes	No 🗔	
b. Home Visit	Yes	No 🗔	
c. After Hours	Yes	No 🗔	
d. A&E?	Yes 🔲	No 🔲	

If you went to your GP did you make an appointment?			
Yes No No			
Were you treated any differently by the doctor, nurse receptionists or other patients?			
Yes No No			
Have you ever been sick and been put off from going to the doctor and not gone?			
Yes No No			
If so why?			
On a scale of 1-5 where 1 is trust a lot and 5 is don't trust at all how do you rate doctors and nurses from your own experience?			
1			
Any reason why?			

(Link to previous question) Did they treat you well?		
20. <u>Traditional healing</u>		
Do you believe in people with cures?		
Yes No No		
Have you ever been to anybody with a cure?		
Yes No No		
M/la a war allial a cara a a tha a ma O		
Where did you see them?		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)		
(If long distance- why did you travel so far?)  Did they help you or cure the problem?		

Would you trust them more than a doctor or nurse?				
Yes	No 🔲			
Section 6: Heal	Section 6: Health Information			
21. Health Information				
If you have a pain or a complaint who do you mention it to?				
Wife	Yes	No 🔲		
Friends	Yes	No 🔲		
Son	Yes	No 🔲		
Doctor	Yes	No 🔲		
Mother	Yes	No 🔲		
Between you, your wife, friends or your mother who makes the				
appointments and gets the medication?				

How do you know it's serious enough to see a doctor?				
Where do you get your	health information f	rom?		
Health Professional	Yes	No 🔲		
(Who)				
TV	Yes	No 🔲		
Internet	Yes	No 🔲		
Leaflet	Yes 🔲	No 🔲		
Poster	Yes 🔲	No 🔲		
Family member	Yes 🔲	No 🔲		
Friend	Yes 🔲	No 🔲		
Other	Yes	No 🔲		

How would you rate the following ways of getting health information (1 is very good 5 not good)				
1.	Health Professional (Who)	12345		
2.	Poster	12345		
3.	TV	12345		
4.	Video	12345		
5.	Internet	12345		
6.	Word of Mouth	12345		
7.	Group education	12345		
8.	One to one	12345		
9.	Leaflet	12345		
10	. Other			
Section 7: What kind of groups would interest Traveller men?				
What?				

When?
Vhere?
There.
January 2
How often?
f not, why not?

How would you get other Traveller men to go to this?			

Thank you very much for your time.

Have you any questions?

# Appendix 4 Letter of Introduction to participant (Researcher) (Revised version post OREC NI Verdict)

Letter of Introduction to participant (Researcher)

My name is Fergal O'Brien and I work as a manager in the Health Service in a team that delivers Health Promotion and Community Development services in the Newry and Mourne area.

I am also involved in groups that plan services with Travellers in Armagh, Dungannon, Craigavon, Newry and Coalisland.

I am undertaking research as part of an educational degree called a Masters to help improve the service I can provide.

My reason for coming today is to get your views on the most important reasons for Traveller men dying 15 years earlier than country men and what you think you can do to keep yourself healthy. Also what you think local services should be doing about this.

Your information will be used to try to improve local services for Traveller men. The results of my research will be published so that others can learn from what you said.

Before I start the interview I would like to give you a list of useful telephone numbers that might be helpful to you and your family. I will refer back to relevant numbers when begin the interview. (Provide information pack)

I would also like to give you some more information about the research and you can ask me about anything that you are unsure of. Your information is confidential. I will use a code number on

any information you provide instead of your name. You cannot be identified in reports by anything you say and your name will not be used when I am writing up the report unless you have given permission. Finally, I will ask you to sign a consent form if you are happy to go on. This will allow me to start the interview with you. Any questions?

#### Lead Researcher:

Dr Anne Campbell

Department of Social Work

University of Ulster

Magee Campus

Derry BT48 7JL

Telephone 028 7375216

Email a.campbell@ulster.ac.uk

#### Researcher:

Mr Fergal O'Brien

Promoting Wellbeing Team

Newry & Mourne Locality

Telephone Number 028 3083 4325

Mobile Number 07825 140 876

Email fergal.obrien@southerntrust.hscni.net

# Appendix 5 Letter of Introduction to participant (Traveller Support Group) (Revised version post OREC NI Verdict)



## **Letter of Introduction to participant (Traveller Support Group)**

Fergal O'Brien works as a manager in the Health Service in a team that delivers Health Promotion and Community

Development services in the Newry and Mourne area. He is also involved in groups that plan services with Travellers in Armagh,

Dungannon, Craigavon, Newry and Coalisland.

Fergal is undertaking research as part of an educational degree called a Masters to help improve the service he can provide.

His reason for coming will be to get your views on the most important reasons for Traveller men dying 15 years earlier than country men and what you think you can do to keep yourself healthy. Also what you think local services should be doing about this.

Your information will be used to try to improve local services for Traveller men. The results of his research will be published so that others can learn from what you said.

Before he starts the interview he would like to give you a list of useful telephone numbers that might be helpful to you and your family. He will refer to any relevant numbers during the interview. He will also give you some more information about the research and you will have the opportunity to ask him about anything that

you are unsure of.

Your information is confidential. Fergal will use a code number on any information you provide instead of your name. You cannot be identified in reports by anything you say and your name will not be used when he is writing up the report unless you have given permission.

Finally, Fergal will ask you to sign a consent form if you are happy to go on. This will allow him to start the interview with you. Have you any questions? If you are interested in taking part I can either pass on your telephone number to him or if you prefer I can arrange a date that suits both of you.

If you wish to speak directly to Fergal or his tutor about any parts of the research their contact information is listed below.

#### Lead Researcher:

Dr Anne Campbell

Department of Social Work

University of Ulster

Magee Campus

Derry BT48 7JL

Telephone 028 7375216

Email a.campbell@ulster.ac.uk

## Researcher:

Mr Fergal O'Brien

Promoting Wellbeing Team

Newry & Mourne Locality

Telephone Number 028 3083 4325

Mobile Number 07825 140 876

Email fergal.obrien@southerntrust.hscni.net

## **Appendix 6 Information pack**

Information pack for Dying 15 years early - what can
Travellers and relevant agencies do?

#### **Contents**

- Pocket-size useful contacts sheet for mental and emotional wellbeing containing telephone numbers for services across the southern area.
- Contact numbers for Smoking Cessation specialists.
   (Southern Trust poster format)

Other useful contacts

# Appendix 7 Revised Participant Information Sheet (Post OREC ruling)

#### **Participant Information Sheet**

#### Title of Study:

Dying fifteen years early: what can Traveller men and relevant agencies do?

My name is Fergal O'Brien and I work as a manager in the Health Service in a team that delivers Health Promotion and Community Development services in the Newry and Mourne area.

I am also involved in groups that plan services with Travellers in Armagh, Dungannon, Craigavon, Newry and Coalisland.

I am undertaking research as part of an educational degree called a Masters to help improve the service I can *provide*.

What is the purpose of the research?

Research called the All Ireland Traveller Health Study was completed in 2010. It showed that Traveller men were dying 15 years earlier than country men. I want to find out what Traveller men and relevant services can do to improve this.

Why have I been invited?

I need to get 20 Traveller men from different families, accommodation types, ages and areas to take part. You have been recommended by:

1. (Name of Traveller) who advised me on what questions to ask in this interview

or

2.	(Name of staff member)
from.	(Name of Traveller Support Group)

Do I have to take part?

It is up to you do decide if you want to take part in this research. Your taking part is voluntary and you are free to withdraw at any time, without giving a reason and it will not affect any of the support you receive.

What will happen to me if I take part?

I will meet with you at a time and place that suits you. I will go through this information sheet with you and you can ask me about anything that is unclear. If you agree to take part I will ask you to sign a Consent Form. I will provide you with you information regarding useful services and then begin an interview with you. Our discussion may last one to one and half hours. I hope to have all my research finished by September 2012.

What do I have to do?

I will ask you a list of questions and write down your answers.

The questions have been prepared by Traveller Advisors. If you want to know their names, just ask.

What are the possible disadvantages and risks of taking part?

There is a risk that you might tell me something that relates to child protection or a vulnerable adult. I would be duty bound to report an issue like this to the relevant authorities to ensure that the child or vulnerable adult is protected from any harm. I would

have to report an instance of professional misconduct for the same reason. In the instance of illegal behaviour I must also report this to relevant authorities. For example if you told me you were dealing with illegal drugs I would have to report this to the PSNI.

What are the possible benefits of taking part?

You will learn more about how to stay healthy. You will get a chance to make some suggestions about how services for Traveller men can be improved.

Will I be out of pocket for taking part in the research?

No you will not be out of pocket. The Trust has a policy which covers your expenses if you incur meal costs, childcare or travel expenses.

What happens when the research study stops?

Once I have seen 20 Traveller men I will discuss the results and recommendations with staff within the Health Service and other support services to see what decisions can be made. If you tell me something very important I may want to use your comments in the report I will be writing up. I will only do this if I have already received your consent to do so. The report may be shared by others in the Trust and at University.

What if there is a problem?

If you have a problem with the way I have conducted the interview please let me know and we can try and sort it out. If you are still unhappy you can contact my supervisor, Mark Irwin at 028 3741 2642 and he will assist you to make a complaint.

Will my taking part in the study be kept confidential?

Your taking part in the study is totally confidential. I will use a code number on any information you provide instead of your name. Only I will know that information. All information you give me will be stored in a locked filing cabinet in my office that only I have access to therefore you cannot be identified in reports by anything you say unless you have given me permission to do so. This information has to be held securely for 5 years and then destroyed by confidential means. The only limitation to confidentiality would be as described above that if a child protection, vulnerable adult, professional misconduct or illegal issue became evident in the course of the interview I would have to report this to the relevant authorities. You would be fully consulted and informed about any action that is required to be taken.

What will happen if I don't want to carry on with the study?

You are free to withdraw at any time during our conversation.

You will let me know at that time if I can use the information you have already given me.

Who is organising and funding the research?

The research is being funded by the Social Services Training Unit.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by the Office for Research Ethics Committees Northern Ireland (NI).

The study has also been approved by the Research Governance Committee of the Southern Health and Social Care Trust (the Trust) and the University of Ulster Ethics Committee. The Trust will also be responsible for monitoring how I conduct the research.

If you require further information to help you decide whether to take part in the research or not you can contact my University Tutor or myself. Our details are listed below:

#### Lead Researcher:

Dr Anne Campbell

Department of Social Work

University of Ulster

Magee Campus

Derry BT48 7JL

Telephone 028 7375216

Email a.campbell@ulster.ac.uk

## Researcher:

Mr Fergal O'Brien

Promoting Wellbeing Team

Newry & Mourne Locality

Telephone Number 028 3083 4325

Mobile Number 07825 140 876

Email fergal.obrien@southerntrust.hscni.net

Appendix 8 Consent Form	Unique Number:
CONSENT FORM	
Title of Project: "Dying 15 years relevant agencies do?"	early: what can Travellers and
I confirm that the researcher has dated (version) and that I have had the opportunity to think questions. I have had my question	understand what it is about. I about the information and ask
Please initial box	
I consent to participating in an int is the researcher. I understand the confidential. Fergal will use a cannot be identified in reports by	hat any information I provide will code instead of my name and I
I understand my taking part is vol from the interview at any time. I my information. Any services I and not be affected by me withdrawing	give permission for Fergal to use main receipt of from the Trust will
I understand that Fergal will give have provided to keep if I reques	
I understand that my information my permission. I understand I withis happens.	may be published provided I give ill not be identified in any way if

I give permission to use quotes from my interview.
(Please initial YES or NO box)
Yes No
I understand that my answers will not be seen by anyone else apart from Fergal, his supervisor at University and his typist who will be typing up responses. I will not be identified by any of the information provided.
Signed: Date:
Witnessed: Date:
When completed 1 for participant; 1 for researcher site file

## Appendix 9 Thank you letter - Traveller Advisor

Promoting Well Being Department

John Mitchel Place, Newry

Co. Down BT34 2BU

Telephone 028 30834325

Email: fergal.o'brien@southerntrust.hscni.net

Date (Insert date)

Dear (Insert name of Traveller Advisor)

I would like to thank you very much for your generous time and invaluable advice in this research.

I will be sharing your recommendations widely within the Health Service and with many other services.

Thanks again for your help.

Fergal O'Brien

Promoting Wellbeing Manager

## **Appendix 10 Thank you letter - Participant**

Promoting Well Being Department

John Mitchel Place, Newry

Co. Down BT34 2BU

Telephone 028 30834325

Email: fergal.o'brien@southerntrust.hscni.net

Date (Insert date)

I would like to thank you very much for the time you have taken to assist with this research.

I will be sharing the results of this survey widely within the Health Service and with many other services.

Thanks again for your help,

Fergal O'Brien

Promoting Wellbeing Manager

## **Appendix 11 Trust Traveller Action Focus Group**

Content of Trust Traveller Action Focus Group

Open with Coffee/ Tea and biscuits Distribute consent form

- 1. Introduce myself and explain that I have been conducting an exploratory study into Traveller men's health inspired by the key finding in the All Ireland Traveller Health Study of Traveller men dying 15.1 years earlier than men in the settled community. The purpose of today's session will be to answer the research question what can relevant agencies do? No-one will be identified personally in the report but there will be a series of general recommendations arising from today's discussion which will be included in the final report.
- Prepare power-point presentation outlining the conclusions from my literature review, key statistics from AITHS pertaining to men, the aims of the research study, methodology, findings and preliminary recommendations.
- 3. Ask group to complete 7 questions:
- 1. What is your reaction to the findings which have been presented to you today?
- What do you feel you are already doing to address issues in the research?
- 3. Can you comment on the preliminary recommendations which have been presented to you today?

- 4. Which of the recommendations do you feel that you or your staff could meet?
- 5. Can you outline what, how, why, when and who is best placed to meet these recommendations?
- 6. Who else do you feel could address these issues?
- 7. Please list any recommendations that you feel are missing?

Allow 1.5 hours for session. Discussion will use flip charts to allow for group feedback. Seek permission for plenary to be recorded.

# Appendix 12 Southern Area Action with Travellers Focus Group

Content of Southern Area Action with Travellers Focus group

Open with Coffee/ Tea and biscuits. Distribute consent form

 Introduce myself and explain that I have been conducting an exploratory study into Traveller men's health inspired by the key finding in the All Ireland Traveller Health Study of Traveller men dying 15.1 years earlier than men in the settled community.

The purpose of today's session will be to answer the research question what can relevant agencies do? No-one will be identified personally in the report but there will be a series of general recommendations to the Northern Ireland Housing Executive, Southern Regional College, Southern Health and Social Care Trust, Public health Agency, Local Councils, Traveller Support groups, Safe and Well and other relevant agencies arising from today's discussion which will be included in the final report.

- Prepare power-point presentation outlining the conclusions from my literature review, key statistics from AITHS pertaining to men, the aims of the research study, methodology, findings and preliminary recommendations.
- 3. Ask group to complete following 7 questions:
- 1. What is your reaction to the findings which have been presented to you today?

- 2. What do you feel you are already doing to address issues in the research?
- 3. Can you comment on the preliminary recommendations which have been presented to you today?
- 4. Which of the recommendations do you feel that you or your staff could meet?
- 5. Can you outline what, how, why, when and who is best placed to meet these recommendations?
- 6. Who else do you feel could address these issues?
- 7. Please list any recommendations that you feel are missing?

Allow 1.5 hours for session. Discussion will use flip charts to allow for group feedback. Seek permission for plenary to be recorded.

## **Appendix 13 Participant Information Sheet (Focus Groups)**



Promoting Wellbeing Team, Southern Health and Social Care Trust

John Mitchel Place, Newry BT 34 2BU

Telephone 028 30 834325

Mobile 07825 140 876

Email fergal.obrien@southerntrust.hscni.net

..... (Date)

## **Participant Information Sheet**

**Title of Study:** Dying fifteen years early: what can Traveller men and relevant agencies do?

#### Introduction:

My name is Fergal O'Brien and I work as a manager in Promoting Wellbeing Team in the Southern Health and Social Care Trust.

Our team delivers Health Promotion and Community

Development services in the Newry and Mourne area.

I am also involved in groups that plan services with Travellers in Armagh, Dungannon, Craigavon, Newry and Coalisland. I am undertaking this research as part of an Application of Research Methods in Social Work Module at the University of Ulster leading to an MSC Professional Development in Social Work. The principal researcher is Dr Anne Campbell from the University of Ulster.

#### What is the purpose of the research?

The All Ireland Traveller Health Study was completed in 2010. It highlighted that Traveller men were dying 15.1 years earlier than men in the general population. I want to find out what Traveller men and relevant services can do to improve this. I have already completed interviews with 20 Traveller men to find out their views on what they feel can be done to improve their lifestyles and I am using a summary of these findings to meet with relevant agencies to establish if there is anything we can do to support improvements. I now need to complete discussions with 2 Focus Groups. In one Focus Group I have selected 10 professionals from the Trust Traveller Action Group and in another I have selected 10 members of the Southern Area Action with Travellers group. All participants were selected according to their relevance to findings from the structured interviews with Travellers.

## Why have I been invited?

You have been invited as a result of your expertise and the relevance of you and your group/ agency/ department to the findings from the interviews that were held with the 20 Traveller men in the first stage of this research.

#### Do I have to take part?

It is up to you do decide if you want to take part in this research. Your taking part is voluntary and you are free to withdraw at any time, without giving a reason

#### What will happen to me if I take part?

If, after reading this information you agree to take part I will ask you to sign a Consent Form to take part in a Focus Group.

At the Focus Group, I will present an overview of the research to date including aims and objectives, lessons from the literature review and preliminary results and recommendations from interviews with Traveller men. You will be asked to answer seven questions in relation to findings from the interviews with the Traveller men in the first stage of this research. Our discussion may last up to one and half hours.

With your consent, the Focus Group will be audiotaped and later transcribed. You will receive a copy of the transcription to enable you to verify the content. You may say something that is of importance and which I may wish to quote in my final report.

Again, this will only be with your consent. You will not be identified personally but reference will be made to your group/agency/department.

My research must be concluded by September 2012.

# What are the possible disadvantages and risks of taking part?

I do not foresee any disadvantages and risks to you of taking part.

The only burden will be on the time needed for you to participate in the research.

#### What are the possible benefits of taking part?

You will get a chance to make some suggestions about how services (including your own) can be improved for Traveller men to hopefully increase their life span.

#### What happens when the research study stops?

Responses from today's focus group will be audiotaped and transcribed for analysis. Once I have analysed the findings from 2 focus groups I will give you the chance to check the accuracy of quotations and recommendations. To enable achievement of the tight timescale for the report I would ask you to confirm your own and your group/ agency/ manager's endorsement within two weeks of receipt of my findings.

You will receive a final copy of my report.

The results will be published in a user friendly format for Traveller men and in an International Journal.

## What if there is a problem?

If you have a problem with the way I have conducted the focus group please let me know and we can try and sort it out. If you are still unhappy you can contact my supervisor, Mark Irwin at 028 3741 2642 and he will assist you to make a complaint.

#### Will my taking part in the study be kept confidential?

Although no one will be identified personally job roles, groups, departments and agencies will be identifiable. There will be a series of recommendations to Traveller men and relevant departments and agencies within health, housing, education, local government and the voluntary/ community sector.

#### What will happen if I don't want to carry on with the study?

You are free to withdraw at any time during our conversation. You will let me know at that time if I can use the information you have already given me.

#### Who is organising and funding the research?

The research is being funded by the Southern Health & Social Care Trust Social Services Training Unit.

## Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by the Office for Research Ethics Committees Northern Ireland (NI).

The study has also been approved by the Southern Health and Social Care Trust Research Governance Committee and the University of Ulster Ethics Committee. The conduct of the study will be monitored by the Southern HSC Trust Research Governance Committee.

If you require further information about the study before deciding to participate you can contact either me or my tutor; our details are listed below:

## **Lead Researcher:**

Dr Anne Campbell

Department of Social Work

University of Ulster

Magee Campus

Derry BT48 7JL

Telephone 028 7375216

Email a.campbell@ulster.ac.uk

#### Researcher:

Mr Fergal O'Brien

Promoting Wellbeing Team

Newry & Mourne Locality

Telephone Number 028 3083 4325

Mobile Number 07825 140 876

Email fergal.obrien@southerntrust.hscni.net

## **Appendix 14 Consent Form Focus Groups**

Unique Number:
CONSENT FORM – FOCUS GROUP  Title of Project: "Dying 15 years early: What can Travellers and relevant agencies do?"
I consent to participating in a focus group with Fergal O'Brien who is the researcher and to having the focus group audiotaped, transcribed and analysed. Please initial box
I understand that Fergal will give me the chance to check the accuracy of my comments when he has analysed information. If I do not respond to him within a period of 2 weeks I understand that Fergal will proceed with the understanding that I am happy with his comments.
I understand that I will be required to seek the consent of my manager/ agency prior to any quotations being published and to ask them to countersign this consent form and return it to Fergal within 2 weeks of receipt.
I understand that information/ quotations I provide may be incorporated into the final recommendations of his report and attributed to the agency/department/ group I represent.

I understand my taking part is volunt from the interview at any time. I give my information.	_
I understand that Fergal will give me information I have provided.	e a final copy of the
I understand that my name will be not role, group/ department/ agency will	
Signed:	Date:
Witnessed:	Date:
Countersigned by relevant manage authorise comments to be published Date:	•
When completed 2 for participant; 1	for researcher site file

## **Appendix 15 Ethical approval from OREC January 2012**



## Office for Research Ethics Committees Northern Ireland (ORECNI)

**Customer Care & Performance Directorate** 

20 January 2012

Dr Anne Campbell Department of Social Work University of Ulster, Magee Campus Northland Road Londonderry BT48 7JL Office Suite 3
Lisburn Square House
Haslem's Lane
Lisburn
Co. Antrim BT28 1TW
Tel: + 44 (0) 28 9260 3619
www.orecni.hscni.net

Dear Dr Campbell

Study Title:

Dying fifteen years early - what can Traveller men and relevant

agencies do?

**REC reference:** 

12/NI/0006

The Research Ethics Committee reviewed the above application at the meeting held on 17 January 2012.

#### **Documents reviewed**

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter Mr F O'Brien		02 January 2012
Evidence of insurance or indemnity Mr N Curry		19 December 2011
Interview Schedules/Topic Guides SAAT Focus Group	2	19 December 2011
Interview Schedules/Topic Guides Trust Traveller Action Focus Group	2	19 December 2011
Investigator CV Dr A Campbell		
Letter from Sponsor Mr N Curry		19 December 2011
Letter of invitation to participant	2	19 December 2011
Other: Investigator CV, Mr F O'Brien		
Other: Letter of invitation to participant, Traveller Support Group	2	19 December 2011
Other: Thank you letter, Participant	2	19 December 2011
Other: Thank you letter, Traveller Advisor	2	19 December 2011
Participant Consent Form: Focus groups	2	19 December 2011
Participant Consent Form: Travellers	2	19 December 2011
Participant Information Sheet: Traveller Advisor	2	19 December 2011
Participant Information Sheet: A3 sheet of contacts		
Participant Information Sheet: Smoking cessation poster		
Participant Information Sheet: Traveller Support Group	2	19 December 2011
Protocol	14	19 December 2011
REC application		03 January 2011
Referees or other scientific critique report RG1a, RG2, RG3, Various Emails, Dr M Irwin, Mr G Rocks		

Providing Support to Health and Social Care

#### **Provisional opinion**

The researcher, Mr Fergal O'Brien was invited to join the meeting, and clarified the following issues.

- a. It was explained to the Committee that the traveller advisors assisted in formulating questions, assisted the researcher in gaining access to the target population, and helped overcome literacy and cultural differences. This method of action research is cited as best practice, and is a model used in Canada in gaining access to Native tribes. The Committees understanding that the advisors are used as a conduit was correct.
- b. The Committee was assured that there would be at least 24 hours, and more probably a week, allowed as a cooling-off period to allow potential participants time to consider whether they want to take part in the study.
- c. The Committee asked for an explanation as to why the 2 Participant Information Sheets are to be used, as this was felt to be confusing. The researcher explained that some advisors would be unable to communicate with other families, and although this would be the preferred route of potential recruitment, a secondary route, through the Traveller Support Groups, may be used, hence the provision of 2 Participant Information Sheets. It was felt that using a single Participant Information Sheet would be sufficient.
  d. It was explained that 1 focus group would comprise health care professionals, and the
- d. It was explained that 1 focus group would comprise health care professionals, and the other would consist of inter-agency professionals responsible for delivering care to the travelling population, for example, housing.
- It was suggested that a letter of invitation or Participant Information Sheet should be provided for the focus groups, informing them of what they would be expected to contribute.

Mr O'Brien was thanked for attending, and left the meeting.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to a meeting of the sub-committee of the REC.

#### Further information or clarification required

It was agreed that the following issues should be addressed in writing.

- Please revise the Participant Information Sheet in line with the discussions with the Committee.
  - o Consistent use of terminology (interviews or questionnaires).
  - With reference to the REC in the Participant Information Sheet, please spell out the relevance of the NHS regarding this project.
  - Use one Participant Information Sheet for referral from Traveller Advisors and Traveller Support Groups.
  - Ensure that the researchers' contact details (Dr Campbell's and Mr O'Brien's) are included in the Letters of Introduction and PIS.
  - Ensure that detail is given regarding the potential consequences of disclosure of illegal behaviour.
- 2. Please provide a letter of invitation and Participant Information Sheet for the focus group participants.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Jan Daley, Committee Administrator using the details provided.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 19 May 2012.

#### Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of conflict of interest.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

12/NI/0006

Please quote this number on all correspondence

Yours sincerely

Dr Hilary Russell

Email: jan.daley@hscni.net

Enclosures: List of names and professions of members who were present at the meeting

and those who submitted written comments.

## Appendix 16 E mail response to OREC NI January 2012 verdict

To: Jan Daley OREC NI

Cc: valerie.hamilton@southerntrust.hscni.net

- R.Manktelow@ulster.ac.uk
- Campbell Anne
- mark.irwin@southerntrust.hscni.net

#### Message flagged:

Tuesday, 24 January 2012, 12:29

#### Dear Jan

I have now addressed ORECNI's request for information or clarification. In documents already submitted to OREC NI I have made any amendments in red for ease of reading. Otherwise I have submitted new documents as requested. I have dealt with each of the queries from ORECNI as follows:

## Point 1: Consistent use of terminology

In letter of Introduction (Traveller Support groups V3 23 Jan 2012)

I have removed references to questionnaire and replaced with
references to structured interviews.

## Point 2: Reference to REC in PIS (V3 23 Jan 2012)

In last section of REC in relation to who has reviewed the study I have included a comment regarding how the Trust Research Governance Committee are also monitoring the conduct of the

research. I have also included this statement in the new PIS for the Focus group.

## <u>Point 3: Use one Participant Information Sheet for participants</u> referred by Traveller Advisors and Traveller Support Groups

I have produced one participant Information sheet to replace the two previous participant sheets which were leading to confusion. The third section of the PIS V3 23 January 2012 deals with the 2 routes of how Travellers came to be invited into the survey.

#### Point 4: Contact details for Researchers

I have amended letters of introduction and PIS to include details of the lead researcher Dr Campbell and myself.

#### Point 5: Consequences of disclosure of illegal behaviour

I have amended the sections in the PIS V3 23 Jan 2012 on risks to participants and the limits of confidentiality.

## Point 6: Letter of invitation and PIS for Focus group

I enclose 2 new documents as requested: Letter of Introduction Focus Group v1 23 January 2012 and PIS Focus Group v1 23 Jan.

Fergal

## Appendix 17 Ethical approval from Southern Health and Social Care Trust Research and Governance Committee to commence research



Research & Development Office

Mrs Anne Campbell Department of Social Work University of Ulster Magee Campus, Derry BT48 7JL

03 February 2012

Our Ref: ST1112/36/IK/MB

Dear Mrs Campbell

Study Title:

Dying fifteen years early - what can Traveller men and

relevant agencies do?

HSC Trust Ref: ST1112/36 (Please quote this number in all future

correspondence)

**REC Ref:** 

12/NI/0006

I am pleased to advise that the Southern HSC Trust has given Research Governance Permission for the above project to commence. Permission is granted for the duration of the project to 30 September 2012.

The following documents have been approved for use in the project:

Document	Version	Date
Interview Schedules/Topic Guides SAAT	2	19 December 2011
Focus Group		
Interview Schedules/Topic Guides Trust	2	19 December 2011
Traveller Action Focus Group		
Letter of Invitation to participant		23 January 2012
Other: Thank you letter, Participant	2	19 December 2011
Other: Thank you letter, Traveller Advisor	2	19 December 2011
Other: Letter of Invitation to participant	1	23 January 2012
(Focus group)		
Participant Consent Form: Focus Groups	2	19 December 2011
Participant Consent Form: Travellers	2	19 December 2011
Participant Information Sheet: A3 sheet of	-	
contacts		
Participant Information Sheet: Smoking		
cessation poster		
Participant Information Sheet	4	02 February 2012
Participant Information Sheet: Focus Group	2	02 February 2012
Protocol	14	19 December 2011

The following personnel have been approved to work on the study at this Trust:

Name	Indemnity Provided by		
Mr Fergal O'Brien	NHS		
Mr Mark Irwin	NHS		

Research & Development Office Ramone Building Craigavon Area Hospital 68 Lurgan Road Portadown BT63 5QQ Email: Irene.knox@southerntrust.hscni.net Tel: 028 3861 4274 / 4275

Permission is granted subject to the attached conditions which I would ask you to please ensure that all members of the research team make themselves familiar. Failure to abide by these conditions will invalidate permission and may result in the cessation of the research.

I wish you every success with your project.

Yours sincerely,

Miss I Knox

Research Manager

Copy To:

Mr Mark Irwin Social Services Workforce Development and Training Team, Hill Building, St. Luke's Hospital, Loughgall Road, Armagh, BT61 7NQ

Mr Nick Curry Research Governance, University of Ulster, Shore Rd, Newtownabbey, BT37Q8

√Mr Fergal O'Brien Promoting Wellbeing Manager John Mitchell Place Newry BT34 2BU

#### **Conditions of Permission**

1

Research Governance permission is issued provided the researcher(s) involved adhere to and abide by the conditions below.

- The researcher(s) must adhere strictly to the research protocol.
- There must be no changes to the research protocol or approved study documentation without the prior consent of the Trust, the Research Ethics Committee and, where applicable, the MHRA.
- There must be no changes in research staff without prior consent of the Trust.
- The Research Office should be informed if the Chief Investigator or Principal Investigator(CI/PI) is unable to continue to fulfil his/her duties as CI/PI for any reason such as long term absence, change in employment etc.
- There must be no increase in the resources required without prior consent of the Trust.
- Researcher(s) must report all untoward incidents and serious adverse events to the Trust.
- Any concerns in relation to the research protocol must be reported to the Trust
- Researcher(s) must adhere to good research practice principles in line with the ICH Good Clinical Practice (GCP) guidelines.
- Researcher(s) must adhere to the Trust's Research & Development
   Standard Operating Procedures (available from the Research Office on request)
- On request, researcher(s) must make their research project available to Trust appointed monitors.
- The lead researcher must make an annual report to the Research Office for the duration of the project.
- The lead researcher should inform the Research Office on completion or termination of the project. Completion reports must be sent to the Research Office, Research Ethics Committee and, if applicable, MHRA.

Research & Development Office Ramone Building Craigavon Area Hospital 68 Lurgan Road Portadown BT63 5QQ
Tel: 028 3861 4274 / 4275 Email: <a href="mailto:lrene.knox@southerntrust.hscni.net">lrene.knox@southerntrust.hscni.net</a>

## Appendix 18 Approval from OREC to proceed with DVD to disseminate research



## Office for Research Ethics Committees Northern Ireland (ORECNI)

#### HSC REC 3

**Customer Care & Performance Directorate** 

Office Suite 3 Lisburn Square House Haslem's Lane

Lisburn
Co. Antrim BT28 1TW
Tel: + 44 (0) 28 9260 3107
Fax: + 44 (0) 28 9260 3619
www.orecni.hscni.net

01 June 2012

Dr Anne Campbell Department of Social Work University of Ulster, Magee Campus Northland Road Londonderry BT48 7JL

Dear Dr Campbell

Study title: Dying fifteen years early - what can Traveller men and

relevant agencies do?

REC reference: 12/NI/0006
Amendment number: 1, 04 May 2012
Amendment date: 04 May 2012

The above amendment was reviewed at the meeting of the Sub-Committee held on 31 May 2012.

#### Ethical opinion

No ethical issues were raised regarding the proposed amendment. However, it was agreed that the researcher should be asked for confirmation of the amount of money proposed as a fee, for completeness of file. A favourable opinion was given.

[NB: The fee was confirmed to be £80 for attendance at 2 meetings].

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form: DVD	1	09 May 2012
Participant Information Sheet: DVD	1	09 May 2012
Notice of Substantial Amendment (non-CTIMPs)		04 May 2012
Covering Letter Mr F O'Brien		09 May 2012

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### R&D approval

Providing Support to Health and Social Care

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

12/NI/0006:

Please quote this number on all correspondence

Yours sincerely

Dr Stanley Hawkins Vice Chair

E-mail: jan.daley@hscni.net

Enclosures: List of names and professions of members who took part in the review

Copy to:

Mr Fergal O'Brien Promoting Wellbeing Manager John Mitchell Place

Newry BT34 2BU

Mr Nick Curry, Research Office

## Appendix 19 Ethical approval from Southern Health and Social Care Trust to proceed with DVD to disseminate research



Research & Development Office

Dr Anne Campbell Department of Social Work University of Ulster Magee Campus, Derry **BT48 7JL** 

06 June 2012

Our Ref: ST1112/36/IK/MB Your Ref:

Dear Dr Campbell

Re:

Notification Of Continued NHS Permission From The Southern Health &

Social Care Trust

Study Ref: ST1112/36

Study Title: Dying Fifteen Years Early – What Can Traveller Men and Relevant

Agencies Do?

Following receipt of substantial amendment which was given favourable ethical opinion by the Office for Research Ethics Committees Northern Ireland, in a letter dated 01 June 2012, based on the following support documentation:

Documentation	Version	Date
Participant Consent Form: DVD	1	09 May 2012
Participant Information Sheet: DVD	1	09 May 2012
Notice of Substantial Amendment (non-CTIMPs)		04 May 2012
Covering Letter Mr F O'Brien	is a second seco	09 May 2012

The amendment was reviewed today by the Chair of the Research Governance Committee and I can now confirm this Trust's permission for the continuation of this study.

Yours sincerely

Miss I Knox Research Manager

Copy to:

Mr Mark Irwin Social Services Workforce Development and Training Team, Hill Building, St. Luke's Hospital, Loughgall Road, Armagh, BT61 7NQ

Research & Development Office Ramone Building Craigavon Area Hospital 68 Lurgan Road Portadown BT63 5QQ Tel: 028 3861 4274 / 4275 Email: Irene.knox@southerntrust.hscni.net

Mr Nick Curry
Research Governance,
University of Ulster,
Shore Rd, Newtownabbey,
BT37Q8

✓Mr Fergal O'Brien
Promoting Wellbeing Manager
John Mitchell Place Newry
BT34 2BU

## **Appendix 20 Code Book**

## Dying fifteen years early – what can Traveller men and relevant agencies do?

<u>Variable Name</u> ( <u>Categories</u> )	<u>Length</u>	<u>Type</u>	<u>Labels</u>
Identification Number	2	Nominal	None
Identification No of Response	ondent		
Variable Name			
Actual Age	2	Interval	
Age Band	1	Nominal	
Variable Label			
Age of Respondent			
Variable Name			
Area	1	Nominal	1 Newry
			2 Craigavon
			3
Dungannon			
			4 Armagh
			5 Coalisland
Variable Name			
Accommodation Site	1	Nominal	1 Serviced
<u>Variable Label</u> Site/			2 Unserviced
Accommodation type			Roadside
Housing			3 Group

4 NIHE
5 Private
6 Other
Please specify

9 No Answer

<u>Variable Name</u>	Length	<u>Type</u>	<u>Labels</u>
Employment Status	S		
Variable Label			
Self-employed	1	Nominal	1 Yes
			2 No
			3 N/A
			9 No Answer
Unemployed	1	Nominal	1 Yes
			2 No
			9 No Answer
Employed	1	Nominal	1 Yes
			2 No
			3 N/A
			9 No Answer
<u>Variable Name</u>			
Trade			
Variable Label			
Scrap	1	Nominal	1 Yes
			2 No

			9 No Answer
Demolition	1	Nominal	1 Yes
			2 No
			9 No Answer
Tarmac	1	Nominal	1 Yes
			2 No
			9 No Answer
Sales	1	Nominal	1 Yes
			2 No
			9 No Answer
Markets	1	Nominal	1 Yes
			2 No
			9 No Answer
PVC	1	Nominal	1 Yes
			2 No
			9 No Answer
Caravans	1	Nominal	1 Yes
			2 No
			9 No Answer
Tree Topping	1	Nominal	1 Yes
			2 No
			9 No Answer
Gardening	1	Nominal	1 Yes

			2 No
			9 No Answer
Painting 1		Nominal	1 Yes
			2 No
			9 No Answer
Power – washing 1		Nominal	1 Yes
			2 No
			9 No Answer
Other 1		Nominal	1 Yes
Please specify 250		String	
			2 No
			9 No Answer
Trade Father same	1	Nominal	1 Yes
Please specify	250	String	
			2 No
			9 No Answer
Trade Father different	1	Nominal	1 Yes
Please specify	250	String	
			2 No
			9 Different

#### **Variable Name**

#### **Trade Health Issue**

#### Variable Label

Asbestos 1 Nominal 1 Yes

2 No

9 No Answer

Burning Plastic 1 Nominal 1 Yes

2 No

9 No Answer

Paint Fumes 1 Nominal 1 Yes

2 No

9 No Answer

How do you protect yourself?

Please specify 250 String

Power-wash protect 1 Nominal 1 Yes

2 No

9 No Answer

Fumes mask 1 Nominal 1 Yes

2 No

9 No Answer

Chloride 1 Nominal 1 Yes

2 No

9 No Answer

#### **Variable Name**

#### **Education**

Variable Label

Age join school 2 Interval

Age leave school 2 Interval

Exams passed 1 Nominal 1 Yes

2 No

9 No Answer

If yes what were they?

Please specify 250 String

Attend night school 1 Nominal 1 Yes

2 No

9 No Answer

If yes what were you doing?

Please specify 250 String

Can read and write 1 nominal 1 Yes

2 No

9 No Answer

If not who reads for you

Please specify 250 String

Would you like to read and write 1 Nominal 1 Yes

2 No

3 N/A

#### 9 No Answer

What's stopping you from learning to read and write?

Please specify 250 String

Attend r/w course 1 Nominal 1 Yes

2 No

9 No Answer

What time should this be at? 4 Interval

Where? 250 String

#### **Variable Name**

#### Lifestyle

How do you keep yourself fit?

Please specify 250 String

Variable Label

Exercise: member of gym 1 Nominal 1 Yes

2 No

9 No Answer

High blood pressure 1 Nominal 1 Yes

2 No

3 Don't know

9 No Answer

What do you eat during the day?

Please specify 250 String

Same food every day 1 Nominal 1 Yes

2 No

9 No Answer

Can you tell me what you think is healthy food?

Please specify 250 String

Can you give examples of bad food?

Please specify 250 String

High cholesterol 1 Nominal 1 Yes

2 No

3 Don't know

9 No Answer

Drugs and Alcohol

Photo 1 recognise (Cannabis) 1 Nominal 1 Yes

If yes name chosen

2 No

3 Don't know

9 No Answer

Photo 2 recognise (Alcohol) 1 Nominal 1 Yes

If yes name chosen

2 No

#### 9 No Answer

Photo 3 recognise (Mephendrone) 1 Nominal 1 Yes If yes name chosen

2 No

9 No Answer

Photo 4 recognise (Diazepam) 1 Nominal 1 Yes

If yes name chosen

2 No

9 No Answer

Photo 5 recognise (Heroin) 1 Nominal 1 Yes

If yes name chosen

2 No

9 No Answer

Photo 6 recognise (Cocaine) 1 Nominal 1 Yes If yes name chosen

2 No

9 No Answer

Know drug taker 1 Nominal 1 Yes

2 No

9 No Answer

Drugs issue better 1 Nominal 1 Yes

2 No

9 No Answer

Drugs Issue worse 1 Nominal 1 Yes

2 No

9 No Answer

How do you think this could be made better if it's got worse?

Please specify 250 String

D&A qualification

1 Nominal 1 Yes

2 No

9 No Answer

Aware of D&A services 1 Nominal 1 Yes

2 No

9 No Answer

Smoker 1 Nominal 1 Yes

2 No

9 No Answer

Age of first smoke 2 Interval

Why did you smoke?

Please specify 250 String

Try giving up 1 Nominal 1 Yes

2 No

9 No Answer

Like to give up 1 Nominal 1 Yes

2 No

If no, what's stopping you?

Please specify 250 String

9 No Answer

Like to know about SC services 1 Nominal 1 Yes

2 No

9 No Answer

### **Variable Name**

#### **Mental Health**

Variable Label

Describe Traveller Culture

Please specify 250 String

What makes you proud?

Please specify 250 String

What makes you ashamed?

Please specify 250 String

Traveller culture affect health 1 Nominal 1 Yes

If yes please explain 250 String

2 No

3 Don't know

9 No Answer

Discrimination 1 Nominal 1 Yes

2 No

9 No Answer

Age of 1<sup>st</sup> discrimination 1 Interval

What happened? Please specify 250 String

Report it to anybody 1 Nominal 1 Yes

2 No

9 No Answer

Anything happen 1 Nominal 1 Yes

2 No

9 No Answer

What happened?

Please specify 250 String

Discrimination within 5 years 1 Nominal 1 Yes

2 No

9 No Answer

What happened?

Please specify 250 String

Report discrimination 1 Nominal 1 Yes

2 No

9 No Answer

Anything happen 1 Nominal 1 Yes

2 No

9 No Answer

Please specify 250 String

Domestic Violence high 1 Nominal 1 Yes

2 No

3 Don't know

9 No Answer

Know man or women suffered DV 1 Nominal 1 Yes

2 No

9 No Answer

Experience of DV repeat 1 Nominal 1 Yes

2 No

9 No Answer

Experience of DV no repeat 1 Nominal 1 Yes

2 No

9 No Answer

Know where to get help DV 1 Nominal 1 Yes

2 No

9 No Answer

How do you cope with stress?

Please specify 250 String

#### **Variable Name**

### **Life Expectancy**

#### Variable Label

Age most men live to 1 Interval

Age of oldest Traveller man 1 Interval

Why do you think Traveller men are dying so young?

Please specify 250 String

Suicide: chose to answer 1 Nominal 1 Yes

2 No

Family affected by suicide 1 Nominal 1 Yes

2 No

3 N/A

9 No Answer

Other Travellers affected by suicide 1 Nominal 1 Yes

2 No

3 N/A

9 No Answer

Know suicide support groups	1 Nominal 1 Yes	
Know suicide support groups	1 Nominal 1 Yes	

2 No

3 N/A

9 No Answer

2 No

What do you think are the main causes of death amongst Traveller men in last 2 years?

Please specify 250 String

### **Variable Name**

### **Accessing health services**

### Variable Label

When was the last time you were at the doctor?

Please specify		250	String
Location of GF	P: Surgery	1 Nominal	1 Yes
			2 No
			9 No
Answer			
	Home visit	1 Nominal	1 Yes
			2 No
			9 No
Answer			
	After hours	1 Nominal	1 Yes
			2 No
			9 No
Answer			
	A&E	1 Nominal	1 Yes

Angwor		9 No
Answer		
Make appointment	1 Nominal	1 Yes
		2 No
		9 No
Answer		
Treated differently	1 Nominal	1 Yes
If yes please specify	250 String	
		2 No
		9 No
Answer		
Been put off going	1 Nominal	1 Yes
If so why?		
Please specify	250 String	
		2 No
		9 No
Answer		
Trust doctors and nurses	1 Ordinal 1	
	2	
	3	
	4	
	5	
Reason why?		
Please specify	250 String	

Treat you well 1 Nominal 1 Yes 2 No If no specify 250 String 9 No Answer Traditional healing believe in cures 1 Nominal 1 Yes 2 No 9 No Answer Been to person with cure 1 Nominal 1 Yes 2 No 9 No Answer Where did you see them? Specify 250 String If long why did you travel so far? 250 String Cure or help problem 1 Nominal 1 Yes 2 No 9 No Answer Trust more than doctor or nurse 1 Nominal 1 Yes 2 No 3 Don't know 9 No Answer **Variable Name Health Information** Variable Label Mention pain to wife 1 Nominal 1 Yes

2 No

		9 No Answer
Mention pain to friends	1 Nominal	1 Yes
		2 No
		9 No Answer
Mention pain to son	1 Nominal	1 Yes
		2 No
		9 No Answer
Mention pain to daughter	1 Nominal	1 Yes
		2 No
		3 No Answer
Mention pain to doctor	1 Nominal	1 Yes
		2 No
		9 No Answer
Mention pain to mother	1 Nominal	1 Yes
		2 No
		9 No Answer
Mention pain to father	1 Nominal	1 Yes
		2 No
		9 No Answer
Who makes appointment and get	s medication?	
Please specify	250 String	
How do you know it's serious end	ough to see a do	octor?
Please specify	250 String	
Health Info from health profession	nal 1 Nominal	1 Yes

2 No

9 No Answer

Who? Please specify 250 String

Health Info TV 1 Nominal 1 Yes

2 No

9 No Answer

Health Info internet 1 Nominal 1 Yes

2 No

9 No Answer

Health Info leaflet 1 Nominal 1 Yes

2 No

9 No Answer

Health Info poster 1 Nominal 1 Yes

2 No

9 No Answer

Health Info family member 1 Nominal 1 Yes

2 No

9 No Answer

Health Info friend 1 Nominal 1 Yes

2 No

9 No Answer

Health Info Other 1 Nominal 1 Yes

If yes please specify 250 String

2 No

		9 No Answer
Rate health professional	1 Ordinal	1
		2
		3
		4
		5
Rate poster	1 Ordinal	1
		2
		3
		4
		5
Rate TV	1 Ordinal	1
		2
		3
		4
		5
Rate Video	1 Ordinal	1
		2
		3
		4
		5
Rate Internet	1 Ordinal	1

	2
	3
	4
	5
1 Ordinal	1
	2
	3
	4
	5
1 Ordinal	1
	2
	3
	4
	5
1 Ordinal	1
	2
	3
	4
	5
1 Ordinal	1
	2
	3
	4
	5
	1 Ordinal

## Appendix 21 Power-point presentation (notes version) used with Focus Groups

## Dying fifteen years early – what can Traveller men and relevant agencies do?

Fergal O'Brien
Promoting Wellbeing Manager
Southern Health and Social Care Trust

Focus Group Presentation (version -19 April 2012)

"It has never been done. It needs to be done, but if it isn't done Traveller men will die of ignorance. They wouldn't answer it to a woman or have the confidence to go to a professional. This survey will give them the confidence. When they voice it - they know they can talk about it. Men believe they have to be strong- this survey is the help they need."

(Ellen McDonagh [Traveller Advisor], 31 October 2011)



### Literature review

- Traveller men's life expectancy lags 15.1 years behind men in the general population (AITHS 2010)
- Traveller, Gypsy and Roma health inequalities (Parry et al 2007; Hajioff and McKee 2000) are reflected in nomadic/indigenous communities across the world (Brown and Macdonald 2009; Young 2003)
- Studies of Traveller men's health which engage men in the research design are rare (O'Neill et al 2008; Clarke 2010) with Traveller women historically taking the lead (AITHS 2010).
- Approaches to men's health which combine health promotion with holistic health and a social determinants/ community development approach are considered best practice (Richardson and Carroll 2008)

## Research goals

- To explore adult male Traveller health in the Southern Trust through Traveller men's own viewpoint in order to inform the development of services to improve their health and wellbeing
- To explore Traveller men's attitudes to findings in the All Ireland Traveller Health Study about inequalities in their health and what actions they and relevant agencies need to take, to improve their health status.
- To identify responses from relevant community, voluntary, and statutory sector groups to Traveller men's expressed views on what would make a difference to their health.
- To conduct an international literature review on male nomadic health in order to explore cultural and service barriers to accessing services and identify models of best practice.

## Design 1

- Two stage mixed methodological study with cross sectional design involving structured interviews and focus groups
- Stage 1: 20 structured interviews with Traveller men (Mixed methods: embedded design)
- Co-designed by Traveller Advisors/ uses action research principles
- ▶ Key informants / purposive sampling



## **Design 2 Focus Groups**

- 2 Focus Groups (N= 10 per group)
- Focus Group 1 Trust Traveller Action Group
- Focus Group 2 Southern Area Action With Travellers
- Answers question what can relevant agencies do?

## Themes covered by structured interview

- Demographic
- Lifestyle
- Mental Health
- Life Expectancy
- Access to Services
- ▶ Health Information
- Groups that would interest men



## Focus group questions

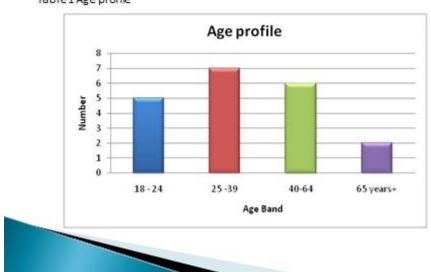
- > Presentation of results and preliminary recommendations
- Reaction to findings
- What is already being done?
- Comment on preliminary recommendations
- Which recommendations could you meet?
- Who, what when, why, how could recommendations be met?
- Who else could address issues?
- Missing recommendations?

# SECTION 1 DEMOGRAPHIC PROFILE



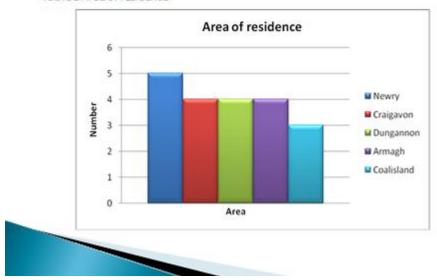
## Demographic profile-age

Table 1 Age profile



## Demographic profile - area

Table 2 Area of residence



## Demographic profile - accommodation

Table 3 Accommodation



## Demographic profile-employment

- ▶ 45% (n=9) normally selfemployed
- ▶ 15% (n=3) currently self employed
- > 75% (n=15) unemployed
- ▶ 10% (n=2) retired
- No-one working for someone else

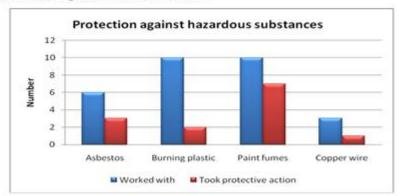
## Demographic profile-experience of trades

Table 4 Experience of trades



## Demographic profile – protection against hazardous substances

Table 5 Protection against hazardous substances



80% (n=16) power-washing 35% (n=7) used protection which included wearing a mask and using goggles

## Demographic profile-school age joining/ leaving

#### Joining school

- ▶ 65% (n=13) went to school between 3-6
- > 35% (n=7) between 7-10

#### Leaving school

- ▶ 40% (n=8) left school by 12
- > 35% (n=7) more by 14
- > 25% (n=5) more by 16

#### Night-school

▶ 5% (n=1) attended night school

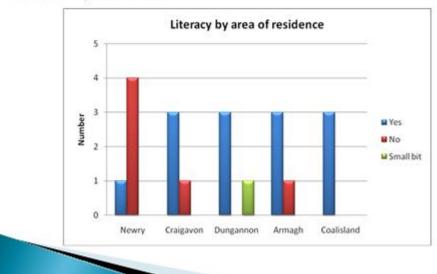
## Demographic profile-qualifications

- Exams-1 in Dungannon 8 GCSES, NVQ 3 in joinery and computer qualifications.
- > 2 junior certs living in Craigavon
- 1 maths, science and sports qualifications in Coalisland and 1 grade C in first year exams in Coalisland.
- > Participants in Armagh and Newry reported no qualifications



## Demographic profile - literacy

Table 6 Literacy across areas



## Barriers to reading and writing

- Bad experience in classroom
- ▶ Too late
- Would like to learn how to order on e-bay (but one to one)
- Itravelled everywhere without education



## **Section 2 Lifestyle**



## Lifestyle-fitness

- ▶ 5% (n=7) said they don't keep fit
- "I don't-I'd be interested in joining a gym, but I have arthritis in the lower spine and in left knee cap, sciatica, and I am blind in one eye"
- > 25% (n=5) referred to the gym
- " I am an All Ireland Champion Boxer with the Panthers"
- "I am a member of the certified Training academy and Armagh Leisure Centre"
- > 35% (n=7) walked of whom 10% (n=2) also hunted, 5% (n=1) golfed
- 10% (n=2) interested in horses 5% (n=1) ran half marathon, 5% (n=1) played handball in Cookstown but wanted facility in Coalisland

## Lifestyle-blood pressure/cholesterol/diet

- ▶ 40% (n=8) reported high blood pressure
- > 35% (n=7) reported high cholesterol
- > 100% recognised healthy and unhealthy food

## Healthy/ Unhealthy food

Examples of healthy food	Examples of unhealthy food
"Anything boiled- grease taken out"	" Chips, Chinese, sweets, fizzy lemonade and cakes";
"Fish and vegetables";	"Fries, burgers and carry-outs"
" Salad fruit and things"	

## Lifestyle-drugs and alcohol

- > 75% (n=15) knew someone who had taken drugs
- > 75% (n=15) said issue of Drugs and Alcohol had got worse
- > 75% (n=15) correctly identified cocaine from picture
- ▶ 60% (n=12) correctly identified heroin
- ▶ 60% (n=12) correctly identified diazepam

## Reasons for drinking

"Reason for drinking - I ended up badly depressed and ended up drinking. When you are out and about you have your freedom moving from place to place - this is one of the biggest factors - you're too much confined in a house. You don't have the same sense of freedom. You don't socialise with other Travellers - you're turning backwards and turning odd - it's the houses that are doing this to you - they're losing a lot of tradition over houses."



_					
Area	Newry	Craigavon	Dungennon	Armagh	Coalisland
Drug					
Cannabis Yes	10% (n=2)	10% (n=2)	20% (n=4)	10% (n=2)	15% (n=3)
No	15% (n=3)	5% (n=1)	0% (n=0)	10% (n=2)	0% (n=0)
Don't know	0% (n=0)	5% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)
Alcohol Yes	25% (n=5)	20% (n=4)	20% (n=4)	20% (n=4)	15% (n=3)
Mephendrone Yes	10% (n=2)	15% (n=3)	20% (n=4)	5% (n=1)	10% (n=2)
No	15% (n=3)	0% (n-0)	0% (n=1)	15% (n=3)	5% (n=1)
Don't know	0% (n=1)	5% (n=1)	0% (n=1)	0% (n=1)	0% (n=1)
Diazepam Yes	10% (n=2)	20% (n=4)	15% (n=3)	5% (n=1)	10% (n=2)
No	15% (n=3)	0% (n=0)	5% (n=1)	15% (n=3)	5% (n=1)
Heroin Yes	15% (n=3)	10% (n=2)	20% (n=4)	15% (n=3)	15% (n=3)
No	10% (n=2)	0% (n=0)	0% (n=0)	%% (n=1)	0% (n=0)
Don't know	0% (n=0)	10% (n=2)	0% (n=0)	0% (n=0)	0% (n=0)
Cocaine Yes	10% (n=2)	20% (n=4)	20% (n=4)	15% (n=3)	15% (n=3)
No	10% (n=2)	0% (n=0)	0% (n=0)	5% (n=1)	0% (n=0)
Don't know	5% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)
Know anyone who has taken drugs?	Yes 15% (n=3) No 10% (n=2)	Yes 10% (n=2) No 10% (n=2)	Yes 20% (n=4) No 0% (n=0)	Yes 15% (n=3) No 5% (n=1)	Yes 15% (n=3) No 0% (n=0)
Has issue got	Better 10% (n=2)	Better 0% (n=0)	Better 5% (n=1)	Better 0% (n=0)	Better 0% (n=0)
better or worse?	Worse 15% (n=3)	Worse 15% (n=3)	Worse 15 % (n=3)	Worse 15 % (n=3)	Worse 15% (n=3)

## Lifestyle – drugs and alcohol – how could issue be made better?

#### Legal

#### Reduced availability of drugs

"If the places selling it would close down - there's too much of it getting in from foreign countries.

#### Stiffer penalties

"Jail, fixed penalties for anyone caught taking them - disqualified from driving for 12 months."

#### Legalize drugs

Legalize, drugs, when its legal people mightn't want it as much."

## Lifestyle – drugs and alcohol – how could issue be made better? (2)

Educational

#### Awareness programmes

"I know they have invested money, but more money should go into drug counselling and drug awareness - going into schools is a good idea."

#### Media

"People are more aware of drugs because of the adverts on TV"

## Lifestyle – drugs and alcohol – how could issue be made better? (3)

#### Social factors

#### Unemployment

"There's people not working and have nothing else to do. They get bad with their nerves sitting in the house. Drugs is all they have on their minds"

#### Paramilitaries

"There's paramilitaries behind drugs"

#### Criminality

"They would take your life for the price of drugs "

## Lifestyle – drugs and alcohol – how could issue be made better? (4)

#### Personal

#### Direct action

"Shoot the c's... that's selling it. I know of 4 Travellers who died of drugs in Ballymena."

#### Association

"We don't associate with Travellers/settled people who take drugs. We stay clear of them."

#### Pessimistic outlook

"You couldn't answer that - when you get stuck on it you couldn't give it up."

## Lifestyle-smoking

#### Prevalence

60% (n=12) smoked

#### Age of first smoke

25% (n=5) aged 8-12; 20% (n=4) aged 13-15; 10% (n=2) aged 18-19

#### Reasons

- Influence of peer group
- Self image
- "Just for the sake of it"
- "Cool the nerves"

## Lifestyle – smoking- what's stopping you? (1)

Personal

#### Will power

"I haven't got the willpower"

#### Age

"At my age I don't know."

#### Religion

"I went off them in Lent and back on again"

#### Choice

"Nothing, I don't really like it but it keeps me happy"

## Tried giving smoking up by area

Of the 12 that smoked 83.3% (n=10) tried giving it up and 16.7%  $(n=2) \ didn't$ 

Area	Yes	No	Not applicable
Newry	20% (n=4)	5% (n=1)	0% (n=0)
Craigavon	0% (n=0)	5% (n=1)	15% (n=3)
Dungannon	15% (n=3)	0% (n=0)	5% (n=1)
Armagh	10% (n=2)	0% (n=0)	10% (n=2)
Coalisland	5% (n=1)	0% (n=0)	10% (n=2)

## **Section 3 Mental Health**

## Mental health – Traveller culture: personal traits (1)

#### Personal values and beliefs

#### Separation from settled community

"We don't let our daughters go to discos or hang round locals — they'd pick up too many bad habits. We don't let them into houses — just stick to our own clan"

" We'd welcome the American but we wouldn't be taking them home"

#### Family values

"Parents are more strict than country people – going smoking and drinking with girls before you're married. They'd have more self-respect than country people. You wouldn't be allowed. When you come to a certain age you take on your own responsibilities – the opposite to country people"

## Mental health – Traveller culture: personal traits (2)

Personal values and beliefs (cont.)

#### Marriage

"Marrying the one woman and being truly faithful"

#### Equality

"We're a proud tradition as good as anyone. We don't have to rob people to be any good. There will come a time when there is no discrimination"

#### Education

" making sure the children are well educated- education is important in our culture and it wasn't always that way"

## Mental health- Traveller culture: personal traits (3)

#### Language/accent

" Our cant";

"Our accent is different"

#### Identity

#### Born into culture

"I'm an Irish Traveller — I was born and raised in a caravan" Hidden identity

"I wouldn't describe a Traveller to an American if he didn't know."

#### Nomadism

"Buffers stay in the one spot – Travellers move from place to place"

## Mental health: Traveller culture: social factors

#### Traditions and culture

"Traditions and beliefs are a big issue – the fact they're still holding on to their culture. I'm proud of my culture. I cannot change it nor wouldn't change it"

"Different Travellers have different cultures"

Dealing with conflict

Fighting

Discrimination

Jobs

"One of the differences is I can't get a job except one in a hundred."

Bars

"How you're treated getting into a bar"

### Mental health: Traveller cultureeconomic definitions

#### Tinsmithing

"We made tin and sold it to farmers — tin pots, buckets, mugs etc. Travellers invented a penny tinker — a yoke with a clip and two washers at the side of a kettle"

- Horse-trading
- " We have different ways of getting on horse-dealing"
- Scrap
- Buying
- Selling

## Mental health: Traveller cultureaccommodation

#### Accommodation

"How we lived in caravans – how tough they had it years ago. We lived up here when there was no running water or toilets. We brought creamery cans of water. My mother hand washed the clothes. We had a wooden hut with a range and a caravan to sleep in."

## What makes you proud of being a Traveller? (1)

#### Value and beliefs

#### Family values

- " our family never do drugs or going around fighting and arguing"
- " my father makes me proud"
- "Some Travellers wouldn't let young girls out after 7-8pm"

#### Marriage

" good marriages"

#### Beliefs

" my beliefs"

#### Equality

"I don't count myself worse than anyone"

## What makes you proud of being a Traveller? (2)

#### Culture

Language

"we have our own language"

- Identity
- "We didn't have to go take GCSEs- we know our own trades"
- "It's being part of that ethnic group"
- Traditions
- " It's the fact of having our own ways and traditions"
- Culture
  - " (although I was reared in house..... I still kept the culture)"
- Nomadism
- "You can move where you want to be. If you don't like it you can move on"

## What makes you proud of being a Traveller? (3)

#### Discrimination

#### Anti-racism

"We like doing our own thing. We don't like people telling us what to do. We don't like being discriminated against"

#### Anti- sectarianism

"We helped Protestants build bonfires and paint flagstones...We still left because we knew that Protestants didn't want the Catholics around during the 12th.... You weren't just a 'Fenian'; you were a 'Gypsy Fenian'"

## What makes you ashamed of being a Traveller? (1)

#### Racism/discrimination

#### Bars

"Getting refused from pubs and clubs"

#### Schools

"Discrimination and hate crime and kids getting bullied"

#### Shops

"refused from shops — getting followed round shops, being treated different for being a Traveller"

#### General

"Nothing — we get painted with the one brush- if there's trouble in another town we get blamed"

## What makes you ashamed of being a Traveller? (2)

Racism/ discrimination(cont.)

#### Media- My Big Fat Gypsy Wedding

"My Big Fat Gypsy Wedding" – the caravan I have is all I need – for settled people to see fancy weddings, cars, glamour and I ask for 50 euros to wash a driveway they'd say 'what do you want 50 euro for?' You'd be struggling to make ends meet."



### Reasons for culture affecting health (1)

#### Racism

"It does stress you out that they're judging you for no reason. It absolutely frustrates you - you feel 'what's the point talking if they're putting you down?'

"Being bullied causes depression and isolation."

"People looking at you coming into a bar - there'd be 20 there. All the people looking at you make you feel embarrassed. We're not asking for nothing."

"You haven't the same facilities as settled people. You haven't the same equal rights - you'would have more pressure. A local man would get in and you wouldn't - you'd have a lot of worry."

### Reasons for culture affecting health (2)

#### Access to services

#### Primary care

" Before St Christopher's Park we had.... no doctors"

"Travellers don't like going to doctors"

#### Education

"You're more educated than you were 25 years ago. Now there are classes for learning - years ago there was nothing"

#### Culture

#### Physical activity

"Travellers are exercising all the time. As some Travellers do the hunting their health is good. They're also walking."

#### Environment

"Back years ago we were out in the rain camped out in caravans and tents, sleeping and eating rough. We never got fair play, the police had us round from place to place"

## Experience of discrimination- general

- 100% (n=20) reported experience of discrimination
- ▶ 60% (n=12) reported experience before age of 10
- 85% (n=17) did not report early discrimination
- 5% (n=1) took successful discrimination case through Equality Commission

### Experience of discrimination - childhood (1)

#### Verbal abuse

#### Racist name-calling

"Gypsy"; "smelly"; "tramp"; "knacker"; "bastard"; "I don't like being called an itinerant which is a higher word than a dog"; "Vile comments about my family"

#### Sectarian name-calling

"We weren't just 'Fenians' - we were classed as 'Gypsy tinkers' "



## Experience of discrimination - childhood (2)

#### Exclusion/ social isolation

#### School

" You are out-casted in primary class. The children wouldn't involve you in groups."

#### Shops

"I got put out of the shopping centre"

#### Leisure facilities

" The football field beside us was denied to us"



## Experience of discrimination - childhood (3)

#### Physical violence

▶ Mild

"Spitting"

#### Moderate

" They tried to bully you"

"Burning clothes off line"

#### Severe

"Thrown through window of school"

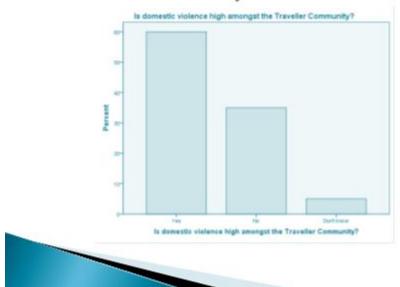
"Burning house"

"When we used to stand waiting for the bus the Protestants kicked the crap out of my 4 oldest brothers"

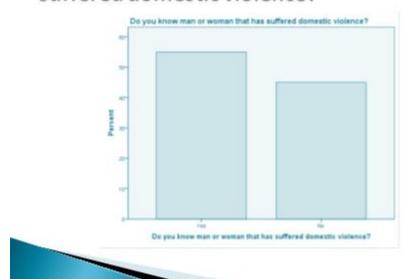
## Reporting early discrimination

Incident	Reported early discrimination	Incident	Didn't report early discrimination
Burned out of house	"My father would have had to report this. We got a different house with no electricity, no windows, facing the graveyard. that house was haunted"	Bullying at school	"No, I was a child at school. the Master gave you slaps too, so you couldn't report it to anyone"
Thrown through school window	"Yes, I reported it to the teacher 5 were expelled - one stared me in the eye and said "don't tell on me". Ever since that fellow looked after me because I didn't report him."		"No, pointless you'd be bullied again for reporting it after school. "He's a tout".

## Is domestic violence high amongst Traveller community?



## Do you know a man or woman who has suffered domestic violence?



## Know where to get help if someone needed it for domestic violence?

		Area				
		Newry	Craigavon	Dungannon	Coalisland	Armagh
Know where to get help for someone if they needed it?	Yes	20% N= 4	15% N=3	5% N=1	15% N=3	15% N=3
	No	5% N=1	5% N=1	15% N=3	0% N=0	15% N=3

## How do you cope with stress?

Negative coping strategies	Example	Positive coping strategies	Example
Drugs/drinking/s moking	"Very bad – smoke Took a cocktail of drugs - odd joint";"Toke tablets to settle me.";"Drink and smoke."	Exercise	"I'm OK until I'm tormented. You just have to put up with it - go for a walk,"; "Handball/exercise."; "Go for a game of football."
Bottle it up	"I would bottle it up - tell my wife."	Leave house	"Get out of the house and get over it - everyone worries."
Depression	"I would suffer from depression and I have a suicidal number on my phone. There's days I feel so depressed I say not another day - tablets only last for so long. Everything is stress"	See doctor	"Go see a doctor,"
Don't know how to	"Don't know how to."	Watch TV	"You come home in evening - let wife out and watch a video and then go to sleep."
		Seek friend to talk to	"If someone hurts/excludes you go for a different friend."
		Sleep	"Sleep it off - relax."
		Work	"go get a bag of scrap."; "Doing things - don't want to be sitting in caravan - you'd clean the car"

## **Section 4 Mortality**



	_	
Theme		Comment
Lifestyle	Drugs and Alcohol	"alcohol- drugs will have an effect in next 12 years."
	Nutrition/ Obesity	"An average Traveller man is eating too much salt and small portion of food, cheap brand of butter (hard block)."; "they put on a lot of weight over 40 "
	Smoking	"Smoking"
	Exercise	"No exercise, no football, hurling, running - mostly driving a car/van and taking no exercise."
	Sleep	"not sleeping right"
Access to services	Primary care	"They don't have an awareness of blood pressure, cholesterol"; "Not seeing a doctor when you should."; " not taking medication"
Mental Health	Discrimination	" discrimination.";" Travellers men do not talk about their problems/they are not open about seeking help/think it is a macho thing. I went to a pub and they didn't serve me and the man was at school with me - very hurtful."
	Stress	"Stress, hardship, providing for family." ; "having no work would affect life expectancy " $$
	Suicide	"There's a lot of Travelling men commit suicide"
III Health	Chronic Conditions	"They could have a family history of cancer or heart disease."
	Other	"don't get kidney infections treated"
Environment	Living conditions	"Years ago all they had was wagons - they were out in the cold."; "Hard life growing up."
	Marie Control of the	

### Suicide

"I have suicidal thoughts - after Christmas I was balling my eyes out I'd bad thoughts about it. I know of 3 chaps that hurt themselves."

- > 90% (n=18) agreed to answer question
- > 25% (n=5) family had been affected by suicide
- ▶ 65% (n=13) family had not been affected
- > 75% (n=15) knew of other Travellers that have lost their life by suicide
- ▶ 65% (n=13) did not know of support groups

"I was drinking with a Belfast lad on Christmas Day and 3 weeks later I went to his funeral. Travellers wouldn't really go to things like that there."



			AREA		
	Newry	Craigavon	Dungannon	Armagh	Coalisland
Anyone in family affected?	Yes 5% (n=1) No 20% (n=4) No Answer 0% (n=0)	Yes 5% (n=10) No 10% (n=20) No Answer 5% (n=1)	Yes 10% (n=2) No 5% (n=1) No Answer 5% (n=1)	Yes 5% (n=1) No 15% (n=3) No Answer 0% (n=0)	Yes 15% (n=3) No 0% (n=0) No Answer 0% (n=0)
Know of other Travellers lost lives?	Yes 15% (n=3) No 10% (n=2) No Answer 0% (n=0)	Yes 10% (n=2) No 5% (n=1) No Answer 5% (n=1)	Yes 15% (n=3) No 0% (n=0) No Answer 5% (n=1)	Yes 20% (n=4) No 0% (n=0) No Answer 0% (n=0)	Yes 15% (n=3) No 0% (n=0) No Answer ( 0% (n=0)
Know of support groups?	Yes 5% (n=1) No 20% (n=4) No Answer 0% (n=0)	Yes 0% (n=0) No 15% (n=3) No Answer 5% (n=1)	Yes 10% (n=2) No 5% (n=1) No Answer 5% (n=1)	Yes 10% (n=2) No 10% (n=2) No Answer 0% (n=0)	Yes 0% (n=0) No 15% (n=3) No Answer 0% (n=0)

## Main causes of death amongst Travellers

Category	Sub-category	Comment	Frequency
Chronic diseases	Cancer	"Cancer"	(13)
	Stroke	"strokes"	(7)
	Heart disease	"Bad hearts";" Heart trouble"; "Heart attacks"	(3)
	Blood pressure	" Blood Pressure"	(3)
	Respiratory	"Their health - some aren't a bit well - all chests and lungs"	
Suicide		"Men are afraid to speak out/ more ashamed to discuss their problems. Should be encouraged to take problems to a doctor/he listens. There's help there if people wants it. If you can get one man to come forward & get help you'll feel good." "suicide (it's depression, everything builds up and they don't talk to anyone)"	(5)
Accidents		"Car crashes - especially young fellow driving hard "	
Lifestyle	Drugs and Alcohol	"Liver problems""; Drinking"; "Drugs"	(5)
Bad health		"Bad health"	(1)
General		"There's Traveller men who never smoked nordrink who died early. My father wouldn't let me go wild or smoke."	(2)

# Section 5 Access to services



## Access to primary care

- ▶ 65% (N-13) visited their GP within the last month
- 90% (n=18) had seen them in their GP surgery
- > 95% (n=19) made an appointment
- > 85% (n=17) did not feel they were treated differently by staff and patients
- One who did feel treated differently commented "They came up with excuses - you were seen as only temporary."
- > 50% (n=10) were put off going to the GP



Fear

"Afraid of what's wrong with you."

Lack of time

"You could be waiting 4 or 5 hours in Craigavon Hospital, so I went home despite pain in head."

Self-healing

"Just try to battle it out"

Shyness

"I would be too shy"

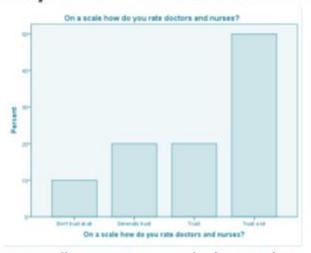
Motivation

"Just never bothered"

Children

"The kids could be sicker than you - you'd get the kids seen first."

### How do you rate doctors and nurses?



90% generally trust, trust or trust a lot doctors and nurses

### Belief in people with cures

- > 90% (n=18) believed in people with cures
- "My father has a cure for ringworm children and adults come to him."
- 65% (n=13) had been to a person with a cure
- "I saw them in Tyrone for murmur in the heart. She got oatmeal, poured it into cork, wrapped hanky round linen top and went round body 3 times praying took hanky off and it was empty. 2nd time cork half full and 3rd to, 3rd time I went up murmur was gone and cork was full."
- 60% (n=12) said they helped or cured the problem
- "I was poisoned with an arrow in the back of my leg aged 15. When I was in Intensive Care parents went to Tommy McGuigan who travelled to Waterford and he cured me."
- > 40% (n=8) did not trust them more than doctors
- "No, a lot of the curer people are looking for hand-out I don't class them as real ones."
- 30% (n=6) trusted them the same as doctors
- "I would believe in traditional healing because of God for tablets I'd trust the doctor."
- 20% (n=4) didtrust them more than doctors

## Sources of health information

Source of health information	%	n
Health professional	95	19
Family member	75	15
TV	65	13
Friend	60	12
Poster	45	9
Leaflet	30	6
Internet	10	2
Conversations	10	2
Cousin	5	1
Locals	5	1

### Rate sources of health information

Source	Not good	Fairly good	Good	Quite good	Very good
Health professional	5% (n=1)	0% (n=0)	20% (n=4)	20% (n=4)	55% (n=11)
TV	15% (n=3)	15% (n=3)	50% (n=10)	10% (n=2)	10% (n=2)
Poster	45% (n=9)	20% (n=4)	20% (n=4)	10% (n=2)	
Leaflet	35% (n=7)	5% (n=1)	30% (n=6)	20% (n=4)	10% (n=2)
Video	65% (n=13)	10% (n=2)	10% (n=2)	10% (n=2)	5% (n=1)
Internet	80% (n=16)				15% (n=3)
One to one	5% (n=1)		25% (n=5)	35% (n=7)	30% (n=6)
Group education	30% (n=6)	5% (n=1)	35% (n=7)	5% (n=10	20% (n=4)
Word of mouth	15% (n=3)		35% (n=7)	30% (n=6)	20% (n=4)

### What kind of group would interest Traveller men?

Type of group	Category	Other considerations
Educational	Reading, writing, ICT	75% (n=15) wanted it at least once a
Trades	Brick Paving; Trades like plastering, bricklaying, plumbing, electrician	week if not more
Traveller culture	Horse training/ horse care, lorry driving, towing licences, forklift driving, HGV, driving theory and licence	65% (n=13) referred to either their own locality or a local community
Citizenship	Traveller rights	centre
Health	Drugs and Alcohol	
Social	"Socialising group chatting about anything"	Highest number preferred evenings 40% (n=8)
Recreation: Fitness	Fitness gym	20% any time ( n=4)
	Boxing	
	Handball/racketball hurling	Majority would promote a group through word of mouth: 85% (n=17)
	Horseshoes, hunting, fishing, driving horses, pony trekking,	
Recreation: Arts	Stories, sing songs and history	

## Appendix 22 Response from Equality Commission N.I. to findings

#### **Equality Commission's response to findings**

#### Overall reaction to findings

Equality Commission staff are generally aware of the inequalities experienced by Irish Travellers because of the nature of the Commission's work. One member of staff had a greater awareness of the scale of inequalities the group faced due to having worked with the community in the voluntary sector for nineteen years.

This person indicated that he was not surprised at the findings in the "Dying 15 Years Early Research" and made the following observations -

- The impetus generated by the Promoting Social Inclusion
  Working Group on Travellers had dissipated and there was
  a need now to look to a revised racial equality strategy to
  address issues identified.
- The situation was not helped by the difficult funding climate for remaining Traveller Support groups and
- There was not enough work supporting capacity building to enable Travellers to have a more effective role in determining their own future.

The Commission would expect that Public Authorities under Section 75 of the Northern Ireland Act would address Traveller issues (where relevant to their functions) when completing their audit of inequalities and, in drawing up an action plan.

#### Action taken to date

A summary of some of the Commission's work in progressing Travellers' equality is as follows -

The Commission has called for a strengthening of the racial discrimination laws to bring them into line with the Equality Act 2010 (21/3/2012)

In the Shadow report (July 2011) to UN CERD Committee regarding the UK Government's 18<sup>th</sup> Periodic Report - the Commission has called for

- Increased legislative protection
- Development of targeted action plans
- A refreshed racial equality strategy
- Raised concerns regarding failure of Government to provide sufficient, adequate, or appropriate accommodation for Travellers
- Drew attention to the longstanding and unparalleled educational disadvantage for Traveller children
- Raised concerns regarding the decrease in life expectancy of Traveller men since 1987 and the suicide rate for Traveller men being almost seven times higher than the general population
- Called for Department of Education to progress an action plan arising from the Report of the Taskforce on Traveller Education
- Highlighted higher mortality rates for Traveller men and women

 Noted negative attitudes towards Travellers amongst sample of public via equality awareness survey and called for the Executive to address this through CSI strategy and to ensure that the promotion of good relations and combating prejudice are targeted and funded.

In the Commission's submission to the Framework Convention for the protection of National Minorities Advisory Committee on the UK's third monitoring report (June 201), the Commission

- Called for the reform of the racial equality legislation
- Highlighted the gaps between the protections provided in the NI Race Relations legislation and the GB Equality Act 2010

In the Commission's ECNI response to the Government's Draft Race Equality Strategy (May 2005), it called on

- The strategy to provide better equality outcomes in key impact areas such as health and education
- Recognition of sedentarism as defined by PSI Working Group on Travellers in 2000

The Commission made representations to DOE on HS3 of PPS12 which allows for temporary accommodation in the countryside for Travellers but does not allow planning permission to be granted for a permanent serviced site for a Traveller family even where they have purchased the relevant land.

The Commission undertook research on Traveller accommodation and published "Outlining Minimum Standards for Traveller Accommodation" (2009). It also engaged with relevant stakeholders in this area.

The Commission produced a Good practice guide to promote racial equality in planning for Travellers (October 2004)

It responded to a consultation on unauthorised encampments legislation and made subsequent recommendations to the Minister on delaying the use of the powers in the Order until sufficient and culturally appropriate accommodation provision was progressed.

The Chief Commissioner, Bob Collins was a member of the Task Force on Traveller Education and staff were involved in the different sub groups.

Staff worked closely with the Department of Education on the revision of the Department's Traveller education circular.

Contributed to a Transnational project - ROMA EDEM Project and held Roundtables on Education and Employment.

Produced two reports (2005-2006) Recommendations made to improve access formed the basis for the Chief Commissioner's engagement with the Permanent Secretary and Department of Education.

#### Section 75

To date the Commission has responded to Public Authority's consultation on equality impact assessment on the following policies -

- Unauthorised encampments
- In the education field to identify the needs of Travellers
- o DOE planning reform

The Commission has also highlighted key inequalities experienced by Travellers in its responses to draft Section 75 audits of inequalities and action plans of a range of public authorities; including those of OFMDFM, Department of Education, Department of Employment and Learning, the Staff Commission for Education and Library Boards, Department of Health and Social Services and Department for Social Development.

#### Communications and Promotional Work

The Promotion and Education Division co-ordinated a Traveller stakeholder engagement campaign, Traveller Focus Week for four years (2007 – 2010). The campaign drew on the "Citizen Traveller" Campaign in the south and was a 'call to action' that engaged key stakeholders and involved partnership work within the community. It was successful in terms of providing platforms for the Commission and stakeholder partners to highlight continuing issues of discrimination for Travellers and in promoting good race relations

A media training event organised in 2011 by Communications and Promotions for internal staff was attended by a young Traveller woman who settled a discrimination case. Materials produced at this event were subsequently used in a successful information event held on 16<sup>th</sup> September 2011on Traveller Rights at Farset International Belfast. Attendees at this event were mainly female.

Along with other contributors Commission staff provided inputs to the Traveller Equality and Human Rights training programme developed by Geraldine Scullion Consulting for An Munia Tober. This course consisted of eleven 2 hour sessions that ran for 12 weeks during the period September – December 2009

The Commission has a representative on SAAT, a strategic alliance of organisations in the southern area working collectively for appropriate actions to improve health, education, accommodation and quality of life outcomes for Travellers.

#### Individual Cases of Discrimination

#### <u>Currently Funded Traveller Cases</u>

Of the 33 Race cases currently assisted by the Commission, 24 are brought by Irish Travellers and 1 other person because of their association with Irish Travellers.

In terms of gender breakdown of the currently funded Race cases only 2 of the 24 cases are from men. In both of these cases there are other female Travellers who have brought related cases and so the men are part of a wider litigation group.

In terms of the nature of the currently funded cases, all involve provision of goods, facilities and services. None involve employment matters. This would be a very different profile of funded cases compared with other Race cases and other discrimination areas.

The nature of the services primarily relate to bars and clubs (14) and shops (13). In addition, the vast majority of cases come to us in groups rather than 1 individual seeking assistance for an individual case. Again this would be a particularly distinct factor for Traveller cases.

The funded Traveller cases are solely related to the individual's Racial group. We do not have any other hybrid or inter-sectional discrimination cases from Travellers which is a distinct factor for Traveller cases. For example we have seen an increasing trend of cases brought by female migrant workers alleging sex and race discrimination which indicates their awareness.

#### Specific Needs for Travellers in Litigation

The Legal Team has attempted to meet the needs of Travellers in providing our services. This has involved more targeted training of Traveller groups, direct outreach work, removal of form filling requirements and adjustments for literacy needs, meeting Travellers in their homes, arranging consultations with barristers in their homes, collecting Travellers to bring them to meetings, more frequent telephone communication and more focus on hearing preparation to ensure consistent telling of their experiences.

In our experience, Traveller women have been much more likely to attend outreach events and to bring forward cases. In particular we have found that Traveller women take on a lead role in any litigation and they are the main point of contact for the group. This certainly improves the quality of communication with the legal team and assists in the progress of the case where a central person will take lead responsibility for gathering the required information for the legal case.

### Case Outcomes

In the Annual Report year of 2011/12 there were 8 Race settlements of the total 50 settlements. Of the 8 race cases, 4

were brought by Travellers. 2 of these involved Travellers complaining about service in a shop (1 male, 1 female); 1 involved a male Traveller not being allowed to rent a private house, and 1 involved a female Irish Traveller who was harassed at work because she was a Traveller *and* a woman (hybrid case). Total compensation recovered for these Travellers was £21,900.

There was 1 Traveller case which went to hearing in the County Court and this was unsuccessful- it was brought by Traveller woman regarding allegedly racist comments made in a shop.

In the Annual Report year of 2010/11 there were 12 Race settlements of which 5 were brought by Irish Travellers. 3 of these cases were brought by 3 sisters regarding allegations of shoplifting and 2 were brought by women regarding treatment in a shop. Total compensation recovered was £5,500.

There were no Court/Tribunal decisions concerning Travellers in this reporting year.

One of the difficulties in gathering information relating to Travellers is that there is no central database concerning County Court decisions which deal with goods, facilities and services cases. In the Tribunal system which deals with employment matters, the Tribunal itself produces statistics and records of decisions by area of discrimination and it would be possible to gather data specifically on Traveller decisions. There is no such central database in the County Court system. This means that the Commission does not know how many cases were brought by

Travellers and the success rates. Legal aid for these cases is available.

#### **Enquiries from Travellers**

<u>Year</u>	<u>Male</u>	<u>Female</u>
07/08	2	9
08/09	21 (Note 1 issue multiple complainants re Ferries)	26
09/10	3	11
10/11	4	16
11/12	9	23

The vast majority of the issues raised have related to the provision of services to Travellers mainly in bars, shops, hotels.

#### Traveller Health Cases

One Traveller health case was brought by a male Traveller concerning his alleged treatment by doctors at a hospital following a road traffic accident. He alleged that the medical staff had been unsympathetic to him because he was a Traveller. The Commission had assisted the case but withdrew following a negative opinion on the merits of the case. The Commission has not received any other cases regarding services provided by GPs or health professionals.

#### **Future Action**

#### **Policy**

Respond to the Department of Education Action- plan on Traveller Education (September 2012)

Respond to the revised Racial Equality Strategy (Autumn 2012)
Update the Commissions Statement of Inequalities originally
published in 2007

Contribute to Joseph Rowntree Foundation "Review of poverty and ethnicity in NI"

Identify any Traveller issues in the forthcoming Research on employment inequalities in NI

Review progress with the Department of Education on the Commission's policy "Every Child an Equal Child".

Highlight key inequalities experienced by Travellers in its responses to draft Section 75 audits of inequalities and action plans of relevant public authorities.

Continue to proactively raise awareness and press for reform of the race equality legislation so that there is greater legislative protection for Travellers and other BME groups against discrimination and harassment.

#### **Communications and Promotion**

Profile public attitudes towards Travellers and other groups identified in the Commission's recent Equality Awareness Survey. This is due to be launched at an event on Wednesday 13<sup>th</sup> June 2012 at Titanic Belfast.

Explore more creative ways of engaging Travellers in the forthcoming race engagement campaign.

Target Travellers who completed the Equality and Human Rights training course along with those who acted as Peer Educators for the Traveller All Ireland Health Study for a round table discussion on engaging Travellers including men to challenge discrimination.

#### Legal

In terms of future work the Commission would like to build on any opportunities to engage directly with Travellers and to raise their awareness of all equality rights and how the Commission can help.

### **Glossary**

AITHS All Ireland Traveller Health Study

**BHF British Heart Foundation** 

BME Black and Minority Ethnic

**CAWT Cooperation and Working Together** 

CCEA Council for the Curriculum Examinations and Assessment

DE Department of Education

DEL Department of Education and Learning

**DETI Department of Trade and Investment** 

DOJ Department of Justice

**DVD Digital Video Disc** 

ECNI Equality Commission Northern Ireland

**GAA Gaelic Athletic Association** 

GSCE- General Certificate of Secondary Education

GP General Practitioner

GRT Gypsy, Roma and Traveller

**HGV** Heavy goods Vehicle

**HSCB** Health and Social Care Board

ICT Information and Communications Technology

LES Locally enhanced service

NI Northern Ireland

NICEM – Northern Ireland Council for Ethnic Minorities

NIHE – Northern Ireland Housing Executive

NISCC Northern Ireland Social Care Council

**NVQ National Vocational Qualification** 

OFMDFM Office of the First Minister and Deputy First Minister

ORECNI – Office of Research Ethics Committees Northern Ireland

PHA Public Health Agency

PIPS – Public Initiative for the Prevention of Suicide and Self Harm

PLIG Protect Life Implementation Group

**PSNI** Police Service of Northern Ireland

PWBD Promoting Wellbeing Department

PWBT Promoting Wellbeing Team

ROI Republic of Ireland

SAAT Southern Action with Travellers

SAW Safe and Well

SELB Southern Education and Library Board

SHSCT Southern Health and Social Care Trust

SPSS Statistical package for Social Science

SRC Southern Regional College

**TETF Traveller Education Task Force** 

TSG Traveller Support Group

TSW Traveller Support Worker

uPVC - Plasticised Poly Vinyl Chloride

TTAG Trust Traveller Action Group

**UU** University of Ulster