# A multi-method evaluation of a community initiative intended to improve the quality of healthcare in the Gypsy and Traveller communities.

**Helen Jane Lewis**

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**Cardiff University,
School of Medicine**

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## Thesis Summary

Although small-scale initiatives have taken place attempting to address the inequality in health of Gypsies and Travellers, these have had little impact nationally, being isolated and lacking impartial evaluation. Consequently, healthcare access and health status of UK Gypsy/Travellers remains very poor.

This thesis is a multi-method evaluation of a complex intervention designed to improve the healthcare of Gypsies and Travellers in Wrexham. An ethnographic method was used providing both 'insiders' and 'outsiders' perspectives. Participant observations and a series of interviews with Gypsy/Travellers and service providers were undertaken, together with a study of Gypsy/Travellers' coronary and mental health status. The combination and interaction of these studies provide an overall evaluation of the community health initiative.

Gypsy/Travellers' culture, lifestyle, health beliefs and experiences of healthcare are described. Gypsy/Travellers hold a strong sense of cultural identity and their lives are governed by strict rules and cultural expectations. To break the rules risks being ostracised from the community. Family life is all important and religion is fundamental to Gypsy/Traveller lives. Also, they experience wide spread discrimination which results in defensive, mistrust of non-Gypsy/Travellers.

Gypsy/Travellers' CHD and mental health status have been described. Results suggest that they engage in higher CHD risk behaviours than the general population and high levels of depression and anxiety were found.

The community health initiative consisting of a full-time Project Health Worker who provides an outreach service by means of a mobile health unit is described. The aim is to increase access to healthcare and develop culturally acceptable methods to improve CHD health of this group. The strengths and weaknesses of the initiative are explored and the complex interactions between culture, health and the initiative are discussed. Finally, several key elements are identified which contribute to the success of the initiative and the continuation of the initiative is discussed.

## DECLARATION

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

Signed ................................................(candidate)    Date..14/08/2007

## STATEMENT 1

This thesis is being submitted in partial fulfillment of the requirements for the degree of PhD

Signed ................................................(candidate)    Date ..14/08/2007

## STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated.
Other sources are acknowledged by explicit references.

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## STATEMENT 3

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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## Acknowledgements

## Glossary of Terms

*Caravan:* Term used mainly by non-Gypsy/Travellers to describe a Gypsy or Traveller's trailer or mobile home, usually a unit that is towed by a vehicle.

*Community Health Initiative:* This term is used for the purpose of this thesis to define the service arm of the Inequality in Health project funded by the Welsh Assembly Government. The service includes the Project Health Worker and the Health Bus.

*Country people/girl/boy/man/woman/folk:* Non-Gypsy/Travellers.

*Evaluation of community initiative:* A multi-method evaluation consisting of three studies; Gypsy and Traveller CHD and mental health study, Gypsy and Traveller culture, lifestyle and health beliefs study, and a process evaluation of the community initiative. Overall understanding is gained by their combination and interaction.

*Extended family:* A family group extending beyond the immediate nuclear family of parents and their children, to include siblings, grandparents, uncles, aunts, cousins, nephews and nieces.

*Gorgia/Gorgio/Gaje (gorger):* Non-Gypsy/Traveller. Any person who is not of Gypsy or Traveller decent and upbringing.

*Gypsy / Romany / Romani / Roma:* An ethnic minority group first recorded in Scotland in 1505, in England in 1514 and in Wales in 1579 and thought to originate from India. The name 'Gypsy' was adopted as the original Romany inhabitants where believed to have originated from Egypt and where first known as 'Egyptians'. These terms are used interchangeably.

*Gypsy/Traveller:* A generic term used by non-Gypsy/Travellers and includes all groups of Gypsies and Travellers who share a similar cultural identity that separates them from the greater non-Gypsy/Traveller populations. This identity is self ascribed. Membership is through birth and living a traditional Gypsy/Traveller lifestyle.

*Hawking:* To sell goods, either bulk bought such as rugs, linen and household wears, or traditional specialist Gypsy/Traveller goods such as lucky charms, lucky heather, and 'hand made' goods such as pegs, baskets and lace.

*Health Bus:* A motorised camper van customised to be used as a mobile health unit for the purposes of the community health initiative.

*Health Project/Traveller Health Project:* The 'Coronary Heart Disease in Gypsies and Travellers: Redressing the Balance' project funded by the Inequality in health Fund. This includes two elements, a community initiative element and an evaluation of the community initiative which includes three studies; CHD and mental health status of Gypsies and Travellers, a study of culture, lifestyle and health beliefs of Gypsies and Travellers and a process evaluation of the initiative.

*Inequality in Health Fund:* A fund set up by the Welsh Assembly Government, Department of Health, to support projects attempting to tackle inequalities in health through focusing on coronary heart disease. 67 projects have been supported by the fund. This thesis describes one of them.

*Irish Traveller / Irish Tinker:* An ethnic minority group of Travellers who originate from Ireland and who maintain links with Ireland through family links and family burial grounds. Thought to have originated from itinerant tradesmen and peasants in Ireland.

*Local people:* Non-Gypsy/Travellers.

*Multi-agency Traveller Forum (MAF):* A group of professionals in North East Wales, across the agencies both public and voluntary, who have an interest in the welfare of Gypsy Travellers. This group also welcomes Gypsy/Traveller involvement.

*Pitch/plot:* a set area on a council run Gypsy/Traveller site often fenced and containing a shed which is hired out to a family for a ground rent.

*Project Steering Group:* A group who meet on a regular basis the direct the Traveller Health Project. This group includes the project lead, project workers, project workers line management, and a research advisor.

*Rigg:* An outfit of clothes, often used to describe a special outfit, for example, a wedding outfit.

*Service Providers:* Inequality in Health funded Project Workers who work in the community health initiative, providing an outreach service to Gypsies and Travellers in and around the Wrexham area and includes the Project Health Worker and Project mental Health Support Worker.

*Service Users:* Gypsies and Travellers who engage with the community health initiative.

*Shed:* A term used to describe a washing/toilet unit provided on a council run site. Usually, there is one 'shed' per pitch.

*Tinkers:* Also known as Irish Travellers. Itinerant people who are thought to have originated from early itinerant tradesmen and peasants in Ireland.

*Trailer:* A mobile home used by Gypsies and Travellers. Usually it is modified to meet the cultural requirements of Gypsies and Travellers and can be towed by a motor vehicle.

*Traveller:* A member of an ethnic minority group who's membership depends on the principles of descent and includes travelling and a nomadic lifestyle as traditional lifestyles. The term 'Traveller' is adopted by those of Irish and Scottish descent as opposed to 'Gypsy' in the UK. This term may also be used by English and Welsh Gypsies as less stigmatising when interacting with non-Gypsy/Travellers.

*Travelling:* Travelling is seen as the 'ideal' way of life and involves moving from one place to another. This can be done as a single family unit or in a group and often follows patterns; following work, horse fairs, visiting family, the sick, weddings, funerals and anniversaries of the dead.

*Welsh Gypsy:* An ethnic minority group who settled in Wales between the sixteenth and nineteenth centuries, descendants of the dominant 'Wood' family became known as the 'Welsh Gypsies' due to their cultural identification and cohesion that is separate from the general Welsh population.

*Yoke:* A term used by Gypsy/Travellers in place of a noun when the correct name cannot be immediately brought to mind, as in "look at that 'yoke' in the road" or "pass me that 'yoke' over there".

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# Chapter One.

# Background

## 1.1 Introduction to the thesis

This thesis is a report of the findings of a multi-method evaluation of a community health initiative designed to improve the healthcare of Gypsies and Travellers in and around the Wrexham area of North Wales. The main components are: a review of the pertinent literature; a study of Gypsy and Traveller culture, lifestyle, health beliefs and experiences of healthcare; an examination of the processes involved in the community health initiative; an assessment of the outcomes of the community health initiative; and the researcher's own reflections of both the initiative and the research process. These components combine to provide an overall evaluation of the initiative.

## Overview of the Main Components of the Evaluation
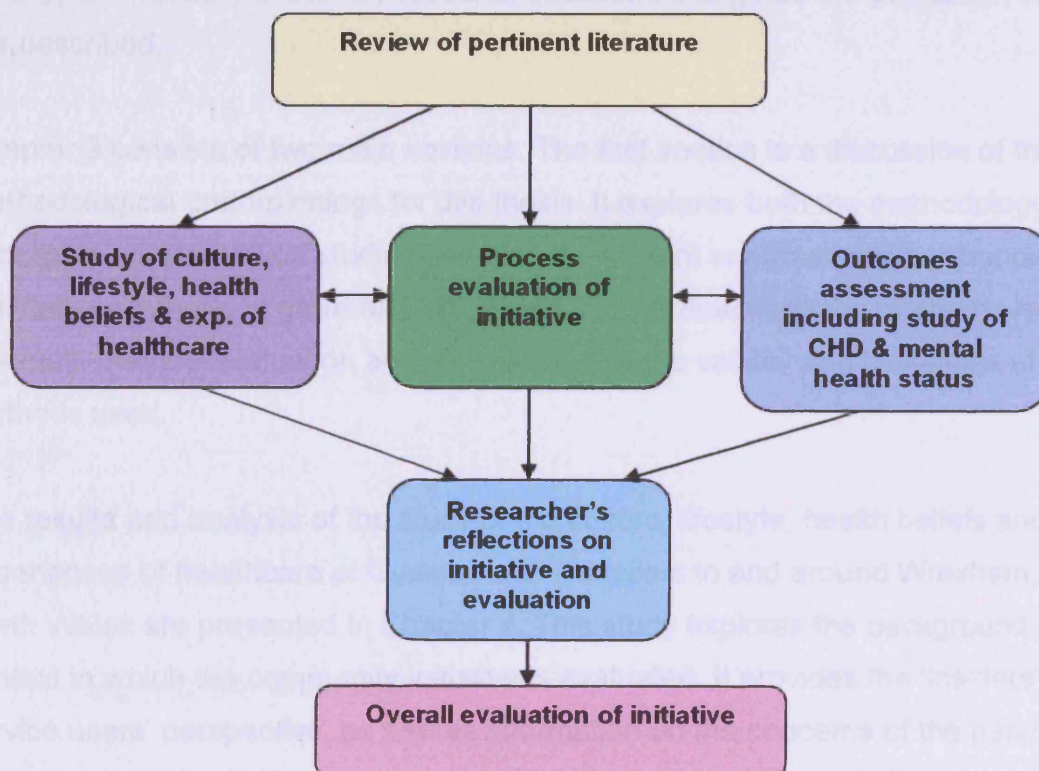


Figure 1.1

A review of the existing literature is presented in Chapter one. The review aims to provide background knowledge and provides the context in which this thesis and the community health initiative are placed. The review explores who Gypsies and Travellers are, their health status, government policies that impact on Gypsy and Traveller health and well-being in the UK, and finally what health interventions have been reported in the literature. The literature is used to compare and contrast with the other main components of the study to reach an overall evaluation of the community health initiative.

Chapter 2 describes the background to the Inequality in Health Funded project in which the evaluation studies sit. It contains a brief description of the Inequality in Health Fund and the development of the bid for funding of the project. Also, brief descriptions of the community health initiative and evaluation studies are given. Finally, an overview of the key research questions that guide the evaluation studies are described.

Chapter 3 consists of two main sections. The first section is a discussion of the methodological underpinnings for this thesis. It explores both the methodology that underpins the evaluation studies and also the current controversies surrounding qualitative methods in general. The second section describes the methods used in this multi-method evaluation and also reflects on the validity and limitations of the methods used.

The results and analysis of the study of the culture, lifestyle, health beliefs and experiences of healthcare of Gypsies and Travellers in and around Wrexham, North Wales are presented in Chapter 4. This study explores the background and context in which the community initiative is evaluated. It provides the 'insiders' or service users' perspective, as well as information on the concerns of the people for whom the initiative is directed.

Chapter 5 is a study of the community health initiative, including a description of the key players in the community health initiative. This is followed by an

assessment of the initiative, describing the processes involved in providing the service and focuses on the service providers' perspective.

The outcomes of the community health initiative are examined in Chapter 6, focusing on the strengths and weaknesses of the community health initiative, and the impact that the initiative has had. This is followed by a report on the results of a quantitative study of Gypsies' and Travellers' coronary and mental health status compared to the general population in Wales, England and the UK is presented. Throughout this chapter, interactions between various areas of study are explored and explanations for findings are offered.

Chapter 7 is an exploration of the evaluation from the researcher's perspective, reflecting on the impact of the research on the community health initiative and the issues that impacted on the final evaluation and reporting of the findings.

Finally, Chapter 8 is a discussion of the overall evaluation. It includes a summary of the study results and analysis, and an exploration of the strengths and weaknesses of the evaluation. The key outcomes are outlined and recommendations offered for future service provision and research.

## 1.2 Gypsies and Travellers: A review of the literature

### 1.2.1 Method

This review of the literature concerning Gypsy and Traveller health and health interventions focuses mainly, though not exclusively, on British literature from 1966 to the current day exploring all aspects of Gypsy and Traveller health, health provision and current government policy in connection with Gypsies and Travellers. Computerised searches were conducted using Medline, PubMed, ClinPSYC, Cochrane Library, ASSIA, CINAHL, National Research Register, Centre for Reviews and Dissemination, The British Library, MedHunt, OMNI, and the National Technical Information Service. This was supplemented by hand searching references from papers, reports, current research protocols, MD and PhD theses, local and national newspapers, interest group publications such as 'Travellers Times' and also searching the world wide web, including Government web sites and special interest sites such as Pavee Point. The censoring for all searches for publications was October 2006. Searches included the following terms: Gypsy, Travellers, Romany, Romani, Roma, Pavee, Kale, and Irish Travellers. The search strategy also included the terms health Inequalities, ethnic minorities, ethnic groups, cardiovascular disease, coronary heart disease, mental health, depression and anxiety. The search was limited to the English language.

The methods used in the research of Gypsies' and Travellers' health are heterogeneous and for the most part, observational, coming from a diverse range of interested parties from health, through to social services, sociology and law. Each brings a different perspective and methodology. A large literature to date consists of accounts of health workers' own experiences with this community and although not case studies per se, are however, valuable information sources. For this reason, using the evidence based medicine guidelines for hierarchy of evidence (Khan 2001) would not be applicable. There would be a great risk of excluding many of the published papers in this field and excluding many areas of knowledge in the area of Gypsy and Traveller health.

Therefore, this evaluation of a community health initiative has been designed to use predominantly qualitative methods of enquiry. These methods have been traditionally viewed by the research community as providing subjective results, and therefore, has been viewed by some as less valid than quantitative evaluations.

Evidence-based medicine (EBM) is a concept that has grown to dominate the medical literature over the past decade and refers to the use of evidence, specifically in the form of quantitative research, concerning the effectiveness of medical interventions with the aim of guiding the use and financing of those interventions. EBM has been developed to determine which evidence is most likely to support truthful conclusions and relies on non-complete ranking of research methods, a 'hierarchy of evidence' (Gupta 2003).

Evidence Based Medicine however, is not without its critics. Gupta (2003) critiqued the concept of EBM, questioning its fundamental values and assumptions and highlighting the technical, publication and funding source biases that exist within EBM, suggesting that recognition should be given that EBM evidence is not neutral but created through a subjective process. That the exclusion of other sources of evidence that are explicitly subjective should be questioned and that dismissing or fearing subjectivity should be replaced with understanding of subjectivity as a part of human endeavour and used appropriately.

Although inclusion criteria are specified to attempt to ensure the highest quality evidence in EBM, it is acknowledged that there are some areas of health care that have not been evaluated with methodologically sound studies (Khan 2001). Upshur (2001) suggests that it is EBM that is at fault rather than any definition of evidence and puts forward a model of evidence that serves to legitimise evidence derived from qualitative studies and seeks to set them on an equal footing with other forms of research. Upshur describes four broad categories of evidence; qualitative/personal, qualitative/general, quantitative/general and quantitative/personal. Evidence in Upshur's model is neither exclusively qualitative and general nor narrative and particular, but an interaction of both. No single method is applicable in all circumstances.

There have been few guidelines in the past concerning how to conduct a review of literature that does not fit the evidence based medicine criteria, however, with the growth of acceptance of qualitative research in recent years, debate has grown in this area and guidelines are beginning to be developed (Mays & Pope 2000, Giacomini 2000).

Mays and Pope (2000) counter the argument put forward by antirealists that qualitative and quantitative research are very different and that it is not possible to judge qualitative research using conventional criteria. They suggest that validity and relevance can be assessed, but that it needs to be operationalised differently, taking into account the distinctive goals of qualitative research. A set of guidelines is suggested for assessing the validity of qualitative research including: Triangulation, Respondent validation, Clear exposition of methods of data collection and analysis, Reflexivity, Attention to negative cases and Fair dealing.

Dixon-Wood (2001) although stressing the important contribution to be made by qualitative methods in systematic reviews, also highlighted the problems and areas that need to be developed (Dixon-Wood, Fitzpatrick & Roberts 2001, Dixon-Wood & Fitzpartick 2001). They suggest that problems still exist in the following areas:
• Searching and identifying appropriate research
• A failure to agree on suitable methods for assessing quality
• How to make qualitative evidence produced with widely varying theoretical perspectives and diverse analytical approaches submit to the disciplines of secondary summary and synthesis.

Mathematical approaches such as Bayesian approaches to meta-analysis have been suggested as offering some hope but systematic means for more narrative based and other forms of synthesis are still clearly needed.

A critique to the form of judgement put forward by the guidelines used in health science for appraising qualitative research has been put forward by Eakin (2003). Eakin posits an alternative evaluation posture, that of 'substantive judgement'. This orientation centres on the relationship between research practices and substantive

findings and interpretations. However, how to incorporate this orientation into an assessment tool is still unclear and remains a formidable challenge.

### 1.2.2 Gypsies and Travellers, who are they?

Gypsies are said to be one of the oldest ethnic minorities in the UK, with the first records of Gypsy groups from the early sixteenth century (Okely 1983). The earliest record of Gypsies in Wales being a letter in the Acts of Privy Council for 1579 and one of the earliest records of a reference to Gypsies in the Welsh language was towards the late sixteenth century by Morris Kyffin (c. 1555 – 98) (Jarman 1991). It appears that Gypsies were also in North East Wales, St Asaph and Wrexham by the late sixteenth century also, having been noted, the first an *englyn* believed to be the work of Siôn Tudur and the other by a rhymester called Hityn Grydd ('H. the Cobbler') who was associated with the Caerwys Eisteddfod of 1567 (Jarman 1991).

Gypsies are believed to have moved from India to Persia at the end of the 9$^{th}$ century. From there they moved to Syria, Palestine and Egypt. One of the first recorded references to Gypsies in 1100 (AD) described them as 'sorcerers and thieves' (Jarman 1991 p.3). They became established in the Balkans in the 14$^{th}$ century and established all over Europe by the 15$^{th}$ century. Gypsies were thought to have established themselves in Britain by the mid 16$^{th}$ century. The first official reference was in Scotland in 1505 in the records of the Lord High Treasurer (Jarman 1991 p.4, Okely 1983 p.3). By 1530 they were hired to dance before King James V but by 1541 an order was issued for them to leave the country within 30 days. Gypsies were first recorded in England in 1514 but by 1530, a law had been introduced ordering all Gypsies to leave England within fifteen days, or risk imprisonment and confiscation of their possessions (Jarman 1991 p.5). By 1554, Gypsies were considered 'felons' and executed (Okely 1983 p.3, Clark 2006 p.25). As mentioned above, Gypsies were first recorded in Wales in 1579 in the Acts of the Privy Council regarding the apprehension of a number of "vagrant personnes, terming themselves Egiptiens" (Jarman 1991 p.33).

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The persecution of Gypsies continued throughout the Tudor and Stuart periods. By the eighteenth and nineteenth centuries however, with the enlightenment, attitudes softened. There were advocates such as the philanthropist James Crabb who wrote 'The Gipsies' advocate' in 1831 (Jarman 1991, p.7). However, there was also the belief by society that Gypsies were idle, not acknowledging their self-employment. Those deemed 'idle' were sent to Houses of Correction in the mid seventeenth century and later to workhouses (Okely 1983 p.5).

In the twentieth century, Gypsies again found themselves as a persecuted group. During the period between 1938 to late 1943, Gypsies were subjected to an extreme form of exclusion in Germany which has been described as "The Great Devouring" or "Gypsy Holocaust" (Burleigh 1991, Kenrick 1972). Gypsies in Germany were sent to camps such as Auschwitz-Birkenau and/or killed with an estimated 250,000 to 500,000 killed during this episode in history (Kenrick 1999). More recently, the forced sterilization of Gypsy women in Eastern Europe during communist rule, as recently as 2004, has been reported (Krosnar 2006, Kovac 2004). As Clark (2006) suggests, it is important to have an understanding of Gypsy history to appreciate how this has shaped, both in the past and present, how Gypsies relate to and interact with non-Gypsy/Travellers.

Although Gypsies and Travellers have been in the UK for such a long time, they are largely an invisible group. The exact number of Gypsies and Travellers in the UK is unknown. There is no systematic method of collecting data on numbers of Gypsies and Travellers in the UK. However, the Council of Europe in 1987 estimated the UK population to be between 80,000 and 110,000. More recent studies have estimated the population to be in the region of 150,000 (Morris & Clements 1999). Travellers in the UK are a heterogeneous group consisting of North Welsh Kale, South Welsh and English Romanicals, Irish Travellers (Pavees, Tinkers or Minceirs), Scottish Travellers and increasingly European Romas. Although they are separate groups, they are genealogically and linguistically related (Feder 1989).

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Irish Travellers, who are heavily represented in the present evaluation, are thought to have originated from itinerant craftsmen and peasants who were forced on the road by war, famine and poverty. It is believed that these early itinerant workers travelled in rural areas providing a variety of services to the local rural communities such as tinsmithing, horse dealing and farm labouring (Gmelch 1985). With the post world war 2 modernisation of farming, Irish Travellers like Gypsies and other Travellers were forced to move to urban areas and adapt their skills to meet the needs of an urban market.

Clark (2006), in a comprehensive study of Gypsies and Travellers in the UK, adopts the definition offered by Professor Liégeois and Nicolae Gheorghe (1995) in a report entitled *"Roma/Gypsies: A European Minority"*, as follows:

> *'Gypsy'* – 'Term used to denote ethnic groups formed by the dispersal of commercial, nomadic and other groups from within India from the tenth century, and their mixing with European and other groups during their Diaspora'.

> *'Traveller'* – 'A member of any of the (predominantly) indigenous European ethnic groups whose culture is characterized, inter-alia, by self-employment, occupational fluidity, and nomadism. These groups have been influenced, to a greater or lesser degree, by ethnic groups of (predominantly) Indian origin with a similar cultural base'.

> *'Roma/Rom'* – 'A broad term used in various ways, to signify: (a) Those ethnic groups who speak the 'Vlach', 'Xoraxane' or 'Rom' varieties of the Romani language. (b) Any person identified by others as 'Tsigane' in central and eastern Europe and Turkey, plus those outside the region of East European extraction. (c) Romani people in general'.

In the UK, there is an ongoing debate concerning the definition of Gypsies and Travellers, whether they are defined by their ethnicity or their nomadic lifestyle. As Clark (2006) suggests, the continuing question of who are Gypsies and Travellers, may in part, be due to the lack of neutrality of the terms 'Gypsy' and 'Traveller' either within (see chapter 4, section 4.2.1) or outside the communities (see chapter 4, section 4.5.1 and 4.5.3). In the Caravan Act (1968) Travellers are defined as "people of nomadic habit and lifestyle whatever their race or origin". This definition

however, does not include those Travellers who live on permanent private sites or houses. However, Okley (1983) suggests a definition of Gypsies and Travellers based on descent. She argues that a Gypsy/Travellers' status is ascribed at birth and reinforced by their upbringing and commitment to Gypsy/Travellers' values and lifestyle. In 1989, a case was brought forward by the Commission for Racial Equality (Cre v Dutton), and a ruling made, that Romanies were an ethnic minority according to the 1976 Race Relations Act. Even with this ruling, they are still largely ignored. Fór example, they are not listed as a distinct ethnic minority in the census and are often excluded from policy documents concerning ethnic minorities. For example, the document "New Deal for Communities: Race Equality Guidance" produced by the Department of the Environment, Transport and the Regions, 1999 does not include Gypsies or Travellers in its definition of black and ethnic minorities.

### 1.2.3 The Health Status of Gypsies and Travellers

It is believed that the health status of Gypsies and Travellers is significantly worse than the settled population (Linthwaite 1993) and they have been described as one of the *"most unhealthy populations in Britain"* (Bunce 1996). Although there are no statistics for the life expectancy of Gypsies and Travellers in the UK, there is evidence from other countries that Gypsies and Travellers have a shorter life expectancy when compared to the non-Gypsy/Traveller population. Barry reported on a national study of Travellers' health status in Ireland, reporting that Travellers had a higher mortality rate for all causes, and that the life expectancy of Gypsies and Travellers has been reported to be ten to twelve years shorter than the settled population (Barry 1987). Furthermore, data from the Republic of Ireland's National census 2002, found that only 3.3% of Irish Travellers were over the age of sixty five years compared to 11% of the Irish general population (cited in Clark 2006 p.196). The poor health status of Roma (Gypsies) is also replicated in other countries. A recent government survey in Hungary found that its Roma population had a life expectancy ten to fifteen years less than the general population (Kovac 2002).

However, there is little evidence of the Gypsy and Traveller health status in the UK as they are largely invisible in the population health statistics, due to their nomadic

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lifestyle and the lack of a separate ethnic group category in the national census for Gypsies and Travellers. Although Gypsies and Travellers are reported as suffering from poor health, there is also a lack of reliable research evidence on their health status (Van Cleemput 2001; Morris 1999). Feder (1989) highlighted the difficulties of researching this group, including mistrust of authorities, a lack of demographics for Gypsies and Travellers and the difficulties in researching a marginalised highly mobile people.

The research that does exist tends to be small scale studies and localised. For example, Edwards (1997) conducted a study of oral health in Gypsies and Travellers focussing on diet and hygiene. Interviews with 42 Gypsies and Travellers were conducted exploring the perceptions of oral health, diet and hygiene.

In a review of the published literature, Hajioff and McKee (2000) concluded that there is almost a complete lack of research into non-communicable diseases and that the health needs of the Roma (Gypsies and Travellers) are considerable. Of the few studies that do exist, many focus on child and maternal health, infant mortality and perinatal death rates, low birth weight and high child accident rates and that 70% of the reports came from just three countries, The Czech Republic, Slovakia and Spain. A more recent review by Zeman (2003) reported that of the 129 articles found, 50 % examined genetic characteristics, 12% were concerned with infectious diseases, and only 15% were categorised as population health or epidemiological studies, with the greatest number of those being studies of perinatal, infant and maternal mortality. Zeman also concludes that surveillance and population health indices for this international minority population are scarce.

Sepkowitz (2006) points out that this lack of information on basic health indicators may hinder the evaluation of programmes that are being planned to improve conditions for minorities by countries in Eastern Europe who hope to join the European Union and have declared that 2005 – 2015 will be the "decade of Roma inclusion".

However, a recent multi centred research project in England has sought to redress this lack of evidence, by conducting a large-scale epidemiological study of Gypsies' and Traveller's health status using standardised health measures including EQ5D, HADS (anxiety and depression),specific illness, medication usage and health service contacts (Parry, 2004). 293 Gypsies and Travellers across five centres (London, Sheffield, Bristol, Leicester & Norfolk) were compared with matched control groups including White, Pakistani and Black Caribbean ethnic groups in both urban and rural areas. In addition, in-depth interviews were conducted with a subset of Gypsies and Travellers concerning their health beliefs, attitudes and experiences of accessing healthcare in England (Van Cleemput 2004). The study concluded that Gypsies and Travellers showed significantly poorer health status and self reported symptoms than other UK residents, English speaking ethnic minorities and economically disadvantaged white UK residents. Those aspects of health that were reported as showing the most marked inequality were self-reported anxiety, respiratory problems and chest pain. Excess prevalence of miscarriage, stillbirth, neonatal deaths and premature death of older offspring were also noted. Furthermore, the study results suggest that there is some evidence of an inverse relationship between Gypsy/Travellers' health needs and the services and therapies used by that community.

Greenfields (Clark and Greenfields, 2006) sought to identify the causes of premature morbidity and mortality amongst Gypsies and Travellers. Although acknowledging the evidence consisted mainly of small scale localised studies and anecdotal evidence from health care professionals, she concluded that cardiovascular disease, chronic renal and urinary-tract infections, cancer, asthma, diabetes, arthritis and smoking related diseases accounted for much of the morbidity and mortality in Gypsies and Travellers.

One of the aims of the present study is to contribute to the knowledge of the coronary health status of Gypsies and Travellers (for background and aims of the project see chapter 2 section 2.1). It is therefore appropriate to address this issue briefly below.

### 1.2.3.1 Coronary risk status of Gypsies and Travellers

Cardiovascular disease (CVD) is the leading cause of death in the United Kingdom and is a worldwide contributor to the global disease burden. Cardiovascular disease in this study includes both ischemic heart disease and stroke. Death rates for CVD have been falling in recent years, with a decrease of 36% in the past ten years for adults under 75 (Office for National Statistics 2004). However, the United Kingdom is recognised as one of the worst countries for CVD. Coronary heart disease (CHD) has been identified as a priority area with targets set to reduce CHD by at least two fifths in people under 75 by the year 2010 (Dept. of Health 1999).

With coronary heart disease posing a major health threat worldwide, many epidemiological studies have been carried out with the aim of identifying the risk factors for CHD. Prevention through modifying those risk factors has been demonstrated (Kuulasmaa 2000). A recent large-scale case control study (INTERHEART), involving 24,767 people from 52 countries established odds ratios and population attributable risks for coronary heart disease. The findings confirm that abnormal lipids, smoking, hypertension, diabetes, abdominal obesity, psychosocial factors, consumption of fruit and vegetables, alcohol and lack of regular physical activity account for most of the risk of myocardial infarction worldwide (Yusuf 2004).

Coronary heart disease has been reported as high in Gypsies and Travellers although there is little evidence available on the collective profile of cardiovascular risk factors in Gypsies and Travellers, despite a literature describing other ethnic risk profiles in the UK (Molokhia 2002). Studies of ethnic groups with markedly differing customs in the US (e.g. American Indians, rural Southern US women)

have demonstrated collective differences in cardiovascular risk factors in these groups (Welty 2002; Appel 2002).

However, a small-scale study by Barry (1987) suggested that the prevalence of coronary vascular disease was higher in the Gypsy and Traveller populations. Morris and Clements (1999) noted that there had been no study to ascertain whether this is a function of poverty or high tobacco consumption. Feder (1994) reported higher rates of smoking in both male and female Gypsies and Travellers in Hackney than any social group in the 1988 household survey. Parry (2004) also found a higher prevalence of cigarette smoking amongst Gypsies and Travellers compared to matched comparison groups in England.

There have been some recent studies of cardiovascular risk factors and Gypsies in Europe. Two recent studies compared cardiovascular risk factors between Gypsy groups and Slovak groups. The Gypsy groups were found to have significantly increased risk factors for cardiovascular disease such as increased levels of triglycerides, atherogenic index, insulin, insulin resistance and a decrease in the level of HDL-cholesterol, smoking and obesity (Krajcoicova-Kudlackova 2004; Vozarova de Courten 2003).

Alcoholism is also associated with coronary heart disease. A cross sectional study of 700 people in Turkey found that Gypsies had a prevalence of alcoholism 3.2 times higher than the general population, according to the Michigan Alcoholism Scanning Test (Ekuklu 2004). Although no UK studies were found looking at the prevalence of alcoholism in Gypsies and Travellers, Greenfields (Clark and Greenfields 2006) described anecdotal evidence such as the Men's Health Forum publication (2003) 'On the Road to Better Health for Travelling Men', which refers to a tendency for Gypsy/Traveller men to drink more than is considered safe levels when under stress. Greenfields also noted that there is evidence of an increased use of alcohol in other marginalised ethnic communities such as Native Americans, Australian Aboriginals and Maori populations.

In summary, the cardiovascular health of Gypsies and Travellers has not been adequately described in the UK. Given their overall poor health and the knowledge that rates of CHD are known to be associated with material deprivation and neighbourhood context (Cubbin 2001), this deserves investigation. Furthermore, it is not clear whether any excess in cardiovascular risk is due to collective differences in individual risk profiles, or to social inequality, which cannot be measured at an individual level (Cooper 2001). Finally, this group has poor access to existing services, which exacerbate any underlying health inequity (Feder 1998).

### 1.2.3.2 Mental health status of Gypsies and Travellers

In recent years, research has also looked into psychosocial risk factors connected with CHD, in particular depression as a risk factor of CHD. Several studies and systematic reviews have been carried out confirming depression as a risk factor in CHD (Barth 2004; Rosengren 2004; Van Melle 2004; Lawson 2003), while other research has suggested that there is a relationship between the magnitude of depressive symptoms and greater risk of CHD (Matthews 2005; Rugulies 2002).

Another area that has been largely neglected in the literature has been that of mental health amongst the Gypsy and Traveller populations. Again, small studies and anecdotal evidence suggest that Gypsies and Travellers suffer from high levels of mental illness including depressive illness, psychotic episodes linked to alcohol and schizoaffective disorder (Lehti 2001; Roberts 2001; Morris 1999; Vernon 1994; Pahl 1988). Alcoholism appears to be a prevalent local problem amongst this group in North Wales (Roberts & McDonald 2001). A recent study, (Parry 2004) found self-reported anxiety as one of the marked inequalities found in Gypsies and Travellers compared to comparison groups in England. More recently, a study by Hodgins (2006) who conducted focus groups with 41 Irish Traveller women in The Republic of Ireland, looked at the lay perceptions of ill-health and health inequalities and also highlighted the apparent prevalence of both depression and domestic abuse in this community.

### 1.2.4 Culture and Broader determinants of health

Many factors have been identified as contributing to the poor health of Gypsies and Travellers, such as forced changes in lifestyle, substandard living conditions, prejudice and poor access to healthcare.

It has been suggested that forced changes to travelling patterns and the related impact on lifestyle may have a detrimental effect on quality of life and mental health of Gypsy/Travellers (Ginnetty, 1993). Gypsies' and Travellers' nomadic lifestyle, which has traditionally been connected with agriculture, has been increasingly under threat in the post war decades. Together with advances in technology affecting the numbers of itinerant farm labourers required on farms, recent legislation has also resulted in less provision and even criminalisation of the Gypsy/Travellers lifestyle.

The Criminal Justice and Public Order Act 1994 repealed the duty of the Local Authorities to provide more sites for Gypsies, withdrew the 100% funding for sites and made evictions from illegal sites easier and quicker by introducing new criminal offences of camping on the land. The result of this legislation for Gypsies and Travellers is marginalisation (Bunce, 1996). Gypsies and Travellers view the authorities as enemies and the media coverage of the Act reinforces old prejudices that Gypsy Travellers are a public nuisance. The recent white paper 'Justice for all' (2002) states that due to the continuing 'problem' of unauthorised sites and anti-social behaviour by a minority of Gypsy and Traveller communities, new eviction powers are to be introduced for the police, tied to adequate provision of a range of sites by local authorities. This again is a threat to a nomadic lifestyle as Local Authorities' support for Gypsy and Traveller sites has been withdrawn by Government.

A report by Derek Hawes (1994), concludes that *"Legal, well serviced sites are an essential pre-requisite to the improvement of Traveller's health and access to primary care".* Also, the policy document from the Department of Health, 1998 'Saving Lives: Our Healthier Nation', identifies 'social, economic and environmental' as primary causes of ill health. However, a report by Morris and

Clements (1999) states *"Travellers experience levels of deprivation in these areas which is possibly without parallel"*. Pahl and Vaile, 1986 (cited in Vernon, 1994) reported that 60% of Traveller mothers in their study reported problems caring for their children due to:

*'...dirt, fast traffic, rats, lack of safe play areas, difficulty drying clothes, overcrowding, mud, dogs, broken glass, the site getting 'used up' by toilet holes, lack of education, noises from factories, smell from nearby sewage works...'*

Furthermore, a recent study (Van Cleemput 2001) notes that Gypsies and Travellers continue to face appalling conditions on some authorised sites and often lack basic amenities when on unofficial sites.

The problems that Gypsies and Travellers experience concerning access to healthcare have been described as both complex and interacting (Van Cleemput, 2001). Factors that often adversely affect access to healthcare include service factors (site provision), poor literacy (only 5% are still in registered or regularly attend school by key stage 4. Morris 1997), cultural beliefs, and prejudice. As discussed earlier, site provision is often poor and many sites are situated in locations 'off the beaten track', often inaccessible to public transport. Poor literacy is a barrier to finding out where to obtain healthcare, causes difficulty with keeping hospital appointments, and causes difficulties with health education. Also, many Gypsies and Travellers experience problems with receiving mail at all, as the Post Office will often refuse to deliver post to temporary addresses and unofficial sites (Streetly, 1987).

Misunderstandings often arise due to health workers lack of knowledge of Gypsies' and Travellers' cultural beliefs, for example, 'pollution' beliefs. Things outside the body and their trailer are considered polluting, while things entering the body or trailer must be kept extremely clean. This may be a contributing factor to the low vaccination uptake of Gypsy/Travellers, as immunisation is seen as putting something 'dirty' into the body (Streetly, 1987). Cultural differences may also have an impact on the effectiveness of health promotion amongst Gypsies and

Travellers. An excerpt below from an interview illustrates this with two Gypsies (Burger 1996):

> *Interviewer:* "How would they respond to someone teaching them how to reduce their cardiac risk factors?"
> *Larry (Gypsy):* "If you're a health worker, they don't want to look at you because you represent sickness. They might get sick just being around you... It would be difficult to help Gypsies see that learning about sickness is not going to make them sick. This is a problem."
> *Linda (Gypsy):* "If you talk about it then it's going to happen. We weren't allowed to talk about this in our homes."

Also, a recent qualitative study by Petek (2006) explored the reasons for widespread cigarette smoking and a lack of success of smoking cessation initiatives in the Roma population in southern Slovenia. It was found that smoking was a strong part of the culture and individual identity of Roma and that they did not associate ill health with smoking but rather, believed in destiny. They concluded that it was these cultural differences between Roma and the wider population which meant that traditional strategies for smoking cessation were ineffective. They suggested the development of more culturally acceptable methods of smoking cessation.

It has also been noted that Gypsies and Travellers experience difficulty being accepted onto many GPs lists (Vernon, 1994; Feder 1989; Streetly, 1987). This may be, in part, due to lack of understanding of this disadvantaged group; seeing them as a 'difficult' client group, and also indirectly influenced by recent legislation (Morris 1999). For example, the legislative consequences of the new GP contracts which penalise practices for not meeting immunisation targets.

### 1.2.5 Government policies

Inequalities in health have been highlighted by several reports in the UK recently and appear now to be in the forefront of government policy in health. An independent inquiry into inequalities in health by Sir Donald Acheson in 1998 recommended that 'policies considering inequalities in health should include consideration of the application of these policies to ethnic groups as a matter of

course, including ways of ensuring that racial prejudice and harassment are overcome.'

The department of health's action plan 'Saving lives: our healthier nation' (1999) outlined its main aims as the improvement of health of everyone, and the health of the worst off in particular. Also, tougher targets were set for cancer, coronary heart disease, accidents and mental illness. 'Health action zones' and 'healthy living centres' were suggested as a means to deal with health inequalities, however, there was no emphasis on ethnic minorities or Gypsies and Travellers.

In Scotland, the Equal Opportunities Committee produced two reports 'Inquiry into Gypsy Travellers and public sector policies' (2001) and 'Report on Gypsy Traveller civic participation event'. Both of these reports found evidence of discrimination, racism and harassment and called on public bodies in Scotland to treat Gypsy/Travellers as a distinct ethnic group. The response by the Scottish Executive was to welcome and accept the recommendations and recognise Travellers as an ethnic minority.

In recent years inequalities in health have been recognised as a priority area for policy in Wales. Several recent documents have impacted on the current policy in Wales. 'Better Health Better Wales' (1998) provided a framework for national and local action. One of the key objectives is 'bringing the level of those with the poorest health up to the level of those with the best health'. 'Better Wales /Plan for Wales 2001' was the National Assembly's first strategic plan setting out three main themes: sustainable development, tackling social disadvantage, and equal opportunities. It set out a commitment to increase awareness of all languages and cultural issues in service delivery, to reduce inequalities in health and to increase life expectancy especially in the most deprived communities. However, the plan does not mention ethnic minorities or Gypsies and Travellers specifically, but rather concentrates on geographical areas of deprivation.

'Health in Wales', the Chief Medical Officer's report 2001/2002, although acknowledging the moves made to date to redress inequalities in health, also suggests that much more needs to be done :

*'There is evidence to suggest that NHS Trusts, the education sector and commerce and industry could give a greater commitment to addressing health inequalities and that more can be done to address the health needs of ethnic minority communities and Travellers.'*

One Country that has gone further in recognising the plight of Gypsy/Travellers and is now attempting to address some of the inequalities experienced by them, is the Republic of Ireland. The Department of Health and Children has produced a National Strategy for Traveller Health for 2002 – 2005. This was the result of the Traveller Health Advisory Committee, with Gypsy/Travellers' involvement, identifying the factors which adversely affect Gypsies' and Traveller's health.

Wales has begun to take a greater interest in Gypsy and Traveller welfare. The National Assembly for Wales' Equal Opportunity Committee has been reviewing the provision for Gypsies and Travellers in Wales. Included in this fact finding exercise was a seminar held in October 2002 entitled 'Providing for Gypsy/Travellers' to further gather information on provision. Following this review process, they produced the document entitled 'Review of Service Provision for Gypsies and Travellers' in 2003. This review covered a broad spectrum of services such as accommodation, health and education. It also focused on prejudice and discrimination, spending on service provision and involvement of Gypsies and Travellers in decision-making and policy development. The Chair summarised the challenges found by the review in the introduction as follows:

> *"There can be no doubt that in many respects Gypsies and Travellers are one of the most discriminated against groups in Wales. The stark realities laid before the Committee by a group of young people from the Gypsy-Traveller community brought home the challenges we face in making a real difference to their lives."*

In the area of health provision, the review outlined several key principles that have informed their approach:

- *"There is a need to guarantee access to health services for all Gypsies and Travellers".*

- *"At present specialist provision, which facilitates access to healthcare is important".*

- *"We believe that specialist services are there to facilitate access to healthcare for a group that is currently excluded from the full range of healthcare services available to the settled community. Specialist provision is not a replacement for mainstream provision, nor is it an excuse for mainstream health service providers to avoid their responsibilities".*

- *"We acknowledge that there are cultural issues that impact on how Gypsies and Travellers access healthcare and their priorities. These cultural realities must be taken into account in the design of health services".*

Several recommendations were made in connection with healthcare provision for Gypsies and Travellers in this review. It was recommended that there should be a full literature review undertaken and further research into the health needs of Gypsies and Travellers in Wales in order to establish baseline provision and to inform future health policy and local strategies. The review recommends that all NHS staff, both clinical and non-clinical receive specific guidance on the removal of barriers to healthcare for Gypsies and Travellers on the point of entry to the NHS and as continuing professional development. It also recommends that where specialist health professionals deliver services, there should be continuity of care and that the service should be properly funded and linked to mainstream services. Another key recommendation was that all Local Health Boards develop and implement strategies that meet the needs of Gypsies and Travellers in their areas, including how they will remove barriers to access to healthcare.

The findings of this review confirm the need for the research conducted in this thesis and its timeliness.

### 1.2.6 Gypsy and Traveller Health Initiatives

Although there have been many health initiatives set up in the past quarter of a century to help improve either access to healthcare, other social services, and health education and promotion for Gypsies and Travellers, there are few reported

that have been systematically evaluated. D'Souza and Garcia (2004) conducted a review of studies in the UK between 1990 and 2003. They looked at studies designed to improve services for disadvantaged childbearing women, with the aim of improving perinatal outcomes. They found few well-designed studies, these provided limited evidence in general and no studies of interventions for Gypsies and Travellers were found. However, they do acknowledge that their search was restricted to one particular subgroup of disadvantaged people and suggest that widening the search to include other subgroups such as interventions to address behaviours such as smoking, and other areas such as social support may provide further evidence.

The present literature review supports D'Souza's and Garcia's findings, that there are no published evaluation studies of health initiatives with childbearing Gypsy and Traveller women. Furthermore, there are no published evaluations of any health interventions with Gypsies and Travellers as a whole in the UK. There are however, a limited number of studies either unpublished or outside of the UK that have evaluated interventions with Gypsies and Travellers (Morrison-Puckett 2005; Fitzpatrick 1997; Feder 1994).

Feder (1994) evaluated a dedicated Gypsy and Traveller Health Visitor service in Hackney, East London, by conducting interviews with the Health Visitor and Gypsies and Travellers, a study of the Health Visitor's workload and a questionnaire directed at general practices in the locality. He concluded that the effects of the Gypsy and Traveller Health Visitor service in improving cervical smear and immunisation rates was limited due to the wide workload of the Health Visitor, including health, welfare and social care and also, a large geographical area and large numbers. This resulted in time constraints for the Health Visitor, which impacted on the time available to develop a full liaison role
with other health professionals or to properly support Gypsies and Travellers utilising mainstream services. It appears that the service was simply stretched too far.

Fitzpatrick (1997) reported on the evaluation of a Community Mother's Programme in Ireland. This programme paired experienced mothers with new mothers and evaluated the outcomes for different groups. Gypsies and Travellers were found to continue to have a poor uptake of infant services such as developmental checks and immunizations, even though they looked favourably on the programme. Fitzpatrick suggests that preventative programmes will continue to be viewed as a low priority to Gypsies and Travellers while immediate needs such as shelter remain unmet.

Finally, a study of the uptake of social services by Roma in Poland (Morrison-Puckett 2005) found little engagement of the Roma with Polish social services. One reason suggested for the lack of engagement of the Roma was one of fear due to their experiences of discrimination and violence from the general society. Morrison-Puckett suggests that service providers should take a more active role in making services available and also should be educated in the culture, traditions and status of the Roma people.

In addition to the above studies, there is a larger literature, mainly from nursing publications, giving first hand accounts by health professionals of health initiatives for Gypsies and Travellers (Van Cleemput 2006; Warriner 2002; Daniel 1999; Matthews 1998; Batestone 1993; Reid 1993; Rose 1993; Eckford 1990; M[c]Cann 1987; Streetly 1987; Peck 1983). Although largely anecdotal, this evidence does provide insight into the cultural considerations necessary in providing services for Gypsies and Travellers and provides insight into the type of service that appears to work best for Gypsies and Travellers.

Several types of services for Gypsies and Travellers have been described in the literature, from the single Health Visitor who works with a caseload of Gypsies and Travellers (Warriner 2002; Daniel 1999; Matthews 1998; Batestone 1993; M[c]cann 1987) to initiatives which involve teams either providing mobile services (Eckford 1990; Rose 1993; Streetly 1987) or clinics (Reid 1993; Peck 1983).

Several key observations are reflected in this literature. One is the importance of providing a service that is culturally sensitive. Some provide descriptions of cultural differences that they have found of importance to their service delivery. Eckford (1990) talks of the importance of working within the strict moral and social codes of Gypsies and Travellers and provides a description of how she works within that framework. For example, she describes how she uses a coded system in the records of women who are prescribed contraception, as this is a very sensitive subject for Irish Travellers due to their Roman Catholic faith.

Other observations include the wide role that a health worker for Gypsies and Travellers adopts, due to the broader issues that affect the health of Gypsy/Travellers and the unmet health needs due to difficulties in accessing mainstream services (Daniels 1999; Matthews 1998; Rose 1993; Eckford 1990; Streetly 1987). The importance of professional liaison and multi-agency working to provide services for Gypsies and Travellers has been mentioned (Warriner 2002; Daniels 1999; Matthews 1998; Batestone 1993; Streetly 1987; Peck 1983). Also, the differing priorities between health professionals and Gypsies and Travellers when attempting to provide preventative medicine and health promotion (Daniel 1999; Fitzpatrick 1997; Rose 1993)

Finally, Reynolds, a health visitor (Reid 1993) raises the question of what type of health care service is most appropriate for Gypsies and Travellers; whether it is better to provide an outreach service or to provide a specialist clinic in a health centre.

Reynolds works from a clinic which specialises in Gypsy and Traveller health and health promotion. She argues that to provide a service such as a clinic that only provides outreach, is to treat Gypsies and Travellers as separate. That it is preferable to encourage the use of a clinic in a health centre, to allow Gypsies and Travellers to become accustomed to visiting mainstream services. Reynolds continues by saying:

*"The families are encouraged to expect a positive response from mainstream health providers – something that they can take away and use when they go to an area with no special clinic service".*

From this statement, it sounds as though Reynolds believes that the problem of Gypsies' and Travellers' lack of engagement with mainstream services may, in part, be due to an 'unrealistic' fear that they will not be welcomed, and that with this positive experience, they will be equipped to engage with mainstream services. However, there is no mention of the discrimination that has been reported in the literature concerning Gypsies and Travellers attempting to access mainstream services.

Reynolds then goes on to describe how the Partnership Project, in which the clinic is a part, also includes outreach work by health professionals to permanent sites in the area and to new Gypsies and Travellers to the area. How the outreach workers from the project encourage use of the clinic and provide transport where needed. It appears that there may be a case for both clinics in health centres and outreach services. However, without some form of systematic evaluation of such services, it is difficult to discern which elements of the service are of most use to those Gypsies and Travellers who make use of them.

The present thesis seeks to address the question of appropriateness of services to Gypsies and Travellers by providing an in-depth evaluation of an outreach service which provides a drop in clinic and health promotion service. The evaluation provides both the insiders (service users) and outsiders (service providers) perspectives and an analysis of their interaction.

# Chapter 2

## Background: the 'Coronary Heart Disease in Gypsies & Travellers: Redressing the Balance' project and its evaluation

## 2.1 The 'Coronary Heart Disease in Gypsies & Travellers: redressing the balance' project

### 2.1.1 The Inequalities in Health Fund

The 'coronary heart disease: redressing the balance' project was funded by the Welsh Assembly Government's Inequalities in Health Fund. The fund was established to stimulate and support new local action to address inequalities in health and their contributing factors. The fund has supported 67 projects across Wales.

The aim of the Inequality in Health Fund projects is to contribute to the implementation of the National Assembly's National Service Framework entitled 'Tackling CHD in Wales: Implementing Through Evidence' 2001. This Plan seeks to:

- *Empower patients to take responsibility;*
- *Enable health professionals to provide high quality services, which have the capacity to develop and keep pace with new evidence;*
- *Ensure health authorities, local health alliances, local health groups and NHS trusts deliver in partnership;*
- *Decrease the number of people at risk of developing coronary heart disease and improve outcomes for people with the disease.*

In recent years, inequalities in health have been recognised as a priority area for policy in Wales. Several recent documents have impacted on the current policy. 'Better Health Better Wales' (1998) provided a framework for national and local action. One of the key objectives is 'bringing the level of those with the poorest health up to the level of those with the best health'. 'Better Wales /Plan for Wales 2001' was the National Assembly's first strategic plan setting out three main themes: sustainable development, tackling social disadvantage, and providing equal opportunities. It set out a commitment to increase awareness of all languages and cultural issues in service delivery, to reduce inequalities in health and to increase life expectancy especially in the most deprived communities.

'Health in Wales', the Chief Medical Officer's report 2001/2002, although acknowledging the moves made to date to redress inequalities in health, also suggests that much more needs to be done. The Welsh Assembly Government's Inequality in Health fund is attempting to contribute to addressing these inequalities. The project 'Coronary Heart Disease and Gypsies and Travellers: Redressing the balance' is one of the 67 projects funded by the Inequality in Health Fund and is the subject of this evaluation.

## 2.1.2 Development of the project

The development and bid for funding for the 'Coronary Heart Disease and Gypsies and Travellers: Redressing the Balance project was a result of a health needs assessment carried out by two Health Visitors in both Wrexham and Flintshire (Roberts 2001). This assessment highlighted the poor health suffered by the Gypsies and Travellers living in the area.

One of the Health Visitors who conducted the health needs assessment, was also a member of a Multi-Agency Traveller's Forum (MAF) in Wrexham, which was attempting to address the health and social issues of Gypsies and Travellers in the local area. MAF, at the time, consisted of workers from various agencies who had a working relationship with Gypsies and Travellers in the area. This group included representation from Social Services, Health (North East Wales Trust), Education (Traveller education), Housing (Wrexham Borough Council), Women's Aid, Sure Start Initiative, Youth Offending Team, Police (domestic abuse) and University of Wales College of Medicine (now Cardiff University).

MAF were informed of the call for bids from the inequality in health fund by the Health Visitor who had developed the initial design of the community health initiative. The Health Visitor was assisted in developing the project bid by a Professor in the department of General Practice at the University of Wales, College of Medicine (now Cardiff University), who is also a GP with a keen interest in Gypsy and Traveller welfare. The project was designed to meet the perceived health needs of the Gypsies and Travellers in the area but also, to fulfil the focus

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set by the Inequality in Health Fund. That focus was to address the inequalities in health found in Wales in the form of the high incidence of coronary heart disease.

MAF supported the successful bid for funding of this project, and were named as the lead organisation on the project agreement, however, they were unable to be fund holders as they were not an agency as such, and did not have the infrastructure to support holding funds and employing staff. As the project was seen as primarily a 'health' project and Principal Investigator of the project was a Health Visitor, the then Local Area Health Authority (later to become the Local Health Board) was designated as the fund holder of the project (see figure 2.1 below). A detailed description of MAF and its involvement in the project over time can be found in Chapter 5, sections 5.2.3 and 5.3.6.

**Funding relationships within the project**

Welsh Assembly Government
(funding body)

Local Health Board
(fund holders)

Community Health Initiative
(service provision)

Cardiff University
(research & evaluation)
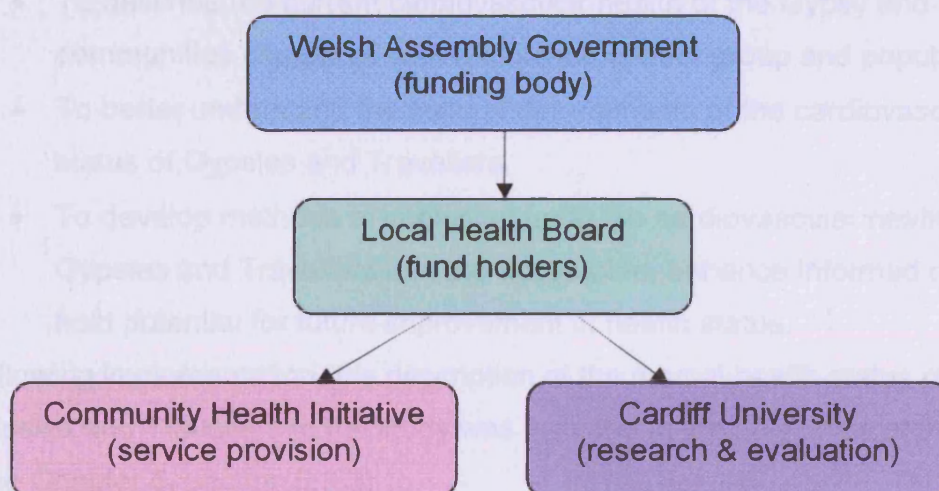
*Figure 2.1*

The Coronary Heart Disease and Gypsies and Travellers: Redressing the balance project was given funding initially for three years. The initial funding period was between April 2002 and April 2005 (later extended to September 2005). This became known as 'phase one' as further extended funding periods became available, first, with an 18 months extension and then a further 12 months, bringing the current funding period to April 2008.

The Coronary Heart Disease and Gypsies and Travellers: redressing the balance project consists of two main elements, a service element (the community health initiative) and a research element (the evaluation). In the latter case, a full-time researcher provided a study of Gypsies' and Travellers' culture, lifestyle, health beliefs, and experiences of healthcare, as well as a study of the cardiovascular and mental health status of Gypsies and Travellers. Both of these studies contributed to the overall evaluation of the community health initiative. A full description of the evaluation studies can be found in Chapter 3, sections 3.3 & 3.4.

### 2.1.3 Aims and objectives of the project

The main aim of this Inequality in Health Funded project was to improve access to health care services, specifically to coronary heart disease services for the Gypsy and Traveller communities. The objectives were as follows:

- To describe the current cardiovascular health of the Gypsy and Traveller communities compared with a matched control group and population norms.
- To better understand the cultural determinants of the cardiovascular health status of Gypsies and Travellers.
- To develop methods of impacting upon the cardiovascular health status of Gypsies and Travellers that are acceptable, enhance informed choice, and hold potential for future improvement in health status.

Following implementation, the description of the mental health status of the Gypsies and Travellers in the study was included in the objectives of the project (see Chapter 5, section 5.3.3).

### 2.1.4 Details of the community based initiative

One of the main aims of this Inequality in Health Fund project was to increase access to appropriate health care services to the Gypsy and Traveller populations by providing an outreach service, which consisted of a full-time Project Health Worker and a mobile health unit.

A specially adapted mobile health unit 'health bus' was driven onto a Gypsy and Traveller's site near Wrexham on a regular basis of three times per week. The

Project Health Worker also visited housed Gypsies and Travellers and those on private land either with the 'health bus' or by car (depending on appropriateness and access). The Project Health Worker worked in the field of prevention and health promotion, also provided a triage facility, worked as an advocate for this community, and collected coronary and mental health data for the project.

## 2.2 Description of the evaluation

Evaluation is a key feature of this project. Of the 67 projects supported by the Inequality in Health Fund, this is the only project to have evaluation built into the main design. Evaluations are conducted primarily to provide decision-makers with informed options for enhancing service delivery (Wholey 1994). The evaluation study of the community health initiative was intended for two main audiences, the Welsh Assembly Government's Inequality in Health Fund and also, potential supporters of the service at local level, post project funding. Although there was a system of reporting progress to the Inequality in Health Fund, both in quarterly reports and annual reports, this did not enable the in-depth knowledge that the evaluation study provided. By providing a rich description of the service, its strengths and weaknesses, a template is provided of a proven service to be rolled out on a national level. It also provides the evidence that would be required to inform the decision at local level whether to adopt the service into mainstream health services.

This evaluation contains both qualitative and quantitative studies designed to provide results that give triangulating information. The scale of this evaluation and the nature of the project and its service users meant that a randomised controlled trial was not an appropriate method of evaluation in this instance. However, the evidence that was available from the evaluation studies may be strengthened by similar findings from companion studies using different methods.

The two main studies were qualitative explorations of both Gypsy/Travellers' culture, lifestyle and health beliefs and an in depth study of the Inequality in health fund community health initiative. An ethnographic approach was used, including

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the use of participant observations over a 2½ year period and a series of interviews with both Gypsies and Travellers and service providers.

Secondly, as part of the evaluation of the initiative and to provide complementary information, a detailed quantitative assessment of the coronary health status and mental health status of Gypsy/Travellers in and around Wrexham was undertaken. This data was compared to general population data for Wales, England and the UK where applicable.

The coronary and mental health status study provides insight into the challenges and focus of the community health initiative. Whereas, the study of Gypsy/Travellers' culture, lifestyle, health beliefs and health care experiences provides insight into why Gypsies and Travellers adopt the health behaviours they do and also how cultural influences and past experiences have affected how, and to what extent the community health initiative works.

### 2.2.1 Culture, lifestyle, health beliefs and experiences of health care study

This study was an in-depth qualitative study using participant observation and in-depth semi-structured interviews (both described in full in chapter 3, sections 3.3.1 and 3.3.2) with Gypsies and Travellers to explore their culture, lifestyle, experiences of healthcare and health beliefs. The study provides a knowledge base of those aspects of Gypsy and Traveller culture, lifestyle, experiences and beliefs that impact on Gypsy and Traveller health and well being and also impact on how they engage with mainstream services and the new community initiative. It is hoped that the results of this study may also be used as a resource to inform health professionals, providing them with an increased depth of understanding of Gypsies' and Travellers' culture in relation to health care provision.

### 2.2.2 Study of Coronary Heart Disease and Mental Health status

A quantitative detailed assessment of the coronary heart disease (CHD) health status and mental health status of this community has been carried out, comparing

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Gypsies' and Travellers' CHD risk factors, lifestyle and health status to that of the general population. As this community's health status has been subjected to little research to date, this descriptive study was necessary to identify the health needs of this community. This information has been used to inform the initiative and is an integral part of the evaluation. It feeds into the overall evaluation of the initiative alongside the cultural findings providing an insight into the levels of morbidity and high health risk behaviours engaged in by Gypsies and Travellers.

## 2.2.3 Process evaluation of the community initiative

A qualitative study of the process of the community initiative was undertaken, using both participant observation and in-depth semi-structured interviews with both the Gypsy and Traveller communities involved with the initiative and professionals who were connected to the initiative, either as service providers or as those who had contact with the initiative in their professional roles. This enabled the exploration of the perspectives of both the service providers and service users. Descriptions of participants are provided, and the process involved in the initiative, outcomes and the continuation of the initiative are explored in depth, providing both service users' and providers' perspectives.

The results of these three studies is brought together, where their combination and interaction has provided an overall understanding of the initiative and enabled an overall evaluation of the initiative.

## 2.3 Unique contribution

There have been no in-depth quantitative studies describing Gypsies and Travellers' coronary and mental health status in Wales to date. There has also been no intervention in Wales, which has attempted to increase access to health care services by providing a dedicated Health Worker and taking a mobile unit onto a Gypsy/Traveller site. This has been a unique opportunity to evaluate a multi-disciplinary project that attempts to assess, understand, and potentially improve Gypsies' and Travellers' health status, in particular coronary and mental health status.

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Furthermore, very few in-depth studies have been carried out that focus on the culture, lifestyle, health beliefs and experiences of healthcare of Gypsies and Travellers. This study provides a deeper understanding of the cultural determinants of health of this group and provides an exploration of how these factors impact on their engagement with health care services in general and the community health initiative in particular. It is important to bring cultural differences to the attention of the medical profession to increase understanding and therefore tolerance of this disadvantaged and hard to reach group of people.

## 2.4 Research questions

There are two main objectives of this PhD study. The first is to evaluate a community initiative designed to improve the quality of health care of Gypsies and Travellers Wrexham. The second is to understand the cultural determinants of the health status of this group by gaining insight into their culture, lifestyle and health beliefs. Whilst the community initiative to improve the quality of health care is posited on and driven by an outsider understanding of the community and its health needs, the second is posited on achieving, through an ethnographic approach, an insider, i.e. Gypsy/Traveller, perception of health, illness and health care (see Chapter 3 section 3.1 for a discussion of insider/outsider perspectives in research). These two objectives will be brought together in a third, which is their combination and interaction out of which an overall understanding or synthesis is achieved. Insight and motivation, through this approach, is revealed and the comprehension, which enables a judgement of the initiative to be made, will be obtained.

From the objectives described, the following research questions are posited in this thesis:

**Primary research questions:**

- Does placing a mobile health unit on a Gypsy/Traveller's site increase appropriateness, accessibility and patient centredness of UK style health care services?
- How are the culture, health beliefs, lifestyle and experiences of health care of the Gypsy and Traveller communities relevant to this initiative?

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**Secondary research questions:**

- How does having access to a health worker and therefore health promotion impact on Gypsies' and Travellers' general views of health and coronary heart disease in particular?

- How does this three-year community project impact on both the Gypsies and Travellers and the other key players' views of each other?

- What lessons are to be learnt from multidisciplinary initiatives, what are their strengths and weaknesses?

- What is the detailed coronary health status, and determinants of coronary risk of Gypsies and Travellers in Wrexham?

- What is the mental health status of the Gypsies and Travellers in Wrexham?

# Chapter 3

# Methods Used in the Evaluation
## of the Community Initiative

## 3.1 Methodology

The methodological framework and approaches that underpin this evaluation study are described here, including the current debates concerned with qualitative research. This is followed by a description of the methods used in the studies presented in this thesis that together constitute the overall evaluation of the community health initiative.

Evaluations in the NHS are conducted primarily to provide decision-makers with informed options for enhancing service delivery (Wholey 1994). To this end, a pragmatic approach to design was adopted by asking the question, what methods would best answer the research questions and provide the type of information that would be of use to the project funders and policy makers? As Patton (2005) suggests:

> "The reigning methodological standard has become the appropriateness of the methods for a specific evaluation purpose and question, not adherence to some absolute orthodoxy that one or other approach is inherently preferred. The evaluation field has come to recognize that, where possible, using multiple methods – both quantitative and qualitative - can be valuable since each has strengths and one approach can often overcome deficiencies of the other."

It became apparent that some of my research questions would be better answered by the use of quantitative methods, such as, what is the coronary and mental health status of Gypsies and Travellers in Wrexham? Other research questions however, were better suited to a qualitative approach, for example, questions concerning the appropriateness and patient centredness of the community health initiative, how culture, lifestyle and health beliefs are relevant to the health initiative, how access to a dedicated health worker impacts on Gypsies' and Travellers' views of health, how the health initiative impacts on how service providers and Gypsies and Travellers view each other and what are the strengths and weaknesses of multi-agency working in this setting? Murphy (1998), in a review of qualitative research methods, suggests that qualitative methods are thought to be useful where the research question is concerned with processes rather than outcomes, for questions of 'How does this come about?' rather than 'How many?' or 'How much?'

In order to answer the research questions above, and design an evaluation that was culturally appropriate, a multi-method approach was adopted, with a main focus on qualitative methods. As Patton (1987) argues:

> "There are no rigid rules that can be provided for making data collection and methods decisions in evaluation. The art of evaluation involves creating a design and gathering information that is appropriate for a specific situation and policymaking context"

What however, is meant by the term qualitative research? It is often described by what it is not. It is an approach that does not use quantifiable data and statistical analysis. Strauss (1998 p.11) suggests that qualitative research mainly involves interpretive analysis of *"persons' lives, lived experiences, behaviours, emotions, and feelings as well as about organizational functioning, social movements, cultural phenomena, and interactions between nations"*. This form of research however is not without controversy; I explore some of these current themes below.

### 3.1.1 Controversies in qualitative research

The methods used in qualitative research have been, and remain the subject of controversy. They have been contested by researchers from the natural sciences, but also have attracted criticism from within the social sciences themselves.

Traditionally, Western science has been dominated by a 'positivist' stance and the use of classic deductive reasoning to obtain universal 'truths'. In medicine, as practiced in the UK today, this has resulted in the dominance of the biomedical model of illness which underpins the views of health professionals and lay people alike. From this stance, disease is viewed as independent from the person and their cultural context. It can be categorised like any other phenomenon and has a pathogenic causal agent. Mental and physical diseases are viewed as separate entities, with the exception of psychosomatic illnesses. The physician is a detached observer, whose job it is to diagnose disease and prescribe remedies, where as the patient is viewed as a passive recipient (McWhinney 1989).

However, this traditional view of science and medicine often does not fit well with qualitative methods, which use inductive reasoning and are orientated towards exploration. That is to say, they attempt to make sense of a situation while attempting to eliminate any pre-existing expectations (Patton 1987), whereas quantitative research is concerned with hypothesis testing. Qualitative research has its philosophical and methodological roots in phenomenology, symbolic interactionism and naturalistic behaviourism, ethnomethodology and ecological psychology, and holds the premise that studying humans is fundamentally different from research in the natural sciences (Patton 1987).

Often, qualitative research is criticised as being non-scientific and merely anecdotal in nature, raising the question of quality in qualitative research. Several qualitative researchers have sought to answer these criticisms by suggesting criteria through which the quality of qualitative research is determined (Silverman 2001; Giacomini 2000; Mays 2000; Poses 2000; Miller 1997; Mays 1995; Hammersley 1990). Mays and Pope (2000) argue from a 'subtle realism' perspective. They suggest that all research involves subjective perception and that different methods produce different perspectives, however, there is an underlying reality which can be studied. They suggest that the quality of qualitative research can be measured by means of addressing issues of validity and relevance and outline methods to ensure validity such as triangulation, respondent validation, clear exposition of methods, reflexivity, attention to negative cases and fair dealing.

This 'subtle realism' approach however, is not shared by all qualitative researchers. For example, Rapport and colleagues (2004) question the adoption of bioscience's rigour and replicability in health care research and suggest that using the criteria outlined by Hammersley (1990) and Mays (1995) may limit the depth of inquiry and undermine the researcher's responsibility, diverting attention from the strength of the individual's view.

Rapport (2004) talks of qualitative research being at the *'interfacial rim'* between natural science and the arts & humanities and uses Shoard's metaphor of the 'edgelands', the no-go area between town and country, to describe qualitative research.

"A vaguely menacing frontier land hinting that here the
normal rules governing human behaviour cannot be
altogether relied upon."

(Shoard, in Rapport 2005)

From this perspective, qualitative methods in medical humanities should be
treated as 'additive' providing contrasting perspectives without either impinging
on the other. Rapport (2005) outlines three new methodologies described as
having interlocking strands; narrative based, arts based and redefined
methodology including interpretive anthropology. Rapport suggests these give
'added value' to health service research. This 'Edgeland' is said to provide a
space in which new approaches can develop. Rapport calls for integration
between human experience and bio-scientific treatments of disease in order to
reach an overall clarity of understanding.

Another author who describes himself as being at the fringes of medical
research and anthropology is the Psychiatrist and Anthropologist, Arthur
Kleinman (1990 & 1995). He uses metaphors such as working at the
'borderlands' or 'margins' to describe his work in medical anthropology.
Kleinman (1995), reviewing some of the more notable medical ethnographies of
the past two decades, including Byron Good (1994), Allan Young (1995) and
others, describes them as a 'new wave' of ethnographies. He goes on to
suggest that the success of these new ethnographies in the area of medical
anthropology means:

> "There is no single agenda that dominates the field; instead,
> there are multiple layers, plural subjects, different
> methodologies, distinctive visions. In each ethnography, the
> working through of anthropology's cultural program and
> current concerns in social analysis takes a special turn. What
> is shared among the books derives as much from the
> recalcitrance of medical subjects as from the project of cultural
> analysis."

Kleinsasser (2000) talks of the importance of the researcher's reflexivity in
qualitative research, citing Geertz's (1975) metaphor, "researchers as
instruments". Kleinsasser describes how qualitative research is distinguished by
the researcher's reflexivity and also acknowledging that data passes through

the many lenses of the researcher, theoretical, practical and experiential. And the researcher's multiple identities and roles.

However, the movement in the 21st century towards evidence-based medicine (EBM) in health care still reflects the traditional positivist biomedical bias. EBM is the use of evidence concerned with effectiveness of medical interventions to guide the decisions concerning what is to be used in medical practice (Gupta 2003), with a core belief that evidence is ranked hierarchically, giving most importance to systematic reviews followed by randomized control trials. Gupta also suggests that there is technical bias in EBM, by favouring research which is familiar and uses investigative methods generally approved by clinicians and natural scientists. This results in a 'systematic bias' that dictates what data is created (Gupta 2003). In a review of the appraisal guidelines for EBM, Eakin & Mykhalovskiy (2003) concluded that the EBM criteria checklists were not well suited to the character of qualitative research, limiting their capacity to relate to, and therefore ultimately assess the 'distinctive contribution' of qualitative research.

Upshur (2001) suggests that it is not EBM that is at fault but the definition we give to 'evidence' and puts forward an alternative model of evidence in health care. In this model, evidence is neither exclusively quantitative nor qualitative, but an interaction of the two. Therefore, there is no single method that applies to research questions and circumstances. In Upshur's model, the type of evidence thought appropriate is determined by considering whether one is looking for meaning or measurement and whether the context is individual or general. This results in four different concepts of evidence, 'qualitative/personal' 'qualitative/general' 'quantitative/general' and quantitative personal'. Upshur suggests that this model serves to integrate the epistemologies found in health care and legitimises that evidence gained by qualitative research, putting it on an equal footing with quantitative research.

These controversies between positivist biomedical models of health research and qualitative inductive models of health research, and between qualitative researchers who follow a 'subtle realist' or 'anti-realist' perspective are set to continue for the foreseeable future. My personal belief is that it comes down to

whether you accept that there is valid knowledge outside that which can be provided by the biomedical model. If knowledge of a person's experiences, beliefs and cultural context are believed to be valid knowledge and valuable in informing health care practices, then qualitative research is valuable and desirable to improve health care delivery.

As for the question of quality in qualitative research, as qualitative research in health sciences grows and becomes more accepted, questions of quality are a natural by-product. However, qualitative research is a broad church including researchers from diverse backgrounds with diverse methodologies. I believe there is room for all. As mentioned at the beginning of this chapter, programme evaluators tend to be pragmatic when it comes to methodology, preferring to use methods that best fit the questions being asked of the evaluation. My belief is that to use the best method to answer a given question is a fundamental of 'good science' that is not always used by either qualitative or quantitative research, when research is placed within a rigid narrow framework.

### 3.1.2 The holistic perspective

As the community initiative to be evaluated in this thesis was a new service with a minority ethnic group that had been little studied in terms of health status or the effectiveness of healthcare initiatives to date, and so was largely exploratory in nature, I have chosen to use a holistic perspective. A holistic perspective views the whole as greater than the sum of its parts (Patton, 1987). McWhinney (1989) provides a description of a holistic perspective in 'general systems theory'. How "all an individual's significant relationships" impact on their health. According to McWhinney, general systems theory believes nature to be a hierarchical series of dynamic systems, both living and nonliving which interact and impact on one another. Each system is both a whole and part of a greater whole (see figure 3.1). Each system is unique and has features that can only be described in terms of that system. An event that impacts on one system will reverberate through the other systems both up and down in turn. These dynamic systems require equilibrium and therefore if something happens to impact on a system, that system will react to adjust to the change to restore that equilibrium.

**Systems Hierarchy**

| |
|---|
| Universe - biosphere |
| ↕ |
| Society - nation |
| ↕ |
| Culture - subculture |
| ↕ |
| Community |
| ↕ |
| Family |
| ↕ |
| Two persons |
| ↕ |
| Person |
| ↕ |
| Nervous System |
| ↕ |
| Organs |
| ↕ |
| Cells |
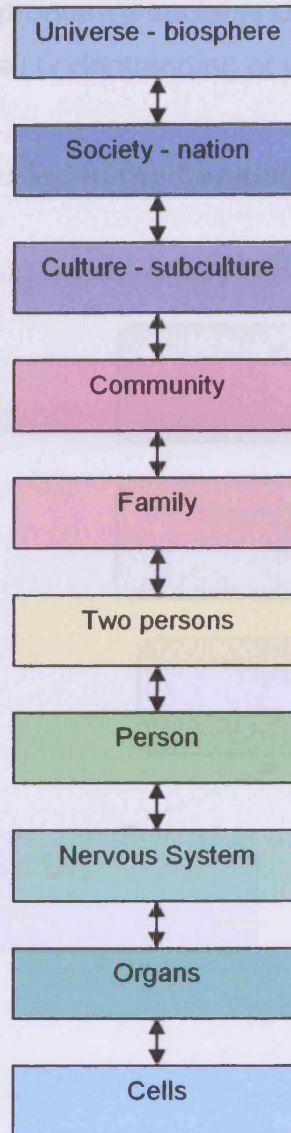
*Figure 3.1*

Understanding the project as a whole and therefore providing the decision-makers with the information required to make the decisions about the effectiveness of the initiative meant seeking to describe those people involved in the community initiative, on several systems levels. On a personal level; by exploring Gypsies' and Traveller's perceptions of their identity, on a familial and cultural level; by describing Gypsies' and Travellers' culture, lifestyle, and health beliefs, and on a societal level; by exploring how the dominant society views Gypsies and Travellers and how this impacts on their daily lives and the community health initiative. I also provide a description of the community health initiative, explore the processes involved in the community initiative, and explore its 'systems' including the interactions at the personal level and health service level (see figure 3.2 below). Patton (1987) also discusses the importance of

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describing and understanding both a program's social and political context and suggests this is essential for the overall understanding of programs.

**Systems Included in the Evaluation**

**Gypsies and Travellers**                          **Health Project**

Personal  ⇅  Personal

Family  ⇅  Community Health Initiative

Ethnic Group  ⇅  Health Service

Society
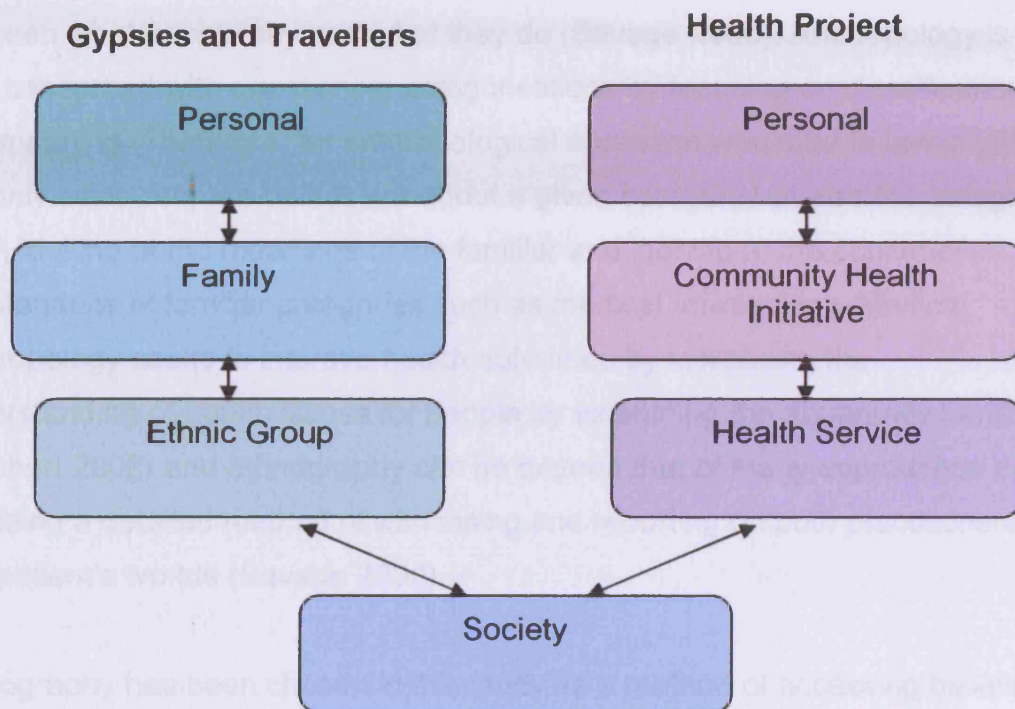
*Figure 3.2*

In order to provide the information needed to fully evaluate the community health initiative, and to provide the kind of in-depth knowledge that is required to look at a program and the context in which activities occur (Patton 1986), its participants' perspectives and its interfaces, an ethnographic method was used. In line with an ethnographic approach, a range of methods, both qualitative and quantitative have been used, in particular, participant observation, which is a defining feature of ethnographic enquiry (Savage 2000).

Ethnography has its roots in cultural/social anthropology. One conceptual feature of anthropology is that what is 'rational' is seen in its local context to be socially and culturally specific and valid (Lambert 2002). This means in practice, that biomedical concepts and practice are variable and therefore the knowledge and practice of lay-people and that of professionals are both valid for empirical

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inquiry. Another feature of anthropology is the acknowledgement that, what people say can differ from what they think and do. To this end, participant observations are particularly informative, bridging the gap between language and actions (Lambert 2002). Ethnography is said to be particularly useful in understanding the organisation of healthcare and allows for comparisons between what people say and what they do (Savage 2000). Anthropology is also concerned with questioning categorisations by focusing on classification and meaning. Therefore, an anthropological approach would be to investigate, not only what people's beliefs are about a given category but also the category itself, looking at the meanings of the familiar and looking at the construction and maintenance of familiar categories such as medical terminology. Medical anthropology seeks to improve health outcomes by increasing the understanding of health issues for people by examining the apparently familiar (Lambert 2002) and ethnography can go beyond that of many approaches by providing a detailed method of witnessing and reporting on both practitioners' and patient's worlds (Savage 2000).

Ethnography has been chosen in this study as a method of accessing beliefs and practices, viewing them in the context in which they occur and providing insight into how patients' cultural practices may impact on health interventions (Savage 2000). In program evaluation, ethnography provides the detailed description of the processes involved in the service in order to gain understanding of its strengths and weaknesses.

Others, such as Cook (2005) go further by advocating the use of 'critical ethnography' in health promotion research, where the primary aim and explicit goals are changing of existing social structures. Where traditional ethnography describes "what is", critical ethnography attempts to speak on the behalf of the often unheard oppressed by stating "what should be" by confronting the social structures and institutions on grounds of racism, sexism and classism. Ethnographic research in medical settings can provide *'the catalyst for reflection and opportunities to feedback to doctors and other healthcare professionals'* (Pope 2005).

When evaluating programmes directed at people from different cultural backgrounds misinterpretations of the ethnographic data can occur through differences in cross-cultural and socio-economic differences between the researcher, participants and other stakeholders. In order to improve sensitivity to cross-cultural differences, insider and outsider perspectives are explored in this study (Patton 2005). The aim was to be reflective of the beliefs and perspectives of both Gypsies and Travellers and those involved with the community health initiative, both at the personal level and cultural level. By adopting this approach, I was able to explore areas from the 'insiders' perspective of the participant, the perspectives of 'service providers' and 'service users' and also reflect on how my own presence impacted on the community health initiative and the study as a whole. Several studies have been reported by Sharon Merriam which explored the 'insider/outsider' issues in terms of "positionality, power and knowledge construction" and highlights the impact that the interviewees' beliefs about the researcher can have on what type of information is given to the researcher (Merriam 2000).

However, I am not a Gypsy or Traveller, but a middle-classed, researcher from a university and therefore, an 'outsider' to this community. How people conducted themselves and what they chose to disclose to me will have been moderated because of this. Also, as a female, my perceptions are influenced by my gender as are the experiences I had during this study, such as who I interacted with and how people interacted with me. All these things have an impact on the data collected and how it is perceived.

Brayboy and Deyhle (2000), exploring the effects of being 'insiders' in ethnographic work by being native Americans studying native Americans, discuss the impact of studies that present the insiders' perspective. They suggest that although it may be impossible to become a complete insider into a community, the researcher can be positioned as 'broker' bringing the 'insiders' voices to the 'outsiders'.

By adopting the 'insiders/outsiders' approach within a General Systems Framework, the perspectives of all the key players within the study were

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described, a voice was provided for Gypsies and Travellers in Wrexham, and the community initiative judged within a cultural and environmental context.

### 3.1.3 Qualitative evaluation of process

Programmes are dynamic and changing in nature and it is important to describe and understand these dynamic processes and their holistic effects on participants, which provides information for program improvement. Ethnographic qualitative methods are well suited to the challenges of capturing not only anticipated but unanticipated outcomes and consequences in the larger context of program implementation and development (Patton, 1987).

A 'process evaluation' was undertaken in order to better understand the community initiative, by seeking to describe the internal dynamics of programme operations and provide a detailed description of program operators. Questions that were typically addressed by a process evaluation included:

- What makes a programme what it is?
- What are its strengths and weaknesses?
- How do clients move through the programme?
- What is the nature of the staff/client relationship?

'Process' in evaluation focuses on 'how' an outcome is produced, that is to say, it is an analysis of processes that enable a program to produce its results rather than the result itself (Patton, 1997).

## 3.2 Ethical Approval

Approval was obtained from the North Wales Health Authority Research Ethics Committee for the evaluation study of the community initiative, the study of Gypsies' and Travellers' culture, lifestyle and health beliefs and the study of the coronary health status and mental health status of Gypsies and Travellers in the Wrexham area. Participant information sheets and consent forms were drawn up and used in accordance with the ethics committee's recommendations (see appendices 1 & 2).

## 3.3 Qualitative methods for culture, lifestyle and health beliefs, and process evaluation studies

### 3.3.1 Participant Observations

Participant observations were the main method used to inform both the study of Gypsy and Traveller culture, lifestyle, experience of health care and health beliefs and to inform the process evaluation of the initiative.

'Observational methods' in social research differ from the non- experimental observational studies made by epidemiologists or the clinical observations of patients. The observational methods used by social scientists involve the systematic, detailed observation of behaviour and talk: watching and recording what people say and do (Mays & Pope, 1995a). Another noteworthy difference is that observations take place in natural settings not experimental ones. 'Participant observation', the method I have used for the qualitative studies in this evaluation, attempts to minimise the impact on the environment being studied, by becoming involved in the activities taking place while also observing. My participant observations involved not only shadowing the Project Health Worker in the 'health bus' and her visits to houses, but also by being part of the service by driving the 'health bus', making tea, being 'door minder', helping Gypsies and Travellers with form filling in and assisting with health promotion events. I also 'participated' as part of the Multi-agency Traveller Forum by attending meetings, helping with 'events' and taking the minutes for the group's meetings.

'Participant observations' are particularly appropriate with Gypsies and Travellers as it has been suggested that other methods such as formal interviews have been unsuitable and unproductive in past studies (Okely, 1983). Okely, having lived with Gypsies and Travellers, describes the negative reaction she experienced while trying to ask questions, even of those who were closest to her:

> "I found the very act of questioning elicited either an
> evasive or incorrect answer or a glazed look. It was more
> informative to merge into the surroundings than alter them
> as inquisitor."

### 3.3.1.1 Participants

The participants under observation were the 139 Gypsy and Traveller adults and their children who had contact with the initiative, the members of the Project Steering Group including project workers, and other agency members who had contact with the initiative over the time of the study, such as members of the Multi-agency Traveller Forum. Participants were provided with a participant information sheet and consent form. The information sheet was read to any Gypsies or Travellers who had difficulty in reading and they were given to the participants to take away with them (see Appendix 1).

### 3.3.1.2 Data Collection

Participant observations were carried out over a 2½ year period between January 2003 and July 2005. Observations were made of the day to day running of the initiative by shadowing the Project Health Worker. I was introduced as a researcher to Gypsies and Travellers by the Project Health Worker, and my role as researcher was explained. Observations were taken in the mobile health unit on the site, or when we visited Gypsies and Travellers in their houses or caravans on private land. I established a presence as described earlier, by adopting several roles including 'driver', 'tea maker' and 'door man'. I also attended the Multi-agency Traveller Forum meetings and the National Association of Health Visitors with Travellers Association meetings.

### 3.3.1.3 Analysis

Hand written field notes were kept on a daily basis, being written during the day, when time and privacy allowed, or immediately on return from a visit. Care was taken that no names were used in field notes that may identify those being observed.

The hand written field notes were transcribed. A thematic framework was developed from the content of the field notes through the use of NUD*ST 6, a computer software package designed to aid in the organisation and analysis of qualitative data. The field notes were independently coded by two researchers and comparisons were made to identify any variations in themes and to arrive at agreed themes and terminology.

The main themes that emerged from the field notes formed the main structure used to develop the interview topic guides, enabling further in-depth exploration of the themes with interview participants.

### 3.3.2 Qualitative interviews

In-depth semi-structured interviews were conducted with a purposive subset of Gypsies and Travellers who had contact with the initiative and had built up a trusting relationship (service users' perspective), Steering Group, and Multi-agency Traveller Forum members (service providers' perspective). The interviews were complementary to the participant observations by providing further detail of different perspectives of those engaged with the initiative. They provided a direct voice for both service users and providers.

The interviews with a sample of Gypsies and Travellers were conducted following the first year of the initiative. This was done to enable relationships and trust to develop between myself and the Gypsies and Travellers. Although Okely had described her difficulties with direct interviewing of Gypsies in her study, others have reported successfully interviewing Gypsies and Travellers (Feder 1994, Van Cleemput 2004). This may be because they both have health backgrounds, Feder had a background as a GP and Van Cleemput had a Health Visitor background. Gypsies and Travellers appear to open up more to health workers than other 'outsiders', provided you gain their trust and they feel that you are working for their welfare. The interviews were used to explore culture, lifestyle and health beliefs as well as to explore the service users' perspective of the initiative.

The interviews with service providers consisted of two series of interviews, baseline interviews in the first year of the initiative and follow-up interviews in the third year of the initiative to enable comparisons concerning people's expectations of the initiative and what they believed the initiative achieved at follow-up. Topic guides were developed to explore themes that had emerged from participant observations and were used to prompt memory rather than as a rigid script. (see appendix 3 & 4). Although I asked direct questions, the interviews were conducted in a conversational style with the interviewees often leading the conversation. However, Gypsies and Travellers were much happier

talking about their culture, lifestyle and experiences than talking about the community initiative, where their answers became brief. Their answers to those questions may have been guarded as they may have seen me as one of the service providers. They may also have said what they thought I wanted to hear in terms of the service in order not to disappoint me.

### 3.3.2.1 Recruitment and Participants

11 'service providers' were interviewed including members of the Project Steering Group, those members of the Multi-agency Traveller Forum who were engaged with the project during the data collection phase and two GPs who had the largest number of Gypsies and Travellers registered with their practice, (one of these being a Steering Group Member also). Follow up interviews were also conducted, where possible, on those who were still in post by the end of the data collection phase (see appendix 5). All service providers who were approached consented to be interviewed.

A subset of 13 of the Gypsies and Travellers who engaged with the initiative were interviewed (see appendix 6). This was a purposive sample designed to reflect the wide range of people involved in the initiative, covering a range of ages, gender, ethnic groups, abode and frequency of use of the service. The age of participants ranged from 16 years to 66 years. There were 10 females and 3 males. 8 lived on the Council run site, 1 on private land and 4 in houses. 10 described themselves as Irish Travellers and 3 as Gypsies.

20 people were approached and asked if they would mind being formally interviewed. Of that 20, 13 agreed and were interviewed, of the remaining 7 people, one refused, saying that they did not like interviews and the remaining 6, although agreeing in principle to be interviewed, became evasive when I tried to make arrangements. Often interview arrangements were cancelled and then made difficult to re-arrange. People were followed up three times then considered a refusal. Recruitment lasted for over several months. This difficulty in recruitment of Gypsy/Travellers to formal interviews was also experienced by Lehti and Mattison (2001) who also described difficulty in interviewing Gypsy women who, although agreeing to be interviewed, were extremely difficult to pin

down to a day or time and who were often prevented from attending due to unexpected local events.

Although a reasonable spread was achieved, the total number of Gypsies and Travellers who agreed to be formally interviewed and tape recorded fell short of that anticipated (see appendix 7). This may be due to the protective culture of the Gypsies and Travellers in general, that they are happy to talk informally on most subjects but less willing to commit their views to tape.

Those who were under-represented were Gypsies, people who lived on private land and males. There are fewer Gypsies than Irish Travellers and fewer people living on private land than on the council site and in houses in the Wrexham area. Also, there was less prolonged contact with males than females during the study, due partly to the men working during the day and partly cultural, as women are not allowed in the company of a man who is not her husband or brother without a chaperone. However, the number and spread was sufficient to provide rich in-depth information as a supplement to the participant observations.

### 3.3.2.2 Data Collection

The project researcher conducted all interviews. Where possible, practical and with participant's consent, all interviews were tape recorded for later transcription and analysis. Hand written notes of any interviews that were not tape-recorded either because of equipment failure or request were written immediately after an interview by the researcher. Interviews were arranged with the interviewees in advance and conducted in various settings to accommodate the interviewees and provide privacy. Interviews with service providers were conducted in private offices either at the service provider's office or a private office in the researcher's office building. Gypsies and Travellers were interviewed either in the 'health bus' or in their own homes.

### 3.3.2.3 Analysis

A thematic analysis of the interview data was conducted using a 'framework' method of analysis as described by Ritchie and Lewis (2003). This is a matrix based method developed to allow the scrutiny of the large volume of data

generated by qualitative methods and allows within and between case investigation. It is a method of synthesising and condensing verbatim transcripts and treats cases consistently and systematically (see figure 3.3).

**Stages of the Analysis Process**



Produced by and used with permission of NatCen National Centre for Social Research
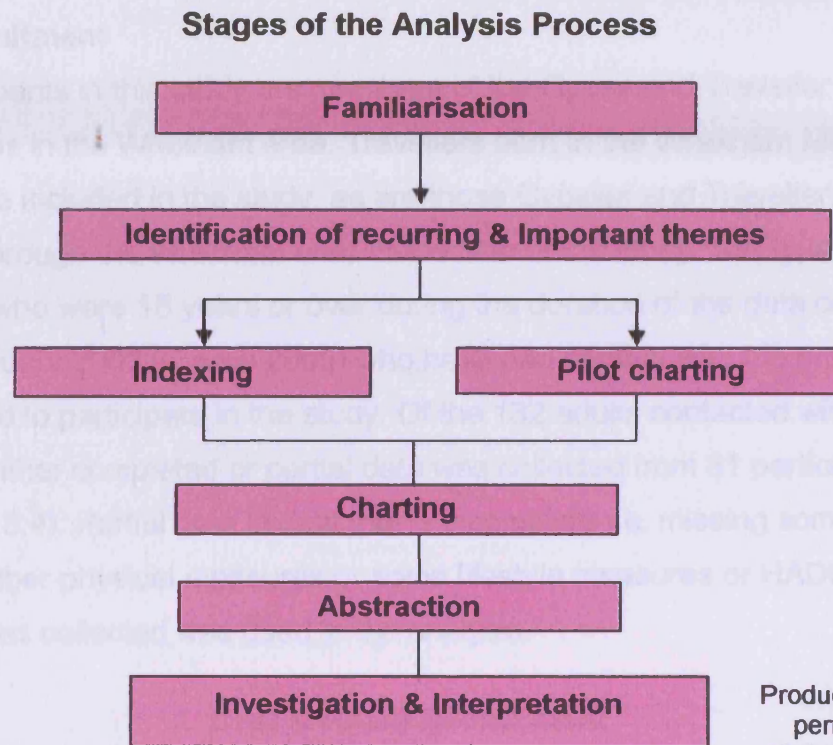
*Figure 3.3*

All interviews, either tape recorded or hand written were transcribed. A process of familiarisation was then undertaken which involved the reading and re-reading of the transcripts. All transcripts were coded in NUD*ST 6 and a thematic framework was developed identifying important themes. The transcripts were coded by two researchers and agreement reached on coding and main themes. Charts were then developed by the researcher in Excel where the data was condensed to allow for investigation between and within participants' narrative. This allowed for themes to be investigated and for the identification of key elements and deviations within each theme to be identified and explored. This method enables the tracing back through the analytic process to the original text which aided in the interpretation of the data.

### 3.3.3 Gathering historical and other supporting data

To complement these techniques, historical written information on the development of the project was gathered, for example, minutes of the Multidisciplinary Traveller's Forum Meetings and news paper reports.

## 3.4 Quantitative method for CHD and mental health status study

### 3.4.1 Recruitment

The participants in this study are members of the Gypsy and Traveller communities in the Wrexham area. Travellers born in the Wrexham Maelor Hospital are included in the study, as are those Gypsies and Travellers living or travelling through the Wrexham area at the time of the study. All Gypsies and Travellers who were 16 years or over during the duration of the data collection phase (January 2003 to June 2005) who have had contact with the project have been invited to participate in the study. Of the 132 adults contacted with details obtained, either completed or partial data was collected from 81 participants (see figure 3.4). Partial data is data that is incomplete i.e. missing some aspects, either physical measures or some lifestyle measures or HADS. The data that was collected was used in the analysis.

**CHD & HADS Recruitment**
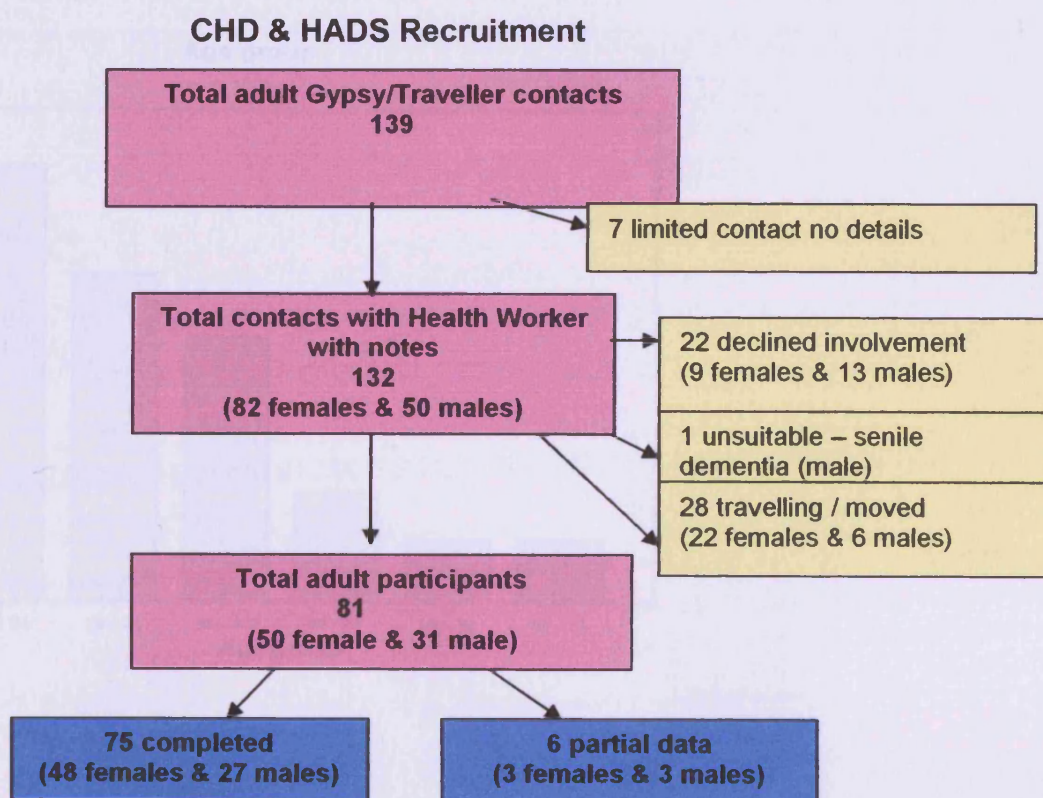


Figure 3.4

### 3.4.2 Participants

CHD and mental health data was collected from 81 participants in total (50 female, 31 male). The age of participants ranged between 16 and 70 (mean 32.9 median 31.9), see Appendix 8.

The age distribution of the sample is negatively skewed. This reflects the Gypsy and Traveller population in general. The family size of Gypsies and Travellers is large, between 7 – 10 children is considered an average family compared to the average UK family of 1.95 (Pearce 1999), resulting in a higher rate of younger members of this population (See figure 3.5). Also, a recent census of Gypsies and Travellers in Leeds has found a lower rate of Gypsies and Travellers in the 60+ age group than the general population (2.3% compared to 19.95%, Baker 2005) this is also reflected in this sample. Therefore, age has been adjusted for, wherever possible, when comparing data with general population norms. In phase 2 of this study, a control group of non-Gypsy/Travellers will be matched for both age and gender.

## Age group distribution
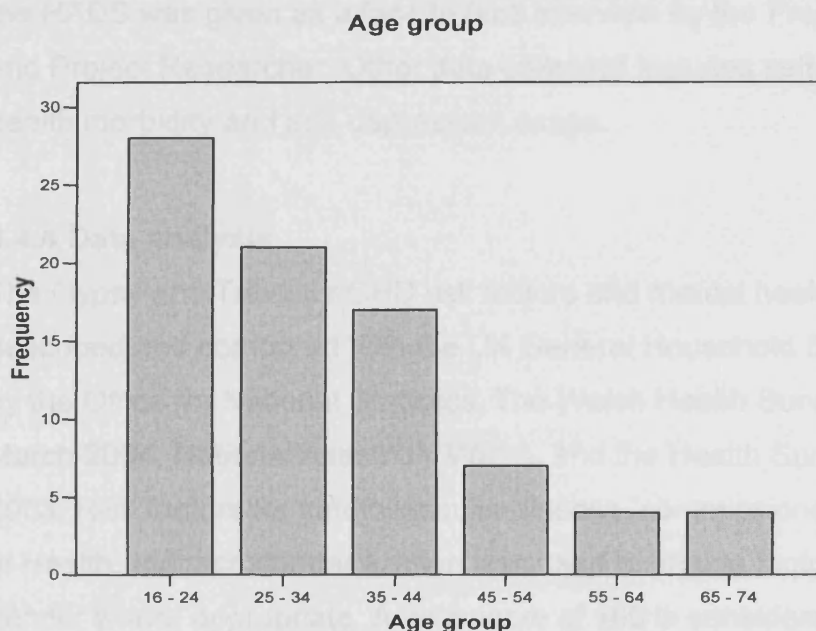


Figure 3.5

### 3.4.3 Data Collection

*Coronary Health Status data collection:*

All data was collected by face to face interview by the Project Health Worker and Project Researcher either in the mobile health unit or in their own homes. Data collected for heart disease risk includes: lifestyle measures (smoking status and history, alcohol consumption, diet and exercise), anthropometric measures (weight, height and BMI), blood analyses (HDL & total cholesterol), blood pressure, and cardiovascular and diabetes morbidity. Details of any existing cardiovascular health problems and medications were recorded (see appendix 9).

*Mental Health Status data collection:*

The HADS (Hospital Anxiety and Depression Scale) (Zigmond & Snaith 1983) was used to measure mental health in this study. This measure was developed to identify both anxiety and depression and has been validated for use in the community (Bjelland 2002, Mykletun 2001). It is felt that the HADS is particularly suitable for this community as it is relatively short (only 14 items) and the language is simple and concise (see appendix 10). Although developed as a self-report tool, due to the prevalence of poor literacy skills in this population, the HADS was given as a face to face interview by the Project Health Worker and Project Researcher. Other data collected includes self-reported mental health morbidity and anti-depressant usage.

### 3.4.4 Data analysis

The Gypsy and Traveller CHD risk factors and mental health have been described and compared with the UK General Household Survey 2003 provided by the Office for National Statistics, The Welsh Health Survey October 2003 – March 2004, National Assembly Wales, and the Health Survey for England 2003: Risk factors for cardiovascular disease, commissioned by the Department of Health. Indirect standardization was used to enable factoring for age and gender where appropriate. A ratio score of 100 is considered comparable whereas, scores above this score relate to higher levels and scores below relate to lower levels than the comparison population. Comparisons were made with socio-economic category (NS-SEC3) Routine & Manual where comparable data exists (see appendix 11).

# Chapter 4

# Results - Gypsies and Travellers: the insiders' perspective

## 4.1 Introduction

The results presented in this chapter form part of a multi-method evaluation of a community initiative that seeks to improve appropriate access to health care for the Gypsy and Traveller communities in and around Wrexham. It provides the 'background' knowledge of Gypsy and Traveller lifestyle, culture and personal experiences that have influenced how the service was provided in the past, giving the impetus for the current community initiative, and hopefully will shape the providers' response to the future healthcare needs of Gypsies and Travellers.

In this chapter the key themes identified during data collection and analysis are considered within the framework of general systems theory (McWhinney 1989), this is illustrated in figure 4.1 below; exploring Gypsies' and Travellers' culture, lifestyle and experiences through the different 'systems' which they inhabit (as outlined above in Chapter 3 section 3.1.2)..

Finally, Gypsies' and Travellers' health beliefs and experiences of healthcare are explored. These are considered in relation to the cultural constraints and expectations of Gypsies and Travellers, and also in the context of how they perceive and are perceived by the wider society.

**Gypsies and Travellers Study:**
**Systems Hierarchy and Topic Themes**

| Box | Topics |
|---|---|
| Society - nation | • Outsider/Insider homeostasis<br>• Stereotypes |
| Culture - subculture | • Travelling lifestyle<br>• Traveller education<br>• Religion<br>• Expectations & punishment |
| Community | • Experiences of health care<br>• Experiences of discrimination |
| Family | • Family life<br>• Childrearing |
| Two persons | • Courtship<br>• Marriage<br>• Gender roles |
| Person | • Cultural identity<br>• Individual vs. collective identity |

*Figure 4.1*

## 4.2 Gypsies and Travellers: a personal identity

### 4.2.1 How do Gypsies and Travellers define themselves?

Before exploring the question of how Gypsies and Travellers define themselves, it may be useful to look at what we mean by identity. Identity is defined in the Collins English Dictionary (2000) as:

> *1) The state of having unique identifying characteristics held by no other person or thing. 2) The individual characteristics by which a person or thing is identified.*

Friedman (1999) however, goes further by describing identity not only in terms of the characteristics which make us unique such as our fingerprints, face etc. but also talks of identity that goes beyond self; the sense of identity that comes from being part of a group. It is the membership of one or more groups that provide us with our framework in which to judge the world, what is good or bad, worthwhile or not.

> *"Identity, then is not just a sense of who we are – a definition; it is a lens through which to see the world".*
> *(Friedman 1999)*

Both Gypsies and Travellers hold a strong sense of cultural identity, one form of group identity; viewing themselves as separate from non-Gypsy/Traveller communities. This appears to be consistent through time, as a strong sense of cultural identity was also described by Okely during her anthropological study of Gypsies and Travellers in the mid seventies (Okely 1983). She suggests that 'ethnic boundaries' are deliberately created by Gypsies and Travellers to protect their identity against a hostile wider society that seeks to assimilate or destroy them. She goes on to suggest that a strict membership is an active method of protection for the group and is based on the principles of descent, self employment, shared values, nomadic lifestyle and pollution taboos. Nickson (1997) also believes that persecution is at the 'heart' of Gypsy identity and perhaps maintains it, and talks of the continued persecution of Gypsies throughout history to the present day. This identity based on persecution has implications for understanding the relationship between Gypsies and the wider community and the importance of *"understanding the ethnic and cultural context"* in delivering services.

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A recent study by Van Cleemput (2004) also confirms the findings of Okely and the findings of this present study, that Gypsy/Travellers "*perceive themselves as a distinct ethnic group with a strong sense of identity and of belonging to a Gypsy Traveller culture*".

This 'separateness' from the general settled population is evident from the terms used by Gypsies and Travellers in this study to describe non-Gypsy/Travellers, such as 'Gorgias', 'Local People' or 'Country Folk'. When I asked Gypsies and Travellers how they would describe themselves, many talked of their group membership either as Gypsies or Travellers, and often qualifying this in terms of their family origin or birthplace. The terms used to describe themselves included: 'Irish Traveller', 'English Traveller', 'English Gypsy' and 'proper Romany'. One person described himself in terms of both birthplace and origin,

> *"I was born in Wales so I'm a Welsh Irish Traveller."*
> *(Resp.6,male ,21yrs,Irish Traveller)*

Others however, describe themselves simply as Travellers.

> *"I'm a Traveller, just a Traveller."*
> *(Resp.1,male, 35yrs, Irish Traveller)*

### 4.2.1.1 Group membership

Membership of a Gypsy or Traveller community is not something one can decide to join simply through choice of lifestyle. As well as living a nomadic lifestyle and sharing a common culture, there are rules of descent. Okley (1983) suggested that the rules of descent fulfilled the function of providing continuity, restricting entry as a means of survival. A person must be born into the community, having traditional origins of at least one parent, it's '*in the blood*'. Also, you must learn traditional Gypsy or Traveller ways that are passed down from generation to generation.

> *"No, you gotta be born into it. You gotta know the skills, you gotta know the ropes, how to survive out in the open, like how to survive out in the open world. Something as you're born inta."*
> *(Resp.5, female, 37yrs, Irish Traveller)*

Endogamy is the norm however, a person can join the community through marriage, but will always be an outsider to some extent. A person who joins a Gypsy or Traveller community is known as a 'wanabee'. If a non-Gypsy/Traveller spouse is prepared to learn the Gypsy or Traveller ways, then they may be tolerated and even accepted into the community, but would not call themselves or be described as a Gypsy or Traveller. There are two examples of non-Gypsy/Traveller women marrying into Irish Traveller families in Wrexham, they do appear to be accepted. However, it can be a long and difficult process of learning to trust and gaining the trust of the community, and can take many years.

> "Well, yes, (regarding marrying into the community) but it would take a long time. You have to learn the Traveller ways and learn to trust and be trusted, cause Travellers don't trust people until they know them really well. It could take years."
>
> (Resp.7,female, 23yrs, Irish Traveller)

Children from a marriage between a 'Gorgia' and a Gypsy or Traveller are accepted as Gypsy/Travellers provided they have been brought up with Gypsy or Traveller customs, skills and values.

Gypsies' and Travellers' differences from 'Gorgias' is also described in terms of different morals and customs. The up-bringing of Gypsies and Travellers is perceived as much stricter than 'Gorgias', in particular with girls. It is vital that unmarried Gypsy and Traveller girls are kept 'pure' (virgins), do not bring 'shame' on the family, whereas 'Gorgias' are described in terms of being promiscuous and dirty.

This was also found by Van Cleemput (2004) who described the differences in morals and customs of Gypsy/Travellers in terms of 'cultural codes of conduct' and provides the example of the 'absolute rules' of gender and sexual behaviour of Gypsy Travellers as being part of their identity.

> "Being a Gypsy to us is.. we just been brought up different, it's like we wasn't allowed to go to night-clubs, we wasn't allowed to have boyfriends, we

*didn't know what it was like to go out drinking and smoking cigarettes, d'ya know what I mean..."*

*(Resp.2, female, 22yrs, English Gypsy)*

Gypsies and Travellers in this study displayed strong links between belonging to their cultural group and their identity, however, they view themselves as belonging to different groups, as described below.

### 4.2.1.2 Gypsies and Travellers as heterogeneous groups

Often people from outside the Gypsy and Traveller communities believe them to be a homogenous group, and so, fail to make a distinction between Gypsies and Travellers. Although there is much that unites them in terms of a nomadic lifestyle and cultural similarities, they view themselves as different communities, with different origins and values. This can result in intolerance of each other. Even the terms 'Gypsy' and 'Traveller' can be viewed as insulting if used to describe a Gypsy or Traveller person incorrectly. Both groups have said that they are suspicious of each other, do not like each other and don't mix. Each group holds stereotypes regarding the other. Gypsies have been described by Irish Travellers as 'not travelling', 'being dirty' and not being strict enough with their children. On the other hand, Gypsies see Irish Travellers as heavy drinkers who cause trouble, with questionable upbringing of children and also being dirty. They both unite however, behind their dislike of being grouped together with 'New Age Travellers' who both groups judge as dirty and not sharing their culture. The term 'hippy' is sometimes used to describe the other group.

*"I'm a Gypsy, not a Traveller. That would be like an insult to me. Travellers are like hippies, not proper Gypsies, they just chose to travel, they don't share our ways, our culture... They (Gypsies and Travellers) don't mix, like oil and water don't mix. People see us as all the same, but we're not. We have our different ways, our different culture. Irish go out drinking and causing bother, then we all get painted with the same brush."*

*(Resp. 9, female, 50yrs, English Gypsy)*

*"Traveller, I don't like the word Gypsy. There's different types of Travellers, just like normal people, like country people, there's different types of those as well, there's different types of Travellers. There's clean Travellers and there's.. Gypsies is like what, they're like hippies, That, they're not*

*travelling people. They have like buses and things like that....Travelling
people and Gypsies is two completely different things, that's like an insult to
us, getting called Gypsy."*

*(Resp.8, female, 20yrs, Irish Traveller)*

Although there are strong feelings concerning membership of one group or the
other, these barriers can be crossed through marriage. There are four known
examples of this in the Wrexham communities and they appear to be accepted by
the families concerned. Although usually Gypsies and Irish Travellers will seek
separate places in which to settle, an extended family of Romany Gypsies is, at
present, staying on the council run site inhabited by Irish Travellers. This is
tolerated because there is a marriage link between one of the Gypsy women with
an Irish Traveller man whose family live on the site.

Interviewer. *"You married an English Traveller, are you accepted by
his family?"*

Respondent. *"Yes, it's ok cause we are all Travellers. We are all the
same really. We have the same ways."*

*(Resp.7, female, 23yrs, Irish Traveller)*

In summary, Gypsies and Travellers have a strong sense of cultural identity.
Membership is based on the principle of self-ascription which has several rules,
including the rule of descent and rules concerning group values and behaviour.
These basic principles of self-ascription and their governing rules are common to
both Gypsies and Travellers. However, they are not a homogenous group and view
themselves as separate groups, with different values and lifestyles. Although they
are different groups, there are points of overlap between the groups through
marriage links between Gypsies and Travellers. This is accepted, as both Gypsies
and Travellers recognise that their overarching lifestyles and values are more
similar than their differences.

### 4.2.2 A collective identity?

A person's sense of self, their identity, is influenced by group membership
(Friedman 1999). As mentioned earlier in this section, it can provide the 'lens'
through which we see the world. However, the extent to which we identify with a

given group, and the group's influence in defining us, varies. Several authors have suggested that Gypsies and Travellers differ from the wider society because they display a more collective form of decision making, in particular, when it comes to decisions concerning health care (Lehti 2001; Burger 1996; Sutherland 1992; Thomas 1985; Wetzel 1983; Mandell 1974). Mandell (1974) described Gypsies in the United States as having a 'collective culture' and illustrates this by describing an occasion where a Gypsy mother, in an emergency room, was told her child had pin worms and that the family would need to be treated. She produced a list with ninety seven names and weights. Lehti & Mattson (2001) have gone further by suggesting that Gypsies hold a 'collective view of health'. They observed that Gypsy women in a Swedish primary health care setting presented with similar symptoms and requested the same treatment. They suggested that the women's attitudes to health and illness were a 'group view'.

In the present study, group responsibility, decision making and punishment have all been observed in Gypsy and Travellers. One example of group responsibility was the care of an Irish Traveller woman's four children by the extended family on the council run Traveller site when she was sent to prison. The family underwent considerable financial hardship to collectively look after the children.

> It appears that 'B's extended family have been looking after 'A's children while she is in prison. Although she got 3 months for driving while banned, they believe that she will be out in approx 6 weeks. The benefits agency has stopped the money for the children and the family are finding it difficult to manage financially looking after four extra children. They felt it very important to keep the children together and to look after them. 'B' said the last thing they wanted was for the children to have to go into care. Shortly after, B's mother arrived and was going with her daughter to try to sort out the money.
>
> (observational field notes Feb. 2003)

One example of group decision making during this study was the group decision made concerning the care of an elderly relative who needed full-time care due to senile dementia. The family came to the decision to care for him at home and provided his wife with suitable accommodation to look after him. This was arranged

because the elder sons had taken the decision that their father should not be cared for in a care home. The wife had no choice but to comply with the decision of the men.

Friedman (1999) provides an explanation and description of how the structure of society influences identity. He describes two types of identity, the *vertical* and the *horizontal*. According to Friedman, vertical identity is strongly connected to the traditional *'ideal-typical'* family structure and community structure where there are clearly defined and pre-determined roles and lines of authority. Families have a hierarchical structure with the father often the ruler of the home. Roles in the family and community are determined by such factors as age, sex, birth order and position in the society.

In contrast, Friedman suggests that the modern society is much more horizontal in its identity and authority. The idea is that, in modern society, people have a greater freedom of choice to form relationships with a wide range of people of equal standing (either real or apparent), such as peers and like-minded people. Identity is more fluid and geared towards the individual's journey of self-discovery. People *choose* to be affiliated or identify with different groups and these affiliations can vary from short lived affiliations to life long ones and make up a small part of identity to an intense, all consuming flame.

If we look at Gypsies and Travellers in the context of vertical or horizontal identities, then Gypsies and Travellers could be described as possessing a vertical identity. They share all those characteristics of the traditional family and community. As will be explored further in this chapter, the family structure is hierarchical, and pre-ordained roles and lines of authority exist within the family and community. Therefore, there is less choice for affiliations outside of the group. To those researchers and health professionals who come into contact with Gypsies and Travellers, this way of being and identity that gives primacy to the group rather than the individual may be interpreted as a 'collective identity' because it is so different from what is seen as the norm in modern society.

## 4.2 The family life of Gypsies and Travellers

### 4.3.1 Importance of family life

In Gypsy and Traveller communities, the family is all important. The size of families is large compared to the general population with an average family today, having between 7 and 10 children. This is in contrast however to the previous generation where 15 to 20 children was commonplace. Families choose to live close to each other and if parted; will often have daily contact. One mature married woman in her late 30s gave an account of how she cannot bear to be parted from her mother for more than a couple of weeks. The extended family (parents, grandparents, children, siblings, cousins, nephews and nieces) works as the Gypsy and Traveller's social network as little socialising is done outside of the extended family.

There are also traditions attached to family life which must be observed. These include the attendance at weddings, funerals, as well as the previously mentioned sick bed of those who are seriously ill or dying and observing the anniversaries of weddings and funerals. This often requires the family members to travel long distances, sometimes at a moment's notice. As Nickson (1997) points out, *"A loss of mobility destroys the fabric of this life"*.

The extended family provides support to individuals in terms of social support, childcare and care for the elderly and infirm. There are strong expectations that 'you look after your own'. Large families, in later life, have an advantage to both, parents and offspring, noted by Okely (1983), providing assistance in old age for parents and adults benefiting from many siblings who provide potential allies.

Gypsies and Travellers have an open door attitude to their extended family. This operates on sites and in houses. It is seen clearly on the Traveller site in Wrexham where relatives will group in a caravan and will freely move from one caravan to another without knocking on doors. Parents tend to feed children that are present at meal times, regardless of whether they are their own children or nieces or

nephews. This collective living has its advantages in the form of support, but also disadvantages due to the lack of privacy. Everyone is concerned with your business and this was mentioned when Gypsy/Traveller women made use of the health bus (see chapter 5 section 5.3.5). Also, because Gypsies and Travellers rely so heavily on each other for support, the threat of being ostracised from the family group could be devastating. This results in people being very aware of conforming to the norms of the group and maintaining tradition. This goes some way to explaining why a wife who is suffering abuse from her husband will eventually return home and why a young single male of 21 years feels he cannot travel the world on his own, because of the threat of being ostracised from the community. One must conform to what is expected of you to survive.

### 4.3.2 Gender Roles

Women's and men's roles in Gypsy and Traveller society are clearly defined. There is a traditional ideal of the women as home makers and men as providers. A man is expected to go out to work and to keep his family. This 'ideal' was confirmed by the accounts of both men and women interviewed in this study, as well as other studies (Rustom 1990, Okely 1983). There is a clear division between women's and men's work, however, the traditional role of the man as bread winner has been eroded with the use of the benefit system by many women. This financial independence was noted by Gmelch (1985) who suggested that this has resulted in the beginnings of a power shift from men to women. However, Gmelch did note that it had been a short time since this financial independence of Irish Traveller women began and that these women still had little control over the activities of their husbands. Gmelch's study was conducted in the early seventies, it is interesting to note that Gypsy and Traveller women today, still appear to be struggling to gain their share of power in male/female relationships.

Unlike the generally held European stereotype of the sensual, enticing and sexually provocative Gypsy woman (Okely 1983), there is a clear expectation that Gypsy and Traveller girls will get married as virgins, and will adopt the same traditional role that their mothers fulfilled, as wives, mothers and homemakers. The myth of the sexually provocative Gypsy woman is reinforced to outsiders by the

dress code adopted generally by many Gypsy and Traveller girls and women. To many outsiders, Gypsy/Travellers appear to be the opposite of what they are, as they often wear short skirts, show cleavage and wear large quantities of both jewellery and makeup. The very opposite of this illusion of promiscuity is true. Gypsy/Traveller women actively reinforce at an early age, their groups' values, such as chastity and the traditional roles expected of them as females. Women are expected to cook, clean and look after children. This traditional role is seen by some as their 'duty', something that they have no choice in. Their future is set by their gender from birth.

There are strict cleanliness rules in Gypsy and Traveller culture. Cleanliness rules include not polluting the inside of caravans by using toilets, and not polluting washing bowels by using them incorrectly (different bowls for different jobs). These rules of cleanliness and purity have also been well noted (Lehti 2001, Edwards 1997, Okely 1983). Okely suggests that because Gypsies are under constant threat of assimilation by the wider society, these cleanliness and purity rules provide and reinforce an ethnic boundary between Gypsy/Travellers and Gorgios.

Cleaning is therefore a very important part of a woman's duties. Cleanliness is also associated with health. To keep the home clean is to keep the family safe and is taken very seriously. The inside of most Gypsy or Traveller's caravans or houses are usually kept spotless with a large amount of a girls' or woman's day being taken up with cleaning. One woman, for example, agreed to be interviewed so long as she could continue cleaning whilst being interviewed.

There are clear demarcations between what is considered women's work and men's work. Cooking, cleaning and housework are clearly women's work, it was suggested that the only time men would step in to help in the home was if their wife was ill or in hospital. Men wash the cars and vans but not the plot itself, this again is women's work. This division of work is reinforced at an early age by mothers; one saying that she would not expect her son to do any housework but would encourage her daughter. There is also peer pressure to conform to these divisions, if a man was caught cooking for example, he would be teased by the others for

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being a 'sissy'. Men also do not get involved with childcare, this is woman's work. If a man does have to look after his children, he will not change nappies, especially girl's nappies. There is a strong feeling that it is inappropriate for a man to change a baby girl's nappy, even by her father. This would be left to another female relative to do.

> Respondent. *"No. I wouldn't let a man change a baby girl's nappy."*
>
> Interviewer. *"Even the father?"*
>
> Respondent. *"No, it wouldn't be right, I just wouldn't like it."*
> *(Resp.4,female, 42yrs, Irish Traveller)*

Men as providers, are expected to work in the traditional self employed work that is taught to them at a young age, this includes a variety of jobs from laying tarmac, paving, roofing, scrap metal to gardening and tree felling. Diversity and adaptability is especially important. Traditionally, women have earned money through fortune telling and hawking (sale of specialist Gypsy goods), but this is seen more as a pastime these days rather than a genuine contribution to the family finance.

> *"My mam goes around the houses selling lucky charms, but she doesn't get much money from that. She does it to get out. I think the man should be the provider."*
> *(Resp.6, male, 21yrs, Irish Traveller)*

There appears to be a split in opinion concerning women gaining employment outside of the home. Some said that they were free to work if they wished to, but that they did not choose to because they had no need, they were provided for. Others, in particular the men, did not like the idea of their wives working outside the home. One woman said that her husband would not allow it and one man said he would not like his wife to work. It may be that men would feel that they were failing in their roles as provider if there wives were seen to be out working.

> Respondent: *"I don't think it's right. (women working) The woman should stay at home and look after the home and look after the children. If I was married, I would expect my wife to look after the home. I would provide for them. There would be no need for my wife to work."*

Interviewer: *"What if she just wanted to?"*

Respondent: *"No, I wouldn't be happy with that. What would she want to do that for? If she was bored she could go shopping or she could go and visit her family. There would be no need to go out to work."*
*(Resp.6, male, 21yrs, Irish Traveller)*

One young man however, told of younger women he knew in other parts of the country who were starting to get jobs (although this was not observed in Wrexham). He would not be opposed to his future wife working and could see the financial benefits of this. He was not however, prepared to cross the work divide between men and women. He was not prepared to share in the housework but did say he would look after his own children provided this did not involve changing nappies.

### 4.3.3 Courtship and Marriage - the road to adulthood

Entering adulthood in Gypsy and Traveller society is strongly linked to marriage. This was also noted by Okely (1983) who said there was no large time span between puberty and marriage. Before marriage, there are strict rules governing the behaviour of both boys and girls, though often stricter with girls. Prior to marriage, young people are not allowed to partake in adult activities such as drinking alcohol, smoking or having sex. Girls may be given strict curfew times to adhere to regardless of age and must ask permission to go anywhere. Boys on the other hand, can seek independence at around 15 or 16 years of age and will travel on their own or in twos and threes around the country visiting family and earning a living. They are not restricted to the home in the way girls are but not quite considered to be adults.

*"Boys and girls can't drink alcohol until they're married, boys and girls. But I think boys do it when we don't see... It's not allowed, especially for girls. They can't drink or have sex until they're married."*
*(Resp.4 female, 42yrs, Irish Traveller)*

Young people can decide to marry at any age after sixteen and many opt to marry young, it is not uncommon for people to marry at the age of 16 or 17 and to be starting families at that age. Once married, the couple are treated as adults and

command the respect of the community as adults. Younger siblings are expected to treat their married sister or brother with respect. Girls in particular are often fearful of getting married too old, of being the object of ridicule if seen to be too old to be getting married.

> *"If you gets married at 18, 19, 20 years of age they think you're old, 'cos to Travellers you are 'cos Travellers is used to having children like 15, 16, getting married...But the girls that don't get married at 16 and wait 'til they're 17, 18, 19 probably to find a boy like that they love, and when they gets married they're ashamed walking down the aisle getting married 'cos they're 'oh, I'm gonna be taken (laughed at), I'm too old, this age I shouldn't be walking down the aisle'."*
>
> *(Resp.6, female, 37yrs, Irish Traveller)*

Gmelch (1985) in his study of Irish Travellers in the 1970s observed that Irish Traveller teenagers were marrying earlier than had been the tradition for their parents. He suggested that this was an adaptive response by Traveller parents to the dangers of adolescents mixing on the urban sites, where they felt less able to control their children's actions. This may result in a girl losing her virginity and this would bring shame on the family. An early marriage ensured that this shame did not befall the family.

An early marriage, however is not seen as desirable with all Gypsy and Traveller women, with some not choosing to get married until they are in their mid twenties, though this is considered to be old. There may be several reasons for this reluctance to marry. This may be because they do not want the responsibilities that come with marriage and having children or that they simply enjoy being single, or that they are the last remaining daughter and the parents are reluctant to let go. Those who do not marry into their 30s and 40s, may be treated as children by their parents but adopt adult habits such as drinking alcohol.

> *"Me mammy now, one out there (sister) she'll be 40 next month and the other one is 41, me brother. And our (another brother) is 30 somethin' yet me mammy's always 'me children, where's me children' they're still her children, still her babbies. If she goes out she says, 'For Gods sake watch me child' Her babby now is coming , yeh 33 years of age, and the other one is 40... But*

*if they were married now, it'd be different. 'Oh get up and let the woman sit down', yer a woman or a man if you're married."*

*(Resp.6, female, 37yrs, Irish Traveller)*

## Courtship

Courting can be a difficult process in Gypsy and Traveller society. Young single female Gypsies and Travellers are not allowed to have boyfriends and date. It would not be seemly to be on your own with a boy un-chaperoned. A girl's reputation and virginity must be intact to be eligible for marriage. This is seen as very important for Gypsies and Travellers, a young woman may bring 'shame' to the family if she is not a virgin when married. Girls would be tested both before marriage and on the wedding night. If you are seen to be with a boy, that is the one you are expected to marry.

We were talking to a young married woman who stays temporarily on site. She was talking about the expectations of women in the Irish Traveller community; that girls were expected to be 'pure' and that a man who was engaged to a girl would test her out to see how far she would go. If a girl let her boyfriend touch her on her legs etc, then the boy would think she was experienced and would not marry her. The woman said that it would be a big scandal if a girl was not a virgin, and that no Traveller would marry her. But that it was different for the boys, they could go with girls and would often choose 'country girls' to gain experience, but would not marry them.

(Observational field notes, September 2004)

When the Project Health Worker explained about sanitary products, the girls (two young teenaged Irish Travellers) mentioned that the use of tampons might mean they would not be seen as virgins. They said there had to be blood on the first night to prove virginity and said they didn't think Traveller girls used tampons for that reason.

(Observational field notes, August 2004)

Boys appear to have more freedom in regard to this, probably because they enjoy more freedom in general.

*"Yeh, like we're not allowed to have a boyfriend, the man we marry, the boyfriend we go out with will be the one we're marrying....The boys, is not the same, I'm not saying Gypsy boys is the same because obviously a man will have a bit of fun, d'you know*

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*what I mean. Like us (girls) all I've ever known is cook, clean and*
*look after me kids really and that's it, it's all I've ever known."*

Young people will meet at fairs or through visiting other sites with family, or may be members of the extended family. They may have known each other all their lives. Because dating is not allowed, couples will meet each other in secret until they are ready for marriage. At this stage, the boy will approach the parents of the girl and ask permission for the two of them to get married.

> *"If a boy likes them and they like a boy, they'll ask them to*
> *go out with them. But they gotta keep it hidden from the parents*
> *until they feel they're in love with each other, then the boy could*
> *come and ask…that's the only way it can come out in the open,*
> *when they're ready for marriage."*

*(Resp.5, female, 37yrs, Irish Traveller)*

Although it is expected that a boy will ask the girl's parents for permission to marry, it appears that in some instances this is seen more as a formality. Some believed that the parents were unlikely to say no due to the belief that the couple would go ahead and marry anyway. If the parents did say no, time would be allowed to pass and the boy would be expected to ask the parents again. Once the parents have agreed to the marriage the couple are engaged. This is known as 'pop the question' and can involve a large celebration sometimes extending to several days if the parents are wealthy.

> *"Well, say if you make a day to get married, well, lets call it*
> *'pop the question', well they has a big celebration."*
> *(Resp.1, male, 35yrs, Irish Traveller)*

Once formally engaged, a girl will gain a little more freedom and sometimes extended engagements are used by girls for this purpose.

> *"Asked me to marry 'im but that was my choice, I didn't want to*
> *get married until I was 25. So I ended up going back out with 'im*
> *when I was 17 and said I'd marry 'im on condition he waited until I*
> *was 25, and he said yeh, so that was it. I knew if he loved me he'd*
> *wait fer me. Ended up me dad couldn't wait to get rid of me 'cos I was*

*very wild (married at 21). Oh, I 'ad a good life, swear to God I did, the best life a Travelling girl ever had."*

*(Resp.5, female, 37yrs, Irish Traveller)*

Because young people, particularly young women, are kept under tight supervision with no prospect of 'dating', couples often meet each other through the family and so marriages between family members such as cousins and even 'double first cousins' are not uncommon (see appendix 12 ). There are several examples of cousin marriages in the Irish Traveller community in Wrexham. Also, two couples who married 'double first cousins' are living on the Traveller site at present (see appendix 13).

Close kin marriages was also noted by Gmelch (1985) and he suggested that this is a response to the uncertain and often threatening relations amongst different kin groups in urban areas. He notes that in the past, marriages between close kin were uncommon. He suggests that close kin marriages are a way of strengthening the kin group and ensuring that marriages do not fail, as both sets of relatives have an interest in the marriage surviving.

### 4.3.4 Married life for Gypsies and Travellers

For most young couples, marriage is their first experience of independence, of having their own trailer and being able to go where they please. This means however, that the couple needs their own caravan and vehicle to live independently. Young men will often start saving for the future once they begin to travel around and start to work. At the point of marriage, they have either acquired these things or will be helped by family. If the man marries into a wealthy family, he can expect to receive a large sum from his father-in law. The newlyweds will often stay near the brides parents for a period of time before starting off on their own.

There is a clear hierarchical structure to Gypsy and Traveller culture and family life with clear expectations and limitations on behaviour depending on family group, gender, age and marital status (Lehti 2001, Ojanlatva 1997, Okely 1983, Wetzel 1983). Wealthier, higher ranking families have obligations to lower ranking families, for example, one poorer family was provided with a new trailer after their old one

caught fire. Men are at the top of the family hierarchy followed by married women, young unmarried men then at the bottom are young unmarried women. This has been also noted in other countries. Lehti and Mattison (2001), in a series of interviews with Gypsy women also found this hierarchy to exist in Sweden.

In Gypsy and Traveller culture, the man is seen as the provider and is the boss. He is the head of the home and will be expected to be obeyed. As described previously (Gender Roles section 4.3.2), the work division between husbands and wives is clearly defined. If there is friction within the relationship, the husband may feel his authority being challenged and may lash out to regain control. Data collected from direct disclosure and observations in the present study suggests that the majority, 61% of the married Gypsy and Traveller women who consented to be in the study have experienced domestic violence in their lifetimes (see Figure 4.2). This figure rises to 81% in the Irish Traveller community (see Figure 4.3). These figures are far higher than those of domestic violence or intimate partner violence (IPV), in England and Wales, where a prevalence of approximately 25% is reported (British Crime Survey 2001/02; Boyle 2003). The high level of domestic violence in the Irish Travellers in this study also appear to be higher than those in other countries worldwide where levels are reported between 15% and 75% (Garcia-Morenoc 2006; Ruiz-Perez 2006; Thompson 2006; Alper 2005; Faramarzi 2005; Fawole 2005; Zink 2005).



Figure 4.2

**Married Irish Traveller Women Who Experienced Direct Domestic Abuse**

4 (15%)

1 (4%)

- ▣ Domestic abuse
- ■ No DA
- ▢ Not know n

21 (81%)
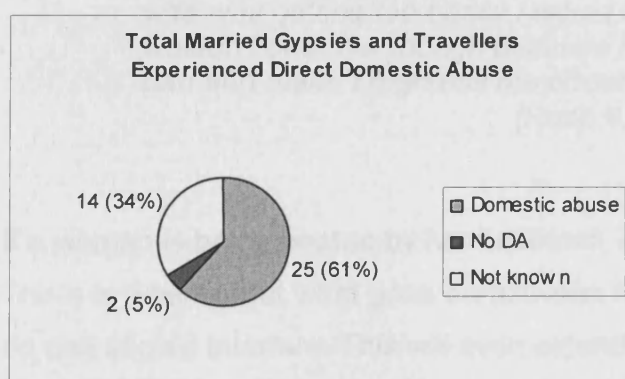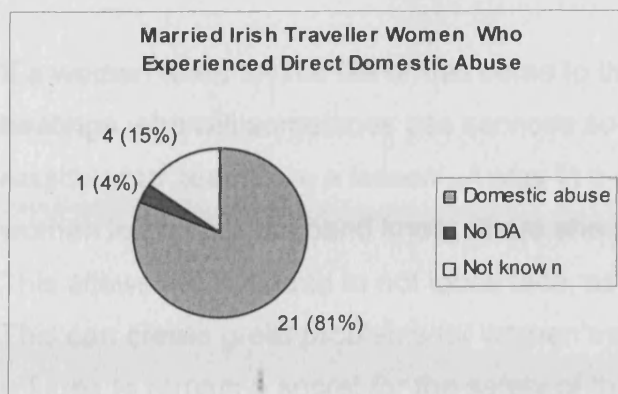
*Figure 4.3*

Hodgins (2006) also found that domestic violence was a feature of domestic life for Gypsy/Traveller women and describes how it was spoken about by the women openly in a series of focus groups exploring Irish Travellers' beliefs of the causes of ill health. Domestic violence is often fuelled by alcohol, which was also noted by Hodgins (2006).

> *"Well, all the Travelling men, you might find it cruel, they shout and things but that's the way they been fetched up. To be honest, when you get married, a Travelling woman is a slave to be honest. From the day they get married, they obey their husbands and if they don't they will get slapped alright, they just 'ave to obey."*
> *(Resp.11, female, 35yrs, Welsh Traveller)*

> *"The man is the boss, that's why I broke up with my girlfriend, 'cos she was getting too bossy. If I got married and my wife was getting too bossy I would show her who was boss. I wouldn't beat her though because I saw too much of that with me dad and mam. I frightens me about my own temper."*
> *(Resp.6, male, 21yrs, Irish Traveller)*

If a woman is being beaten by her husband, other men are reluctant to interfere. There is a belief that what goes on between husband and wife is private and that no one should interfere. This will even extend to a woman's own brothers who will not step in. Women though, have been known to defend another woman if they feel that they can, for example, if it is her brother beating his wife, the sister may step in to try to stop it.

If a woman fears for her life or has come to the end of her ability to tolerate such beatings, she will sometimes use services such as women's aid, but only for respite or to 'teach him a lesson'. A stay in a refuge is often short, ending with the woman letting her husband know where she is so he can come and collect her. This allows the husband to not loose face, as the man is in charge of the family. This can create great problems for women's aid which requires the location of their refuges to remain a secret for the safety of the occupants. For this reason, and also the task of finding a refuge that can accommodate a large number of children, these agencies are often reluctant to accommodate Gypsy/Travellers.

Gmelch (1985) also observed that temporary separation of a married couple was commonplace, but it was described as 'desertion' of the wife and it was as suggested that this was often a response to the instability of the marriage relationship. He suggests that the Traveller woman's desertion represents the same response to conflict as Travellers in general use to avoid conflict, that is to move the whole family. This was not what was observed in the present study, where women would endure repeated beatings for many weeks and months, until they were often afraid for their lives before removing themselves from their husbands. This difference may be due to the time in which Gmelch's study took place, in the early 1970's, it was less acceptable for women from any background or culture in Britain to leave their husbands. Also, Gmelch was gathering data as a man and one may assume that much of his information came from the men in his study. By contrast, the present study is informed largely by women.

When violence breaks out between husbands and wives, the police are called as a last resort and only called when a woman is in fear of her life. Often the call is made by one of the woman's children. There is however, reluctance for women to prosecute their husbands but they do sometimes seek restraining orders. However, following new legislation, one incident was witnessed during this study, where the police charged a man for Grievous Bodily Harm without the consent of his wife. The man was prosecuted.

Current research around the world (EU, USA, Mexico, Spain, Bangladesh, Tanzania, Nigeria, Iran & Turkey) has sought to identify factors that are associated and may predict domestic violence. Several factors have been suggested, including; cultural acceptance (Agoff 2006; Gracia 2006), male gender empowerment (Gracia 2006; Faramarzi 2005; McClowskey 2005), family history of abuse (Fawole 2005; Naved 2005), Education (Ergin 2005; Faramarzi 2005; Naved 2005) and psychological factors such as male and female dependency (Bornstein 2006) and misinterpreted jealousy (Power 2006).

These factors however, are mediated by culture. For example, although many studies have identified lack of education as a risk factor in domestic violence, it was found that in Bangladesh (Naved 2006), education of males in urban areas had a protective effect but that education of women in rural areas was associated with increased risk. This has large implications when a society attempts to tackle domestic violence; it is important to be aware of what factors influence a particular group and how.

Alcohol has been also linked to domestic violence, but this is controversial. Several recent studies have suggested an association between alcohol and domestic violence (Snow 2006; Fawole 2005) however, a systematic review carried out by Gil-Gonzalez (2006) concluded that the evidence was of low quality and there was currently not enough empirical evidence to support preventative policies based on alcohol as a risk factor. Furthermore, a qualitative study by Galvani (2006) explored women's views of the role of alcohol and their experiences of domestic violence. The women blamed the men for their actions and not the alcohol consumption.

Some women, in the present study, have been affected by their childhood experiences of domestic violence and this has influenced their expectations and views of marriage. One woman said she would not get married because of the beatings her mother went through but was happy to have her children and concentrate on them rather than a relationship or marriage, even though to be an unmarried mother is seen to be scandalous in Gypsy and Traveller communities.

*"Me dad was cruel to me mum fer years and years, very, very cruel, bad man he was... He was extra good to his children but he was bad like to me mother. And whenever I used to be asleep and he's come back from the pub and he'd start arguing and whatever. When you look at things like that it's very hard because it's two people you love and you don't know which one to really take up..... it did affect me an awful lot. I think that's why I don't really think about marriage. I've got me child and I'm just happy. I've got what I want."*

*(Resp.8, female, 20yrs, Irish Traveller)*

Gmelch (1985) in his study of Irish Travellers in the early 1970's, also noted that domestic violence was commonplace but also noted that women also inflicted violence on their husbands if they were large enough. He observed that the size and strength of the spouse was often a deciding factor in who got their own way in Irish Traveller society. This however, was not observed in the present study. Many incidences of domestic violence were reported to me and the Project Health Worker but not of violence by a woman to her husband. This may be due to the women in the present study being generally smaller than their spouses, as many of the women were concerned about their weight and would often diet to stay thin.

Gmelch (1985) described Irish Traveller marriages as being characterised by mistrust, jealousy, quarrelling and fighting. He suggests that this is due men no longer being the 'breadwinners' of the family.

However, this view of the husband as the boss and the woman as subservient is not shared by all. One newlywed woman described her relationship with her husband as that of 'best friends'.

*"We never fight, he's like my best friend, we never argue."*
*(Resp.7, female, 23yrs, Irish Traveller)*

Recent research suggests that domestic violence has health implications far beyond the immediate injuries suffered by the victims. Recent studies suggest that domestic violence or intimate partner violence (IPV) results in serious emotional and mental health consequences including depression, psychological distress and

post traumatic stress disorder (PTSD) (Avdibegovi 2006; Heru 2006; Loxton 2006; Miriam 2006; Ruiz-Perez 2005), poor general health consequences (Bonomi 2006; Loxton 2006) and adverse effects on the general and mental health of childhood witnesses of domestic violence in later life (Griffing 2006; Hindin 2006; Kaplow 2006; Levendosky 2006; Sternberg 2006; Turner 2006; Street 2005; Dube 2001; Felitti 1998)

Ehrensaft (2006) in a prospective longitudinal study of 980 young adults concluded that psychological disorders are a risk factor of involvement in an abusive relationship but also, abuse is a contributing factor in psychological disorders amongst women but not men. The complex nature of economic dependency in women and emotional dependency in men has been discussed by Bornstein in 2006, and Garcia-Moreno (2006) found increased domestic violence amongst more controlling men. All of these have implications for the general and psychological health of the women in this study and may have a contributing influence on the high levels of depression and anxiety found amongst Gypsy/Travellers in this study, in particular the high levels of anxiety found (see Chapter 6 section 6.4.4) and high levels of cigarette smoking amongst Gypsy/Traveller women (see Chapter 6 section 6.3.1.1).

Although there is recent literature regarding the acceptability of screening for domestic violence in the healthcare setting (Boyle 2006; McDonnell 2006; Zeitler 2006 ) several studies have questioned this strategy while the effectiveness of subsequent interventions has not yet adequately been assessed (Coker 2006; Ramsey 2002) and in particular, when cultural differences have not been fully explored such as cultural barriers (Anderson 2006; Fernandez 2006; Sumner 2006). In the Gypsy and Traveller communities, these cultural barriers exist, such as the taboo of divorce for women.

For a Gypsy or Traveller woman, marriage is for life. If a marriage does break down, a woman can separate or even divorce her husband, but she will never re-marry or have another man in her life. Even women who have been widowed are not able to re-marry. For a woman to have another man in her life after her

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husband would bring shame and scandal to the family. This is also recounted by Okely (1983), *"A woman should ideally remain with her husband for life, and is supposed to be subordinate to her husband's wishes".* This is however, not the case with men. It appears that men are free to re-marry and this does not carry the same stigma as for a woman.

> *"No, no that's a bad thing (re-marry after divorce). You'd be disgraced and scandalised if you done that....the men can do what they want, the men can go with 50 different women. Yeh, they can re-marry, have another family, do what they want, but a Travelling woman can't. They can't do that because they'd be a disgrace. Not only that, the husband would be back...because it's a man's world. The man is the boss...but a Travelling girl, one mistake and that's it, they'd be disgraced fer life."*
>
> *(Resp.5, female, 37yrs, Irish Traveller)*

> 'X' (young unmarried Irish Traveller) said that she wished she wasn't a Traveller. That there was nothing for Traveller women and that the best day of your life is your wedding day. Before that day and afterwards, you are nothing. She said that there was no escape, no way of changing your life. If you chose to leave, people would look for you, it would be hard to disappear and if you did you would be totally on your own, "you could never come back".
>
> (Observational field notes, February 2003)

Women are also expected to remain faithful to their husband and this has to be *seen* to be the case, therefore no man is allowed to be alone with a woman who is not an immediate family member. This was also observed by Okely (1983). Chaperoning is most important in Gypsy and Traveller culture to protect the reputation of the woman. This is also something that should be considered in healthcare settings where care should be taken concerning male practitioners and lone females (Wetzel 1983).

> A Traveller woman came to the site to see another Irish Traveller 'P' because she was worried about her very sick baby who was in hospital. The mother feared that the baby would not survive. 'P' said she had some holy water and would come with them to the hospital and bless the child herself with it. The mother agreed to this. However, they had to find another Traveller to accompany them in the Transit Van as 'P' would be driving back the father of

the baby back alone as the mother planned to stay at the hospital. This would leave 'P' and the father alone in the Transit Van which is not allowed in Traveller culture. Therefore another passenger was needed and found to accompany them.

(Observational field notes, June 2003)

### 4.3.5 How Gypsies and Travellers bring up their children

Children, especially babies and young children are very highly prized by both Gypsy and Traveller families. Family size tends to be large compared to the general population (Rustom 1990, Okely 1983). Okely (1983) described the way children were valued and how it was unacceptable to abandon or voluntarily hand over children to Gorgias, this was believed to be something that Gorgias did, not Gypsies. Even though the average size of families appears to be decreasing from previous generations, it is still commonplace to find families of 7 – 10 children, people in their fifties plus talk of being in families of 19 – 20 children.

The care of young children is almost exclusively the responsibility of the women in the family. Men will only help on a temporary basis if their wife is ill or in hospital. Older female siblings are expected to look after their sisters and brothers. This begins at an early age under the supervision of the mother and is one reason for leaving formal education, often by the age of 13 or 14 years of age. This tradition is still being encouraged with young Gypsy and Traveller mothers saying that they will expect their daughters to do the same. This was also noted by Rustom (1990), who suggested that children as young as 10 were given responsibility for siblings and saw this as a preparation for motherhood. On caravan sites, the children tend to be looked after collectively, with food being given to all children who happen to be in at meal time, this will include extended family members such as nieces and nephews. Gypsies and Travellers would not use an outsider to look after their children such as a babysitter or nanny. There is strong suspicion of outsiders and a lack of trust.

*"I'll get someone now to look after my children, that wouldn't be anyone outside, that would be someone in the community, a Traveller. And when you see on telly now, these daft things, a woman heard her babysitter, molests this baby or smacks it."*

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Gypsy and Traveller children are expected to show their parents respect and to do as they are told. This was also found by Van Cleemput (2004) who stated that "the respect and deference to older relatives did not appear to diminish as they aged". For example, one married woman in her 30s with four children will not drink or smoke in front of her parents as a sign of respect. She too wants her children to be brought up the same. Girls are treated more strictly than boys, with much less freedom. This is also seen as a good thing by many, as it is a way of protecting girls.

> *"Yeh, that's what I said to 'im like, I want my kids to be fetched up 'ow I was. Like they ask and then I say they can go. Even to my 9 year old now, he goes to like a gym, he says 'I'm going' and I say No, you ask me and I'll tell yer if you can go. You gotta start listening like I did. And when I say you can't go, you can't go."*
> *(Resp.11,female, 35yrs, Welsh Traveller)*

## 4.4 Gypsies and Travellers as an ethnic group

### 4.4.1 Gypsy and Traveller communities in Wrexham

The Gypsy and Traveller communities in Wrexham comprise three main groups: Irish Travellers, Welsh Travellers and English Gypsies. As described in the cultural study, these groups see themselves as separate and seldom mix, with the exception of the occasional inter-group marriage. The Gypsies and Travellers living in the Wrexham area reside in both caravans (council run sites and private land) and in social housing. Although the population of the site varies due to the nomadic lifestyle of its residents, during the time of writing this report, an estimated 51 adults plus 41 children were resident on the council run site and 42 adults and 52 children were either living in caravans on private land or in houses.

The council run Traveller site is by far the largest site in the Wrexham area. It is a permanent site of 19 pitches. The site comprises mainly Irish Travellers, however, there are a small group of English Gypsies staying on site at present who have links to the Irish Traveller residents through one marriage.

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The majority of housed Travellers in Wrexham are from the Welsh Traveller community. Many were formerly resident on the council site but left when there was an influx of Irish Traveller residents. This influx was compounded by the forced closure of an unofficial site in Wrexham. The Welsh Traveller community felt they were forced to move into houses and some resentment towards the Irish Travellers remains. This is an example of an authority's lack of cultural understanding, believing that they could all be housed together on one site.

## 4.4.2 The travelling lifestyle

Gypsies and Travellers in the Wrexham area live in a variety of settings, a council run caravan site, small groups of caravans; either tenants on privately owned land or on own land, houses owned by either housing trusts or the council and those who are travelling. Pitching up by the roadside or on unused land is not tolerated in this area so those who are travelling will stay with relatives, either pitching their caravan on a relatives' plot or staying in houses with relatives.

### 4.4.2.1 Experience of travelling

Although the Gypsies and Travellers in this study consisted of both caravan and house dwelling Gypsies and Travellers, nearly half were either living a nomadic lifestyle or had only recently stopped travelling. Of those who had adopted a more settled lifestyle, several said that they still travelled in the summer months. Most recounted living a nomadic lifestyle while young and described either travelling with immediate family members or with larger groups of family and friends. Okely (1983) observed that Gypsies and Travellers did not travel around aimlessly, but rather that their travelling was complex and involved the influences of political, economic and ideological factors as well as being influenced by seasonal patterns, work opportunities and relationships. Many in this study described travelling as a way of life that was governed by the father's work, either travelling from town to town for work or following the many fairs that existed for the purpose of horse trading.

> "Travelled, all me life we travelled.. me dad would only settle probably a couple of weeks, wherever he gets work 'cos like, he's a scrap dealer and that, tarmacer. If you get work that's where you'll settle fer awhile."
>
> (Resp.5, female, 37yrs, Irish Traveller)

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*"That's when I was young (travelling)with me father and mother back in Ireland...Dad was a horse dealer he was. He'd get horses and asses and he'd go down to the fairs and sell 'em. It was, it was a lovely life, lot better than the life we have now, beautiful it was...we'd just pull into places, y'know wid the caravans, old fashioned caravans, we'd stay there so long then we'd go on again."*

*(Resp.3, female, 65yrs, Irish Traveller)*

The nomadic lifestyle of the past was described as a good life and people talk in terms of feelings of 'freedom'. This is in sharp contrast to the descriptions of life on the road today, where Gypsies and Travellers describe finding it difficult to find places to stay, as the traditional stopping places are no longer available and roadside evictions are commonplace. Feder (1994) also found that most of the families he interviewed had been repeatedly evicted from unofficial sites in the 12 months prior to the interview. This was cited as the reason for several of the interviewees giving up the traditional nomadic lifestyle, either finding the life too difficult now or not wanting the problems that came with travelling and evictions for their children.

*"When I was young I travelled with my parents all over, we travelled all over, staying places for a few months then moving on. We would sometimes travel on our own and sometimes with uncles and aunties in a group. It's more difficult now 'cos you get moved on a lot. You can only stay a couple of days before the police come and move you on...some places don't have caravan sites anymore, so there's nowhere to go."*

*(Resp.4, female, 42yrs, Irish Traveller)*

*"Travelled, travelled all me life. I've only been in this house for three months from being in a trailer and it's the first time I ever lived in a house... we are going away for the summer but we'll probably come back for the wintertime 'cos as I say, there's nowhere for us to go. We've done a thousand mile in a day looking for somewhere to pull into, but we couldn't, well nobody would have us on, nobody, all the camps, all the sites, they just wouldn't let us on, they just says 'sorry, we don't accommodate people like you'."*

*(Resp.2, female, 22yrs, English Gypsy)*

Van Cleemput (2004) describes the association between 'freedom and nomadism', and how the loss of freedom experienced has had a profound effect on the psyche of Gypsies and Travellers. Young males and newly married childless

couples are the most likely to travel today, possibly because of the problems described with stopping places. However, there does appear to be restrictions culturally on travelling. Travelling must follow certain criteria such as visiting relatives, attending horse fairs or for work.

Another reason for travelling is conflict avoidance. This was observed by Gmelch (1985), who noted, *"Tinkers cope with many of their problems by physically moving away from them. Even though some families wish to remain settled, shifting is often the only solution they know to certain problems"*. Travelling to avoid conflicts was also observed in the present study on many occasions. One example is a family that had been living in a house but had run up debts and begun to get complaints from neighbours concerning the behaviour of their children. When a meeting was organised by Social Services concerning the family, they feared that the children would be taken from them and left the house without warning. They did eventually return to the area, once things had 'settled down'. Another example was the exodus of Welsh Gypsies from the council run site once Irish Travellers began to move on as the two groups do not readily mix (see Chapter 5, section 5.2.1).

### 4.4.2.2 Experience of living in a house

A recurrent theme to come out of the Gypsy and Traveller interviews was a feeling of isolation whilst living in a house. This isolation could be experienced within the family group due to the internal layout of houses, or isolation from the rest of the community due to the location of houses. Isolation within the house itself was due to the houses having walls and ceilings, this made people feel that they were split up due to the divisions of rooms and floors. It was expressed that this resulted in family members talking to each other less and children spending too much time in their bedrooms away from the family. Those who had experience of living in houses, even if for a short period of time, described feelings of being 'closed in', 'like being in prison', of having nowhere to walk and unable to look out. Van Cleemput (2004) described how Gypsies and Travellers in England also had a strong aversion to living in houses and saw this as 'unnatural'. Many in this study experienced feelings of loneliness and missed the company of family and other Travellers. As Gmelch (1985 p.146) observed during his study of Irish Travellers, in

the Republic of Ireland, *"a sense of isolation and loneliness often develops when families are housed apart from their kinsmen".*

> *"It is lonely (in a house), very very lonely because you haven't got your people around you. 'Cos I'm used to going from caravan to caravan, I'm not used to sitting like indoors all the time on your own. I'm used to just going in and out, mixing."*
> *(Resp.5, female, 37yrs, Irish Traveller)*

Gypsies and Travellers often try to remedy this by living as close as possible to other family members. It is not unusual to find three or four houses being occupied by an extended family on the same road.

> *"Like me mum's family now, they're getting old, so they decided to buy houses but then at the end they got houses but there's other Gypsy people round 'em. See, they're all next door, still in the travelling community,...so they're still having a social life...But me down 'ere by meself, I'm living 'ere and I'm by meself, there's no Travellers around me..so I'm finding it harder to fit in 'ere, very hard."*
> *(Resp.2, female, 22yrs, English Gypsy)*

This however is not the case for everyone and one person who liked living in a house said that he liked the privacy of a house and the lack of arguments. The issue of safety was discussed by some. One person said a house made her feel 'safe', whereas another person described feeling 'unsafe' in a house. Safety was also discussed concerning children and one woman felt that it was safer for children to be on caravan sites as they could be looked after collectively, where as children in houses were more likely to be at risk if playing outside.

> *"We had a house once, fer a couple of months, but I hated it. I didn't feel safe. Like you lot feel safe in a house and would be scared in a trailer. It's different for us Travellers, I feel scared in a house and safe in a trailer."*
> *(Resp.6, male, 21yrs, Irish Traveller)*

> *"With Gypsy life.. you can go to anybody's caravan , sit down, have a chat, have a smoke and you know your kids is ok, Here, where I'm living now at the moment (a house), I'm frightened of me little girl going outside, playing outside, for the simple reason why, you don't know who's on the streets, you don't know what men or anybody, and my little girl could go through the gates and play on the road, which is not a very safe thing. On the*

*site there was none of that, all the kids play together and there's
no big roads for kids to get runned over and everybody's watching
everybody else's kids."*

*(Resp.2, female, 22yrs, English Gypsy)*

Ill health has been attributed to living in a house when you are not used to it. One woman described how she started to suffer from asthma while she was living in a house for three years. She had not suffered from asthma since she was a baby and believed that it was the result of living in a different atmosphere, which her body wasn't used to. She would be reluctant to live in a house in the future for any period of time due to this experience. The belief that living in a house may contribute to ill health was also found by Gmelch (1985) who suggested that this was one of the reasons that Irish Travellers leave houses for the open road.

One person talked of not being able to change the scenery in a house, and another that a house is not your own to do as you please like a caravan is.

*"Because it's yours isn't it, in a house is a council
house, and even if you bought your own house, you still don't
own it. So in your own caravan you can do what you wantin' it
and it's yours."*
*(Resp.13, female, 21yrs, Irish Traveller)*

Gypsies and Travellers will often use houses as a temporary living arrangement, moving from house to trailer and back again. Because of this mobility, it is often not helpful to differentiate between housed Gypsies and Travellers and those who live in trailers, particularly in terms of their health and education needs. Some Gypsies and Travellers seek to make their house resemble the layout of a trailer by removing doors and not using the upper floor, however, this is not by any means universal. I have visited many houses where the family did use the first floor and all their doors. It is something that can cause distress however, especially to the older members of the community where change is harder to accept.

### 4.4.2.3 Experience of living on council run site

Several people described their experience and feelings of living on the Council run site, Wrexham. Concerns were voiced about the location of the site in terms of

safety for the children. There are two main roads that run alongside the caravan site and fears were voiced concerning the danger this posed to young children (see appendix 14) Another concern was that there was no play area for the children.

> *"There is nowhere for the children to play (points to waste land next to health bus), just a pile of nettles and the road is very busy, you have to watch the children all the time. There is no gate at the entrance and holes in the fence by the road so the children can get out, you have to watch them. It makès me nervous."*
> *(Resp.4, female, 42yrws, Irish Traveller)*

Another woman compared the site to others she had known and said that it was much worse. She described how other sites had a play bus that would come to the site and had equipment and play workers for the young children and how that did not happen here.

Other concerns about the site were connected with the running of the site, its cleanliness, rat infestation and concerns about privacy on the site. Some were concerned about the feelings of lack of privacy because there is a CCTV camera on the road opposite the entrance to the site. There are concerns about how much the camera can see and the feeling that it is always pointing on the site rather than on the road. Other privacy concerns include mistrust of the Site Warden, who they perceive as an authority figure and not to be trusted.

> *"Like this site now, you're like in prison. You're watched 24 hours, you've got a camera 24 hours on top of yer. You've got a prison fence all around yer."*
> *(Resp.5, female, 37yrs, Irish Traveller)*

> *"If a Traveller took over this site there'd be a big difference in it. It'd be a lot cleaner than what it is now. It'd be kept cleaner.....(refers to warden) Looking at what everyone's doing. If there's anyone visiting, he's on to the police straight away. You can see the police coming down then, know what I mean."*
> *(Resp.12, female, 20yrs, Irish Traveller)*

The location, poor cleanliness, perception of a lack of privacy and mistrust of the site warden have health implications for the residents on site. They are a contributing factor in the poor mental health seen on the Gypsy and Traveller site and issues of safety and cleanliness have serious health implications in terms of accidents and illness.

### 4.4.3 Gypsy and Traveller education

A very large proportion of the Gypsies and Travellers in this study had poor or no literacy skills, with many of the adults having little or no formal state education. Of the 13 Gypsies and Travellers interviewed, 8 could not read or write, 2 had limited reading and writing skills and three could read and write. Those who could read and write were all aged 21 years or younger. Although the majority of Gypsy and Traveller children today attend primary school, most have left by the age of 13 to 14 years of age. For Gypsies and Travellers, more importance is placed on obtaining the skills needed to survive as a Gypsy/Traveller. These are the traditional non-wage labour skills of the self employed.

A traditional Gypsy or Traveller education involves learning from your family the skills needed to maintain a Traveller lifestyle. As Okely (1983) describes, *"the family or trailer unit is the primary means for education of the next generation of Travellers and has many attributes which, for the wider society, are fulfilled by organisations external to the family"*. What is taught is determined by tradition and has clear gender demarcations. Traditional education starts early in life, and can begin, by the age of 5 or 6. The skills learned are in line with the different roles assigned to each gender. Boys will begin to go out with their father or other male relatives from an early age to learn how to make a living and support a family. This is work in which the men are self employed and can easily be done in any location. The work carried out has changed over time, whereas traditionally this would include horse trading and seasonal farm labouring, this has been replaced by scrap metal collection, landscape gardening, tarmacing, block paving and painting. This adapting to new demands is a key to Gypsy and Traveller survival.

*"They'd start collecting scrap metal...stuff like that, all kinds of metal, and landscape gardening and then tarmacing. All kinds of work, like, jack of all trades, like y'know, the Traveller would never go hungry, if you know what I mean, like, they'd make money out of, you know...taught by my father before me, and his father before him."*
*(Resp.1, male, 35yrs, Irish Traveller)*

One young man talked of learning the 'old ways' of horse training by his grandfather, but felt that this was taught at the expense of 'modern Traveller ways'. Even though he had gained skills at school that others hadn't, he felt at a disadvantage with his peers and felt that he had to catch up on Traveller skills.

*"When I was younger, helping me granddad with horses and stuff, I was the only one that knew how to go about horses and what way they work and what way they don't. And what's the best way to lead a horse off and then like best way to get a horse into a horse box. What you should do and shouldn't do with horses.....I'm what you call, I used to hang around with the old, the old ones, the old timers, but now like there's new times, there's new ways of doing stuff. I'm basically old fashioned... I don't know basically how to work the new system, but you could say I do 'cos I know how to work a computer. I know basically what the kids don't know."*
*(Resp.10, male, 16yrs, Irish Traveller)*

Girls, however, are not expected to work outside the home and are taught to clean, cook and look after children. This will start with small tasks around the home at an early age and progress to looking after younger siblings or cousins by the age of 12 or 13 years of age. Several women talked of leaving school to look after children and learn Traveller ways. These skills are taught by the mother, but if a child is the youngest and there are no children to look after locally, she may be sent to a relative who has children to learn child care.

*"Like now, when she's (daughter) five, I'll get her a stool and I'll sit her on top in the kitchen so she can wash up. Won't do it in a bad way, make her do it...if she don't wanna do it, encourage her more to do it, d'you know what I mean. Encourage her to have a tidy home when she gets to be a big girl and a family of her own."*

*(Resp.2, female, 22yrs, English Gypsy)*

### 4.4.4 The importance of religion to Gypsies and Travellers

Religion plays an important role in many Gypsies and Travellers' lives. Most of the Irish Travellers in this study are Roman Catholics where as the Gypsies interviewed were a mixture of Roman Catholic and Born Again Christians. All appeared to be united in the importance placed upon religion. It is felt important by most to attend church on a regular basis and most said that they were regular attendees at church. Religion provides a basis for the Gypsy and Traveller moral code and religion has a strong influence on the behaviour of Gypsies and Travellers, supporting the status quo. One Gypsy woman talked of how the nuns had taught her what was important in life.

> "We used to 'ave a nun come to us. We got teached by a nun us, and we got teached like the most important things of life, d'you know what I mean. Like what can I say, grow up, be a proper woman, 'ave a family, raise yer family....no trouble, no violence and things like that there. This is why I don't like violence, this is why I don't go to the pub, this is why I don't drink, because of religion."
> *(Resp.2, female,22yrs, English Gypsy)*

There is a strong belief in the divine power of the church, particularly in the Roman Catholic Gypsies and Travellers, and the power of prayer in both Roman Catholics and Born Again Christians. There is a belief that the divine power of the church is akin to a mystic power that can affect the outcomes of day-to-day life and rituals such as having a new caravan blessed by the priest are sometimes undertaken to promote good luck. This belief and the importance of attending church is said to be less strong in the young of today. This has been blamed on a lessening of authority by parents who are seen as less strict in forcing young people to attend.

> "I think religion is not so strong now with young people as with older people. Years ago people were forced to go to Mass but now they say 'Do you want to go?' The kids have a choice now. There is less discipline these days."
> *(Resp.10, male, 16yrs, Irish Traveller)*

### 4.4.4.1 Religion and health beliefs

The idea that ill health was a punishment from God for some transgression in your life is a belief that was traditionally held and is said now to be held only by the older

members of the Gypsy and Traveller communities. None of those interviewed held this view.

> "Ill health is like a punishment for things that they've done
> bad in their lifetime y'know. Spiting one another and stuff like that.
> It's an old tradition what's carried out y'know. I don't think that way
> now, no. The older generation, that's the way they think, do y'know
> what I mean, that it's like a punishment."
>
> (Resp.1,male, 35yrs, Irish Traveller)

Although the belief that ill health is a punishment is dying out, there is still a very strong belief in divine intervention, be it in the form of direct power of the church, the power of holy places, the use of healers, or the power of prayer. The importance of religion and the strong belief in 'curing people' and sacred places was also noted by Van Cleemput (2004). An example of the belief of the direct power of the Catholic Church intervening in health, is the practice of writing to the Pope to ask permission to marry if the couple are first double cousins. Because the couple are so closely blood related (see appendix 12 for illustration of first double cousins), there is a fear that if they do not get approval from the Pope they will suffer misfortune with their children. The belief is that the Pope has the direct power from God to 'divide the blood' of the children of such marriages and therefore prevent ill health and birth defects. This belief is so strong that a couple will not get married if they are first double cousins, without this division of the blood. This belief in the divine power of the church to 'cleanse' the blood was also noted by Gmelch (1985) in his study of Irish Travellers in the Republic of Ireland.

> "Like now when I got married to my husband, I couldn't just
> walk into a chapel and get married to 'im....because me and he's
> blood is the one, because we're double first cousins. I had to get
> permission from the Pope, I had to write a letter to Rome to the Pope
> fer him to separate our bloods before we could get married. Because
> if we'd gin and got married...well, we'd never have a normal child. I'd
> have all disabled kids, all me children'd be sick because our blood is
> too rich, too rich the one, our blood is one."
>
> (Resp.5, female, 37yrs, Irish Traveller)

Many believe in healers and the power of holy places such as Holywell, Lourdes and Fatima, and have personal experience or know close relatives who have been helped by these types of divine intervention. Healers are believed to receive their

power from God. Generally, they are loosely connected with the church and often come from Ireland. The belief is that using healers or attending holy places in combination with prayer is a powerful tool to help a family member who may be suffering from ill health.

The few that did not believe in divine intervention believed that modern medicine was the answer and that there was no need for prayer.

> "Well I know some people mix prayer with medicine but I think well, there are all these highly educated people that make this medicine and it's like 100 percent guaranteed to work, isn't it. So there is no need to pray."
>
> (Resp.10, male, 16yrs, Irish Traveller)

Some held a fatalistic belief that death was a form of divine intervention. That God chose you to be with him. For others however, death was seen as a natural occurrence and God was there to see you into heaven and to block you from the devil. But for others, it was seen much more as chance, the luck of the draw and not to do with God's choice at that time.

> "If God wants you he'll go and get you won't he. If you're standing in a line or asleep or no matter where you are, if God wants you he'll go and take you, that's all. Like we believes every day God goes out and picks a red rose, cause every day you hear of someone dying."
>
> (Resp.13, female, 21yrs, Irish Traveller)

> The way I look at it, in this world, we're all each and every one of us are only given a number, we're just passing through. It's tough but it's the way of it. Our number's called and that's it.
>
> (Resp.1, male, 35yrs, Irish Traveller)

## 4.4.4.2 The 'Pledge'

The Pledge is a method used in the Catholic Church to assist people in making life changes, especially if the behaviour in question requires change because it is becoming a concern to family or friends or is causing suffering to others. The Pledge involves visiting a Priest and promising in front of God and the Priest that

you will change the behaviour in question. Often a time limit is agreed upon as to how long the Pledge will be in force. In the Catholic Irish Traveller community it is often used to control alcohol consumption. A woman will often give an ultimatum to her husband to take the Pledge if she feels her husband's drinking is becoming a problem. The Pledge is very rarely broken because it is believed that if you break the Pledge, it will bring bad luck to the family and that you are going against God.

> "All our people says it's bad luck, 'cos they're not supposed
> to (break Pledge). That's why a lot of Traveller men don't like taking
> the Pledge. They be afraid. Yeh, because nuthin will go right fer yer.
> It's like breaking a vow. It's like vowing against almighty God and
> promising him you won't do it and then just, it's like you don't care
> about him. Yer promises are nuthin. If you break 'em, you've gone
> against 'im."
>
> (Resp.5, female, 37yrs, Irish Traveller)

It is however, possible to reverse the Pledge by visiting the Priest and telling him that you cannot hold with the Pledge. Often a man will approach the Priest because there is a celebration or funeral to attend and he feels he cannot go without a drink. The Priest may suggest that he is released from the Pledge for a set period of time and then the Pledge would come back into effect after that agreed period of time. It is also possible to be released from the Pledge indefinitely. Again the person would need to request this by visiting the Priest. It would also require a token payment such as candles for the church.

> "Well I've always got me husband (Irish Traveller) going to
> do the Pledge. He won't break it, it's just that he don't take the
> pledge fer long enough, and if he's going to break it he goes down
> to the priest and says that he's sorry , that 'e can't."
>
> (Resp.11, female, 35yrs, Welsh Traveller)

## 4.4.5  Cultural expectations and punishment

### 4.4.5.1 Gypsies' and Travellers' cultural expectations

As we have seen in this chapter, Gypsies and Travellers do not live the 'free and easy' lifestyle that has been so often romantically portrayed historically. They live with clearly defined cultural expectations and family obligations. They are expected

to live a nomadic lifestyle which includes a collective living style with their extended family. Their livelihood comes from self employed work with skills that are passed down from older family members to the young.

The Gypsy/Traveller calendar is a full one. Many family and group obligations must be met. Weddings, and especially funerals, must be attended. Also, the anniversaries of the death of family members must be observed, often by a mass and trip to the grave, and visiting the sick at their hospital bed is expected (Lehti 2001, Wetzel 1983, Thomas 1985, Mandell 1974). This was also seen by Lehti and Mattson (2001) in their study of Gypsy women attending a primary care centre in Sweden, where they describe the Gypsies' lives as being "characterised by unplanned events by constantly being on the move". This has implications for planned health promoting activities, planned appointments and health interventions that require regular attendance. Sutherland describes the custom of visiting the sick as one of the strongest values in Gypsy culture, showing the genuine concern for the ill person and their immediate family (Sutherland 1992).

### 4.4.5.2 Cultural constraints on community members

As well as the cultural expectations that Gypsies and Travellers aspire to, there are also cultural constraints. These are rules that must be adhered to in order to be fully accepted in Gypsy/Traveller communities. The majority of constraints are directed at females and are hierarchical in nature, with elders having more freedom than younger members, as described in section 4.3, the 'family life system'.

These constraints include gender roles, chastity/purity, fidelity, marriage, cleanliness and respect for elders. Many of these rules involve behaviour at the family life level, which has been discussed in section 4.3, 'family life system'. It is not surprising that many rules work at this level, as the family is at the core of Gypsy and Traveller life. By protecting the coherence of the family, Gypsy/Traveller culture is protected.

Other constraints however, appear to work more at the personal level, such as the rules concerning pollution. There is a belief that the inside is clean, whereas the

outside is polluted. This can be seen in the trailers of Gypsies and Travellers where the inside of the trailer is kept exceptionally clean with many hours of work devoted to this task daily. This however, appears to be a contradiction when the accounts of the outside being equated with healthy living and good health are considered. The immediate physical 'outside' appears to be polluting and therefore requires the many hours of work involved in keeping the inside of trailers clean. There is always a risk of pollution that must be addressed. However, the great outdoors and fresh air are seen as health giving because they are part of life when travelling and seen as important to mental well being. The idea of the inside being pure and outside polluting is also mirrored in the insider/outsider division, where the outsider (non-Gypsy/Traveller) is seen as at risk of polluting the insider (Gypsy/Traveller). It is also seen at the personal level, with beliefs about the purity of the inside of the body as opposed to outside the body. There is also a demarcation between upper and lower body, with the lower body being polluted. This gives rise to rules concerning cleanliness, such as not having toilets inside the trailer as this would pollute the inside of the trailer and the use of separate bowls for washing different things and parts of the body. These rules have been described at length by Okely (1983 pp. 77 - 104). She explores the symbolic nature of pollution rules, suggesting that the inner body purity is a symbol for the Gypsy/Traveller's "secret ethnic self" that needs protecting from the polluting 'gorgia' society outside. The outer or public self provides that protection. Again, this is another way of protecting the coherence of the cultural group, but this time at the personal level, by providing a personal barrier between Gypsy/Travellers and the wider society.

There are also rules attached to travelling. Young unmarried women are not allowed to go travelling. If she wishes to spend time with another family member, this must be done with the permission of her parents. Also, Young unmarried men, although afforded greater freedom than unmarried women, are still expected to only travel to other relatives and are not able to travel alone or purely to experience new places. For example, one young male in his early 20s described how he would like to travel the world, to see different lands but said that this would not be acceptable in the community, and said it would be seen as 'turning your back on

them'. He had been to America recently but had gone with a cousin to stay with other family members.

By having strict rules, both at the family level and personal level, boundaries are created within which to live. These constraints are instrumental to the survival of Gypsies and Travellers by setting them apart from the wider society and helping to define what it is to be a Gypsy/Traveller (Ojanlatva 1996).

### 4.4.5.3  Punishment and the concept of 'shame'

There is one concept that runs through the fabric of Gypsy and Traveller culture and ensures the adherence to cultural rules; that is the concept of 'shame'. Gypsies call it *marime,* meaning impure, polluted and unclean both in terms of the physical self and also the moral self (Sutherland 1992).

Shame is defined as:

"A painful emotion resulting from an awareness of having done something dishonourable, unworthy, degrading, etc."

(Collins English Dictionary, 2000)

This is a powerful mechanism of control. To break the cultural rules can bring shame, both to oneself or worse, to one's family and is to be avoided at all costs.

Many things are considered 'shameful' or 'marime' in Gypsy and Traveller culture, many of which are connected with women's bodies or bodily functions such as menstruation and breastfeeding. Knowledge of or talking about the reproductive system or sex education is also viewed as 'shameful'. Things that are shameful are hidden and not discussed openly.

> The Project Health Worker talked to two young pregnant Irish Traveller women, one in her early 20s and her sister-in-law in her late teens, about pregnancy and breast feeding. They asked what was good about breast feeding and the Health Worker discussed the advantages of breastfeeding with them. One of the sisters said that such things were not discussed with parents, but would be discussed between peers. She said that she wouldn't mind trying to breast feed but it was difficult

because it would be 'shameful' if someone saw her. Her sister-in-law said she would try when she was on her own. The only problem with breastfeeding babies in an environment where it can't be shown is that the caravans have no privacy. There isn't a room that you can go into to feed a baby.

(Observational field notes, May 2003)

She (young Gypsy woman in her 20s) said that women do not talk of periods, and certainly not to men. She said she had very painful periods before the birth of her daughter. She could never tell her husband. She said that she came on her period the week after her wedding and she was so ashamed and embarrassed she packed some clothes and was going to stay with her mother. Her husband saw her walking and asked where she was going and what was wrong. She made an excuse about some name calling a couple of days before. When she finally got in his car, he asked her if it was 'women's problems'. She said she felt so embarrassed that she "wanted the earth to open up and swallow me up". She says she still can't talk to him about periods.

(Observational field notes, September 2004)

If a Gypsy or Traveller breaks the cultural rules and brings shame on their family, they run the risk of being ostracised from the group. This results in social isolation (Sunderland 1992). As Gypsies and Travellers are so dependent on the family group, this is the worse possible punishment, and in the worse case scenario can lead to a person's death through suicide. There was an example of this in Wrexham during the time of the study, where an unmarried Irish Traveller woman was accused of sleeping with her sister's husband. The result of this was that her family members left the site, leaving the accused woman behind. Communication with her family was restricted. The woman became severely depressed and began to hear voices. She finally died from an overdose of medication and alcohol. At the woman's funeral, we were told by another Traveller woman in attendance that the family members present were to blame for her death. She meant that the death was brought about by the woman being excluded from her family.

Lehti and Mattison (2001) illustrate this well when they talk of the 'Gypsy collective' and the hierarchical relationships inside the collective. To contravene the rules results in a collective punishment; which is to land outside of the collective.

## 4.5   Gypsies and Travellers and the wider society

### 4.5.1 How Gypsies and Travellers are viewed by the wider society

Gypsies and Travellers have a long history in the UK, dating back to the 15th century and also an equally long history of discrimination and persecution. Gypsies and Travellers have been singled out either as a threat, or romanticised as wild and exotic. In more recent times, during the twentieth century and into the twenty first century, Gypsies and Travellers have been, and still are viewed as a threat to settled society and often regarded with contempt. Enoch Powell, writing in 'The Times' in 1970, called for the abolition of the 1968 Caravan Act, suggesting that 'alien' Gypsies and Travellers should be dealt with through the laws of nationality and immigration. As Okely (1983 p.19) questions, what 'foreign' Gypsies was Powell talking about in 1970? She suggests that it was the foreign origins of the 'true Gypsies' that are used against them.

Enoch Powell was not the only politician to outwardly attack Gypsies and Travellers, in more recent years, politicians have attacked the lifestyles of Gypsies and Travellers and have sought to criminalise their way of life by introducing laws that attack travelling lifestyles. This has been done by reducing the obligation for local councils to provide sites while increasing police powers to evict. This has created a situation where Gypsy/Travellers are left with a shortage of 'legal' sites and are often forced to camp illegally.

In 1999 the then Home Secretary, Jack Straw was reported as saying that Travellers were "exploiting peoples sympathetic view of 'true Romanies' to burgle, thieve, break into cars and defecate in doorways" (Guardian 20th August 1999). There is no other minority group where such language is used against them by politicians in high government office in the UK. This may be because Gypsies and

Travellers are seen as the 'outsiders' and have little in the way of a political voice or political leverage. There are no votes to be gained by supporting Gypsy and Traveller rights and many votes to gain from people who feel threatened by the presence of Gypsies and Travellers in or near their communities.

In more recent years, Gypsies' and Traveller's nomadic lifestyle has come under renewed attack by some politicians. Conflict has arisen between settled people and Gypsy/Travellers due to a lack of 'official' Traveller sites. Gypsies came under attack from the leader of the opposition, Michael Howard, in 2005. He ran a press campaign including adverts in two Sunday newspapers promising to "clear away illegal Gypsy sites", suggesting that Gypsies were getting away with wrong doing and that he wanted to scrap the Human Rights Act as it was being used by Gypsies to challenge orders to leave unofficial sites (Observer 20th March 2005). He was also reported as promising to make trespass by Gypsies a criminal offence (Guardian 21st March 2005).

This campaign by the leader of the opposition was run on the back of a publicity campaign run against Gypsies and Travellers by some of the daily newspapers including the Daily Mail and the Sun. The language used when reporting conflicts between Gypsy/Travellers and local communities both in local papers and the national press has used provocative language designed to elevate fear and hatred of the 'outsiders'.

> "My 19 months of hell". Villages' 20 protests to police after invasion
> of travellers.
> 'Outrage as Gipsies ruin wildlife haven'
> (Daily mail 24th November 2004)


> "Prescott's mad order to police: Hands off Gipsies"
> (The Sun 10th March 2005)

*"Gipsies: thousands join our fight; Sun campaign; Illegal gypsy camps"*

*(The Sun 11th March 2005)*

*"I cleared out travellers...Britain should do the same"*

*(The Sun 13th June 2005)*

*"Coming to a field near you...; Gipsies get the boot from site"*

*(The Sun 14th June 2005)*

Although these papers claim to be fighting a campaign against illegal sites, they also report any attempts to alleviate the site shortage with contempt. Reports use such headlines as *'Gipsies get £8m for new sites...An £8 million handout to open 58 new Gypsy sites was unveiled by ministers yesterday...' (The Sun 23 July 2005).* The article goes on to quote Tory MP Ann Widdecombe, stating that this will result in *"even more gipsy camps and more travellers camping illegally".* The article ends with the statement: *'The Sun is campaigning for new laws to kick out lawless travellers'.*

This is a campaign designed to persecute a minority group (the outsiders) by those who are themselves outsiders in government, the opposition. There can be no 'win' without the elimination of the 'threat' which is the existence of the Gypsies and Travellers. These campaigns by newspapers and politicians, as well as reflecting the views of the wider society, also in themselves increase fear and incite hatred by demonising Gypsy/Travellers and reinforcing negative stereotypes. They suggest that there should be no provision or public money invested in official sites and unofficial sites should be outlawed. However, others have tried to present a more considered and balanced approach to Gypsies and Travellers, such as the reporting in the Guardian. Over the past six years, the Guardian has featured articles highlighting the discrimination suffered by Gypsies and Travellers and the problems that have arisen concerning safe places for Gypsies and Travellers to live. It appears however, that politicians still choose to jump on the sensationalist bandwagon to gain votes.

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Local newspapers, over the period of this study, have tended to concentrate on the issue of 'unofficial' campsites in the local area. The language used is often unsympathetic to Gypsies and Travellers and is similar to that used in the national press.

Following the forced eviction in 1999 of Gypsy/Travellers from an unofficial site that had been occupied by Gypsy/Travellers for over two decades, the local newspaper, the Wrexham Evening Leader, featured the story on the front page with the works 'EVICTED' in bold letters. A commentary, also found on the front page on the day of the raid illustrates the way the local press clearly had opinions on the raid which were far from neutral.

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***EVENING LEADER COMMENT (September 17<sup>th</sup> 1999)***

It took a near military plan and execution to clear travellers off the "hospital site" this morning. No one wants to see people dragged away kicking and screaming but this sorry episode had to end. It should never have happened in the first place!
  The site has been allowed for one reason or another to linger on for more than two decades bringing misery to people at the hospital and sadly to people in the town.
  The final cost will be astronomical but with only one official site to contain, the council and police will be able to use the full force of the law to monitor the situation.

---

The tone of local reporting changed briefly following the unlawful killing of Johnny Delaney in 2003 (for a description of this see section 4.5.3), the Wrexham Evening Leader ran a full page article on the plight of the Gypsy/Travellers in Wrexham. The article was entitled 'Running the daily gauntlet of hatred and prejudice', and featured interviews with a family that were directly related to Johnny Delaney. It was a thoughtful piece of journalism and accurately reported the experiences and feelings of the Gypsy/Travellers on the council run site. However, time has passed and the reporting of disputes over Gypsies' and Travellers' unauthorised

encampments continues with the familiar use of inflammatory headlines and reporting. For example, the headline in the Wrexham Leader in September 2005 which states: 'Travellers occupy town centre site'. As resent as June 2006 the Wrexham Evening Leader used a dispute over Gypsy/Travellers stopping near a service station near a bypass in the town as front page news. The main headline ran: 'FURY OVER GIPSY INVASION' and language such as "the group descended on the site" was used.

Finally, The Sun proposes 'kicking out' the lawless Travellers. This echoes the demands of Enoch Powell forty years previously. Who are these 'lawless Travellers'? And where should they be 'kicked out' to? It appears that little has changed for Gypsies and Travellers concerning how the wider society perceives them. The stereotyping and discrimination of Gypsies and Travellers is so ingrained in our society that racist comments and mockery goes without comment let alone condemnation. One example that illustrates this acceptance of the intolerance towards Gypsies and Travellers in society was the televised performance by a popular female comedian, Katherine Tate, at the Royal Variety Performance in November 2005. Katherine Tate delivered a monologue in character, as a belligerent teenager. As she faces the royal box she says to the Queen:

> "Am I bovered, yeh, but am I bovered, I ain't bovered,
> look at my face, am I bovered, you calling me a Pikey,
> you calling me a Gypo, you saying my dad's a Pikey,
> you calling my dad a Gypo..."
> (Royal Variety Performance, 2005)

This is seen as good harmless fun, but would it have gone unnoticed if we changed the works 'Pikey' and 'Gypo' for 'Darkie' 'Packi' or 'Jew'.

Gypsies and Travellers are still seen as something to fear and are still perceived as legitimate targets for hatred. This however, is not a new phenomenon, Gypsies and Travellers throughout history have been persecuted and perceived as the 'outsiders'. They set themselves apart from the greater society, this provides them

with their strength and identity but comes at a cost, the cost of suspicion and mistrust.


## 4.5.2 Gypsies and Travellers and the Education System

### 4.5.2.1 Experience of formal education

As described earlier in section 4.4.3. Gypsy/Traveller education, many Gypsies and Travellers either have limited or no formal education. For those who do attend, formal education ceases in their early to mid teens and none of the Gypsies and Travellers interviewed or encountered in this study had education extending beyond the age of 16 years. The reasons given for this lack of formal education are a nomadic lifestyle, lack of interest in learning, and a lack of encouragement from parents. This was also found by Van Cleemput who described the reasons for a lack of formal education were a travelling lifestyle, forced moves, discrimination, and an inability to get children into preferred faith schools. Arayici (1998) put forward the argument that Gypsies' reluctance to send their children to school has worked to their advantage in the past by preserving their difference from the wider society which threatens assimilation. It is therefore a way of protecting the culture and cohesion of the group by staying outside the education system. This has also been observed in this study where there are cultural expectations for young people to follow a more traditional Gypsy or Traveller lifestyle in which men are self-employed and women look after the family at home.

Also, some reported experiencing segregation and discrimination in school and felt the education system had failed them.

> "Went fer two year to high school. I didn't like it. They had no time fer me. I used to be in classroom by meself like with one teacher. Like they used to have all the Travelling children, t'was six in a class, like there were six in the whole high school and they used to have that six in a class on its own...just that six in a classroom and just give 'em a load of colouring pens and books and 'colour in' all day. That there is why I never used to like going to school. And that's why some Travelling children don't like going to school, 'cos they know the teachers is not learning them anything. They're going to school fer nothing 'cos they don't learn....like they don't treat you the same way

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*they treat the other children. 'Cos with the other children, they're giving them all the proper work to do, with you they just give yer something silly to do. So how could you learn?*

*You can't improve anything if they're doing that to you. Nearly every school I went to they did that to me.... my mother mostly learned me how to read."*

<div align="right">(Resp.8, female, 20yrs, Irish Traveller)</div>

**Respondent:** *never learnt nothing... because, usually some school teachers have no patience with you at all because of who you are.*

**Interviewer:** *So you thought you were treated differently because you were a Traveller?*
**Respondent:** *Yeh, you go to a schools and you look, they haven't got very little room for two, for a group of local people, a group of local people but they did for the Travellers, the Travellers was put into a room abut the same size as this room here.*
**Interviewer:** *A separate room?*
**Respondent:** *Yeh, and thrown there all day with colouring books and pens, you could do what you want, play games*
**Interviewer:** *Did you have a teacher with you?*
**Respondent:** *Yeh, the teacher was there but she never, she'd sit you down on the floor and read stories to ya..*
**Interviewer:** *but she never read with you to teach you?*
**Respondent:** *no, not to teach us, sit us down with and pens with all the big classes, we took over our own classes and put in, like into a big room with all the, I could be in group 4 and someone else could be in a higher class like 7.*
**Interviewer:** *so all the ages were mixed?*
**Respondent:** *Yeh, all the ages were put in together, so, there's like (names several sisters and brothers) they all learned in Ireland, they can read newspapers and ...*

<div align="right">(Resp.13, female, 21yrs, Irish Traveller)</div>

There was also a feeling that academic education, in particular, further education could not offer a pathway to employment because of perceived discrimination in the workplace, and so was of no value. Traditional Gypsy/Traveller acquired skills were seen as of more use in providing in income and skills for the future.

The main reason for attending school is to learn to read and write. Several interviewees expressed regret at not being interested or attending school and therefore not being able to rèad and write. One young male who was literate and had attended school until the age of 16, said that he felt that he had gained an

advantage in that he had gained skills in computers which his fellow Travellers did not have, but also felt that he had missed out on some of the skills his contemporaries had acquired through traditional means. He now felt it was important to 'catch up' with them.

### 4.5.2.2 Academic aspirations for own children

The expectations expressed by the parents interviewed, were, that their children would attend school and some said that their children enjoyed school. It is important for their children to attend school, but not necessarily through to the end of secondary school.

It is seen as important for children to learn to read and write so they can live independent lives in a modern world, it as necessary for form filling, driving and reading instructions for DVDs etc. Also, several wanted their children to have the opportunity that they didn't have themselves, to learn. One parent expressed a concern that their child may get bullied in school because she is a Gypsy, but she felt that this was something that her daughter was going to encounter in life and that school would be a place to learn to deal with it. Another woman was worried because her younger brother was being bullied at school.

> "You can get some children going to school now and they can get bullied in school, ..... (brother) has been bullied today....it'd be you Gypsy this and you Gypsy that , no, we go to school, why do people call us 'you Gypsy this' and 'you Gypsy that'. We're all brought in the one place, like we're all brought in the one world."
> (Resp.13, female, 21yrs, Irish Traveller)

On the subject of education potentially providing a pathway to employment, parents' opinions varied. Some believed that education would be important for their children to obtain jobs, whereas others felt that tradition dictated that this was not the case. They anticipated that their children would follow a traditional lifestyle and not look for paid employment.

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*"I never went to school, that's what I regret. I never was interested in school. It's different with my children, they have all gone to school. They like school and that's good. I don't have a problem getting them there. I want them to learn like I didn't. It's important that they can read and write so if they want a job they can get one. I want them to have what I didn't."*

*(Resp.5, female, 37yrs, Irish Traveller)*

*"But they wouldn't* (go to college or university), *that's the thing. They wouldn't, wouldn't even dream of it. Not for the sake of me encouraging it, d'you know what I mean, I know they wouldn't want to do it anyways, because a Travelling girls' life is cook, clean, look after yer home, it's never been any different, been like that fer centuries, d'you know what I mean. I was the same, me girl'll be the same."*

*(Resp.2, female, 22yrs, English Gypsy)*

Formal education beyond the basic skills of reading and writing is seen by Gypsies and Travellers as incompatible with their lifestyle and their continuing Gypsy/Traveller membership. As described earlier, much more emphasis is placed on acquiring the skills to survive as a Gypsy/Traveller. These include traditional skills for girls, such as child care, cooking and cleaning and non-wage labour, self-employed skills for boys.

### 4.5.3  Gypsies' and Travellers' experiences of discrimination from the wider society

*"We bleed, we eat, we sleep, we do everything. We wash the same, so what's the difference really. Just because we live in a caravan and we're called Travellers, that's it."*

*(Resp.12, female, 20yrs, Irish Traveller)*

Gypsies and Travellers experience discrimination and intimidation on a regular basis. This is so commonplace that all those questioned had experiences of discrimination to recount. This discrimination is widespread throughout society. Gypsies and Travellers experience discrimination by private businesses such as shops, pubs and restaurants, and by institutions such as political parties (section 4.5.1), local councils, police, health services and schools (section 4.5.2.1). Examples of discrimination are below. There is a wide held belief within society that all Gypsies and Travellers are actively involved in criminal activity and are

trouble makers. Although there is an element of criminality in the Gypsy and Traveller communities, as there is in all society, this is by no means all of the community and this perception often causes real distress to Gypsies and Travellers who are not involved in criminal activity or unruly behaviour.

The discrimination experienced takes many forms, from signs posted outside public houses saying 'No Gypsies or Travellers' to being refused entry at nightclubs, to being put under close surveillance in shops, and being subjected to verbal abuse. Most Gypsies and Travellers recount these types of discrimination occurring on a daily basis.

> *"I have had a lot of problems with that (discrimination), d'you know. How can I say to yer...went into a pub, because we was what we are, they wouldn't serve us, d'you know. And we get that problem every day. Somebody who, I can guarantee will turn around, 'Oh look at them, it's Gypsies', or you walk around the market and everyone's grabbing everything...y'know, 'Just watch 'em'. I mean you walk into a shop, because we're Gypsies, the security guards may not be there when you walk into a shop, but you're guaranteed by the time you're walking around the shop there'll be two security guards at the door, and there's ladies stood where you're stood, d'you know what I mean, and when you walk out of the shop they laugh at yer. We get that everywhere we go, not just one place, it's everywhere."*
> *(Resp.2, female, 22yrs, English Gypsy)*

> *"Things like going into town when, when I went to a nightclub or anything, they just tell you, 'you can't come in tonight'. Call you Gypsies and that. Like one fella out of...(clothes chain store), he's a security guard, he's a bouncer is what he is. Me and a cousin was walking through the town and 'The best place for you is in the skip', he said, 'You smelly Irish bitch', he said. He banned me out of the shop fer nothing. It's like when you go into town, you're on a CCTV camera, all through town. You get watched in every shop you go into. Soon as you go in someone says 'Oh here's the Gypsies in here, Gypsies'. And they ring the bell straight away."*
> *(Resp.12, female, 20yrs, Irish Traveller)*

As mentioned previously, institutional discrimination also exists and appears to be widespread. In recent months, some political parties have used Gypsies and Travellers as a political football, inciting fear and reinforcing stereotypes (see

section 4.5.1). Discrimination can be seen at local council level when Gypsies or Travellers apply for permission to live on their land. For example, the local Council in Wrexham has gone to great lengths to fight an application of a local Irish Traveller family to live on their land. They have taken the Traveller family to various court hearings including the High Court and refuses to acknowledge their status as Travellers, yet they hold a plot for their eventual eviction to the council run Traveller site.

The health service is an institution that discriminates against Gypsies and Travellers in perhaps more hidden ways, for instance the trouble experienced by this community when trying to register with a GP if you do not have a permanent address with a post code. Feder (1994) following a questionnaire of all GPs in East London, found that 10% stated they did not take on Gypsy/Travellers. He also found that one quarter of those Gypsies and Travellers interviewed reported exclusion from GPs in Hackney and two thirds elsewhere. One example of the reluctance of GPs to register Gypsies and Travellers occurred during this study. The Project Health Worker was assisting a young Irish Traveller woman to register with a local GP. She wrote to the GP to explain the health needs of the woman and accompanied her on her visit to the GP. The Project Health Worker overheard the GP saying to the receptionist that she had been 'tricked' into accepting the woman as she did not know she was a Traveller. Furthermore, the Project Health Worker on several occasions through the time of this study recounted encounters with Health Visitors who did not work with Gypsies and Travellers and expressed their feelings and stereotyping of Gypsies and Travellers, asking the Project Health Worker why she bothered with such people and how they would not want to work with this group. This problem of access to primary care is explored further in the section looking at Gypsy and Travellers' experiences of healthcare section 4.6.2.2.

Perhaps one of the most disturbing accounts comes from discrimination within the police force which extends from verbal abuse through to harassment such as searching caravans without warrants to stopping and searching women in the high street. Several people described how the police, on more than one occasion, came to the Gypsy/Traveller site and proceeded to search the caravans late at night

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without warrants. One woman recounted a raid where she refused to allow access to her caravan without a warrant and was arrested.

> *"They comes in here and they comes into yer caravan to search and you can't do nothing about it. Try to stop 'em yer gets arrested, 'cos they done that to me. I tried to stop 'em, I said 'yer not coming into my caravan 'til yer have a search warrant'. I got arrested fer it. Tried to do me fer it. 'You're not coming into my caravan' I said, 'You've got no right'. 'Yes I am' he said, 'I can come in here anytime I want. I don't need a search warrant fer yous people, fer yous people we don't need it' he said, 'Fer any of these caravans, we can come into these caravans anytime we want to search, and take what we want out of it' and there's nothing you can do, we don't need search warrants'."*
> *(Resp.5, female, 35yrs, Irish Traveller)*

Another woman recounts an incident that happened recently when she was shopping in town with her sister and pre-school aged niece. They had been clothes shopping and had spent £90 between them in a well known high street clothes shop. On leaving the shop and walking down the high street, a police car stopped them. They were accused of shoplifting from the shop that they had bought the goods from. The police searched them in the middle of the street in front of all the other shoppers, opening their bags and pulling out their purchases, bodily searching them even down to taking off their shoes...

> *"Yeh, all the people was looking at us and one policeman called over this young lad and said 'Ah look, we're just searching these Gypsies' and when they found nothing on us, they didn't even say sorry or it was a mistake or nothing. They just got back in their car and went back to the shop."*
> *(Resp.13, female, 21yrs, Irish Traveller)*

Gypsies and Travellers also experience segregation and bullying in schools and are fearful of violent attacks on their children. As mentioned earlier, some Gypsies and Travellers have experienced being segregated from the rest of the school by being put together in a class of their own, where they describe being given little in the way of teaching and say they spent most of their time colouring. It appears that at times, children who have the greatest need for extra tuition receive the least. Some people described being bullied at school or fearing that their children will be bullied, and a fear of violence against their children was expressed. School

children from the local town have been heard shouting and jeering from the school buses when passing the council run site.

It is difficult to say how wide spread this may be, but the local Traveller community recently suffered the loss of a boy in their community who was unlawfully killed by a group of boys on a housing estate in nearby Ellesmere Port. The victim was a member of an extended local family in Wrexham. The police involved in the case expressed the belief that the killing was racially motivated and witnesses in court described hearing the perpetrators say that the victim was 'only a Gypo'. However, even with eye witness testimony, the judge decided that it was not a racially motivated killing and the perpetrators were convicted of the lesser charge of manslaughter rather than murder. This has brought home some of the Gypsies' and Travellers' greatest fears, the fear that their children will be persecuted or even killed.

> "Everything revolves around violence today and I don't think it's very nice. I don't want my children brought up in a violent situation, d'you know what I mean. But then again, when they go to school, they only learn, the kids what play with only learn what their mother and father's teaching them. They wouldn't know what a Gypsy is. It's like when my little girl starting going to school, it's obvious they're gonna call her Gypsy...but they don't know that, they're only taking heed of what their mothers and fathers are saying... So they're bound to have a problem with it, everybody's got a problem with it."
>
> (Resp.2 female, 22yrs, English Gypsy)

## 4.5.4 Gypsies' and Travellers' perceptions of 'Gorgias'

The high level of discrimination experienced by Gypsies and Travellers has led to a deep mistrust of outsiders and an expectation of discrimination. This was also described by Van Cleemput (2004), when she described how discrimination results in defensive hostile reactions, resourcefulness, avoidance of encounters and overall mistrust by Gypsies and Travellers. I put forward that these are natural defensive reactions to a hostile world. They are however, not the only ways that our hostility towards Gypsies and Travellers is received. Gypsies and Travellers

are proud people and can be saddened by the way they are perceived by the wider community. For example, it was reported to me by one of the GPs who has Gypsies and Travellers as patients, that an Irish Traveller woman had come to see her in the surgery and had broken down in tears at the things that were being said about Gypsy/Travellers at the time of the Michael Howard campaign.

Because Gypsies and Travellers perceive the outside world to be threatening, they often demonise Gorgias. Stories abound which act as a warning to Gypsies and Travellers about the dangers posed from 'outsiders'. There are stories of terrible doctors who come to sites to kill their children with injections and the terrible things that happen to children in the wider society, such as murders and molestations, are cited as reasons why Gorgias are not to be trusted.

> *"like I can't see why people, like even local people can go and get a stranger, a black stranger off the streets, don't know nothing about them, I could say 'yeh, I'll look after your kids' and I could say 'how old are you?' 'Have you ever looked after children before?' I could say 'yeh', anyone could go out and get copies saying yes she is a very good babysitter, I could even fraud all them and people are not looking into that are they? There's this school girl now, she's been raped at this side of the chapel, and they're saying they got this man, how do they know they got the proper man that done it? She's dead, she can't tell the tale. So, they do, they (local people) go look for different kinds of people to look after kids.*
> *(Resp.13, female, 21yrs Irish Traveller)*

Their own personal experiences of discrimination and acts of violence against them such as that of the unlawful killing of Johnny Delaney, reinforce their worse fears about Gorgias, that they are dangerous people.

Gorgias also, are seen to possess looser morals than Gypsies and Travellers. The 'freedoms' enjoyed by Gorgia women are sighted as evidence of loose morals in the wider society. Gorgia girls and women are seen as permissive because they drink alcohol, date and will openly admit to pre-marital sex, which is not allowed in Gypsy and Traveller society.

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*"well, little girls today(non-Gypsy/Travellers), as far as I can see of 'em, they go out, they 'ave men, they come back with love bites, they drink, they smoke, they take all sorts of drugs, they 'ave babies when they're not even married....to me that's, because of the way I've been brought up, that seems dirty.."*

*(Resp.2, female, 22yrs, English Gypsy)*

Gorgias are also perceived to be less clean than Gypsies and Travellers because they do not follow the Gypsy/Traveller rules of cleanliness and purity. If a Gorgia uses a caravan for holidays, they will defecate in it by using the toilet inside the caravan, which to a Gypsy or Traveller is a sign of their uncleanliness. By not following the Gypsy/Traveller's rules of cleanliness and purity Non-Gypsy/Travellers are, by definition, unclean and of loose morals.

There appears to be a polarization of views between Gypsy/Travellers and the wider society, with each holding stereotypical ideas about the other, resulting in fear and demonising of one another. Nickson (1997) describes this polarization of stereotypes well when she talks of society seeing Gypsies as "rogues, liars, thieves, as being cruel to animals and above all, dirty". She then goes on to talk of how Gypsies see Gorgias as the "enemy, the objects of economic exploitation" and goes on to say that Gypsies compensate for their bad treatment from Gorgias by taking pleasure in small triumphs over them, either in the form of cheating a Gorgia in a business deal or moving on without paying outstanding debts. This often results in furthering the cycle of persecution through increased interest by the police.

## 4.6   Health beliefs and experiences of health care

This section is an exploration of Gypsies' and Travellers' health beliefs. This evaluation study is directed at a community health initiative, therefore, Gypsies' and Travellers' health beliefs and experiences of healthcare have been studied in depth, as these have direct impact on the initiative. Why investigate people's health beliefs? Morgan (2004) discusses the body of evidence from social anthropology, medical sociology and cross-cultural psychiatry which demonstrates the link between health beliefs and help seeking behaviour. Morgan goes on to suggest

that a persons' responses to illness are consistent with their 'cultural framework', how people make sense of their experiences.

The themes explored in this section are located within different levels of the 'systems hierarchy'. For example, Gypsies' and Travellers' health beliefs are situated within both the culture and community systems whereas health care seeking is situated at the personal system and experiences of healthcare are situated within the community system.

## 4.6.1 The health beliefs of Gypsies and Travellers

> "There are three things that are important to a Gypsy, family, happiness and good health. Your family bring you happiness. But you can't enjoy your family without good health."
> (Old Gypsy saying)

### 4.6.1.1 Gypsy/Travellers' definition of health

The interviewees were asked what their definition of good health was. Most people had difficulty understanding the question and it was rephrased as 'How would you describe a healthy person?' Most people could answer this question.

Definitions of a healthy person were divided into two main responses. Some saw being healthy in terms of an absence of illness, not needing medication, and being able to continue with your daily routine. Only one person talked of being healthy in terms of quality of life, of being happy.

> "Healthy, I'm healthish or I think I am, d'you know what I mean, I get up in the morning, I do everything. I cook, just the same as everybody I think, and I don't know nothing else....good blood, good nerves, things like that you're on about."
> (Resp.2, female, 22yrs, English Gypsy)

> "Good health is when there's nothing wrong with yer. yeh, good health innit. Be happy. Well, and yer up and going places and things like that and enjoying what years is left in yer."
> (Resp.3, female, 65yrs, Irish Traveller)

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Others, in the present study, also, talked about health in terms of lifestyle, suggesting that a healthy person is one who looks after themselves by eating 'good' food, taking regular exercise, not smoking or drinking alcohol.

> *"Somebody in good health I reckon meself, somebody in good health don't smoke, never smoked in their life, and they go to leisure centres, to keep fit classes and running and jogging and cycling, stuff like that. That's what I call a really healthy person."*
> *(Resp.1, male, 35yrs, Irish Traveller)*

> *"Someone who doesn't drink or smoke and who eats good food like lots of vegetables and fruit and who do lots of cleaning cause that is good exercise for you, being active."*
> *(Resp.7, female, 23yrs, Irish Traveller)*

Gypsies and Travellers also associate health with cleanliness. Much time is spent cleaning the house or caravan, often using strong cleaning agents such as bleach. Health is also associated with personal hygiene. To keep yourself and your home clean is to keep yourself and your family healthy.

> *"I enjoy being like cleaned up, 'cos it's very, like it's a thing that it's nice to be about it, it's very, what d'you call 'em, it's like health kind of ways. Like keeping yer home clean and stuff like that there....So whenever I get up in the morning, I wash me hands and face and I'll feed me child. I'll wash her. I'll strip her down and I'll finish cleaning up..."*
> *(Resp.6, female, 20yrs, Irish Traveller)*

Good health was seen as important to most interviewees. It was seen as important because of responsibilities that people have and also personal happiness.

> *"Very important (good health). I've got to raise me kids the best way I can like y'know and you've got to be strong to raise your kids."*
> *(Resp.1, male, 35yrs, Irish Traveller)*

But when asked about their own health, most people said they were not in good health. Again, people either saw their health in terms of the presence or lack of illness or in terms of their lifestyle.

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*"I'm not very healthy. I have asthma and very bad knees. I try to walk 'cos it's good fer my nerves but I can't walk far because of my knees, though they are better if I move about. But if I walk then my asthma gets bad and I'm all out of breath."*
*(Resp.9, female, 50yrs, Romany Gypsy)*

*"Yeh, I'm very healthy...well, I've never been to hospital with serious things, so, nothing like that, yeh, I'm very healthy."*
*(Resp.13, female, 21yrs, Irish Traveller)*

*"Not really 'cos I don't eat very well, I eat too much red meat and chips. Some say they're bad for ya, too much fat can clog up yer heart."*
*(Resp.10, male, 16yrs, Irish Traveller)*

In contrast, a study of people from South Asian origin, living in London, who also largely held the belief that health is mainly a lack of illness and an ability to perform everyday functions without pain, reported the causes of ill health being much more wide ranging with both 'external' and 'internal' factors ranging from social situations of the individual, economic pressures to environmental pollution, to stress and diet (Lambert, cited in Kelleher & Hillier, 1996).

### 4.6.1.2 Perceptions of lifestyle and health

Many Gypsies and Travellers in this study believed that they could change their health. Some believed this could be done through changing their lifestyles to more healthy ones, such as modifying behaviours which were seen as unhealthy, including smoking, alcohol consumption, exercise and diet.

Smoking was mentioned by several as being an unhealthy habit. Although people talked of wishing to give up or cut down on their smoking, it was seen as a necessary evil to cope with 'nerves' and depression problems.

Many acknowledged that excess alcohol consumption was damaging to health and several said they had seen this damage first hand in family members who were alcoholics. Often this experience will influence the drinking habits of the other family members, making them more aware of the damage done personally and to the whole family by alcohol abuse.

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*Interviewer: Does alcohol affect peoples' health?*

*Respondent: An awful lot of people, yeh. It does yeh, but only if you're fond of it.*

*Interviewer: So it's only if you drink too much you're saying.*

*Respondent: If you drink too much, yeh. Not if you drink too much, it's nice like if you go out, I don't know 'cos I don't really drink meself. Not with seeing me dad like, 'cos me dad's an alcoholic.*

*Interviewer: Do you think that's affected his health?*

*Respondent: Yeh, it has a lot over the years...He goes stupid. He's not the same man as when he's off it.*

*(Resp.12, female, 20yrs, Irish Traveller)*

Exercise was seen as a good thing for a healthy body and also for a healthy mind. Men talked of exercise in terms of activities such as jogging, cycling and boxing, whereas women associated exercise with keeping active doing housework and looking after the children.

Eating a healthy diet was seen by some as important for good health and several mentioned the importance of eating vegetables daily and fruit and yogurts. It was acknowledged that too much 'grease', fried food and red meat can be bad for your health.

Other ways of improving health were also mentioned such as preventative measures, for example, vaccinations, keeping up with prescribed medications, living in caravans and also cleanliness.

These findings are slightly different in emphasis than those found by Feder (1994) who found environmental factors such as dangerous sites and absence of facilities were considered main contributors to ill health. Hodgins (2006) also found that environmental and social factors were given more importance than lifestyle measures such as smoking and diet as contributors to ill health. However, that may be a reflection of the fact that there are no temporary sites or roadside encampments in Wrexham. As mentioned previously, cleanliness is seen as

directly affecting the health of those around you. Living in a caravan rather than a house was seen as a much healthier lifestyle because you lived in the open air rather than an enclosed building.

> *"Cos you're out in the open, you're always out in the fresh*
> *air...That's the travelling life, yeh. You hardly ever see a Traveller*
> *like, really sick. When they settles down that's when they get sick."*
> *(Resp.5, female, 37yrs, Irish Traveller)*

Also, as mentioned earlier, religion and health are closely linked. The health of others can be changed by faith, divine intervention either by petitioning the Pope, pilgrimages to holy places and prayer. This however, is often used either when conventional medicine is failing or alongside conventional medicine. The exception to this being the dividing of the blood executed by the Pope, which is done to protect the children of a double first cousin marriage from abnormalities due to the 'richness of the blood'.

The close connection between religion and health is not unique to Gypsies and Travellers, but has been reported in other groups of people where religion has a strong influence on life. For example, Bangladeshi mothers interviewed in East London used both Western Medicine but also would consult mullahs, persons at the mosque, prayer and spiritual healers (pir) if their children were ill. Both physical illness and behavioural problems in children were believed to have a possible non-physical cause (Hillier, cited in Kelleher & Hillier 1996, p.58 – 59). Furthermore, it has been suggested by some studies that religion may be a stronger factor in poor health than ethnicity. Those who are more devoutly religious may have more in common with one another than other members of their own culture (Greenhalgh 2004; Ypinazar 2006). An example of the possible influence of religion in health is observed in the poor health of people of Irish descent in England, Scotland and Wales (Abbotts 2001; Harding 1996; Kelleher 1996). Abbotts (1996) reported that there remain significant differences in health in 'Catholics' compared to 'non-Catholics' in people of Irish descent, even after accounting for gender and social class.

Also, in the present study, there are those who did not believe that the health of the individual can be changed. Health to some is seen as a matter of luck, what will be, will be. That nothing a person does will affect their health in the end.

> *"Yeh, its luck of the draw. Some people says that drink is this and drink does that and drink is bad for you, it is really bad cause it can do damage to your inside, but then some people drinks like alcoholics and can pull through it. So you can't just blame the cigarettes and drinking, can you."*
>
> *(Resp.13, female, 21yrs, Irish Traveller)*

Feder (1994) also found that some of the Gypsy/Travellers that he interviewed expressed a fatalistic belief of health. Although he found that Gypsy/Travellers also talked of environmental factors influencing health, these factors, he suggests, are believed to be outside the Gypsy/Travellers' individual control and so transcend the fatalism/lifestyle dichotomy. Gmelch (1985) suggested that this fatalism seen in Irish Travellers in his study was a coping mechanism when resources and opportunities are severely restricted.

Fatalism, believed to be linked to religious beliefs, has also been found in other ethnic minority groups. For example, Afro-Caribbeans living in the UK, who had been diagnosed and had been living with hypertension also talked of their 'fate' and 'what will be, will be' in relation to their long-term worries about their condition (Morgan, cited in Kelleher & Hillier 1996, p.25). Also, Gujarati immigrants in the UK had increased supernatural and chance reasons for ill health compared to a British caucasian beliefs (Jobanputra 2005).

Others interviewed talk about the traditional view of health by Gypsies and Travellers, in particular, the reluctance of men to see to their health needs. Many men do not register with a GP, choosing to ignore health concerns until they become a serious problem. Men talk in terms of healing themselves. There is a belief that a 'strong' man does not need to go for help for 'minor' ailments. This reluctance by male Gypsies and Travellers to engage with health care services has been explained by Hawes (1997) in terms of "vague 'matcho' reasons". I put forward the argument that for Gypsy and Traveller men, illness poses a threat to

their male identity. Because illness is linked with the idea of 'weakness' it threatens the ideal of the strong Gypsy and Traveller male.

Also, some Gypsies and Travellers expressed a view that their focus was with the 'here and now', that they live from day to day, they don't look too far to the future so eat whatever they want. That they always have seen life like this and that this will not change.

> "We take every day, step by step, we take life as it comes to us, we take things in our stride. We wake up in the morning and we don't think to ourselves 'we're not going to eat that today', we don't think nothing like that, d'you know what I mean, we just go to the supermarket, we get what we want, we come back and eat it."
> *(Resp.2, female, 22yrs, English Gypsy)*

### 4.6.1.3 Perceptions of mental health

Why look at people's perceptions and beliefs of mental health? As Kleinman (2004) observes, *"how depression is confronted, discussed and managed varies among social worlds. Culture, meaning and practice shape its course"*. Kleinman illustrates this by using the example of Chinese society, who express depression in physical rather than psychological terms. This has a great impact on what is viewed as appropriate treatment.

Mental health problems are generally accepted in the Gypsy and Traveller communities as 'health problems'. Often Gypsies and Travellers will refer to mental health problems as 'suffering with nerves'. This is a generic term covering most common mental health conditions such as depression and anxiety. Several people suggested that mental health problems could go on to affect your general health. Two main reasons were given for mental health problems. The first is that it is a natural reaction to an event that has happened to you in the past or some current stress or worry. Often the onset of depression is linked to the death of parents or children. The family unit is very close in the Gypsy and Traveller communities. Suffering the loss of parents or a child causes severe grief that often results in long term depression lasting for years or even a lifetime. Another cause is the effects of being a victim or witnessing domestic violence as a child.

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The second reason for mental health problems is that you are the type of person that suffers from 'bad nerves'. There is no specific trigger. It is often seen as bad luck if you suffer from nerves. This has also been observed in other cultures such as Aboriginals where the concept of depression does not conform to Eurocentric perceptions of illness but rather it is a state that is inaccessible to treatment as it is the way that person is in the world, *"that's just the way he is"* (Vicary (2004).

Many people in the Gypsy and Traveller communities suffer from mental health problems (see mental health status results, Chapter 6, section 6.2.4), 9 of the 13 Gypsies and Travellers interviewed said that they were suffering from mental health problems currently, mainly depression. Of the four remaining, two said they had suffered from depression in the past, one said they were OK and one did not mention their own mental health. Van Cleemput (2004) also discussed the prevalence of mental illness in Gypsies and Travellers *"Virtually all respondents spoke of personal experience or of a close relative suffering from clinical depression"*.

Many of the mental health problems suffered by the Gypsy and Traveller communities are both severe and enduring. Depression and anxiety is often experienced for many years. Onset can be as early as in their mid teens and several people described becoming depressed at the age of 16 or 17. The types of symptoms described are severe, ranging from paranoia, sleep disorders and panic attacks through to withdrawal and suicidal thoughts. One woman admitted to being hospitalised due to her 'nerves' and having to go 'cold turkey' to come off a cocktail of medication. Several women suggested that the only thing that stopped them from succumbing to their suicidal thoughts was the thought of the impact this would have on their children. Unfortunately, one woman who lived on the Gypsy/Traveller council site and was well known to the project workers did commit suicide recently.

*"I do get depressed and that a lot, an awful lot like. Sometimes when I get depressed, I don't like communicating, don't like going out around people, imagine everyone is talking about me. Everything comes to me head and I get that bad that sometimes I feel like killing*

*meself. And then I think of me little child, and like me children, more than..that's the only thing I think of in life, and it's like I brought them into this world and I have to bear it."*

*(Resp.8, female, 20yrs, Irish Traveller)*

Although Gypsies and Travellers acknowledge that mental health problems are a health issue and that they would see a doctor, some are reluctant to seek medical intervention. Many describe having to 'fight' it, that it is something one must strive to overcome, to find the strength to overcome.

*Respondent: Oh ay yeh, I did, I went to the doctors and he gave me some anti-depression tablets. They gave me a full course but I never took the full course and I took about three or four of them and I cured meself. That was it then. I didn't take any more, put the rest down the toilet.*
*Interviewer: So you decided, you did it yourself without them.*
*Respondent: Mmm. Self willpower. You've got to just fight it.*
*(Resp.1, male, 35yrs, Irish Traveller)*

*Interviewer: And do you seek help for that, have you seen a doctor or anything?*

*Respondent: No, I try to do it meself, always 'ave done. I'm just frightened of going on the tablets in case I get addicted to 'em. And I 'ave done it meself and I do get better.*
*(Resp.11, female, 35yrs, Welsh Gypsy)*

Many recognise the signs of the onset of depression and adopt strategies to overcome it. These strategies often include distraction techniques therefore not allowing themselves time to stop and think about their troubles. Women in these communities often use cleaning the home as a distraction. Cleaning, therefore, serves two main functions in Gypsy and Traveller communities, that of keeping the family safe and healthy and also keeping yourself mentally healthy. It establishes an order and routine to their lives.

*I sometime gets depressed but then I know the warning signs and I just try to snap myself out of it. I just keep busy so that I can't think about things.*
*(Resp.7, female, 23yrs, Irish Traveller)*

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*"If I never cleaned up and never had to do what I have to
do every day as a person, I would be on a lot of medication
because I wouldn't know what to do with meself in this house...I
couldn't just sit 'ere and just think to meself 'well, I'm not doing
that today', I just can't do it, because I'd crack up, I would, 'cos
it's too lonely, it's too quiet, I haven't got nobody to talk to...So
keeping busy is my way of not being mentally ill, to put it to yer,
it's not to be mentally ill and to keep me own mind occupied.
Because if I sat and I think, and I think, and I think, I would be in
hospital."*

*(Resp.2, female, 22yrs, English Gypsy)*

Although mental health problems are generally accepted within the community, people often choose to hide their problems, stating that they feel embarrassed to admit they have problems. This is probably connected to the view that one should summon up the strength to overcome mental health problems yourself and therefore risk being seen as weak if this is not possible. Concealment of mental health problems was also found by Van Cleemput (2004) where she talks of the fear that people will perceive you to be incapable of looking after your children and a fear of their removal. Also, there is always the risk of becoming the object of ridicule if perceived to be not quite the same as the group.

*"It's like people say Donna Dingly about me mam. Donna
Dingly, that means daft, mental Donna...oh, God love her and
everything...and deep down inside they don't understand what's
really going on inside her brain. They just see it as a crazy woman
doing it for attention...Well I don't think that's right. I see mental ill as
she is not well. She has her good days and me Mam has her bad
days, and bad days is really bad, I mean really bad. I see me Mam in
an awful state, but other Gypsy people don't see that."*

*(Resp.2, female, 22yrs, English Gypsy)*

Seeking help from outside the community is often done as a last resort. People will seek help from inside the community first, from family members. The closeness of the Gypsy and Traveller communities, is one of its strengths as family will often come together to look after those with problems of anxiety and depression. Distraction is often used as a means of helping someone with mental health problems.

*"If they (community) see you crying or depressed, they'll make
you laugh or 'we'll go shopping' or ' go and get your hair*

*done'...they'll try to snap you out of it 'let it go now, take it out and put it in your pocket and sit on it', they'll make jokes out of it. And they'll say , no matter how angry you're getting, how depressed you're getting and you say 'go away from me, I don't want you, I want to be on me own', they won't let you be on yer own, they'll make yer, more or less force yer to get out of it."*

*(Resp.5, female, 37yrs, Irish Traveller)*

If finally, a Gypsy or Traveller does seek outside help by visiting their GP, they may agree to take medication. However, some avoid going to the GP because they fear being put on medication and fear becoming addicted to tablets. Many Gypsies and Travellers do take medication, but not always on a regular basis, often stopping medication once they begin feeling better, only to deteriorate again.

'Talking cures' such as counselling were not popular with Gypsies and Travellers in this study, the opposite to that found by Hodgins (2006), who found that Irish Travellers in focus groups articulated a belief that counselling would be of benefit if one was suffering from depression. Gypsies and Travellers in Wrexham often expressed their feelings that there was little point in going through the pain and discomfort of talking about their thoughts and feelings. There is a belief that talking about problems will only make them worse and therefore there is no point to counselling.

**Respondent:** *"I keep it to meself and I'll go for a walk. I like keeping it to meself, I can't talk about it. I just don't wanna talk about it. I'm trying to help meself. Me family, me mother now and me sisters, they help me an awful lot... I talk to them. I talk to me mother more...I don't really know like, I would go to a doctor now to just get me medication like. They gives me depression tablets and some liquid iron and like painkillers and stuff like that. That's it."*

**Interviewer:** *"Would you ever think about counselling?"*

**Respondent:** *"No, they've already asked me and I've said I don't want those. Not interested 'cause I don't like 'em really talking, talking, talking, like when I'm like that. I just like to be left alone. Think it over."*

*(Resp.8, female, 20yrs, Irish Traveller)*

However, a reluctance to seek help from GPs for mental illness such as depression is not exclusively found in Gypsies and Travellers. A focus group study carried out on a cross section of 127 people living in Wales also found that there was reluctance in the general population to seek help for mental health problems from their GP (Pill 2001). Like the Gypsies and Travellers in the present study, they voiced a belief that mental health problems were not worth visiting a doctor for as they should be able to deal with it themselves, that it was a sign of weakness and that symptoms of emotional disorder were viewed as 'trivial' and a normal part of human existence. They also expressed the belief that GPs were not able to deal effectively with mental illness and like the Gypsies and Travellers in this study, regarded medication with suspicion. Where Gypsies and Travellers in the present study differed was their belief that counselling was of little value which was the opposite of that found in the Welsh study where an expressed preference was for a consultation with a trained counsellor.

### 4.6.1.4 What is old Age?

Gypsies' and Travellers' perspectives of old age appear to be influenced by two factors, the early age at which Gypsies and Travellers are considered adults in their communities, marry and have children, and also, by their shorter lifespan compared to the general population (Barry, 1987). A couple of women in their mid thirties considered themselves to be no longer young, with one of the women commenting that she believed her tiredness and inability to walk up stairs without getting out of breath was due to her age slowing her down at 35 years. One married woman of 22 years of age believed that she was no longer young because she had been married for so long and was responsible for the care of two children with a third on the way.

> "Once you're past the age of 30, you're not young anymore, you're getting on in life. I class meself like an old woman, honestly I do."
>
> (Resp.5, female, 37yrs, Irish Traveller)

Many saw 'old age' as being someone between the ages of 50 and 70. Many commented on how you rarely saw Gypsies or Travellers over the age of 60 or 70,

that Gypsies and Travellers die young. A couple did say they felt that you were old if you were in your 80s but mentioned that you did not see this often.

Respect was mentioned in relation to old age. Gypsies and Travellers are respected for their age and the experience gained through life.

> "One's 54 and one's 50 (parents), and I do see them..I say 'Leave the old man alone will yer' or 'Leave the old woman alone will yer', do y'know what I mean, 'cos I see me Mam and Dad as old people. I don't see 'em as young, I mean, I got respect for them. Lot of respect."
>
> (Resp.2, female, 22yrs, English Gypsy)

### 4.6.1.5 Death beliefs

*Death and funeral obligations*

To not visit the sick bed or attend the funeral of someone you have known in life would bring 'shame' on you and would certainly be talked about within the community. This is a large obligation for Irish Traveller families, both in terms of time and financially.

Irish Travellers maintain strong connections with Ireland. They have family burial grounds located where their families originated. Most Irish Travellers are buried in their family plots in Ireland. They have a strong affiliation to their 'motherland' and even the children can point on a map to the site of their family's burial ground.

> We took the health bus on site today and again it was a very busy day. First in was a group of teenage lads. They came in because they were bored and I asked about the map of Ireland we have on the door of the health bus. They were keen to tell me where the various burial grounds were for different families. A fight almost broke out between two lads when one said his father had bought a plot in a burial ground that was not his families'. The other lad said he wouldn't do that. It was quickly resolved between them by letting the moment pass.
>
> (Observational field notes, March 2004)

After the death of an Irish Traveller, usually a mass is conducted in the place where that person or their family now reside. Then the main funeral is held in Ireland, where they are buried. Due to the large families and high death rates in Gypsies and Travellers, it is not unusual for a family to attend several funerals in a year, sometimes more than one in a month. This will take several days with travel and attendance at the funeral, and several hundred pounds in ferry costs.

*Death Beliefs*   .

Following the death of a Gypsy or Traveller, the trailer of the dead person is burnt and the remaining family are provided with a new trailer by the Gypsy/Traveller community in which they belong. Okely (1983) also found this to be the case. She offered the explanation that it was to stop the dead person, who after death took on a malevolent form, from returning and spreading misfortune. Although I did not witness a death directly on the council site in the time I was there, I knew of this happening and had discussed this with Gypsies and Travellers. The explanation for the burning of the possessions of the dead was not given as one of fear of malevolent spirits, but a more 'acceptable' to Gorgias reason was given of not wanting to be reminded of the person constantly.

> When we were in one of the Irish Traveller's trailer today, we got onto the subject of customs etc. I asked if they burnt the caravan of the person who died. They all (three Irish Traveller women) said yes, that a dead person's trailer would be burnt. They said this was to stop you being constantly reminded of the dead person. I asked what would happen if it was a man, for example, with a wife and children left behind. I was told that the trailer would be burnt and a new one provided for the family. I said that Okley had described the same, but had said that it was done so that the spirit of the dead person didn't come back to upset people and bring misfortune. One of the women agreed that this was so.
>
> (Observational field notes, July 2003)

If the death is an unexpected one of a young person, then the expressions of grief can be very strong (Sutherland 1992, Thomas 1985). Sutherland describes how Gypsies under these circumstances will "scratch their faces, drawing blood, beat themselves on the chest and head, wail and scream". Although I attended two

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funerals during my study of Gypsies and Travellers in Wrexham, both of young people in difficult circumstances, I did not witness firsthand this type of expression of grief. I did, however, hear a description of this type of expression of grief from an Irish Traveller woman who had recently attended a wake and funeral for a family member, a young man of 19 who had hung himself.

> She then went on to describe the distraught state of the mother of the deceased. She described how she had been given sleeping pills and a large amount of alcohol but it still didn't knock her out. She said they had all been in the pub (2 pubs near the site were full of grieving Travellers), and described how the mother was so grief stricken that she was pulling chunks of hair from her head and scratching the skin from her face, "pulling the face from her".

(Observational field notes, October 2004)

## 4.6.2 Gypsies' and Travellers' experiences of healthcare

In this section the experiences of healthcare by Gypsies and Travellers is explored. There is a growing body of evidence highlighting the complexity of health and access to healthcare. Links have been identified between socio-economic deprivation, ethnicity and gender in poor health outcomes (Cooper 2002; Greenhalgh 2004), and Adamson (2003) goes further by examining the influence of ethnicity, socio-economic position and gender on individual's perceptions of the need to seek healthcare. She concludes that the inequalities to access are not the failing of the patients who fall into these groups, but that they occur at the level of the health professionals. Furthermore, evidence of inequity of healthcare has been suggested by several studies (Smaje 1997; Morris 2005) where people from socially deprived and ethnic minorities appear to be over represented in primary care and under represented in secondary care. Webb (1996) discusses the barriers to healthcare of minority ethnic communities and suggests that the 'medical model' central to healthcare in the UK results in a service that is inflexible, and does not take into account Britain's multicultural and multi-faith society.

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### 4.6.2.1 Experiences of seeking healthcare

There are several factors that influence Gypsies' and Travellers' use of health care. These are cultural, environmental, and as a result of experiences of the healthcare system.

Gypsies and Travellers, especially males, view ill health as something that can be overcome, 'fought' by the person. This view of general health is also reflected in attitudes to mental.health. Men will often say they don't need a doctor because they never get sick; they are not the type of men that need a doctor.

> "It's pretty rare if I get ill, do y'know what I mean, I'm not that kind of fella, like in hospitals all the time or doctors. It's very rare if I go to a doctor."
>
> (Resp.1, male, 35yrs, Irish Traveller)

Because there is a belief that illness must be fought, often people will try to delay seeking medical help. Sometimes painkillers are taken and a 'see how you go' strategy is adopted, this occasionally results in a condition worsening with the eventual need to use A&E departments rather than a GP, often resulting in hospitalisation.

Another factor that influences the choice to use A&E departments rather than a GP as a first 'port of call', is the perception of the severity of the illness. The majority of people, when asked where they would seek help, said that if they were 'really ill' they would go to A&E. It is the perception that their illness is severe and possibly life threatening that influences their choice of where to be seen. Also, several people talked of choosing to go to A&E because they could be seen quicker than waiting for a GPs appointment. This may also be associated with the perception of severity. If the illness is perceived to be serious, then it must be seen quickly.

> "If you were really really sick you would have to take them to the hospital wouldn't you. You wouldn't have time to take them to the doctors...because you ring up and they say 'oh, we are fully booked'. There are new things coming out now, you have to ring the morning before, the morning you want to go, and sometimes you can't go that

*morning because they are fully booked, so you have to take 'em to A&E."*

(Resp.13, female, 21yrs, Irish Traveller)

The time of day was also given as a reason to choose A&E. Some people felt that they would see a GP if their illness developed during the day, but would use A&E if it was night time. None said they would contact the out of hours service.

Some believed that the care they received in hospital was superior to that of a GP. The reasons given for this were that the hospital had more time for you. Also, there was a perception that their illness was taken more seriously in hospital, that they would be checked out thoroughly and given all necessary tests. There is a belief that the hospital is obliged to give you a 'proper' check-up. Some felt that they did not get this level of care from a GP.

*"Well, if I wasn't too bad I'd see my GP but if I was really ill I would go to the hospital. They take more care of you there. The GP just gives you a prescription without even looking at you. The hospital will give you more time, will do tests, check you out properly. They have to."*

(Resp.9, female, 50yrs, Romany Gypsy)

One young male Traveller, although he uses a GP surgery while in Wrexham, said that he would go to a chemist for advice or A&E if ill when travelling. He would not feel comfortable walking into a doctor's surgery that was unfamiliar. He felt that this would be inappropriate behaviour.

Not all people interviewed however, said their first port of call would be the A&E department. Some did say they would see their GP or seek advice from their relatives or the Project Health Worker first. Their past experiences of the Primary Care Service greatly affects there views on the worth of consulting with a GP.

### 4.6.2.2 Experiences and Perceptions of Primary Care

Registration with a GP is one of the most important aspects in gaining access to the Primary Care Service. The experiences of trying to get registered and staying

registered can affect use of the service. The majority of people interviewed were registered with a GP, only one male said he did not wish to be registered. This however, does not mean that difficulties have not been experienced with registration. Many of those interviewed recounted difficulties obtaining registration with a GP, and also of being removed from GPs lists. One reason why this was not mentioned as a reason to visit A&E departments in preference to GPs may be that the Project Health Workers' role of assisting with access to primary care had been successful. Therefore, this was no longer seen as a major barrier. Feder (1994), by contrast, following interviews with Gypsy/Travellers in Hackney, London, found that inaccessibility to general practice was viewed as the most important factor in their choice to use A&E.

Many Gypsies and Travellers find they have difficulties obtaining registration with a GP surgery when they are travelling. There are three main reasons for this. One is that without a 'proper' address, many surgeries will refuse to put them on their list as a patient, and will only offer to register them as temporary patients. Secondly, Gypsies and Travellers often find it difficult to register because of their level of literacy, if they are not assisted by staff at the surgery to fill in the forms, this can be problematic. Particularly if it is the registration of a large family with many children, the receptionist may feel they have not got the time to fill in all the forms. The third is the prejudice against Gypsies and Travellers by some healthcare staff. There is a view taken by Gypsies and Travellers that some surgeries view Gypsies and Travellers as troublesome.

> "Like when I was in Blackpool, it took me 8 months to get a
> doctor… and all we had to use was the A&E. I tried registering but they
> kept refusing me. No, no, no, until I got onto the NHS Service Line, and
> they located a doctor for me and got in contact with me and said
> 'We've located a doctor for you, she's the one that's got your
> files'….but walking in and asking for a full resident, no chance, no way.
> Soon as you mention caravan site, didn't want to know."
> (Resp.2, female, 22yrs, English Gypsy)

> "My mother, she always used to get us a GP, It'd be like an
> emergency ehm, (temporary) Yeh. Then if she wants to get the
> babies fully injected, stuff like that, she'd book 'em in for it. She'd just
> explain that she was a Traveller or whatever. Some people'd just tell

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> *you 'no, we're not taking you on'. There were so many places, like in*
> *Queensferry now fer instance, it takes ages to get a doctor over there*
> *and there's that many surgeries, like surgeries that won't even take*
> *on Travellers. Just so ignorant."*
>
> *(Resp.8, female, 20yrs, Irish Traveller)*

As well as experiencing difficulties registering with a new GP, some Gypsies and Travellers, sometimes whole families, have found themselves removed from a GPs list, for what are perceived to be either minor reasons or no reason at all.

> *"Yeh, I got took off before because I never got sick. I was*
> *about 6 or 7 months without going to a doctors and I never had to*
> *bring me kids because, thank God, they were never sick or sore, so*
> *with not going they took me off... Because I never used to use 'em".*
>
> *(Resp.5, female, 37yrs, Irish Traveller)*

Although many of the people interviewed said they had positive experiences with both receptionists and doctors, there were several who believed that they had encountered bad treatment or prejudice either by the receptionist or the GP. Some feel that the receptionists block you from seeing the doctor and feel this may be due to them being Gypsies or Travellers, because of the way they are spoken to. In one instance, the receptionist refused to help a mother fill in the registration forms for herself and her children even though the receptionist was told by the woman that she could not read or write. Some GPs too, can be perceived as being prejudiced towards Gypsies and Travellers.

> *"But then sometimes you do yer best, and they keep on being*
> *ignorant, snobby, what's the point in trying fer a doctor there then if*
> *they're so snobby like that. It's the people that works at the desk*
> *mostly, because most people are so prejudice."*
>
> *(Resp.8, female, 20yrs, Irish Traveller)*

> *"Some doctors, when they know you're a Gypsy, won't touch*
> *you. They think you're dirty. They think they're gonna catch*
> *something from you."*
>
> *(Resp.9, female, 50yrs, Romany Gypsy)*

These negative experiences can result in mistrust and fear that they, or their children, will not be given proper attention. The feeling their children may be at risk.

> *"No, they say, 'no sorry, we're fully booked up'. Minute they hear your voice, just says 'No sorry we're fully booked up'. And often we like try it this way to see is the surgery prejudice because sometimes Travelling people be's afraid to use some surgeries when they're prejudice like in case they do something wrong to their child, like give 'em wrong medication, sort of thing, 'cos they're not really interested."*
>
> *(Resp.13, female, 21yrs, Irish Traveller)*

This experience of mistrust of health professionals due to past negative experiences was also found in other studies such as Hodgins (2006) with Irish Travellers in Ireland and Van Cleemput (2004) with Gypsies and Travellers in England. This fear may be why Gypsies and Travellers, having found a sympathetic doctor, are reluctant to lose them. They will often travel many miles to see their own trusted GP rather than risk seeing another doctor who may turn out to be unsympathetic to Gypsies and Travellers. Of the people interviewed, a large majority felt that they were happy with their GPs and several had the same GP for many years and had built up trusting relationships with them.

> *"My doctor is very good. He knows all my problems and is very kind. I've had him for years. My mum goes to him too so he knows the family."*
>
> *(Resp.7, female, 23yrs, Irish Traveller)*

Experiences of racism and its impact on the health seeking behaviours in ethnic minorities has also been described in the study of African-Caribbeans' interactions with mental health services in the UK (Mclean 2003). Mclean found that the experiences and expectations of racism and mistreatment where key factors in discouraging early help seeking from mental health services. Furthermore, Kelleher (1996) suggests that 'stereotyping' of Irish immigrants in England may be interacting with material and cultural factors contributing to the poor health of this ethnic group.

Even when Gypsies and Travellers do find a surgery where they can register, other factors can create a barrier to accessing healthcare or the correct treatment. The lack of understanding from healthcare professionals regarding the difference in culture can create problems:

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One example of this lack of cultural understanding is the case of an Irish Traveller in her mid thirties who has seven children. The birth of her last child was difficult, resulting in the woman requiring several operations and blood transfusions. She has been advised that to have another child would put herself at risk. Her youngest child however, is now four years old and the woman is unhappy about not being able to conceive. She has not had periods since the birth of her last child. She has now become fearful that the doctors at the hospital might have given her a hysterectomy without her knowledge.

Culturally, a woman's role in Gypsy and Traveller society is one of mother. This is what defines most women in these communities, therefore, the psychological pull to produce offspring is very great. What this woman wants is for her concerns to be taken seriously and to be referred to a gynaecologist, some reassurance that 'all is well'. Her GP's response was that the woman needed psychiatric help and needed referring to a psychiatrist. There was a lack of understanding that a woman could really want another child after having seven children, a lack of understanding that in this culture seven children was not an unusual number of children to have. For that woman, her family was not yet complete.

Those providing healthcare do not always appreciate the cultural divide between women and men in Gypsy and Traveller communities. In Gypsy and Traveller society it is not acceptable for a woman to be alone with a man who is not her husband, father or brother. This has the potential to bring the woman's name into disrepute. Also, it is not acceptable for women to talk about sexual or feminine matters in front of a man. This creates problems if a girl or woman cannot arrange to see a female doctor, especially for anything that is seen as sensitive, this may be anything considered 'women's problems' or of a feminine nature.

> "Yeh, cause they tells ya now, you can get an appointment to see such a body or such a fella, but you're not gonna tell a man your problems are ya. I wouldn't tell a man my problems, and think that's the difference of Travelling life, they don't explain like, a local person will tell them anything, but the Travelling girls won't. They have their own privacy and the boys have their own privacy."
> (Resp.13, female, 21yrs, Irish Traveller)

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This lack of cultural understanding also affects other ethnic minorities in the UK. For example, people from South Asian origin have described a failing of the medical profession in the UK by not providing advice on diet when giving medicines, which is an integral part of South Asia medicine. Their expectations of appropriate advice is not leading to dissatisfaction in healthcare services (Lambert, cited in Kelleher & Hillier, 1996). Furthermore, Griffiths (2001) found one of the reasons that South Asians in Britain experience higher admissions to hospital for asthma was a lack of confidence to control the management of their condition. Griffiths suggests that this may be due in part, to inadequate and inappropriate services. Also, the expectations of the relationship between patient and doctor can work as a barrier for patients in 're-framed' consultations as seen in the Pakistani community (Bissell 2004).

These experiences of discrimination and lack of cultural awareness have an impact on people's trust that in the healthcare system to deliver. Thiede (2005) discusses the importance of trust within the transactional process of information exchange or communicative interaction. He argues that trust plays a role in the utilization of information and is a prerequisite of effectiveness of information with regards to access.

In the present study, high levels of poor literacy skills within the Gypsy and Traveller communities results in difficulty keeping appointments. Because many Gypsies and Travellers cannot read or write, they are unable to write down appointment dates and times. This information has to be kept in their heads, a difficult task if the appointment is an out-patient appointment some time in the future. Some have tried to remedy this by marking appointments on a calendar. This is helpful to some, but not all, as often the calendar is forgotten. Some have difficulty in knowing the day of the week or time of the day.

> "It's easy to get appointments, if you want an appointment, but sometimes we forget most of our appointments, with literature, we can't read or write. Best part of our appointments we miss 'em...And even though we got a calendar, we forget looking at the calendar,

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*know what I mean."*
        *(Resp.1, male, 35yrs, Irish Traveller)*

        *"Because I can make an appointment maybe now, right, and*
*with not reading and writing properly, I can read and write bits but not*
*like complicated words, and I've got to find everything from my*
*memory, it's like dyslexia. I've got to remember everything, focus on*
*everything up 'ere...and how can I put it to yer, I forget. I've got that*
*much to think about...Maybe if they could understand more about our*
*situation."*
        *(Resp.2, female, 22yrs, English Gypsy)*

Another area of healthcare that is affected by the high level of poor literacy skills in the Gypsy and Traveller community is taking medication. Several people who do not read or write said that they managed to take medication by taking it at meal times. There can be problems however, if the prescription includes more than one medication. Even if explained by the doctor or chemist, by the time the tablets are put in a bag, it can be difficult to know which medicine is which and when to take them.

        *"Yeh, I don't take 'em at times, can't tell the time, never*
*interested me, time. I tell the time by, I give me little girl morning,*
*afternoon and 5 o'clock's night time to me, so that's the way I give the*
*medication... I don't give it at 10 o'clock."*
        *(Resp.2, female, 22yrs, English Gypsy)*

        *"If I ask them (chemist), they tell you very quick and you may not*
*pick it up. If you have three or four boxes of tablets, you put them all*
*back in the bag and how are you supposed to know which one is*
*which?"*
        *(Resp.13, female, 21yrs, Irish Traveller)*

Finally, the physical proximity of some Gypsy and Travellers sites can make access to healthcare difficult for those who are elderly or who do not have access to a car. For example, the Council run site in Wrexham is located outside the town with no public transport provided. This makes visiting the GP surgery difficult for those on site who do not have direct access to a car. Those people must rely on a family member taking them, which is not always suitable in terms of privacy for the individual who will have to explain the nature of the visit to the driver.

*"I wouldn't be able to walk (to surgery) with the arthritis I have.
A few year back I'd run that road, say 15 year, 10 year back, I'd run it,
be nothing to me...not now...I have to have a car to go to see 'em.
Never walk, never get to 'em...there's no buses. It'd be handy if there
were a bus, do y'know, to bring yer into town and bring yer back."*
*(Resp.3, female, 65yrs, Irish Traveller)*

## 4.7 Summary and discussion

This chapter has focused on Gypsies' and Travellers' culture, lifestyle, health beliefs and experiences of healthcare.

Gypsies and Travellers hold a strong sense of cultural identity and a sense of 'separateness' from the general population. The cornerstone of Gypsy and Traveller society is the family, with children being highly prized, and families large. Women are homemakers and mothers and men hold the status of the head of the home. Their lives are governed by strict rules and cultural expectations, which are far from the romantic stereotypes created by non-Gypsy/Travellers of a care free existence with no rules. These rules and cultural norms are highly influential in how people live their lives. To break a rule is to risk being ostracised from the community. Rules include: cleanliness rules; purity rules; gender rules; division of labour between men and women, young and old; cultural expectations concerning visiting the sick and dying; and attendance at ceremonies such as weddings and funerals.

Gypsies and Travellers in the UK, like their counterparts in the rest of the world, have experienced and continue to experience discrimination and intimidation on a daily basis. This is wide spread and runs through the fabric of our society. With this level of discrimination against Gypsies and Travellers, the result is a deep defensive, mistrust of non-Gypsy/Travellers.

In summary, all the systems that have been observed in this study, including the personal (identity), personal relationships (marriage relationships), family structure, cultural expectations and constraints, and societal views (experiences of discrimination, formal education and experiences of healthcare) have a large

impact on Gypsies' and Travellers' general and psychological health and their health beliefs. The information gained from the study of Gypsy and Traveller culture, lifestyle and health beliefs provides the context in which to evaluate the community health initiative. In the next chapter, a description is provided of the community health initiative that has been designed to improve the healthcare and health status of the Gypsies and Travellers in this study. An analysis of what the demands of such a service are, and what elements of the service worked and what did not, are considered in light of the findings of this cultural study.

# Chapter 5

# Results - The community health initiative

## 5.1 Introduction

This evaluation of the community health initiative together with the study of Gypsy and Traveller culture, lifestyle and health beliefs, as outlined in Chapter 3 is designed to provide triangulating information to inform the overall evaluation of the initiative.

In this chapter, a full description of the community health initiative is provided along with a description of the various groups who are involved with the initiative, their relationship to the health initiative and how this may have changed over the time of the project. A process evaluation is reported, exploring the key elements of the community health initiative and how cultural constraints and expectations influence how people interact within the initiative. Finally, this Chapter provides a description of what actually happened in the community health initiative during the time of the evaluation and moves on from the stated aims and objectives of the project as described in Chapter 2.

Information from participant observations and a series of interviews with Gypsy and Traveller participants provided insight into the 'service users' thoughts, feelings and experiences of the initiative. Participant observational data and a series of interviews with members of the Multi-agency Traveller Forum and Steering Group describes the 'service providers' perspective of the initiative (see chapter 3 for a full description of the methods used).

## 5.2 The participants involved with the community health initiative

The participants of this study included the Gypsy and Traveller communities in the Wrexham area, the Project Steering Group and the Multi-agency Traveller Forum members.

### 5.2.1 Gypsy and Traveller Communities

The Gypsy and Traveller communities in Wrexham comprise three main groups; Irish Travellers, Welsh Travellers and English Gypsies. As described in the cultural study (Chapter 4, section 4.2.1), these groups see themselves as separate and seldom mix, with the exception of the occasional inter-group

marriage. Gypsies and Travellers living in the Wrexham area reside in both caravans (council run sites and private land) and in social housing. Although the population of the site varies due to the nomadic lifestyle of its residents, during the time of writing this study, an estimated 51 adults plus 41 children were resident on the council run site and 42 adults and 52 children were either living in caravans on private land or in houses in the local area.

Historically, there were two main Gypsy/Traveller sites in Wrexham. One was an unofficial site situated near the main hospital in the town of Wrexham known as the Croesnewydd site. The other site is the out of town, council run site known as the Ruthin Road site. The Croesnweydd site had been in existence for over two decades. The facilities were basic with tarmac hard standing and standpipes for water. The site was occupied by over twenty caravans.

On 17th September 1999 the occupants of the Croesnweydd site experienced a dawn raid. Involved were 100 police officers, 30 court officers, and a police helicopter. Trailers were forcibly removed from the site by cranes and chalets and temporary structures that could not be easily removed were bulldozed down. The residents were offered plots on the existing council run Ruthin Road site. The Ruthin Road site had been expanded and had doubled in size to nineteen plots to accommodate the new residents. A discussion of how the local press covered this event and Gypsies and Travellers in general, can be found in Chapter 4, section 4.5.1.

Originally, Welsh Gypsies occupied the Ruthin Road site. Over time the site had started to become occupied by Irish Travellers. These two distinct groups do not usually chose to live together as they view themselves as different groups culturally. As Irish Travellers moved on to the site, Welsh Gypsies on the Ruthin Road site sought to move out, some chose to travel but many were housed in the Wrexham area by the council. Following this, the Ruthin Road site became exclusively Irish Travellers. Many of the Welsh housed Gypsies still express the feeling that the site was 'taken over' by the Irish Travellers.

Following the forced closure of this site, those that did not choose to or could not move elsewhere were relocated to the Ruthin Road site. This swelled the number of Irish Travellers on the Ruthin Road site. During the following months,

friction within Irish Traveller families escalated and feuding between families occurred resulting in several families leaving the Ruthin Road site to either be housed or to move to their own land nearby.

In recent months, Four English Gypsy families have moved onto the Ruthin Road site. One of the family members has a connection with one of the main Irish Traveller families on site through a marriage link and fled from a site in Bedfordshire due to the threat of violence on that site. These Gypsy families are grouped together at the far end of the site and are rarely seen mixing with the Irish Travellers on the site.

*The Ruthin Road site*

The Ruthin Road site is situated approximately 2 miles from Wrexham. It is positioned next to a busy road junction, flanked on one side by a dual carriageway, the other by a busy 'A' road and the other side backing onto woodland and fields. A 12-foot security fence, resulting in one entrance to the site, runs along the boundary wall. A CCTV camera is positioned opposite the entrance to the site, it can be positioned to point either to the road or into the site (see Appendix 14). A Traveller liaison officer, a security guard and a site warden man the site. The warden's office is situated near the entrance to the site. The council employs all. There are no play areas for children on site and no communal areas. There is no public transport from the site.

The site comprises 19 plots. Each plot has a breeze block structure known as a 'shed'. The sheds vary in size, but all house a bathroom area with toilet, sink and bath or shower and a kitchen type area containing a sink, cupboards and electricity. Each plot has an outside tap. The plots are all concrete and fenced with low wooden fences. The plots are occupied by between two and nine people per plot with an average of 6 occupants per plot. A plot may house either one large caravan 5/6 berth (occasionally a mobile home) or several small 2/4 berth caravans. Often parents and young children will occupy a larger caravan while teenagers and young adults will occupy the smaller caravans, sharing a plot with their parents.

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*Illustration 1. A plot on Ruthin Road Gypsy and Traveller site, near Wrexham*

### 5.2.2 The Project Steering Group

In the early, developmental stage of the project, the Steering Group was made up of representatives of the Inequality in Health funded project, Cardiff University and the Multi-agency Traveller Forum (MAF). Representatives from the 'service' side of the project included the Project Lead, who has a background in Health Visiting, and the Project Health Worker, who is a trained Health Visitor. Representatives from Cardiff University included the project research advisor who is also a working GP in the local area, and the project researcher, who carried out the evaluation of the community health initiative and is the author of this thesis.

The Chair of the Multi-agency Traveller Forum (MAF), who was employed by Social Services, was also a member of the steering group as MAF members were named on the original bid for funding to the Welsh Assembly. Following the early stages of development of the project though, the chair withdrew from the group, stating other professional demands as the reason and expressing a belief that once the project was in an operational phase, her input would be limited as it was a 'health' project. In addition, she said the project workers were members of MAF and report progress to that group at their regular bi-monthly meetings.

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In the early stages of the project, a project manager was also provided by the Public Health Department to assist in the organisation and acquisition of equipment for the project. Unfortunately, the Project Manager had an extended period of sick leave and a replacement was not offered by Public Health. On her return to work, she was re-deployed to other duties within the Public Health Department.

Following these departures, the Project Steering Group remained a stable group. It was made up of: the Project Lead, Project Research Advisor, Project Health Worker and Project Researcher, who remained together throughout the rest of phase one of the project. Then, following the identification of high levels of mental illness within the Gypsies and Travellers in this project and a successful bid for extended funding in phase two, the project employed a Project Mental Health Support Worker who also became a member of the steering group (see figure 5.1 below for group membership through time).
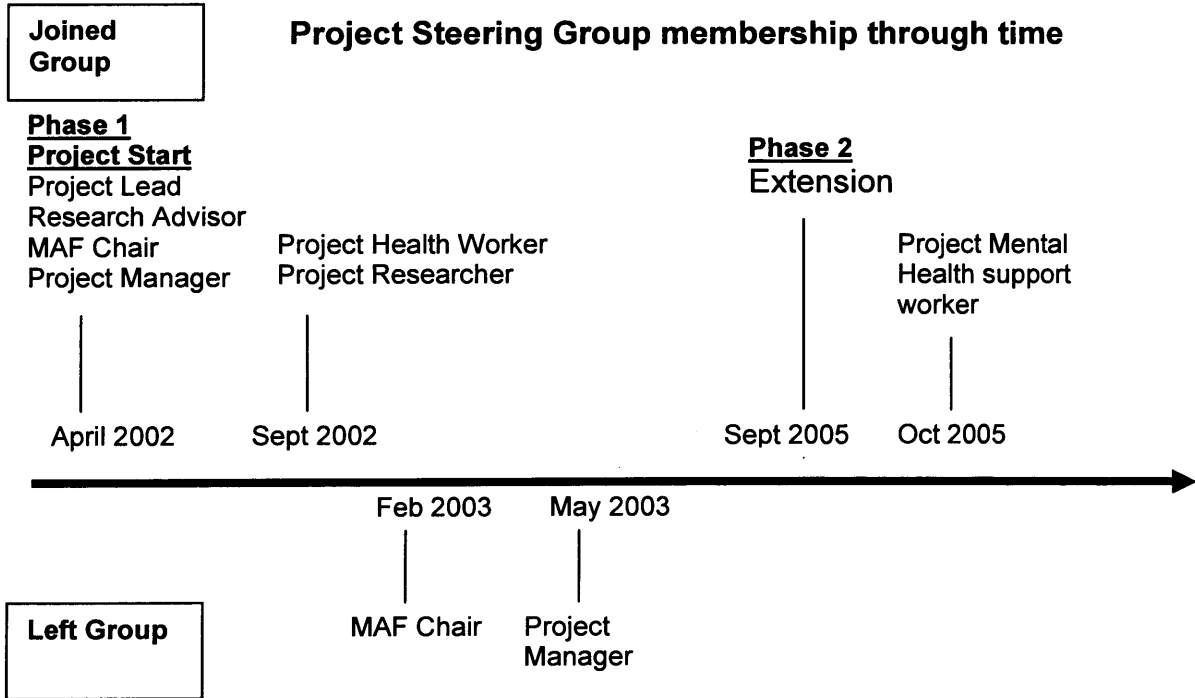


*Figure 5.1*

Meetings were held on a monthly basis for the early planning and development phase of the project from April 2002 until April 2003, progressing to bi-monthly meetings when the project was in a more stable service and data collection phase of the project.

The Steering Group is still in place and operational as the project has secured added funding beyond the phase one and phase two funding periods, from the Welsh Assembly, to April 2008 (see Chapter 2, section 2.1.2). The Steering group provides advice and support to the project workers and also monitors the progress of the project. Both the Project Health Worker and the Project Researcher provide reports on progress to this group. It is the forum in which new ideas and directions for the focus of the project are discussed, where outputs and outcomes were developed in the form of a programme logic model (see chapter 7, section 7.7.1) and where difficulties are brought to the attention of the Project Lead and Research Advisor.

Other people attend Project Steering Group meetings by invitation. For example, finance officers from the LHB are invited when budgeting issues require discussion and line managers to the project workers are invited when staffing and service provision issues arise.

### 5.2.3 The Multi-agency Traveller Forum

The Multi-Agency Traveller's Forum (MAF) in Wrexham is a group of professionals from a number of agencies who have some involvement with Gypsies and Travellers in the Wrexham area in a professional capacity and are attempting to address health and social issues in the Gypsy and Traveller community. MAF has been an active forum for several years. It meets bi-monthly and supported the successful bid for funding for this project. The group at present, consists of workers from agencies including Wrexham Local Health Board, North East Wales NHS Trust, Commission for Racial Equality, Traveller Education & Social Work, Housing, the Voluntary Sector, Women's Aid, Probation, Youth Offending team and the Police.

The Multi-agency Traveller Forum is a fluid group with members changing over the time of the project as their jobs changed. Few members work with Gypsies

and Travellers exclusively. They are more often part of a larger caseload. Members therefore, attend MAF because of personal interest in this group or to seek assistance. It is therefore susceptible to loss of members when staff leave their posts. However, there is a core membership who has remained throughout the time of the project. Apart from the Project Health Worker, these core members include representatives from Health (Community Midwife), Education (Traveller Education Officer & Education Social Worker), Housing (Housing Dept. Borough Council & Cymdeithas Tai Clwyd) and the Catholic Church (local Priest).

Prior to the project, MAF held several 'coffee mornings' at the Catholic Church to enable Gypsies and Travellers to gain access to MAF members and to enable MAF to find out what issues were important to Gypsies and Travellers in the local area. However, little action resulted from these meetings and they were discontinued. They were however, restarted during the beginning of the time of the project and have proved to be successful (see section 5.3.6).

The project has representation in this group, and at present, the Project Health Worker is acting Chair due to the death of the original Chair and no further involvement from Social Services, the agency where the Chair was employed. MAF was involved in the developmental phase of the project (see section 5.3.1 for a description of MAF's involvement in the development of the bid and contribution to the design of the project). MAF members involved in Gypsy/ Traveller education also ran a competition through the local schools to design the logo for the project. This had two aims, first, to raise the profile of the community initiative amongst Gypsies and Travellers and members of the local community, and second, to provide a feeling of ownership for the initiative by the local Gypsy/Traveller communities. The Gypsy/Traveller children's artwork was used in a logo that is displayed on the 'Health Bus' and the winning design is used as the logo for headed paper and presentations (see illustrations below)

*Illustration 2. 'health bus' logo*
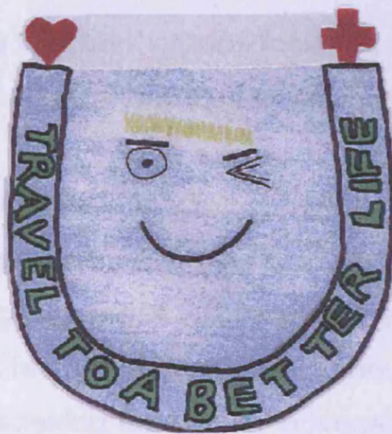


*Illustration 3. Logo for community health project*

Over phase one of the project, the project workers provided regular project updates on service provision and research to MAF. The project was the main focus of MAF during this time, however, with an influx of new members, bringing a new enthusiasm, new terms of references for the group were developed in April 2005, resulting in a wider remit encompassing both health and social issues, see below:

### Remit of Multi Agency Travellers Forum
- To support best practice by agencies and organisations in carrying out their work with Gypsies and Travellers in the Wrexham area.
- To engage agencies and organisations in partnership working for the benefit of the Gypsy Traveller community in the Wrexham area.

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- To establish task groups responding to identified issues or emerging needs identified by the Forum and the Gypsy and Traveller community.
- To comment upon and advise about the development of policies and programmes to meet the needs of Travellers and Gypsies.
- To make recommendations about service provisions by agencies and organisations in order to develop more inclusive services for the Gypsy and Traveller community.
- To support the development of a direct 'voice' for the Gypsy and Traveller community in the Wrexham area.
- To support increased participation by the Gypsy and Traveller community in expressing their needs and concerns to relevant local agencies and organisations.
- To build a body of specialist knowledge, which can be shared with other interested professionals.

The group now has four task groups focusing on: developing a community voice, raising awareness, site provision and service provision.

The Multi-agency Traveller Forum, over the time of this project, has become a small group with expert knowledge of the Gypsy and Traveller communities in the local area. The group feeds into local strategy, for example, the site provision group has fed into a local 10 year housing assessment plan. MAF has also been active in seeking funding for advocates for the community, such as a community development worker, employed via the voluntary sector, funded by the Fair Share Initiative from the National Lottery.

## 5.3 The community health initiative (CHI): a process evaluation

### 5.3.1 Design of the community health initiative (CHI)

#### 5.3.1.1 Service providers' perspective of design

*The Welsh Assembly's Inequality in Health's influence on the design*

The need for a health initiative designed to improve the health of Gypsies and Travellers in North Wales was identified following a health needs assessment carried out by the Project Lead and a Health Visitor co-worker prior to the initial bid for funding from the Welsh Assembly's Inequality in Health Fund (see Chapter 2, section 2.1.2 for an account of the development of the bid for funding). This fund was designed to reduce inequalities in health by funding

initiatives that sought to produce a positive impact on the high levels of coronary heart disease (CHD) found. Therefore, the community health initiative (CHI) was designed to have a focus on CHD and its risk factors. An emphasis was placed on the importance of health promotion as a major area of focus for the Project Health Worker (see aims and objectives Chapter 2, section 2.1.3).

The original award from the Inequality in Health Fund was for a period of three years. However, there was suggestion in the Project Agreement Terms and Conditions, that subsequent funding would be considered by the Welsh Assembly subject to approval. In practice, the Welsh Assembly has extended the project twice since the initial funding, resulting in the present funding now due to end in April 2008. Although the project has been extended, the Welsh Assembly has asked projects to consider an exit strategy. This was expressed in the first bid for extended funds towards the end of the first phase of the project. The exit strategy planned was for the local LHBs in both Wrexham and Flintshire to take on responsibility for the health initiative, spreading the service and expense over the two areas. This was believed to be a more realistic and palatable proposition to present to the LHBs by the Project Lead than the expectation that one LHB would support the service alone.

Evaluation of the project was also an expectation of the Welsh Assembly. In the Project Agreement Terms and Conditions, it was stated that evaluation should be developed and implemented to demonstrate progress and achievement against the stated aims and objectives of the project. In particular, it states that the evaluation should demonstrate the specific contribution that the project makes towards the implementation of the National Service Framework for Coronary Heart Disease. This certainly had an impact on the design of the evaluation and influenced the decision to include the CHD health status study in the design.

### 5.3.1.2 Multi-agency Travellers Forum's influence on the design

In the design and early implementation phase of the project, input was sought from MAF concerning operational issues with the design and roll-out of the community health initiative. MAF discussed the inclusion criteria for the health initiative and research and decided that all Gypsies and Travellers who came in

and out of the area and Gypsy/Travellers who were born at the Wrexham Maelor Hospital would be included, but 'New Age' Travellers would not be included as this group did not share the same cultural background.

Questions were raised in MAF meetings concerning how they (MAF) could contribute to the project. It was agreed that MAF members could raise awareness of the community health initiative with the Gypsies and Travellers they came across in their work. Decisions were made concerning operational issues such as safety on site. Involvement with the community initiative from MAF agencies in terms of visits in the health bus was also discussed. It was agreed that only those agencies that would be viewed by Gypsies and Travellers as being of use to them, i.e. 'givers' should attend. These agencies were identified as Health, Education and Homecare (see section 5.3.6. for a description of partnership working between MAF and the project).

Following this initial input from MAF, the involvement became more one-way with regular reporting of project progress being given to MAF by the project workers, but with little in the way of decision making by that group, this fell instead to the Project Steering Group. There are several reasons for this, one is that the leadership of MAF had several interruptions due to the long-term sickness and eventual death of the MAF Chairperson. Also, the project came to be viewed by the group as a 'health project', and so was distanced from it as they had no functional role in the project. Figure 5.2 below illustrates the professional group relationships with the project.

## Professional Group Relationships with Project



Cardiff University Researcher & Advisor employer

Local Health Board Fund holders PI and Project Health Worker employer

Project Steering Group PI, Project Workers, Research Advisor

Project Community Health Initiative Workers & Evaluation

Welsh Assembly Government Funders

First Access Mental Health Agency Mental Health Support Worker employer (phase 2)

Multi-Agency Traveller Forum Project Workers Other Local Agencies Occ. Traveller rep.

*Figure 5.2*

### 5.3.1.3 Gypsies' and Travellers' influence on design

There was no formal involvement in the design of the CHI by Gypsies and Travellers in the area, however, their opinions were sought in an informal way by the Project Lead prior to the start of the community health initiative. User involvement has been encouraged throughout the project and is one of the objectives of the project. There is, however, reluctance on the part of Gypsies and Travellers in Wrexham to get involved with organised groups, due mainly to scepticism of their voice being heard and also due to suspicion of outsiders and authority figures. This however, is now beginning to change and several Gypsies and Travellers have attended the Multi-agency Traveller Forum Meetings in the life of this project, although limited to single attendees with infrequent attendance to represent an issue of importance to that individual at the time. There is reluctance in the local Gypsy/Traveller groups to speak for, or

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represent the views of these communities as there is no formal structure to allow for this. As discussed in the previous chapter, Gypsy/Travellers are believed to have a 'collective culture' (Lehti 2001, Burger 1996, Sutherland 1992, Thomas 1985, Wetzel 1983, Mandell 1974), however, this appears to function more at the extended family level rather than community level in Wrexham.

### 5.3.1.4 Roll-out of Community Health Initiative

There was a push by the Project Lead in the early phase of the project to be seen to provide a service quickly, this was in part, due to the delay in appointing the project workers by five months after the project funding had been obtained (see section 5.3.2). This resulted in writing protocols whilst 'doing the work' of providing the community health initiative. Project workers expressed difficulty in trying to set the project up whilst delivering a service and felt that it would have run more smoothly in the beginning had roles been more defined and protocols and policies had been in place before service began.

As this was a new service, the design of the initiative had to be adapted as the project team came across difficulties. Problems were identified and solutions and new approaches were developed to meet those challenges. One example of this is the unforeseen mental health need of the Gypsies and Travellers in Wrexham. Both service and research was altered to accommodate this need (see section 5.3.3 for a full description).

### 5.3.1.5 Service users' perspective of design

Although many of the Gypsy and Travellers interviewed said that they did not know about the CHI before it started, the general feeling was that the project was well designed and that they were happy with the design. When asked if there was anything that could be improved, the majority could not think of any improvements. However, one person suggested extending the hours that the 'health bus' visited the site to include evenings to reach those male Gypsy/Travellers who were not around during the working day. Another expressed a desire for other mobile services such as a play bus for the children on site.

### 5.3.2 Implementation of the community health initiative (CHI)

The implementation of the CHI was impeded by several delays. The first delay was in the recruitment of the full-time staff. Initially, the start date for the initiative was to be in March 2002. This was set back by six months due to lengthy recruitment procedures and the project workers were finally in post by September 2002.

Other delays in the initial implementation resulted from differences in procedures and protocols between the Local Health Authority (the fund holding organisation) and the CHI. This resulted in delays in the purchase of the mobile health unit and essential equipment.

With reference to the former, one case was the purchase of the mobile health unit (Health Bus). The purchase of a 'health bus' was included in the project agreement with the Welsh Assembly Government's 'Inequality in Health Fund'. Resources had been provided for that purpose. However, the fund holding organisation, the Local Area Health Authority, refused to release the money to purchase the 'Health Bus' stating that there were no procedures in the Health Authority set up for the purchase of vehicles and that we should hire a vehicle in line with their protocols. This however, was not a realistic alternative, as the vehicle would need to be modified in order to meet the needs of the initiative. The inability of the Health Authority to adapt their procedures to accommodate the needs of the CHI resulted in a three month delay in the purchase of the 'Health Bus'.

Liaison had taken place between the Project Lead and the then Local Area Health Authority finance department, but they did not proceed with the agreement to purchase the vehicle. This may have been due to unfortunate timing due to the impending replacement of the Local Area Health Authority by the Local Health Group and Local Health Board. However, this did result in delay and may account for some of the rush for the service provision of the initiative to be rolled out as soon as the 'health bus' was acquired.

### 5.3.3 Main Focus of the community health initiative

*5.3.3.1 Service providers' perspective of focus*

The main focus of the CHI remains unchanged from that expressed by the Multi-agency Traveller Forum and Project Steering Group members at the beginning of the project. That is to improve access to health care services for Gypsies and Traveller, to describe the CHD health status of the Gypsy and Traveller communities and attempts to improve the CHD status of this community by developing culturally appropriate health promotion initiatives. The focus however, broadened to include mental health which also impacts on coronary heart disease (see Chapter 1, section 1.2.3). From the start of the community initiative, it became evident that Gypsies and Travellers were suffering from high levels of depression and anxiety, as they were presenting to the Project health Worker with these problems. This was not foreseen in the original design and is an example of the project adapting the service to the needs of the community. Adaptations were made to both the service provision and the research. The Project Health Worker spent time informally counselling people and developing links with psychiatrists and mental health agencies. The research was extended to include a study of mental health status alongside the study of CHD status in these Gypsies and Travellers. Also, the inclusion of a Project Mental Health Support Worker was included in the successful bid for extended funding and that person was appointed in October 2005. This broadening of focus has been observed in another health initiative with Gypsies and Travellers reported by Streetley (1987), where a mobile service was set up for Gypsies and Travellers in England. Their focus initially was with child health but spread to adult health once the severity of the need was recognised.

In the initial phase of the CHI, the immediate health and social needs of the community were focused upon, to help meet the wide ranging unmet health needs of many people in this community, and to enable the building of trust, and access to the community. This approach is still used with new Gypsies and Travellers encountered by the Project Health Worker, although much of the social needs are now referred to other agencies.

### 5.3.3.2 Service users' Perceptions of Focus

The Project Lead informed those Gypsies and Travellers that she had contact with prior to the community health initiative, that it was being organised for them and provided a description of the proposed service. However, many of the housed Gypsies were not known to the Project Lead at that time and also, due to the nomadic lifestyle of many of the Gypsy/Travellers, new Gypsy/Travellers had contact with the CHI who were not present at the beginning of the initiative.

When the Gypsies and Travellers were asked what the main focus of the CHI was, the answers were split between two main themes. The first theme was improving general health and the second was increasing cultural awareness.

The majority of Gypsies and Travellers interviewed regarded the CHI as primarily a health project, aimed at improving the general health of the Gypsy and Traveller communities. People talked in general terms of the CHI helping with health problems or promoting healthy lifestyles. One person said it was concerned with heart disease after prompting. And some talked about the project testing people to see how healthy they were.

> "I think it's to do with health, (Project Health Visitor) takes people's blood pressure and talks about things that are bad for you."
> (Resp.7, Female, 23yrs, Irish Traveller)

> "Well, it's about health. About letting people know how to be more healthy."
> (Resp.10, male, 16yrs, Irish Traveller)

The second main theme to emerge from the interviews was that of raising cultural awareness. Several people believed that the research side of the CHI was aimed at learning about Gypsy and Traveller culture and lifestyles. It was seen as an attempt to learn and then educate the general population about Gypsies and Travellers, with the aim of improving understanding of their communities.

> "Well, you're trying to put our point of view over to them. The way we feel, and the way we are, to make them understand what we're going through. Which I think is a good way, because for us to sit down and tell 'em, it would just go in one ear and out the other. Where as if it's coming from somebody other than us, I

*think it would make a big difference, would make things a lot better to be honest, so we could 'ave the same treatment and the same equal rights as everybody... It's making people understand what we're really like..."*

(Resp.2, female, 22yrs, English Gypsy)

### 5.3.4 Project Health Worker's (PHW) Role



*Illustration 4. Project Health Worker with Irish Traveller in the 'health bus'*

### 5.3.4.1 Service providers' perspective of PHW

The Project Health Worker has a background as a trained Health Visitor and had worked with the Wrexham Gypsies and Travellers several years prior to joining the project team. This proved to be advantageous, as a large proportion of the community remembered her from her previous role. She had built up relationships with several of the Gypsy and Traveller families in the area and therefore, was accepted more readily than if she had been a stranger. The families that knew the Project Health Worker were able to 'vouch' for her to other Gypsies and Travellers who did not know her. On several occasions, when new Travellers arrived, rumours had circulated that the project workers were informants either to the police or social services. It was the Gypsies and Travellers who knew the Project Health Worker who dispelled these rumours.

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The Project Health Worker's role has, however, changed with time. At first, the role was one of 'nurse', attempting to meet the immediate health needs of the community. The reason for this was twofold, first, due to the high level of unmet need in the community and second, to help to gain the trust of the community. The hope was that Gypsies and Travellers would feel that the initiative was theirs and that there was some benefit to visiting the 'health bus' initially. Later, the role broadened and shifted in emphasis to health promotion and coronary health status collection, as well as advocacy work which often involved bridging the gap between health and social care.

> *"At the beginning I think I would have done any nursing task....just to get them on board.....and then when they gained confidence in me, we then really focused on the heart disease stuff...but I don't think we could have done that straight away, there were people who had major issues that needed to be dealt with first."*
>
> *(Project Health Worker)*

The advocacy role has grown as more people in the community trust the Project Health Worker and more problems are disclosed. Often health is not seen as the most pressing issue to Gypsies and Travellers, immediate life problems such as immediate accommodation needs and site provision, take precedence over long term health goals, and the Project Health Worker is trusted as a person who can liaise with other professionals. This difference in priorities between the project workers and the Gypsy and Traveller communities was not fully expected by those in the project team. Feder (1994) evaluated a dedicated Traveller's Health Visitor in East London and also found the role to be much wider than anticipated. He found that in the absence of input from other professionals, the Traveller Health Visitor adopted responsibility for medical, welfare and social advice.

> *"The big issues are about accommodation, about site provision and those major issues. They don't seem to think about their health the same."*
>
> *(Steering Group Member)*

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*"I think the current bulk of the work has been advocacy and I think the reason for the change is the nature of the client group who in terms of thinking of their immediacy and needs, and felt needs, are not the same as our perceived needs, not sure we could have anticipated that.."*

<div align="right">

*(Steering Group Member)*

</div>

The role of the Project Health Worker has now developed as a signposter and co-ordinator to other services by forging strong links with other health and social agencies. Pathways to enable improved access to health and social care have been established (see figure 5.3). Gypsies and Travellers engage with the service in several ways. The majority will make contact with the community health initiative by using the drop-in mobile health service. Referrals to the service also occur through relatives of a person either suggesting they contact the service or by asking the Project Health Worker to contact a relative, if they have a particular unmet health need. Other ways of referral are through Primary and Secondary care professionals contacting the Project Health Worker or through contact with the site warden who will notify the Project Health Worker of any new arrivals on the council run site.

On first contact with a new Gypsy or Traveller, the Project Health Worker carries out a health needs assessment. This includes assessing whether the person or family has any particular unmet health or social needs and whether they are registered with a GP. If they are not registered with a GP and are experiencing difficulties or have any unmet health or social needs then the Project Health Worker will assist in meeting these needs. Due to the high levels of poor literacy skills in Gypsies and Travellers, help is often required to register with a GP and to contact other agencies.

Many of the Gypsies and Travellers that have contact with the community health initiative have chronic health complaints that have resulted from travelling. These have not been addressed, or have been partially dealt with by other health and social care agencies in other parts of the country. One job of the Project Health Worker is to 'unravel the maze' of partial care by attempting to trace past diagnosis, treatment, and assessments of health needs from the information given by the clients. Once the health needs are established, the

Project Health Worker assists the Gypsy/Travellers to arrange appointments with GPs and other health professionals if this is required.

Gypsy/Travellers often miss appointments with health professionals because they have difficulty remembering future dates, if they are unable to read or write. Also, they are often required to travel to visit a sick relative or attend a funeral at short notice. This often results in a breakdown of contact with health professionals and therefore, a break in treatment, often resulting in Gypsy/Travellers having to start again with new referrals. The Project Health Worker will remind those Gypsy/Travellers that have difficulty, that an appointment is due and if they miss an appointment, will liaise with health professionals to commence treatment rather than removing them from treatment/consultant lists. She has also introduced calendars to those who are able, to record their appointments, but with limited success as possessions in the trailer are often discarded due to a lack of space.

For Gypsies and Travellers who experience problems with treatment or communication problems with other health professionals, the Project Health Worker liaises on their behalf. She also accompanies those Gypsies and Travellers who express a wish for her to do so, to consultations, where she often acts as an interpreter between the client and the health professional, providing support to both parties.

# Gypsy/Traveller Access to Health Care Pathway
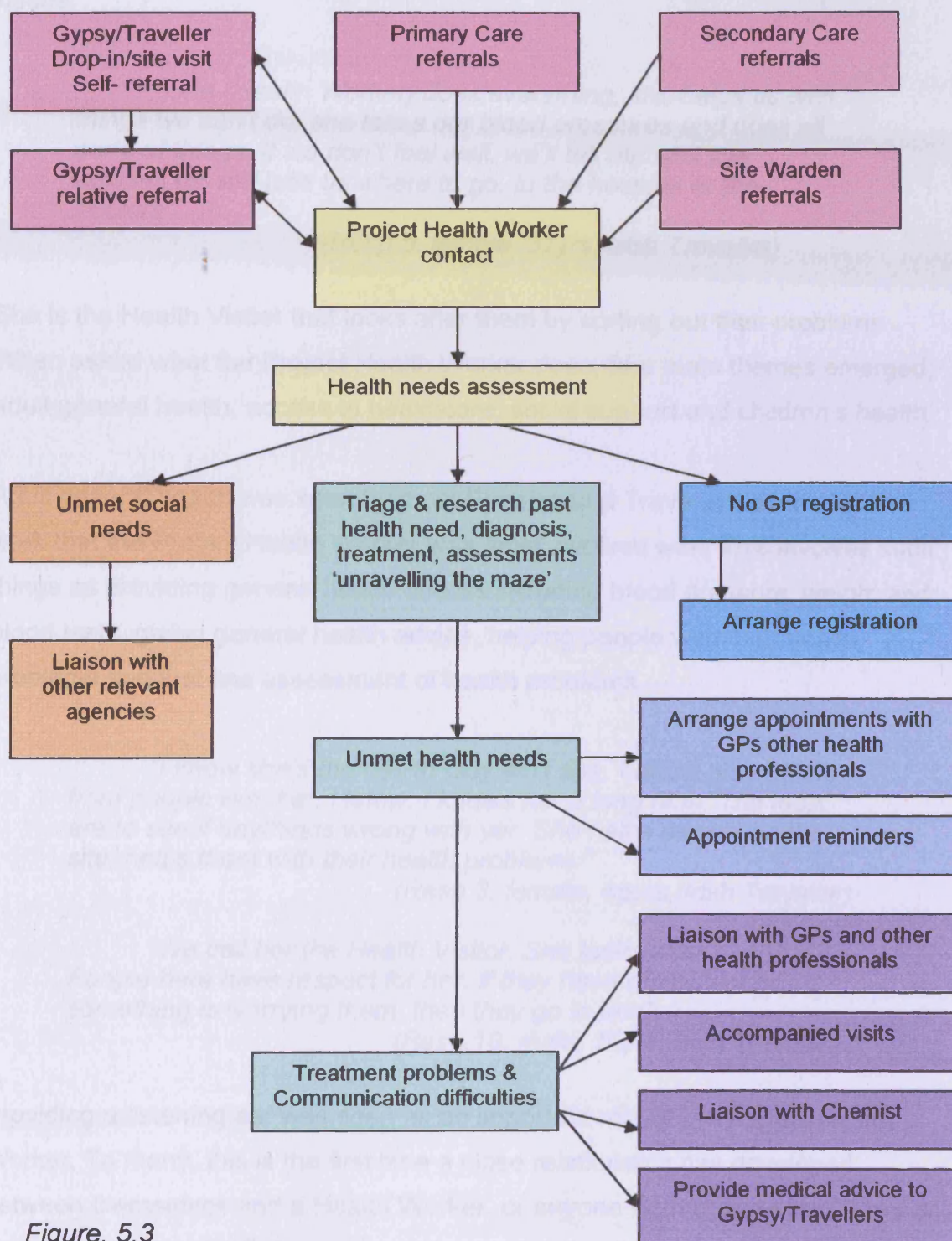


Figure. 5.3

### 5.3.4.2 Service users' perspective of PHW role

To the Gypsies and Travellers involved with this project, the role of the Project Health Worker is seen as wide, encompassing a range of health and social care needs.

> "She (Health Worker) does everything, she helps us with things we can't do, she takes our blood pressures and does all sorts of things. If we don't feel well, we'll tell her and she advises us and tells us where to go, to the hospital or the doctors"
>
> (Resp.5, female, 37yrs, Irish Traveller)

She is the Health Visitor that looks after them by sorting out their problems. When asked what the Project Health Worker does, four main themes emerged, adult general health, access to healthcare, social support and children's health.

Adult general health was seen by most Gypsies and Travellers as the type of work that the Project Health Worker was most involved with. This involves such things as providing general health checks including blood pressure, weight and blood tests, giving general health advice, helping people with their health problems and first line assessment of health problems.

> "I know she's the health lady ain't she. Taking blood tests from people like that, I know. I knows her a long time, The tests are to see if anythings wrong with yer. She helps people on the site, helps them with their health problems."
>
> (Resp.3, female, 65yrs, Irish Traveller)

> "We call her the Health Visitor. She looks after our health. People here have respect for her. If they have a problem or something is worrying them, then they go to her."
>
> (Resp.10, male, 16yrs, Irish Traveller)

Providing a listening ear was seen as an important role of the Project Health Worker. To many, this is the first time a close relationship has developed between themselves and a Health Worker, or anyone from outside the Gypsy or Traveller community. Being able to talk your worries through is seen as valuable.

> *"She's more like, how can I say to yer, she's more like a friend than a Health Visitor because she'll sit and talk to yer. It's like she's not frightened to talk to yer, she's not frightened to touch yer...She's a person you can sit to and you can tell what you need to say...and she'll just sit there and listen."*
> *(Resp.2, female,22yrs, English Gypsy)*

Access to Primary Care was an area that was mentioned frequently by the Gypsies and Travellers interviewed, many said they had been helped to register or re-register with GPs.

Communication was also mentioned. The Project Health Worker has assisted in communication between the GP or other health professionals and the Gypsy and Traveller communities as mentioned above. The Health Worker has accompanied people on visits to see their GP when they felt that they were having problems with communication. This may take the form of the patient needing to have what the doctor is saying explained or reinforced or it may be the other way around, with the Project Health Worker explaining the patient's viewpoint or culture. The Project Health Worker also liaises with GPs through writing letters of explanation concerning a person's worries.

> *"She can help you get a GP and she has helped me by writing a letter to the doctor once explaining what I was worried about."*
> *(Resp.7, female, 23yrs, Irish Traveller)*

> *"She, when I needed to get to hospital now, I couldn't get there, I needed someone to come and explain things and she come."*
> *(Resp.13, female, 21yrs, Irish Traveller)*

Social support was also seen as a role of the Project Health Worker. This includes liaison with other agencies on behalf of Gypsies and Travellers, as well as providing advice about entitlements and help with filling out forms.

Finally, the Gypsies and Travellers interviewed saw the Project Health Worker's role as one including preventative health care for children in the form of vaccinations. One woman said she would not go to the surgery, to the Health Visitor, she preferred the children to be vaccinated by the Project Health

Worker, having been influenced by her mother's belief that the Health Visitor (in general practice) is an authority figure who might take your children away.

> *"Like my son with his injections. I 'aven't taken him anywhere else, I'm waiting for her (Project Health Worker) to come and do 'em…Well I don't understand what a Health Visitor does to be honest with yer, I've always seen the bad side of a Health Visitor to be honest with yer, because me mam's always said 'Oh, the Health Visitor's coming, I'm gonna 'ave me children took off me'."*
> *(Resp.2, female, 22yrs, English Gypsy)*

### 5.3.5 The role of the 'Health Bus'



*Illustration 5. The community health initiative's 'health bus'*

The original idea to use a camper van as a mobile health unit came from the past experiences of the Project Lead and Project Health Worker as Health Visitors, working with Gypsies and Travellers prior to the project. The Health Visitors did not work with Gypsies and Travellers exclusively, but as part of a larger case load. They were aware of the low immunisation rates in this group and attempted to provide an outreach service to the Gypsy/Traveller site to immunise the children. The difficulties they experienced carrying the equipment from caravan to caravan drew them to the conclusion that outreach work would

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be better done from some type of mobile unit where Gypsies and Travellers could visit it on site, rather than the Health Visitors trying to visit every caravan.

The 'Health Bus' is a 23 foot camper van that has been converted into a mobile health unit. It has two distinct areas that can be divided by a curtain if needed. One area is fitted as a clinical examination/treatment area. The clinical area has an examination couch, washing facilities and is fully equipped. In this area, the Project Health Worker is able to carry out blood pressures, venepuncture, immunisations and other simple nursing procedures. The other area is a less formal seating area where people can talk and informal and formal health promotion takes place.

The 'Health Bus' is taken onto the council run Traveller site three times a week and is used to visit private sites and housed Gypsy/Travellers (where appropriate) on the remaining days. When on the council run site, the 'Health Bus' is parked near the entrance to the site. A drop-in service is used, where Gypsies and Travellers are free to come and discuss any problems they may be experiencing. It is also used as a venue for more formal health promotion activities.

### 5.3.5.1 Service users' perspective of health bus

The Health Bus is very much valued by the Gypsy and Travellers communities who make use of it.

> *"I think it's very good. I think they should be on every site."*
> *(Resp.8, female, 20yrs, Irish Traveller)*

The Health Bus fulfils several functions; by far the most important to the Gypsies and Travellers is the privacy that it provides. The Gypsy and Traveller's culture is one of close communal living; people live in an open door fashion, where people will walk into another person's caravan without knocking. People do not lock their doors when they are in. Often, several people will be sitting together in a caravan. Seldom is there privacy and it is not acceptable to ask people to leave.

The Health Bus is run differently, it is an open door, drop-in style service, but the Project Health Worker can lock the door or ask people to leave on the grounds of needing to talk to someone privately about their health. This is accepted by the Gypsy and Traveller communities.

The privacy that the Health Bus provides is a vital element, allowing Gypsies and Travellers to open up to the Project Health Worker. Without this privacy, it would be very difficult to establish the close, trusting relationships that have been forged since the start of this project. Furthermore, it is unlikely otherwise, that the high levels of depression or domestic violence would have come to light.

The privacy that the 'Health Bus' provides also allows Gypsies and Travellers to talk to the Project Health Worker about health concerns that would be seen as culturally taboo, such as women's health, knowledge of the reproductive system, contraception and sexually transmitted diseases.

This privacy is highly valued by the Gypsy and Traveller communities.

> "In the bus you can sit there, you can talk, you can express the way you feel, you can express your feelings, you can tell yers whats up with us and how you're feeling...They can open up more. They can see more what's up with 'em, you can see deep down what's inside. I'm not being funny with yer and I might be the only Gypsy person that's got the guts to say it, every one of 'em puts a face on, nobody knows deep down what's happening inside, nobody."
> (Resp.2, female, 22yrs, English Gypsy)

> "The health bus is really good. You can come in here and talk to Janine in private. You can't do that in our caravans cause there is always people coming and going. People would know your business."
> (Resp.7, female, 23yrs, Irish Traveller)

> "Yeh, because you can come in and sit down and have a chat, with no one like, if someone came in and you didn't want them listening, the Health Worker would put them out. When they come into your caravan you can't, can you."
> (Resp.13, female, 21yrs, Irish Traveller)

As well as providing privacy, the Health Bus also provides a quiet environment to discuss worries and concerns and to talk over health issues. Gypsy and

Traveller caravans are far from quiet. They are often full of friends, family, and children. Gypsies and Travellers have large families and are a young population, so many families have young children at home. As well as the noise, children are a natural distraction when trying to talk. Often, a woman will leave the children with another family member to come to the Health Bus for this reason.

> *"If you want to talk and you want somewhere peaceful, then you can just sit with the Health Worker, and want to know about health and asking things about the kids and you can relax. No, can't (do this in own caravan) because everyone's in the caravan, there's always the kids and people just walks in and out, visiting and whatever."*
> *(Resp.5, female, 37yrs, Irish Traveller)*

People liked the service being 'drop in' and felt reassured by the Health Bus's presence. They can call in with any problems while it is on site. Other's felt that it was good to have the Health Bus because all the equipment for health checks could be easily transported. One person mentioned that she felt easier visiting the Health Worker in the Health Bus than going to the doctor's surgery where she felt uncomfortable because she felt she was 'looked down on' there. She felt that she was shown more respect in the Health Bus. Also, being a camper van, it is a familiar environment to Gypsies and Travellers, a more culturally acceptable environment that puts people at ease.

### 5.3.5.2 Service providers' perspective of health bus

The health bus has enabled the gathering of CHD and mental health status data. The privacy that the health bus offered allowed participants to be candid in their accounts of CHD lifestyle and mental health questions without fear of being overheard by other members of the community. This may be a weakness in other studies that use interviews in the Gypsies' and Travellers' own caravan or house, as they are seldom alone and liable to be interrupted. These interruptions had been witnessed at first hand by the Project Health Worker and Project Lead while they were Health Visitors and they hoped that the health bus would provide a more suitable environment for data collection.

The practical advantages to the community health initiative of having the health bus are that equipment is always available and at hand, for example,

vaccinations are carried on board, as are other pieces of equipment such as a sphygmomanometer, scales and syringes for blood testing. Also, health promotion equipment and materials are carried on board, such as books, visual aids and health promotion videos. Often when a topic arises in an informal discussion of health in the health bus, educational and health promotion materials can be used to help illustrate a health message. Having these materials to hand is very important as Gypsies and Travellers prefer a casual approach rather than a scheduled 'session' about a health topic.

The privacy that the health bus provides is also valued by the project workers, enabling them to have more intimate conversations and therefore gaining a better understanding of people and their problems. The extent to which people would 'open up' in the health bus and discuss their most private concerns was not foreseen by the project workers. It proved invaluable in learning about some of the problems that Gypsies and Travellers suffer but do not necessarily wish to talk about openly, such as family planning and domestic abuse issues.

> "The bus brings privacy to an extent, although its an open door type thing, you can lock it up a little bit, you couldn't do the same practically, equipment wise, it gives the Travellers a chance to come and have a word with us, because quite often you will go to a trailer and there will be several women in their and its difficult to have a personal conversation."
> (Multi-agency Traveller Forum Member)

## 5.3.6 Partnership working within the community health initiative

### 5.3.6.1 Multi-agency working

The Multi-agency Traveller Forum provides a network of professionals who have contact or an interest in Gypsies and Travellers in the area. Because of this, much of the partnership working with the project has been directed towards this group.

Initially, members of the Traveller Forum and Steering Group voiced the desire for the health bus to be more a partnership venture with members of the Traveller Forum being involved with using the health bus. This, however, did not

happen during the early phase of the initiative. There are several reasons for this. First, the concept of outreach was new to some agencies. Second, it was felt that it was not appropriate for all agencies to be in the Health Bus, such as the police or social services. To involve such agencies would have seriously compromised the community health initiative. Also, direct involvement with the CHI was limited by the limited capacity of the Multi-agency Traveller Forum (MAF) members because Gypsies and Travellers formed only a small proportion of most professionals' case loads. Furthermore, Gypsies and Travellers themselves stated that they preferred the health bus to be used mainly by health professionals, although other agencies that were perceived to be of value to the community such as citizens' advice was also thought to be acceptable.

Some professionals believed that there was less partnership working outside of the MAF meetings amongst members than hoped for. However, since the participant observation phase of the evaluation concluded, there has been growing involvement from MAF members including more visits on site from members of MAF.

Some MAF members have, however, have had a good working relationship with the project throughout its lifespan. One of the members of MAF who has had frequent professional contact with the Project Health Worker has been a midwife who often visits the Gypsy/Traveller site to visit clients. They complemented each other by information sharing and providing expert advice for one another in their given fields.

> A midwife came to the health bus today. She was on site to see one of the young women, who she could not find, so came to have a look at the health bus. She is part of the Multi-agency Traveller's Forum, so has been hearing about the project for a long time, and is known to both the Project Health Worker (HW) and myself. While talking, the subject of 'X's (Traveller woman) health arose and the midwife explained how serious 'X's health problems are, that if she were to get pregnant again, it would be a serious threat to her life. HW expressed fears that 'X' wanted another baby. Although this was not a formal professional meeting, a lot of important information was gained by talking to the midwife. It had given HW a better insight into 'X's health problems.
>
> (Observational Field Notes)

Traveller Education and the Education Social Worker are also MAF members who have worked well with the project. Again, this is facilitated by these professionals visiting the site on a regular basis as part of their normal business. This allows for the professionals to 'drop in' the health bus when on site as well as planned joint working. As with the Midwife, these informal visits provided opportunities for sharing of information and professional expertise. One result of the joint working between the Project Health Worker and the Traveller Education Officer has been a successful bid for a part-time play worker for Gypsy and Traveller children in the area. They have also built up a working relationship where shared common education goals such as health promotion means that they complement and reinforce each other's health messages in school and on site.

One aspect of partnership working that has worked well and involved all members in MAF has been the informal 'coffee mornings' held by the Multi-agency Traveller Forum. These events take place on a three monthly basis and are held in the Catholic Church Hall. Members of MAF, the community health initiative and Gypsies and Travellers in the area get together. It is an opportunity for information exchange. Where Gypsies and Travellers can discuss any issues they are experiencing with the relevant MAF member, either on a one-to-one level or wider issues to be brought up at MAF meetings at a later date. Both housed and caravan dwelling Gypsies and Travellers attend these events, however, the majority of attendees are women as many of the men are out working during the day.

A 'healthy food' hamper was offered as a raffle prize at each event and was intended to act as an incentive for the Gypsies and Travellers to attend, and also has a health promotion element by including healthy ingredients in the hamper. The Project Health Worker has also used these gatherings to reinforce healthy eating by providing healthy snacks, such as healthy wraps and sandwich fillings and fruit and vegetables. This has also proved successful and the Project Health Worker involved several young Irish Travellers in preparing the snacks.

One of the 'coffee mornings' was attended by Jane Hutt in January 2004, the then Welsh Assembly Minister for Health. This event enabled the minister to see the type of work that MAF and the Community Health Initiative is engaged with as displays were arranged around the hall and members were present to talk to the minister about their work. More importantly, the minister was able to hear some of the issues that concern Gypsies and Travellers first hand from the community members themselves. The event also helped to raise the esteem of the Gypsies and Travellers involved, and the communities as a whole, as it demonstrated that there was interest in them as a group and their welfare by at least some members of Government.

### 5.3.6.2 Other Health professionals

The Project Health Worker has worked in partnership with a number of different health professionals including GP's, Practice Nurses, Consultants, Hospital Nurses, Psychiatrists and Community Mental Health Nurses. The Project Health Worker often works to bridge the gap in understanding and communication between health professionals and the Gypsy and Traveller communities. A particularly good working relationship has developed between the Project Health Worker and GPs who look after most of the Gypsies and Travellers in the area. Information is shared, and joint initiatives have been undertaken such as childhood immunisations. The Project Health Worker will liaise by writing or telephone conversations.

As mentioned earlier, the Project Health Worker will also accompany a Gypsy or Traveller either to a GP or specialist appointment if requested by the Gypsy or Traveller, particularly when there has been 'difficulties' such as a lack of understanding between the practitioner and the individual. The Project Health Worker mediates; assisting the Gypsy or Traveller to understand what is being said and also providing a 'voice' for their concerns. Often, there is a lack of understanding of Gypsy and Traveller culture which can lead to a miss-match of expectations on both sides.

> The Health Worker (HW) accompanied 'P' to the GP this afternoon. 'P' had been prescribed a lotion for her long standing psoriasis. She was instructed by the doctor to put the lotion in a bath and soak in it. 'P' has had problems following this instruction as she lives in a trailer with her family, but they do not have running water. It is therefore,

impossible for her to use this medication. 'P' appeared unable to explain this to the GP.

When this was explained to the GP by HW, he turned to 'P' and said 'Why don't you just live in a house? As Travellers the family would not choose to live in a house. He also did not appear to understand the cultural constraints, that even at 22 years of age, she is expected to live at home with her parents, there is no possibility of a single girl living on her own, and that the family were engaged in a long protracted fight with the local council over being allowed to live on their own land and this is why they have no running water.

(Observational Field Notes)

The network of contacts that the Project Health Worker liaises with has steadily grown over the period of this study, below is a list of those services.

**Project Health Workers' Liaison Contacts**

**Health Care Liaison**

| Health need: | Service: |
|---|---|
| General health (acute/chronic)........... | General Practitioners |
| Secondary care referrals.................... | Consultants |
| Dental health..................................... | NHS Direct: emergency service |
| Mental health..................................... | First Access: assessment service |
| | Mental Health Team: Psychiatrists & CPNs |
| | Project Mental Health Support Worker |
| Hospital care...................................... | Ward Staff |
| Childcare & development.................... | Health Visitors/ School Nurses |
| Anti-natal care...,.............................. | Gypsy/Traveller Midwife |
| Community treatments........................ | District Nurses |
| Disabilities........................................ | Occupational Therapists/ Physiotherapists/ |
| | Wheelchair Services/ Disability Aids Service |
| Substance misuse.............................. | Drugs & Alcohol Service |
| Continence........................................ | Continence Service |

**Social Care Liaison**

| Social need: | Service: |
|---|---|
| Housing............................................. | Housing Department/ Housing Association |
| | Site Warden |
| Domestic abuse................................. | Women's Aid/ Refuge/ Homeless |
| | Department |
| | Police |
| Child welfare..................................... | School Nurse & Health Visitors |
| | Traveller Education/ Education Social |
| | Worker |
| | Social Services |
| Benefits............................................. | Welfare Rights |
| Discrimination.................................... | Police/ Commission for Racial Equality |
| | Citizen's Advice Bureau Traveller Worker |
| | (appointed 2006) |
| Criminality......................................... | Probation/ Youth Offending Team/ |
| | Prison Service |

*Fig 5.4*

### 5.3.7 Health Promotion within the community health initiative

Health promotion in terms of CHD healthy lifestyle education and promotion has been a feature throughout the project. This has taken on several forms, one-to-one lifestyle advice, informal group sessions, formal group sessions and organised activities.

One-to-one lifestyle advice occurred when gathering the CHD data on lifestyles for the coronary health status research project. The Project Health Worker offered advice on heart disease and lifestyle after obtaining information on Gypsy and Traveller's lifestyles, this often led to discussions on diet, alcohol, smoking and exercise and led to interest in how these factors might affect other family members. This led to more Gypsies and Travellers being recruited and being offered advice. Often, this would take the form of a wife deciding that it would be a good idea for her husband to get advice on some aspect of lifestyle. She would then become instrumental in persuading her husband to come to the 'Health Bus'. This was seen many times during the first phase of the project and resulted in reaching many more men than first anticipated.

Because the culture of Gypsies and Travellers is to gather in one another's caravans to chat, this also tends to happen in the 'Health Bus'. It becomes the ideal setting for informal chats on health topics. Often similar groups will congregate in the 'Health Bus', for example, young mums, mature women, young unmarried females or young men. This becomes an ideal opportunity to turn the conversation to a lifestyle topic of interest to the given group. For example, successful sessions concerning the effects of smoking and support available to give up smoking have been undertaken with groups of young men.

They showed great interest and were able to talk freely, whereas, they did not want their mothers knowing that they smoked, and denied this in their presence. Another example is healthy eating with young women. Dieting and losing weight seems to be a high priority amongst Gypsy and Traveller women, often a woman will ask advice on diet, and a group discussion will develop with the Project Health Worker providing advice on healthy eating and safe ways to control weight.

Formal group sessions and group activities have been arranged by the Project Health Worker, either by conducting them herself, or with invited professionals. There has been mixed success with this approach due to cultural demands and the nomadic lifestyle of these communities. If a professional visitor or an activity is organised for a specific day, there is a good chance that those who agreed or expressed a wish for such a session will not be available. Many times this has

happened during the lifetime of this project, often people have had to attend weddings, hospitals or funerals or have moved on to another location. Also, time is not always given the importance that non-Gypsies give to it; some Gypsies and Travellers are not able to tell the date or time and judge time in terms of meal times. A full exploration of culture and lifestyle is discussed in Chapter 4 and differences in priorities between Gypsy/Travellers and service providers is discussed in chapter 7 section 7.3.2.2. However, even a small turnout can have a 'knock on effect' if materials from the session are available, as one person will tell another about the session.

> Later 'E' came into the bus with his friend. Last week the Project Health Worker had gone on site with a smoking cessation officer and 'E' was keen to try the smokalyzer (carbon monoxide monitor) and to show his friend. 'E' has given up smoking for 3 months. They both had a go at the monitor and 'E' was keen to get the others in the 'health bus' trying it and showing them the health promotion visual aids ( bottles of tar) we have on board.
>
> (Observational Field Notes)

## 5.3.8 Gypsies' and Travellers' reflections of the community health initiative as a whole

Generally, Gypsies and Travellers are happy with the community health initiative as a whole and expressed feelings that little could be done to improve it and believed there would be long term benefits from the project. One person believed that as a result of the project, Gypsies and Travellers would become better informed and have increased awareness of their rights. It was also believed that the health of the community would be improved by not missing so many appointments with the GP. Several Gypsies and Travellers believed that they would benefit in the long term by increased awareness of the culture and lifestyle of Gypsies and Travellers, and hoped for a decrease in discrimination as a result.

> "I can honestly say, this is something that we've never had before. So to me, you're just doing us the world of good, not only in my family but other families as well, d'you know what I mean. You're, how can I explain, you're putting a good point of view over to other people about us. Where they only see the bad, you're coming and seeing the good....you're opening other people's eyes up to see what we're living

*like and saying 'they're not all like that'...'They don't all do that'... and we couldn't do that, you're trying to earn us respect, that's all."*
                                                        *(Resp.2, female, 22yrs, English Gypsy)*


One person suggested that the service should be extended to evenings and weekends to involve more of the men on site.


There were however, mixed feeling concerning the benefit of the health promotion work. One Traveller woman felt that the advice on smoking and exercise was useful whereas another said that she didn't find the advice on smoking useful because she felt giving up was pointless, believing the damage to have been already done. This is an example of a fatalistic attitude to health that many Gypsy and Travellers expressed throughout the time of the project. Another felt that he was already used to getting advice on healthy living anyway and so it was not needed.


*"Giving up smoking...exercises...'Cos it keeps you.. 'cos I'm always, over being a heavy smoker, I'm always chesty, I get chest infections, d'you know what I mean. I'm always chesty. But when I'm doing exercises, it just clears everything out and makes me feel more fitter. It makes me feel ten times better when I'm doing exercises."*
                                                        *(Resp.5, female, 37yrs, Irish Traveller)*


*"No, cause I'm used to smoking now innit, the damage is done, if it's done it's done isn't it, can't turn back the clock, and going to the GPs and all 'you've got to give up smoking' and it's no good if the damage is done isn't it, it would be pointless."*
                                                        *(Resp.13, female, 21yrs, Irish Traveller)*


## 5.4 Summary and discussion

The key participants in the community health initiative include the Gypsies and Travellers in the Wrexham area (service users), both on the main council run site, on private land and in houses; the members of the Multi-agency Traveller Forum (MAF), a group of professionals who have a professional interest in Gypsies and Travellers locally; and the Project Steering Group, who are involved in the design and provision of the service (service providers).

The main focus of the community health initiative has remained access to healthcare and coronary health, however, it has also widened to meet the needs of the community including areas of need not recognised until the project began, such as the high level of mental health problems.

The qualities of the Project Health Worker, the health bus and partnership working appear to be the key elements to the success of the initiative and its acceptance by the Gypsy and Traveller communities. Simply by having a service dedicated to this hard to reach and neglected group of people has raised their self-esteem, as they believe someone feels they are worth the attention. Also, there is a belief by the community that the project will raise cultural understanding and will result in less discrimination in the future.

Gypsy and Traveller communities in Wrexham have accepted the new service well and feel they have ownership of the service. It is their 'health bus' and they have clear views about what the service is primarily for, including providing general health advice, health promotion and access to health care.

Finally, all the groups connected with this project, the Project Steering Group, the Multi-agency Travellers' Forum, GPs and Gypsies and Travellers themselves all value the project and feel that it should continue.

In the next chapter, the goals set by the Project Steering Group are considered, how far has the community initiative gone to accomplishing these goals? Also, the outcomes of the quantitative study of Gypsy/Travellers' CHD and mental health status are reported and discussed with reference to the culture, lifestyle and life experiences of this group and the efforts of the community health initiative reported in this chapter.

# Chapter 6

# Outcomes of the community health initiative

## 6.1 Introduction

This chapter provides a description of the major outcomes of the project both in terms of the community health initiative and the research, which had been identified by the Project Steering Group through the development of a programme logic model, described below in section 6.2.

Another outcome reported in this chapter is a description of Gypsies' and Travellers' coronary and mental health status with reference to cultural influences from Chapter 4. A description is provided of Gypsies' and Travellers' coronary risk factors including lifestyle and physical measures compared to Welsh National, English and UK population data where available. Also provided is an exploration of Gypsies' and Travellers' mental health status compared to UK population data and a study of Gypsy and Traveller health in England.

## 6.2 Outcomes of the community health initiative

*Logic Model – Identification of project outputs and outcomes*

Two workshops were run by the project researcher in the development stage of the project, and involved all members of the Project Steering Group. A Programme Logic Model (Kirckpatrick 2001, McNamara 2000, Funnell 1997, McCawley 1997) for this project was developed outlining the structure of the project and its main outputs and outcomes (see Appendix 15). This development process by the group was carried out over two full afternoon sessions. It proved useful in exploring and making solid the main focus of the project and maintaining that focus.

The Programme Logic Model as well as providing the focus for the project, is a means of identifying the goals of the project and allows evaluation of the outcomes against these stated goals. The criteria on which the community initiative has been evaluated were developed from the stated aims and objectives of the project, and the goals identified in the programme logic model for the project. The criteria incorporate the short and medium term goals as follows:

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1. Evidence of the cultural acceptability of the community initiative by Gypsies and Travellers.

2. Improvement in access to services in primary care evidenced by increased numbers of registrations, decrease in missed appointments and better adherence and appropriate use of medications.

3. Improved appropriate access to other healthcare services.

4. Improved access to social care services.

5. Recognition of acute and chronic unmet health needs.

6. Improvement in partnership working to improve access to all services to Gypsies and Travellers by increased involvement in MAF.

7. A change in health professionals' perceptions of Gypsy/Travellers evidenced by better willingness to engage with Gypsy/Travellers.

8. Evidence of child engagement with healthy activities sessions.

9. Evidence of a shift in awareness of CHD risk factors through culturally appropriate health promotion.

Below is a list of the stated goals and how far the project has gone to meet these goals. This includes an assessment of the impact of the community health initiative by using the service providers' identified short, medium and long-term goals and service users' reflections on the initiative.

### 6.2.1 Short term goals
#### *6.2.1.1 Improve access to services in primary care*
The project has focused much effort in ensuring that all those Gypsies and Travellers who wish to be registered with a GP (as a small number of men chose not to) are registered. This has now been achieved, with only those who are new to the area and those who occasionally are removed from a GP's list needing assistance. Access to Dental services remains a challenge due to the lack of NHS dentists taking new patients in the area. It has also been noted by GPs that follow-up appointments for chronic illness has also improved and several people have received minor operations.

### 6.2.1.2 First aid and triage to appropriate healthcare agency

This service is ongoing and is provided by the Project Health Worker during her contact time in the Health Bus. She is also obtainable during office hours by phone. Gypsies and Travellers value this service and often seek out the Health Workers' advice. This was noted by one GP, saying that he had found he was getting more Gypsies and Travellers coming to see him on the advice of the Project Health Worker and that they would have otherwise gone to A&E.

### 6.2.1.3 Recognition of acute problems

The project has identified previously unappreciated health and social problems such as mental health problems, domestic abuse and alcoholism. These problems have been little described previously in the literature, although the health impact is great. Links have been established with other professionals to promote effective treatment and care. Other chronic conditions that have not been successfully dealt with in the past have also been identified and steps taken to better manage chronic problems such as psoriasis in one young Irish Traveller woman and Lymph Oedema in another young Gypsy woman in a more culturally sensitive way.

### 6.2.1.4 Number of contacts

The number of Gypsy and Traveller contacts made has far exceeded our original estimate. At the time of writing this thesis, the Project Health Worker has come into contact with 139 Gypsies and Travellers. During the period of this study, between January 2002 and July 2005, women had on average 23 contacts with the Project Health Worker, with a maximum of 73 and a minimum of 1 contact. Men had an average of 13 contacts with a maximum of 42 and a minimum of 1.

Due to the nomadic lifestyle of this population, new contacts are regularly being made, for example, 41% the participants in the CHD study have since moved on and new Gypsies and Travellers have arrived in their place. Also, the project has identified those 'invisible' Gypsies and Travellers who live in houses who have unmet health needs.

### 6.2.1.5 Improved access to social care

Some Gypsies and Travellers had social care problems that they were unable to address, for example, one elderly woman required home help for an elderly incontinent and infirmed relative but was unsure who to contact or what she might be entitled to. Access to social care has been improved in two ways, first, the Project Health Worker liaises with social care agencies on behalf of people in particular difficulties, and second, there is now a presence of some social care agencies in the health bus on a regular basis such as Welfare Rights and Scope (voluntary sector).

### 6.2.1.6 Improved partnership working

Partnership working is viewed as an ongoing goal and has steadily improved through the life of this project; both through group activities with the Multi-agency Traveller Forum and through the liaison work of the Project Health Worker with other professionals (see partnership working section 5.3.6).

### 6.2.1.7 Equity of access to health care

Equity of access with non-Gypsy/Travellers is viewed as an on going goal and is one of the main focuses of the project. Inroads have been made to enable equity of access to health care through the liaison work of the Project Health Worker and also by raising awareness of Gypsies' and Travellers' culture, lifestyle, health beliefs and health needs. Presentations are made to student nurses and to professional conferences. Publications in relevant health journals are planned. However, there is still a long way to go before there is true equity. The development of materials for cultural awareness training, featuring Gypsy/Traveller culture, for all Public Health Workers should be a priority.

### 6.2.2 Medium term goals

### 6.2.2.1 Appropriate CHD management in primary care

The information gathered from the study of the coronary and mental health of Gypsies and Travellers in Wrexham has proved helpful in identifying those people with high CHD risk factors. GPs have used this information to treat those patients at high risk and have commented on how they value the feedback from the Project

Health Worker on the CHD lifestyle information. At present, a health needs assessment is carried out by the Project Health Worker for any new Gypsies and Travellers who move to the area and details are forwarded to their GP.

### 6.2.2.2 Focus for Multi-agency Traveller Forum

The project has provided a focus for the efforts of the Multi-agency Traveller Forum during the time of this study. The focus has now widened to include other areas such as awareness raising, and service provision (see Chapter 5, section 5.2.3)

### 6.2.2.3 Health /other professionals' willingness to visit site

This is slowly changing due to the awareness raising activities of the project. After being approached by the Project Health Worker concerning the gap in services and need of Gypsies and Travellers, Welfare Rights have started to visit the site on a regular basis. There has been a marked improvement in the willingness of some Health Visitors to visit the site. However, these are new Health Visitors who have recently qualified and have either had experience of the site through student placements or through contact with the Project Health Worker on the job. There is still much progress that can be made as institutional discrimination does exist, with some health professionals still holding deeply entrenched prejudice towards this community (see Chapter 4.5.3).

### 6.2.2.4 Introduce healthy activities for children

Healthy activities have been encouraged by the Project Health Worker with the children on site. However, this has been limited to skipping and 'hop scotch' due to the lack of safe spaces on site in which children can play or participate in any organised outdoor activities. Health education sessions with the children in the 'Health Bus' have proved to be very successful. They are well attended and liked by the children. In addition, the project has supported the efforts of the Youth Offending Team to provide a Youth Club for young Gypsies and Travellers in the area and the project has collaborated with Traveller Education in a successful bid for a part-time play worker who takes children out for sporting activities such as swimming.

### 6.2.2.5 Shift in awareness about CHD risk factors

We are now seeing the beginnings of change in some of the Gypsies' and Travellers' attitudes towards CHD risky behaviours. However, changing risky behaviours such as cigarette smoking has been less successful. Several people have attempted to give up smoking and have sought assistance from the Project Health Worker. Also, some women on site have modified their diet in the light of health advice. Although there has been limited success with organised health promotion in the form of exercise in the adult communities, informal, opportunistic advice on a one-to-one basis or in small groups on topics that Gypsies and Travellers feel are important to them at that time, have proved to be of value. Formal health promotion sessions with the children have proved to be more successful, with children taking messages of healthy lifestyle to their parents. A further discussion can be found in Chapter 5, section 5.3.7.

### 6.2.3 Long term goals

The project has made a good start towards meeting its long-term goals identified through the programme Logic Model and listed below.

### 6.2.3.1 The improvement of the general health of Gypsies and Travellers It

has been reported by health professionals that there has been a general increase in interest in health amongst the Gypsy and Traveller communities and an increase in immunisations. Although it is too early to see changes in morbidity in terms of CHD and mental health, lifestyle messages have had some limited early success in terms of smoking cessation and healthy diets. Previously unmet health and social needs have been identified and the project continues to work towards enabling appropriate help to become available as health is inexorably linked to social and environmental needs as well as cultural constraints and health beliefs.

### 6.2.3.2 Appropriate use of health services by the Gypsies and Travellers

Through the liaison work of the Project Health Worker, there has been an increase in appropriate access to health care, this will in time, impact on the communities' general health. For example, it has been reported by a GP that there has been a marked improvement in antenatal care, with Gypsies and Travellers coming to the

surgery much earlier in their pregnancy. Also, there has been an increase in the use of mental health services since the introduction of the Mental Health Worker to the project. It is hoped that a suitably interested and informed person from the Gypsy and Traveller communities will come forward in the future with the aim of becoming an advocate for their community. The project is helping by increasing awareness of health issues and actively encouraging involvement in the Multi-agency Traveller forum and meetings and conferences concerning Gypsy and Traveller issues.

### 6.2.3.3 Increase in understanding and valuing of cultural diversity between both professionals and the Gypsy and Traveller communities

This long term goal is slowly starting to be addressed by both the Multi-agency Traveller Forum and the community health initiative. Presentations and seminars with health professionals are ongoing (by the project workers) and help to raise awareness of Gypsy and Travellers' culture and health beliefs. The direct liaison work of the Project Health Worker with both health and social care agencies has also had the added benefit of raising cultural awareness. However, there is still evidence of institutional prejudice against the Gypsy and Traveller communities in both Primary and Secondary care, often health workers see them as 'troublesome', because they do not always comply with the expectations of the service providers concerning appointments, screening or medication. This is seen as a 'problem with Gypsies and Travellers', rather than a 'problem with the system' that is not culturally sensitive. Entrenched views are not overturned quickly.

A series of visits to both primary and secondary schools was undertaken in the early phase of the project. This was to educate non-Gypsy children of Gypsy and Traveller lifestyles.

> They seemed impressed with the bus (school children). The Head of one of the schools said she was pleased we had come as it gives children who are not Travellers a chance to see what it is like in a mobile trailer. That most would not have experienced this before and it would help them understand other cultures and ways of life. I feel it also gave kudos to those Traveller children in those classes as they are known to

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An interactive school theatre company visited the site, housed Gypsies and a local
Roman Catholic school. The script writers held workshops with Gypsies and
Travellers assisted by the Health project in order to gain an understanding of
issues of culture and discrimination facing the community. The play was later
performed in two of the local schools.

The community health initiative is also enabling Gypsy and Traveller communities,
who have long held suspicions of 'outsiders', to come into contact with a health
professional on a much more personal level than has been seen before. This
'exposure' has led to Gypsies and Travellers who are involved with the project,
becoming much more at ease with health professionals and non-Gypsy/Travellers
in general, as ideas and culture are shared. The mere existence of the initiative
has raised the self-esteem of the Gypsy and Traveller communities as they feel
they are finally valued as people and worthy of attention.

## 6.3 Outcomes: CHD & mental health status of Gypsies and Travellers

Reported here is a summary of the findings of a quantitative study of Gypsy and
Traveller coronary and mental health status. This study was conducted alongside
the qualitative studies in this thesis for two reasons; firstly, to provide further insight
into the lifestyle and health of Gypsies and Travellers in order to better inform the
evaluation of the community health initiative. Secondly, to put Gypsies' and
Travellers' health care experiences and health beliefs into context with their health
status, thereby enabling an investigation of the interactions between health status
and Gypsy and Traveller culture and health beliefs.

Information was collected by myself and the Project Health Worker concerning
Gypsies' and Travellers' lifestyle, including smoking, alcohol consumption, exercise
and diet, physical measurements including body mass index, blood pressure and

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cholesterol level and reported morbidity and family history. Mental health measures included both self- reporting of mental health problems and prescribed medication alongside the Hospital Anxiety and Depression Scale. All data was compared by standardised ratios to factor for age group, gender and socio-economic group with both the Welsh general population, UK and English general populations where applicable. A full description of the method and participants is provided in chapter 3, section 3.4.

As mentioned in the review of the literature in chapter 1, little research has been conducted in the past on adult health that does not concentrate on communicable diseases or genetic disorders (Morris 1999, Hajioff 2000, Van Cleeput 2001, Zeman 2003, Sepkowitz 2006). There are however, two notable exceptions that have sought to describe adult Gypsy and Traveller health status in England. The first is the study of Gypsy and Traveller health in East London by Feder in 1994, who looked at the coronary health of Gypsies and Travellers in terms of risk factors such as lifestyle and physical measures. The second is a more recent multi-site study of Gypsy and Traveller health in England by Parry and her team in 2004. This study focuses more on general health and well being but does describe smoking prevalence and the mental health status of Gypsies and Travellers. The findings of these studies will be used to compare and contrast with the findings of the present study where comparable results exist.

## 6.3.1 The lifestyle of Gypsy/Travellers as CHD risk factors

### 6.3.1.1 Cigarette Smoking Prevalence

The prevalence of cigarette smoking in the Gypsy and Traveller communities was compared to that of the general population of Wales and of the UK. Standardized Smoking Ratios (SSR) were calculated for age group, gender and socio-economic NS-SEC group 3.

Self reported cigarette smoking prevalence in the Gypsy and Traveller group was 73% compared to 26% in the Welsh and UK general population.

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Prevalence in the Gypsy and Traveller group when adjusted for age was nearly two times greater than expected (SSR 198.8 for Wales & 195.4 for UK) (see appendix 16, table1). When gender is adjusted for, smoking prevalence in the study group rises to over twice the expected rate compared to Welsh and UK general populations (SSR 223.7 for Wales & SSR 231.5 for UK). Prevalence in females is over 3 times that expected compared to the Welsh general population, whereas males are over twice the expected rate (see Appendix 16, table2).

The prevalence of smoking was higher amongst Gypsies and Travellers (73%) when compared to NS-SEC3 Manual and routine (33%) and also those who had never worked or were long term unemployed (36%) (See figure 6.1 below). The Gypsy and Traveller group were higher than the expected rate with an SSR of 185.9 when adjusted for gender (see appendix 16, table3) compared to UK NS-SEC3 (Routine and Manual).
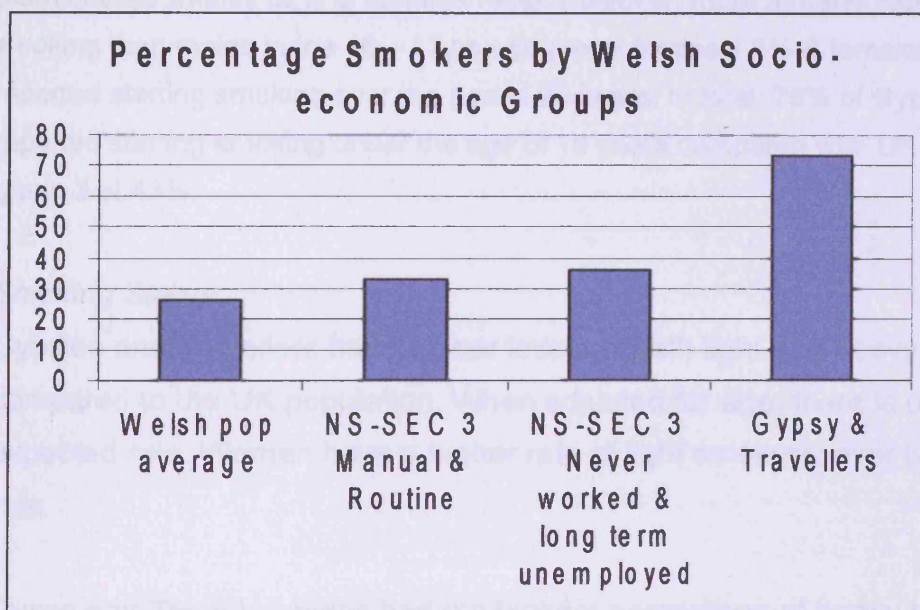


Figure 6.1

Feder (1994) also found a higher percentage of Gypsy/Traveller smokers (63%) compared to a control group (39%). Interestingly, this differs from the percentage of smokers found in the current study of Gypsy/Travellers in Wrexham of 73% and the general population of 26%. Also, he found less difference between the cigarette

smoking prevalence of Gypsy/Traveller men to women (68%/62%) in East London than found in Wrexham (58%/82%). Why prevalence of smoking should be so much higher in Gypsy/Traveller women in Wrexham is uncertain but may be a reflection of the heterogeneousness of these groups or may be a result of the reporting method. There may have been a reluctance of women to report their cigarette smoking to their GPs as was the method of data collection in Feder's study whereas they may have felt more at ease with the Project Health Worker who they knew and trusted.

*Age Started Smoking Cigarettes*

The self-reported age range for starting smoking cigarettes amongst Gypsies and Travellers was between 4 and 23 with a mean age of 13.9 years

The majority of both male and female Gypsies and Travellers reported starting smoking before the age of 16, with slightly more males starting in this age group than females (males 82% & females 74%). However, more females reported starting smoking than males in the 16 – 17yrs age group (males 4.5% & females 19%). None reported starting smoking over the age of 25 years. In total, 76% of Gypsies and Travellers reported starting smoking under the age of 16 years compared with UK Socio-economic group 3 at 43%.

*Smoking Status*

Gypsies and Travellers have higher levels of both light and heavy smoking compared to the UK population. When adjusted for age, there is over 1½ times the expected rate. Women have a higher rate of light smokers, over twice the expected rate.

Gypsy and Traveller males had the highest percentage of heavy smokers (32%) closely followed by Gypsy and Traveller women (28%). When adjusted for age, there are over 3 times more heavy smokers than expected. Adjusted for gender, both men and women have rates around 3 times the expected rate.

### 6.3.1.2 Alcohol Consumption

Gypsy and Traveller participants were asked questions about their alcohol consumption, how regularly they drank alcohol and an estimate of how much in terms of drinks per week and maximum daily consumption on an average week.

When looking at average weekly alcohol consumption in this group, the distribution is of particular interest. Although the mean weekly alcohol consumption is 21.66 units per week compared to 12.1 in the UK general population, the Standard Deviation is 52.2 and a median of .00. This suggests a large number of none drinkers and a number of very heavy drinkers.

Observations of Gypsies and Travellers on the council run Gypsy/Traveller site support the findings that there is a core of very heavy drinkers on site. These tend to be mature males and have been seen consuming alcohol in the mornings on a regular basis. Several men visited the 'health bus' during the time of the study and revealed that they had been living mainly on alcohol for several months and one man could not remember the last time he had eaten solid food. Gmelch (1985) also noted high levels of alcohol consumption amongst male Irish Travellers and suggested that this was adaptive behaviour to lessen the immediate anxiety and psychological pain experienced by a new environment where their traditional role in the family is in flux.

### Frequency of Alcohol Consumption

Of those participants who reported drinking regularly (at least once in a typical week), 11% reported drinking at least once but less than on five occasions in an average week compared to 28% reported drinking on more than five occasions in an average week. Men drink more frequently than women, with 16.7% of men compared to 8.2% of women drinking at least once but less than on five occasions in an average week. 36.7% of men compared to 22.5% of women drank over five days in a typical week

Younger age groups (16 – 24yrs) drank less frequently and none reported drinking more than five days in a typical week. Those in the 25 – 49 age groups reported

drinking most frequently (see figure 6.2). None over 50 years reported drinking alcohol.



**Frquency of Drinking by Age**
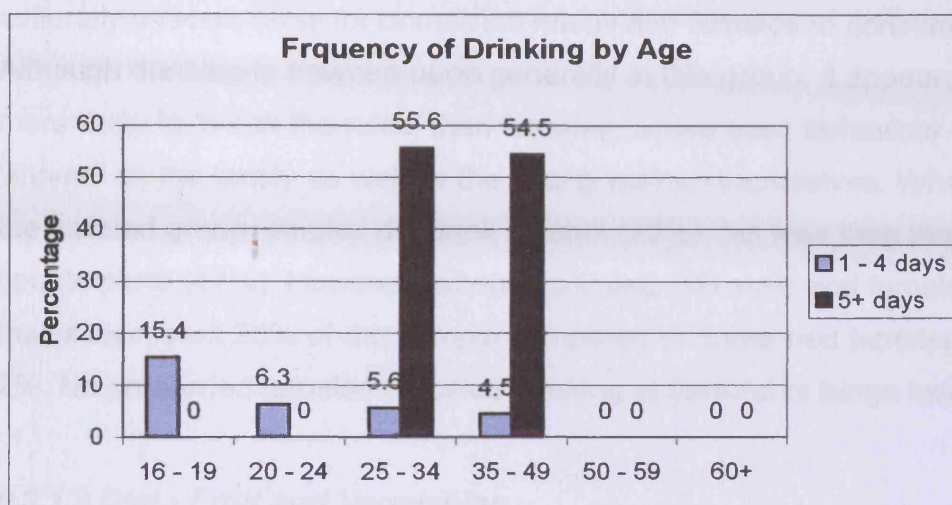
*Figure 6.2*

*Quantity of Alcohol Consumed*

There are more non-drinkers than those who drink alcohol in the Gypsy/Traveller participants with 60.7% either drinking only occasionally or not at all.

When adjusted for gender, Gypsies and Travellers' prevalence of drinking above the recommended guidelines is less (SR 59.8) than the Welsh General population. Gypsies and Travellers' Standardized Ratio score for binge drinking indicates a slightly lower level to the Welsh general population with an SR of 84. Inspection of the Standardized Ratio table suggests this is due to lower than expected levels of women binge drinking.

When Comparing harmful drinking to the UK Socio-economic group 3 (Routine and Manual) by gender, again the Gypsy and Traveller participants scored lower than expected with a SR of 37.6, lower than the UK General population comparison, but this is to be expected as alcohol consumption decreases with the rise in socio-economic categories.

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*Marital Status and Alcohol Consumption*

Marital status was explored in connection to alcohol consumption in the Gypsy and Traveller participant group. Observational and Interview data suggests that it is culturally unacceptable for unmarried males and females to consume alcohol. Although drinking is frowned upon generally in this group, it appears that males are more likely to 'break the rules' than females, where such behaviour would bring 'shame' on the family as well as the young women themselves. When compared to the married group, singles did drink alcohol (25%), but less than their married counterparts (47%). However, when separated into male and female, unmarried males represent 20% of the sample compared to unmarried females who represent 2%. No unmarried females reported drinking at harmful or binge levels.

### 6.3.1.3 Diet - Fruit and Vegetables

Gypsy and Traveller participants were asked questions about their diet, including how much fruit and vegetables they consume in a typical day. This was converted into portions as suggested by the Foods Standards Agency Guidelines (Food Standards Agency 2005), which suggests 5 or more portions per day as a healthy diet.

This information was then compared with the Welsh general population. The percentage of participants reporting no fruit and vegetable consumption on a typical day was 39%, this compares with 5% of the Welsh general population. 45% of participants reported consuming at least one but less than five portions in a typical day compared to 58% of the Welsh general population. The percentage of participants who reported consuming more than five portions of fruit and vegetables in a typical day was 16% compared to 37% in the Welsh general population and 35% for socio-economic category 3 (Routine and Manual).

Standardized ratios were calculated compared to the Welsh general population. Adjusted for age group, Gypsies and Travellers were over 4½ times the expected rate for consuming no fruit and vegetables. Adjusted for gender, this rose to over 6½ times the expected rate, with females 7 times the expected rate. This may be

due to female Gypsies and Travellers being weight conscious and using not eating as a form of weight control.

There were a smaller proportion of Gypsies and Travellers who ate the recommended amount of fruit and vegetables in a typical day. When adjusted for age and gender the rate was less than half the expected compared to the Welsh population.

### 6.3.1.4 Exercise

Department of Health guidelines (Chief medical Officer 2004) suggest that adults should partake of moderate physical activity for 30 minutes per day, at least five days per week. However, the 30 minutes can be taken as smaller units, say ten minutes 3 times a day.

Participants were asked questions about their physical activity in the past week. What activities they were engaged in, the duration of the activity and how often they carried out these activities. This information was used to categorise participants in terms of physical activity.

30% of Gypsy and Traveller participants reported physical activity levels at or above the recommended guideline compared to 65% in the Welsh general population. 70% fell below the recommended level compared to 35% of the Welsh general population.

Gypsy's and Travellers' level of Physical Activity was less than half that expected compared to the Welsh and English general populations after using standardized ratios to factor for age and gender.

## 6.3.2 Physical Measures of Gypsy/Travellers as CHD risk factors

### 6.3.2.1 Body Mass Index

Gypsy and Traveller participants' weight and height were measured by project workers in order to calculate their Body Mass Index (BMI). The BMI is calculated as weight (kg)/height (m$^2$) and is a method of defining overweight or obesity.

However, it should be noted that it does not take into account muscular physique or fat distribution.

When BMI scores were looked at in terms of categories, more men than women were either underweight (17% men 8% women) or obese (17% men 10% women), with more women either at a healthy weight (53% women, 45% men) or overweight (27% women 21% men).

Gypsies and Travellers are between 16 – 27% less overweight and obese than the Welsh general population when standardized ratios are used to factor for gender (SR 56.8) and age (SR 80). This effect is also similar to the English general population (SR 50.6).

Although equally lower by gender, Gypsies and Travellers showed a slight effect of age, with people in the 25 – 54 age groups being less overweight and obese and the rate being approximately 1.2 times higher in both the younger age group of 16 – 24 and again in the over 55 age groups. This age effect in the younger age group may be explained by the occurrence of several outline scores in the younger age group distribution affecting the scores.

The percentage of adults in Wales that are overweight or obese in NS-SEC3, Routine and Manual is 56% and 62% in England compared to the Gypsy and Traveller participants at 38.5%.

### 6.3.2.2 Total cholesterol and HDL-cholesterol

A non-fasting blood sample was offered to Gypsy and Traveller participants and was analysed for total cholesterol and HDL-cholesterol. The blood samples were collected by the Project Health Visitor. Of the 81 participants, a non-fasting blood sample was taken from 54 (66.7%) of the participants. The remaining 27 (33.3%) either refused or the Project Health Worker was unable to obtain a sample from them.

Lipid lowering drugs are suggested by current guidelines to lower total cholesterol levels below 5 mmol/l or by 30% in people considered to be at high risk of cardiovascular disease (NSF 2000) for this reason, and to allow comparison with current English survey data (Dept. of Health 2003) a total cholesterol level of 5 mmol/l or over is considered a raised level in this study. An HDL- cholesterol level of 1.0 mmol/l is recommended for all people with a high risk of cardiovascular disease and a level below this is considered low in this study (Sacks 2002). Participants on lipid lowering drugs are included in this analysis.

*Total Cholesterol*

Women have a slightly higher mean total cholesterol level (4.719) than men (4.226). The mean total cholesterol rises with age from 3.807 in the 16 – 24 age group to 5.733 in the 55 – 64 age group. The mean then falls in the 65 – 74 age group to 4.975.

The prevalence of raised total cholesterol (≥5 mmol/l) was compared to the English sample, using standardized ratios for gender and age. Gypsies and Travellers have a lower prevalence (SR 22.7 by gender and SR 25.8 by age) of raised total cholesterol than the English sample. Men have the lowest prevalence at 7 times less than the expected rate, while women were 3½ times less than the expected rate. Younger Gypsies and Travellers had a smaller rate of raised total cholesterol than the English sample levelling off with the older age groups. When compared to the English sample by NS-SEC semi routine and routine, Gypsies and Travellers were still lower than expected (SR 23.4).

*HDL-Cholesterol*

Gypsy and Traveller participants have a much greater prevalence of low (<1.0 mmol/l) HDL-cholesterol than the English sample population. When standardized ratios are used to adjust for age and gender, Gypsies and Travellers have a much higher prevalence of low HDL-cholesterol (SR 628.3 for gender and SR 542.8 for age. Women had a prevalence over 8 times that expected. The prevalence for low HDL increases with age, rising to over 13½ times the expected rate by age group

55 – 64. When Compared to NS-SEC semi routine & routine, Gypsies' and Travellers' prevalence to low HDL-cholesterol was over 5 times the expected rate.

### 6.3.2.3 Blood Pressure

Gypsy and Traveller participants were invited to have a blood pressure reading taken by the Project Health Worker. Methods of taking blood pressures in this study varied from that of the English comparison sample. One measure of blood pressure was taken, due to the shortness of attention span in this group, compared to three in the English comparison group. The reason for taking several readings on a single session is to try to counteract the 'white coat effect'. Therefore, comparisons with the English sample must bear this difference in method in mind.

Recent guidelines on blood pressure suggest that a threshold of 140 mmHg systolic/90 mmHg diastolic be used to identify hypertension or high blood pressure in general and 130 mmHg systolic /80 mmHg diastolic in diabetics (Guidelines Committee 2003). This guideline was used to define the 'raised blood pressure' category in this study.

Both male and female Gypsy and Traveller participants had lower mean SBPs (m - 121.5 & f - 116.96) than the male and female English sample (m – 131.4 & f – 125.9). However, Gypsy and Traveller males had the highest mean DBP at 78.5 compared to English men at 74.3. Both Gypsy and Traveller and English women had similar mean DBPs, with Gypsies and Travellers slightly higher.

Gypsy and Traveller participants' SBPs, followed a similar pattern to the English sample by age, but with a lower SBP in the 16 – 24 and group and a higher SBP in the 65 – 74 age group. Gypsy and Travellers had a higher mean DBP in all age groups except the 16 – 24 age group.

However, Feder (1994) found no significant difference in the SBPs of the over 30s compared to a control group and although he found a raised percentage of DPBs in his Gypsy/Traveller participants, this was not significant due to the low number in the study.

## Raised Blood Pressure

Gypsy and Travellers had a lower rate of raised blood pressure (≥140/90) when standardized ratios are used for gender compared to the English sample group (SR 59.3), and also when compared to NS-SEC semi routine & routine (SR 54.1) by gender. However, when standardized for age, Gypsies and Travellers prevalence to raised blood pressure is slightly above expected (SR 117.7) with age group 45 – 54 being nearly double that expected. However, the sample size for the over 45 group was small. The raised blood pressure in this more mature group may be a reflection of the high levels of smoking, poor diet and high levels of anxiety described below, in the participants of this study.

## 6.3.3 Morbidity

### 6.3.3.1 Cardiovascular disease

Gypsy and Traveller participants were asked if they suffered from any heart disease diagnosed by a doctor. If yes, they were then asked if they suffered from Heart attack, Angina, Coronary Artery Bypass Graft and Angioplasty. They were also asked if they were on any medication and what type it was. Of the 81 participants, 6 (7.4%) said they did suffer from heart disease (excluding high blood pressure) compared to the Welsh General population (10%) reporting any heart disease excluding high blood pressure and 13.3% in the English sample. This may be due to the young age profile of the study population. As the prevalence of cardiovascular disease is so low and the sample size is limited, it was not practical to perform standardized ratios for age and gender.

### 6.3.3.2 Diabetes

There were no cases of diabetes in the Gypsy and Traveller participant group, this compares with a self-reported rate of 5% in the Welsh General population. However, diabetes prevalence increases with age and is as little as 1% in the 16 – 34 age group and 2% in the 35 – 44 age group. Our participant distribution is skewed to younger age groups, tailing off in the older age groups. Therefore, a larger sample size is needed to detect such low prevalence rates.

### 6.3.4 Mental Health

#### *6.3.4.1 Self reported mental health problems and medication*

The Gypsy and Traveller participants were asked if they had any current health problems, and if so what they were. They were also asked what medication if any they were taking at present. Mental health problems in this study were defined as any diagnoses of depression, anxiety, schizophrenic disorder or any other diagnosed mental health problem.

18.5% of Gypsy and Traveller participants reported suffering from some mental health problem. This compares with the Welsh general population which has a self-reported prevalence of mental illness at 9%. However, self reported anti-depressant medication usage was 24 (29.6%) in Gypsy and Traveller participants. This discrepancy may be explained by the lack of a specific question about mental health being included, rather a general question about health. Gypsies and Travellers have strong cultural ideas about mental health, seeing it as a weakness, and therefore, may not self disclose this information unless a direct question is asked.

#### *6.3.4.2 Hospital Anxiety and Depression Scale*

In both the anxiety and depression scales, scores $\geq 11$ were categorised as raised levels, scores between 11 and 15 were considered moderate cases and scores $\geq$ 16 were considered severe cases (Snaith 1994). HADS scores were compared to a UK non-clinical population sample of 1792 participants (Crawford 2001) and an English Gypsy and Traveller health study (Parry 2004).

For the HADS anxiety scale, Gypsy and Traveller participants had a mean score of 11.54 (Std. Deviation 5.77 median 11). This compares with a UK general population mean for Anxiety of 6.14. For the depression scale, Gypsy and Traveller participants had a mean score of 8.83 (Std. Deviation 5.87 median 8). This compares with a UK general population mean for Depression of 3.68. The total mean score for both depression and anxiety for Gypsies and Travellers was 20.37

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(Std. Deviation 11.05 median 21.5) compared to 9.82 in the UK general population (see figure 6.3)



**Gypsy and Traveller Mean HADS Compared to UK Population Means**
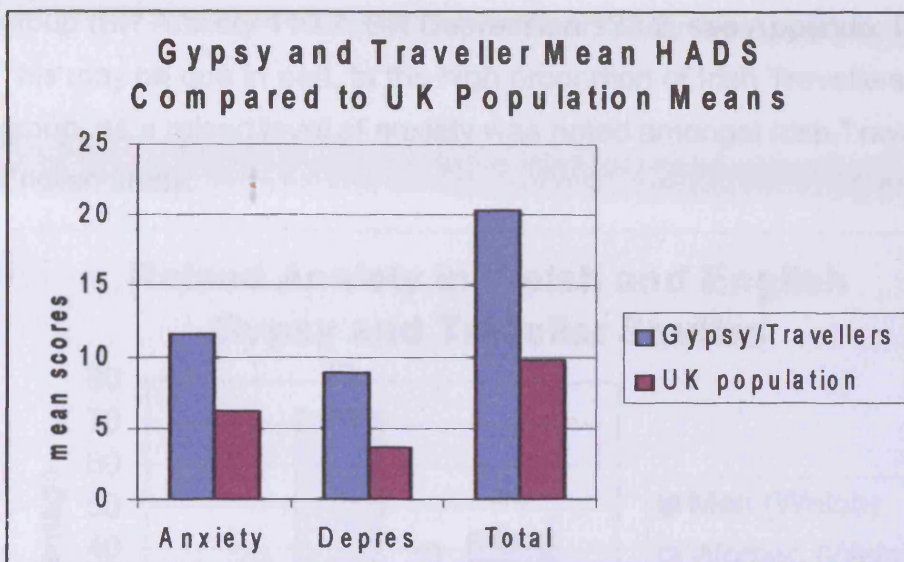
*Figure 6.3.*

As reported in previous studies of both the UK population and Gypsies and Travellers in England, women scored higher on both anxiety and depression scales than men. Gypsy and Traveller women scored a mean of 13.17 compared to a mean score of 8.75 for men on the Anxiety scale. For the HAD depression scale, women scored a mean of 10.52 compared to men who scored a mean of 5.93. This was true also of total HADS scores where women scored a mean of 23.69 compared to men's mean score of 14.68.

The Gypsy and Traveller female participants in this study had a much higher prevalence of raised anxiety and depression (scores $\geq$ 16) than males (Anxiety = F: 35/48 (72.9%)  M: 8/28 (28.6%) and Depression F: 23/48 (47.9%) M: 3/28 (10.7%)). These high female rates were also higher than those reported in the English study of Gypsy and Traveller health, although the rate of male raised anxiety and depression scores was similar to those of the English Gypsy and Traveller sample (see figures 6.4 & 6.5).

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When standardized ratios are used to adjust for gender, Gypsy and Traveller women participants in this study have a higher prevalence of both anxiety and depression than that expected compared to the English Gypsy and Traveller study group (SR Anxiety 110.7, SR Depression 123.2, see Appendix 16, tables 1 & 2). This may be due in part, to the high proportion of Irish Travellers in this study group, as a raised level of anxiety was noted amongst Irish Travellers in the English study.
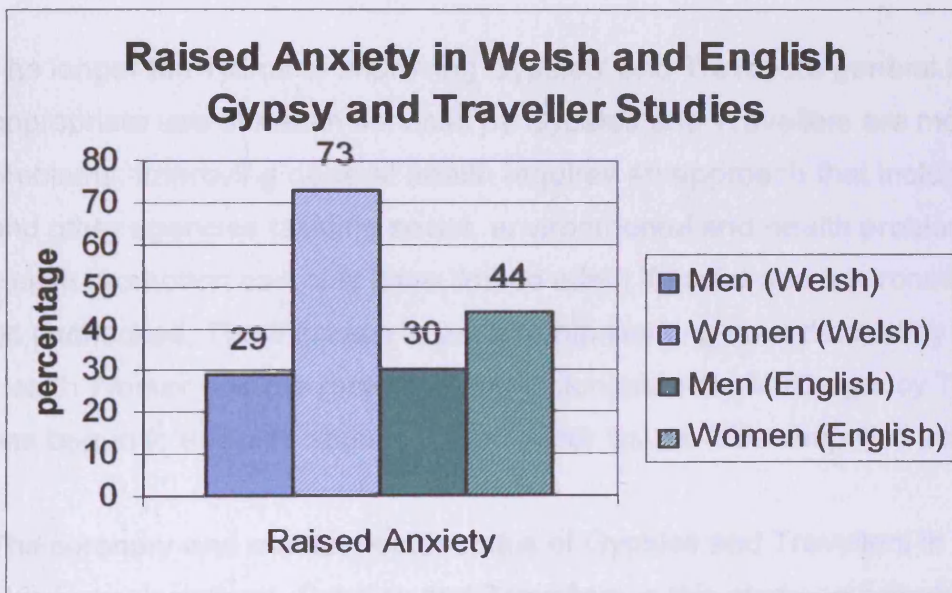


*Figure 6.4.*
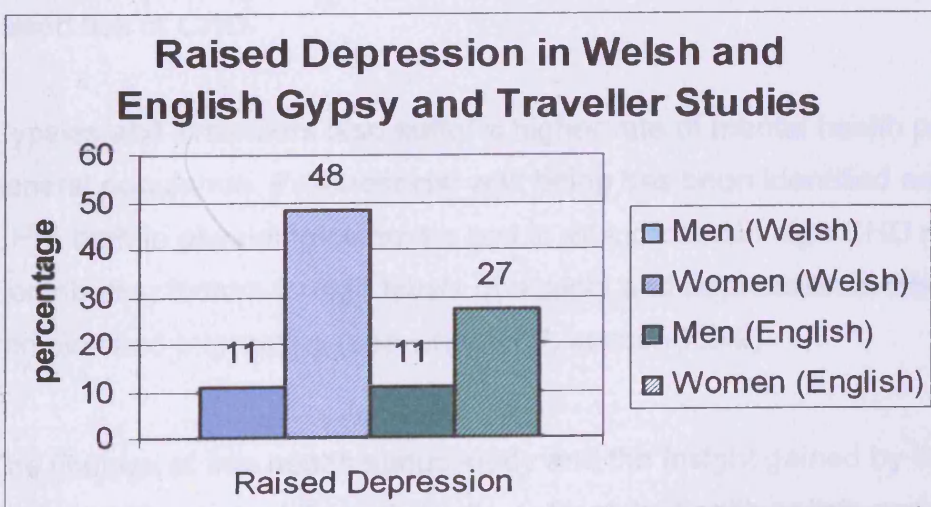


*Figure 6.5*

## 6.4 Summary and discussion

The project has worked well and delivered its short and medium term goals and is working towards meeting its eventual long term goals. Access to appropriate health and social care has improved, acute and chronic health problems have been identified, partnership working has been strengthened, appropriate CHD management and awareness of risk factors has improved and other professionals are now beginning to gain more understanding and have less fear of visiting the Gypsy and Traveller site.

The longer term aims of improving Gypsies' and Travellers general health and the appropriate use of health services by Gypsies and Travellers are more complex problems. Improving general health requires an approach that includes both health and other agencies tackling social, environmental and health problems together. Health promotion can only have limited effect if social and environmental problems go unchecked. The increase in partnership working co-ordinated by the Project Health Worker and the project working alongside the Multi-agency Traveller Forum; has begun to address some of these wider issues (see chapter 5 section 5.2.3).

The coronary and mental health status of Gypsies and Travellers in Wrexham has also been described. Gypsies and Travellers in this study participate in higher CHD risk behaviours than the general population and physical measurements show a raised risk of CHD.

Gypsies and Travellers also suffer a higher rate of mental health problems than the general population. Psychosocial well being has been identified as a risk factor in CHD, both in physiological terms and in an increase in high CHD risk behaviours. Contributing factors to high levels of anxiety and depression in this community are complex and interacting (see Chapter 7, section 7.3.2).

The findings of this health status study and the insight gained by the qualitative study into Gypsy and Traveller culture, lifestyle, health beliefs and experiences of health care provides a better understanding of this community, its needs in terms

of healthcare and enables the design of culturally appropriate health and social care interventions.

However, in order to determine the type of healthcare that works best to improve access to healthcare for Gypsies and Travellers, the following chapter will explore what the strengths and weaknesses are of the present health initiative and attempts to describe some of the complex interactions between the initiative, culture and the health status of this group. It offers some explanation for why such high CHD risk behaviours and high mental health problems exist in this group.

# Chapter 7

# Researcher's reflections of the research process and evaluation findings

# 7.1 Introduction

This chapter is my evaluation, as researcher, of the research process and its findings. It contains my reflections of the experience of fieldwork in this setting, some of the difficulties that arose and what worked well, and provides an account to how the research progressed over time.

Furthermore, the process of providing the community health initiative is examined, drawing on the findings of the studies included in this thesis, and providing the researcher's reflections of its strengths and weaknesses. This is followed by an exploration of the complexity of interactions between culture, experience, the community health initiative and health.

## 7.2　Process of conducting evaluative research in this setting

### 7.2.1 The process of conducting field work

The following is my account, as researcher, of my experience of conducting fieldwork with the community health initiative and the Gypsies and Travellers in this study.

I joined the project team as the researcher around the same time as the Project Health Worker (PHW). We were to form a 'team', as I shadowed her for the next 2½ years. Before receiving the 'health bus' and starting the service proper, the PHW took me onto the council run site to allow me to meet some of the Gypsy/Travellers. She had been a Health Visitor working with this group several years prior to this project, so she knew some of the residents.

My feelings on entering the site were mixed. I was excited to finally be meeting some of the people that I would be studying but, I also felt wary of how I would be received by these people that I had never had contact with before. Would they be indifferent or even hostile to us? I also did not know what to expect of the council run site, as I had only seen brief glimpses of it from the road. I was first struck by the 12 ft high fence which ran along the edge of the site. It felt like I was entering a restricted area of some sort. The other thing that struck me was how closed-in the

plots were with little room and no green space between pitches. The site was very clean and one woman was outside, washing down with a hose, the concrete that was the hard surface of the pitches.

The PHW decided to introduce me to a woman who she had known for many years and had a close relationship with when she had worked as a Health Visitor. We were received warmly by the woman who was in her thirties, and as I was to find out, had seven children. Her mother was also in the caravan. I was introduced and welcomed by both of them. We were asked to sit down and offered cups of tea from fine china cups. This was a new experience for me, as I was used to drinking from mugs. As we settled and began to talk, the conversation turned to the death of the woman's father. Both the daughter and wife of the dead man were keen to tell how he had unfortunately, died of an accident, years earlier. The striking thing about this initial encounter was the way both women told the story. They poured out their feelings simultaneously. Neither appeared aware that the other was speaking. I was not used to this and found myself unsure who to look at. I did not want to offend either of the women by not looking at them as they spoke. Also, they were both speaking, with what sounded to my ear at the time, as very strong Irish accents. With time, I became accustomed to both of these traits.

When we started visiting the site with the 'health bus' I got to know many more people, as they popped in to say hello and find out what we were about. There was a lot of curiosity at the beginning, mostly from the children and teenagers. They would come into the 'health bus' asking who we were and what we were doing there. I believe this was reported back to parents as slowly, adults, mainly women turned up to see us. Initially, women would come to ask the PHW about development checks and immunisations for their children. Each time a person came into the 'health bus' the project was explained to them and within a short time, the word got round that we were there for adults too. I was introduced as the researcher and an explanation was given to what I was doing. This seemed to be accepted and I made sure I made myself 'useful' by driving the 'health bus', making tea and coffee and later, helping people with letter reading and form filling in.

Whereas the women would come in groups to sit and discuss health problems and general concerns, the men's approach was very different. They initially would pop their head into the 'health bus' and ask whether we were selling it and how much we wanted for it. This allowed us to explain the project to them without them admitting that they were interested in health or the project. However, contact with the mature, working men remained limited throughout the study.

The level of acceptance varied between those who knew the PHW previously, and were warm and accommodating, and those who did not, and were wary of us. They would come to the 'health bus' only when they found that they needed the advice or assistance of the PHW. Over time, people became more relaxed and at ease in our company. However, there were always new arrivals to be won over. Often rumours would go around that we were the police or social services in disguise when new people arrived on site. These rumours would die down once the family became familiar with us. There were however, a small number of Gypsies and Travellers who did not trust us and did not visit the 'health bus'; fortunately these were very few.

The Gypsies and Travellers who live in houses and private plots of land were more difficult to get to know well. It was a more intrusive process to visit them. Arrangements had to be made in advance and we only became close to a handful of families in houses for this reason.

Fieldwork progressed and categories and questions emerged over time. The PHW was often used to initiate conversations on topics that I had expressed an interest in or that I felt had not been adequately explored. This worked very well as the PHW was the person that people came to see and was the one they naturally engaged with first. This was a system that developed naturally rather than overtly planned. In this respect, we worked as a team, with her bringing up topics and me later recording the outcome of these conversations.

Fieldnotes were an essential element of the participant observations. The fieldnotes were hand written and 1½ - 2½ hours each day were devoted to this

task. This was done either in the 'health bus' when there was a break for lunch and the door was locked for privacy, or on return to the office after a visit. It was interesting to note how my ability to recall events and conversations improved with time until I was able to recall conversations nearly verbatim.

I was accepted by the Gypsies and Travellers, largely due to the association with the Project Health Worker. Also, the long period of time shadowing the Project Health Worker meant I was able to blend into the background with time, as people got used to my presence. Over the 2½ years of being involved with the Gypsies and Travellers in this project, they have welcomed me into their lives. I have attended a wedding, two funerals and been on visits to a holy site at Holywell and to sports centres with the women. I have been invited into many people's caravans during this study.

The building up of trust and familiarity over a period of time also facilitated the series of interviews with some Gypsies and Travellers enabling open and often rich, detailed accounts of their culture, lifestyle, health beliefs and experiences of healthcare. The information gained by these interviews provided further insight into the thoughts and beliefs of Gypsies and Travellers and explanations for some of my observations.

### 7.2.2 The process of collecting quantitative data

The study of Gypsies' and Travellers' CHD and mental health status involved the collection of data on participants' lifestyle, medical history, physical measurements and a mental health questionnaire (HADS). The data was collected by me and the Project Health Worker. The majority of the data was collected from participants while in the Health Bus. This provided the privacy necessary to ask personal questions regarding a person's medical history, lifestyle and mental health. All adults in the Gypsy and Traveller communities who had contact with the project were invited to participate.

The response to the request to participate in the study was good. Most people were interested in the project and felt that they would benefit from participating in

the data collection, particularly in having their physical measurements taken (for details of study method, see chapter 3). There was great interest amongst Gypsies and Travellers, young and old, concerning their weight, so most of the participants were keen to know their weight and height. However, it was not unusual for the data collection to be carried out over several sessions with an individual, as often they would become restless leave before finishing. Also, the lifestyle information led to conversations about healthy living and so was used as an informal health promotion tool as well as a data collection tool.

The project has shown that this type of data collection is possible in Gypsy and Traveller communities. There is however the limitation of Gypsies' and Travellers' suspiciousness of 'outsiders', although they may agree to participate in research to appear hospitable, the quality of the answers may be questionable, as the community seeks to protect itself from outsiders by providing answers that they perceive interviewers want to hear or may give false information. An exception to this appears to be those medical professionals for whom Gypsies and Travellers have built a trusting relationship. This has been a key to the success of the research and a reason that data collection was done over a long time span, to allow trust to develop.

### 7.2.3 Evaluation reporting

As researcher and evaluator of the community health initiative, I was expected to provide quarterly, yearly and finally, an end of phase one report (after 1st 3 years) to the Inequality in Health Fund. 'Independent' evaluation had been built into the project from the beginning and was included in the 'Declaration of Interest' prior to project approval by the Inequality in Health Fund. This was the only project of the 67 supported by the Inequality in Health Fund to employ a researcher to provide evaluation within the project.

Difficulties did however, arise from being placed both inside the project, providing some of the objectives of the project such as the CHD and Mental health status study and the cultural study, and outside it, as the independent evaluator. By being part of the project team, my final evaluation was presented as part of the final

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phase one report. Because this was a report that went to the Inequality in Health Fund from the project, it first went through the Project Lead. This in the end compromised the evaluation and resulted in the delay of the report by five months as it had to be revised 6 times. There were conflicting interests at play. The Project Lead was responsible for developing the eventual exit strategy for the Community Health Initiative and responsible for 'selling' the service to the intended future funders. She therefore, was very sensitive to any form of criticism of the initiative. Initially minor changes were requested such as 'weaknesses' being described as 'challenges'. However, following meetings with both the Project Lead and the Project Health Worker's line manager, the Director of Nursing, further changes were made to the document. Being aware that it was important to represent each person fairly and accurately, more changes were made. However, this began to impact on the meaning of some of the evaluation, in particular, the discussion of the different perspectives of the Health Worker's remit (see section 7.3.2.2) where most of the unease with the evaluation appeared to centre. The Project Lead believed that it contained personal criticism of her approach. Words such as 'top down' approach were removed. Each time the report was revised following feedback from the Project Lead, it would be rejected again with new comments. Finally, a line was drawn when I was asked to change some of what other people had said in the report. Eventually the report was submitted to the Inequality in Health Fund.

This problem arose because the evaluation was not kept separate from the project reports. It proved difficult for the evaluation to remain independent when the evaluator is expected to report through the project being evaluated. The line of reporting allowed for subversion of the material. Although feedback from those involved in the project was welcome and changes were made where appropriate, for clarity and accuracy, some of the meaning in the final report to the Inequality in Health Fund was lost due to interference. Trying to show a project in its best light is understandable, due to the pressure the health initiative was under to deliver to ensure future funding, but can result in a disservice to those who wish to follow such a model and have not been given an honest account of the difficulties that can arise as well as the successes.

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## 7.3 Reflections of the community health initiative process

### 7.3.1 Strengths of the community initiative

#### 7.3.1.1 Project Health Worker

*A dedicated health worker*

Although there are other health workers, mainly Health Visitors, that work with Gypsies and Travellers, it is rare in the UK to find a qualified health worker that has Gypsies and Travellers as their complete caseload. Usually, a Health Visitor will work with Gypsies and Travellers as part of a larger case load if there happens to be a site within the GP's surgery catchments. Having a full-time dedicated Project Health Worker has proved to be an important element of the community health initiative by providing the contact and time necessary to start to address the unmet health needs of the Gypsy and Traveller communities. The service also provides continuity with regular visits to the Gypsy and Traveller site and to housed Gypsies and Travellers.

The Gypsies and Travellers interviewed all appeared happy with the service provided by the Project Health Worker. General comments were that she is 'very good'. One person said there were no bad sides to her coming and no one provided any negative feedback. People were happy with the amount of access to the Project Health Worker, with people saying the frequency of visits is 'about right' and that people feel they can contact her when needed. It was also mentioned that the Project Health Worker had more time for people then traditional Health Visitors.

> *"Other people 'aven't got the time, no, they 'aven't got the time or the energy. They 'aven't got the time or the place to do it in...I wouldn't go to my, if I have got a Health Visitor, I don't know, I wouldn't say to her 'Would you check me blood for me', or sit down and have a conversation with her, I couldn't do anything like that with a normal person, another person."*
> *(Resp.2, female, 22yrs, English Gypsy)*

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*Personal Qualities of the Project Health Worker*

The personal qualities of the Project Health Worker have been an important element in the success of the service. When talking about the project, Gypsies and Travellers described the Project Health Worker as being approachable, a person who treats individuals with respect and most importantly, a person you can talk to, a good listener.

In addition, the Project Health Worker has proved to be a good communicator and link worker, both to the Gypsies/Travellers but also to other health professionals and other agency workers. The liaison work done between the Project Health Worker and other health professionals has worked particularly well.

> *"I went with a lady for a hospital appointment this week and she was reflecting back on how it went with her appointment last year, this was about eight months ago, and she went for a particular thing and the doctor was saying 'no, you can't have this' and she ended up ranting and raving at this consultant and she didn't understand why this consultant wouldn't give her what she wanted. Um, and being sent away and being really frustrated, so we were in the waiting room this week, and she started saying 'If I don't get what I want this time I'll shout at her again and I'll punch her' but because I was there, I said, 'well slow down, there must be a reason why she's not giving you what you want and we'll go in there and you say what you want and I'll help to fill in the gaps, and there shouldn't be so much difficulty this time because I've been in contact with this consultant by e-mail, by phone, I've got all the information from your GP, from the other consultants and it's all pulled together now.' And we went in and it was a superb consultation, it really was good on both sides. And she came out of there and said, 'That was great'."*
>
> *(Project Health Worker)*

This is very important to the success of the initiative. The networking and professional relationships that the Project Health Worker has made has ensured that help is sought and received when needed from others, both in Primary Care and beyond. A lack of partnership working was one reason that a Health Visitor with Gypsies and Travellers in Hackney was believed to be less effective (Feder 1994).

### 7.3.1.2 Mobile Health Unit

The open door, drop-in service with the 'Health Bus' fits in with the way Gypsies and Travellers live and relate to one another, so it is culturally acceptable. It has also provided a shift in the power base. Until this project, health professionals would come to the site to 'do' things to the Gypsies and Travellers, such as come to immunise their children. There was no choice of what the agenda was. Although there is a focus on health and the project focus on coronary heart disease, the Gypsies and Travellers who have had contact with this initiative know that they can raise any subject that is worrying them, and they do.

As mentioned previously, the 'health bus' provides a private and quiet environment. For many women, this is the only time during their week that they have for themselves, a time that they can come along and discus their problems and concerns.

### 7.3.2 Weaknesses within the community initiative

### 7.3.2.1 Professional isolation and challenging role

The role of Project Health Worker, working solely with Gypsies and Travellers, has at times been an isolating experience as she was the only health worker in the area working solely with Gypsies and Travellers. This role is very different from that of a Health Visitor in primary care, where the emphasis is mainly on the under fives and their mothers, many have little or no experience of working with this client group. Even the Project Health Worker, who had past experience of working with this group, admits that in hind sight, her knowledge of the strong cultural values and restraints of this group was limited prior to working on this project. Therefore, local Health Visitor support groups can be of limited value and line managers are not always the appropriate people for such support.

Also, due to the severe and enduring health and social needs of this group, the role of Project Health Worker can be very different from that of a traditional health visitor. Along with the wider work load that a group with such a breadth of health needs creates, is also the emotional cost. Often the Project Health Worker is

presented with very distressing situations involving the people she is working in close contact with, in the lifetime of this project, these have ranged from women seeking help suffering from domestic abuse, knock on effect of a murder of a young Traveller male who was closely related to the Wrexham site and known by the Project Health Worker to a recent suicide of a woman who lived on the Wrexham site who was well known to the project staff. This type of demand without professional support could lead to 'burn out.'

There is, also, a National Association of Health Worker for Travellers (NAHWT) which is a special interest group of the Community Practitioners and Health Visitors Association. This group provides peer support, shares experiences and knowledge, health care initiatives, examples of good practice and is concerned with the broader determinants of health for Gypsies and Travellers. It has membership throughout the UK. This has proved to be a valuable support to the Project Health Worker and she has become an active member, now chairing the group. Working towards a co-ordinated network of health workers working with Gypsies and Travellers across Wales may be a way forward for the future.

### 7.3.2.2 Differences in perception of Project Health Worker's remit

There is broad agreement from all Steering Group members concerning the main aims and objectives of the community health initiative and also agreement concerning service delivery, in terms of facilitating appropriate access to health care and managing Gypsies' and Travellers' immediate health needs. However, there are aspects of the Project Health Worker's role that have provided areas of conflict during the period of this study. These will now be explored.

*Project Management's Perceptions of Health Worker's Role:*

The project management has had the job of delivering the aims and objectives of the project and fulfilling the remit set by the Welsh Assembly Government's Inequality in Health Fund for a focus on cardiovascular health. Also, the project management has been accountable throughout the project for ensuring a viable exit strategy.

To meet these ends, the project management has been responsible for maintaining the focus of the project and working within the framework of the 'SMART' objectives. This has meant that the project has had to be specific, measurable, achievable, realistic and time related. Sustainability needed to be measured in terms of performance indicators, outputs and outcomes to enable the Local Health Board to assess the usefulness of the service for future adoption.

Therefore, the approach adopted by Project Management focused mainly on measurable outcomes such as client contacts and organised health promotion. As there was limited direct involvement in the design of health promotion initiatives by the Gypsy and Traveller communities due to cultural constraints, a trial and error approach to evidence based health initiatives which had been successfully piloted elsewhere were adopted. This involved evaluation and reflecting on the effectiveness of initiatives as they were introduced. Also, there was an expectation that the Project Health Worker would have a mixed role, one of facilitator, signposting to other services, as well as providing a service herself.

*Gypsy and Traveller's Perspective*

The Gypsies and Travellers who use the service have different priorities. Although health is important to them, many Gypsies and Travellers have severe social needs. For them, relief from immediate social problems and immediate health problems is seen as most important, and long-term health gains from living healthier lifestyles as a lower priority. In terms of Maslow's hierarchy of needs, often, Gypsies and Travellers are struggling with survival, such as a safe place to stay. Until basic issues of safety and survival are met, long-term health aims will remain a low priority. The immediacy of the culture does not sit comfortably with the referral system and waiting for appointments for other professionals to become involved.

*The Project Health Worker's Perspective*

The Project Health Worker reported that at times she felt that there was tension between what she was expected to focus on in terms of the project requirements and the demands put upon her by the differing expectations of the Gypsies and

Travellers themselves. There was also a requirement to obtain the CHD data for the evaluation which required a focused effort at times. The Project Health Worker envisioned her role as focusing on the broadest definition of health, recognising that social needs directly affect health. Her perception was therefore, that her role was a wider one than that viewed by project management. At times this has resulted in tension concerning what is appropriate service delivery and what are the boundaries of the Project Health Worker's role (see figure 7.1 below).

The Project Management has approached areas of the service delivery by adopting a top-down approach. For example, in the area of health promotion, organised group activities were encouraged with topics suggested by the Project Lead. These were not always the topics of most concern to the Gypsies and Travellers. This created tension for the Project Health Worker who expressed a preference for a more informal, one to one approach. A more bottom-up approach, where the broader determinants of health, which include social and environmental as well as direct health messages, could be explored and developed. This tension has resulted in a lowering of morale of the Project Health Worker at times.
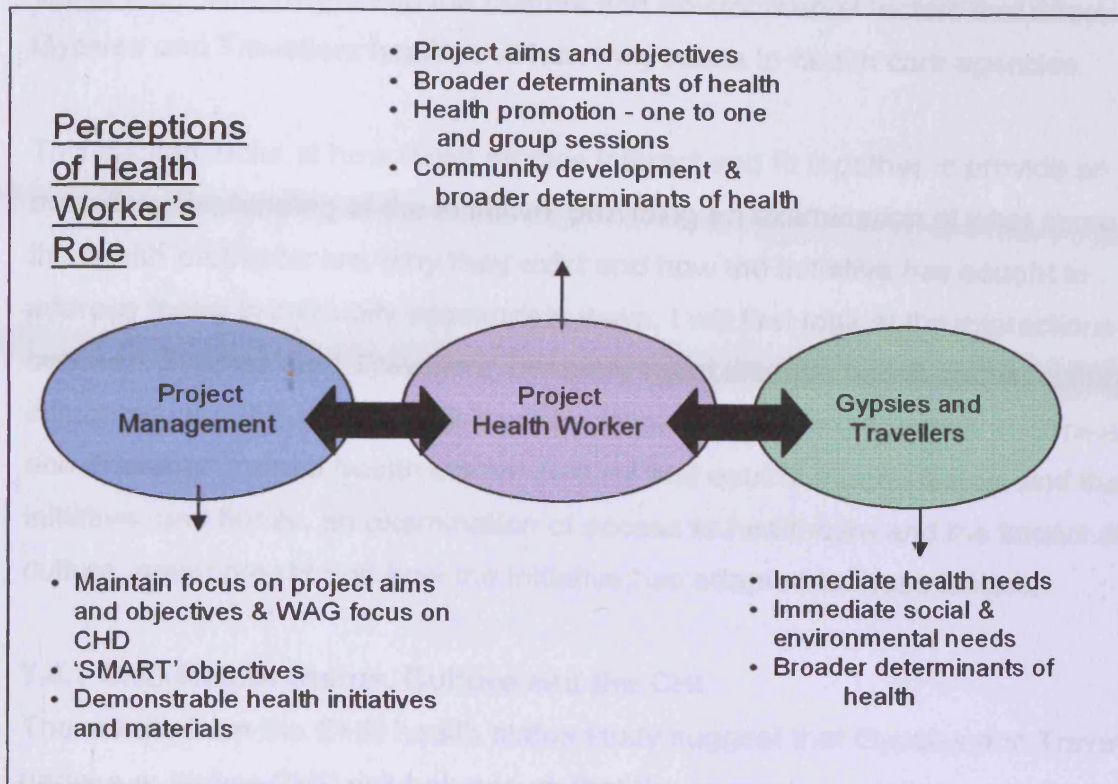
Figure 7.1

## 7.4 Interaction between culture, the initiative and health

The coronary health and mental health study has provided insight into the general health of Gypsies and Travellers in Wrexham. The results suggest that Gypsies and Travellers live less healthy lifestyles than the general population and are therefore at greater risk of cardiovascular disease. The results also suggest that Gypsies and Travellers suffer from a higher rate of mental health problems than the general population.

Health is a very complex issue with culture, health beliefs, environment, social needs and education all influencing our physical health and mental wellbeing, and the degree to which we live healthy lifestyles. The study of Gypsies' and Travellers' culture, lifestyle, experiences of healthcare and health beliefs provides some

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explanation and insight into the cultural and environmental factors that affect Gypsies and Travellers health and how they relate to health care agencies.

This section looks at how these studies interact and fit together to provide an overall understanding of the initiative, providing an examination of what some of the health problems are, why they exist and how the initiative has sought to address these in culturally appropriate ways. I will first look at the interactions between Gypsies' and Travellers' coronary heart disease health status, cultural influences and the initiative. This will be followed by an examination of Gypsies' and Traveller' mental health status, cultural and environmental factors and the initiative, and finally, an examination of access to healthcare and the impact of culture, environment and how the initiative has adapted to these factors.

### 7.4.1 CHD Health Status, Culture and the CHI

The results from the CHD health status study suggest that Gypsies and Travellers partake in higher CHD risk behaviours that the general population.

A notable risk factor is the high prevalence of smoking amongst Gypsies and Traveller, and in particular the high levels of smoking in women. Why is it that with all the health promotion in society in general is smoking so high in Gypsies and Travellers? The study of culture and health beliefs goes some way to understanding this.

As described in both the health status study and the cultural study, there are high levels of depression and anxiety in Gypsy and Traveller women. Smoking is seen as a culturally accepted way for women to 'cope with nerves'. This may be particularly so for young unmarried women who have many cultural constraints. Also, Gypsy and Traveller women view smoking as a means to control weight gain, again, an important issue for younger women in these communities. In addition, many people voiced a fatalistic opinion that there would be no point in quitting as the 'damage was already be done' (young Traveller aged 22yrs). This form of cognitive dissonance is found in many smokers in general. The community initiative recognises the limitations that health information can have in such

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circumstances and so has adopted an approach which as well as providing one to one health promotion concerning smoking, and smoking cessation support, also attempts to provide and facilitate mental health support.

A high level of alcohol consumption amongst mature Gypsy and Traveller men was described in the CHD health status study. This appears to be a culturally accepted way for Gypsy and Traveller men to 'cope' with distressing life events such as the death of parents and children. Alcoholism has an impact on the physical wellbeing of the person concerned but also a large impact on the family. It often leads to episodes of domestic abuse which in turn affects the mental wellbeing of the wife and children. It appears that some men become trapped in a cycle of unresolved grief, alcoholism and violence. Women do have some control if they can persuade their husband to take the 'pledge', but this is usually only a temporary solution. The initiative has taken a holistic approach to the health problem of excessive alcohol consumption by providing individual health information, facilitating access to both GPs and alcohol services and by providing and facilitating mental health support.

The CHD health status study also found that Gypsies and Travellers ate less fruit and vegetables than the general population. There are several cultural factors that may explain this. A nomadic lifestyle can be one where obtaining fresh food is not always an easy option, if you are on the move or do not end up near a shop. Also, many of the caravans do not have grills and therefore, people will fry food. There are financial constraints due to the large size of families and confusion concerning ingredients due to poor literacy skills. Also, it is believed to be cruel to deny young children what they want and this extends to food and drinks. The initiative has provided both individual advice on healthy eating and group sessions. Children have also been targeted with health promotion activities.

Gypsies and Travellers were described as participating less in physical activities than the general population. However, culturally, Gypsies and Travellers have physically demanding work. The men's work is hard manual occupations such as tree felling, tarmacing, roofing and scrap metal. Women have large families so are busy with caring for young children and also, have very demanding cleaning

regimes that involve heavy cleaning such as scrubbing floors and cleaning windows as daily activities. Therefore, younger Gypsies and Travellers do not show signs of being overweight. It is only when they become older and begin to slow down that weight becomes a problem. In addition, the site location makes it difficult to walk from as there are no safe footpaths from the site. Culturally, Gypsies and Travellers will be expected to leave what they are doing at a moments notice if someone becomes ill or has a wedding or funeral. This interferes with any planned activities. This has proved to be the case when the initiative has attempted to introduce organised exercise sessions. One to one introduction sessions appear to be more successful. The initiative has worked in partnership to improve general conditions for Gypsies and Travellers. Table 7.1 below provides an overview of how risk factors, culture and the initiative are linked.

## CHD, Culture and the Initiative

| CHD Risk Factors | Culture | Initiative |
|---|---|---|
| High smoking prevalence (especially women) | - Culturally acceptable<br>- Cope with nerves (mental health)<br>- Weight control<br>- Fatalism | - Mental health support and facilitation<br>- Health information<br>- Cessation support |
| High alcohol consumption in men | - Culturally acceptable<br>- 'Cope' with life events<br>- Leads to domestic abuse<br>- Controlled by women 'the pledge' | - Health information<br>- Facilitate access to alcohol agencies<br>- Facilitate GP involvement<br>- Mental health support and facilitation |
| Poor diet (fruit and vegetables) | - Nomadic lifestyle<br>- Restrictions in caravans (e.g. Small or no grills)<br>- Lack of knowledge of risk<br>- Financial constraints (large families)<br>- Poor literacy skills<br>- Do not deny children | - Health information<br>- Healthy eating initiatives<br>- Health info to children |
| Physical Activity | - Men have labour intensive work<br>- Women heavy housework routine and small children<br>- Site location<br>- Cultural commitments , can't commit to regular schedule | - One to one introduction to gym and swimming<br>- Group activities (limited success)<br>- Partnership working for better site conditions<br>- Facilitation of physical and social outings for children |

*Table 7.1*


## 7.4.2 Mental Health, Culture and the CHI

As discussed previously, Gypsies and Travellers suffer from higher levels of mental health problems than the general population. The study of culture, lifestyle and health beliefs may provide some insight into some of the causes of this raised

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incidence of mental illness (see table 7.2). Several cultural, health beliefs and environmental factors are described below that have an influence on the mental wellbeing of Gypsies and Travellers.

**Factors influencing mental health and the initiative**

| Culture & health beliefs | Environmental | Initiative |
|---|---|---|
| - Sign of 'weakness'<br><br>- Counselling 'harmful'<br><br>- Powerlessness, gender roles<br><br>- Domestic abuse<br><br>- Death of close relative | - Poor site conditions<br><br>- Evictions<br><br>- Discrimination | - Provision of 'safe' informal environment<br><br>- Listening skills of PHW<br><br>- Provision of Project Mental Health Support Worker<br><br>- Facilitate engagement with mental health services<br><br>- Facilitate engagement with Women's aid<br><br>- Accompanied visits to psychiatric professionals |

*Table 7.2*

There are strict cultural constraints that Gypsies and Travellers are expected to live by, especially for young people and young women in particular (see Chapter 4 section 4.5). This can lead to feelings of powerlessness, feelings of lack of control over one's future.

Domestic violence has also been cited as a contributing factor to depression and anxiety (Avdibegovi 2006; Heru 2006; Loxton 2006; Miriam 2006; Ruiz-Perez 2005). Nearly all of the women that had contact with the project had experienced either direct or indirect physical violence. This was either by experiencing violence firsthand from a husband or witnessing domestic violence as a child (See chapter 4 section 4.3.4). Nehls (2005), in a qualitative study of women's experiences of living

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with a history of physical abuse, talks of the 'cycle of abuse'. Many of the women in this study talked of the cycle beginning in early childhood, either being abused or witnessing abuse. For these women, life was lived fearfully and violence was part of a woman's day to day existence with profound and ubiquitous effects. Witnessing domestic violence as a child has been linked to profound effects on the health and mental well-being of people in later life (Griffing 2006; Hindin 2006; Kaplow 2006; Levendosky 2006; Sternberg 2006; Street 2005; Dube 2001) and a higher risk of death and suicide (Shanta 2001, Felitti 1998). This may have even greater impact in Gypsies and Travellers where all the family live and sleep in one caravan. There is no opportunity to keep violence 'behind closed doors'. The children are witnesses at close proximity. Recent research has also linked witnessing of domestic violence in childhood with trauma related guilt, PTSD and avoidant coping strategies in women (Street 2005). Avoidance coping has also been linked to physical abuse, with men identified as using avoidance coping and being problem drinkers more likely to use both physical and psychological abuse on women (Snow 2006).

Furthermore, the death of a child or parents has been described as the cause of depression in many Gypsies and Travellers. Some Gypsies and Travellers have described feelings of intense grief for the loss of a family member that has lasted for decades, in one case over 30 years, and still has an impact on their daily lives. This in turn can lead to alcoholism in men, as a way to cope with their grief.

Cultural beliefs (see Chapter 4 section 4.6.1) that mental illness is something to be hidden from family, a source of shame and a weakness, the belief that professional treatments such as counselling or hospitalisation are harmful also contribute to the high incidence of mental illness. Also there is a belief amongst Gypsies and Travellers that nobody is able to keep a 'watchful' eye on a sick relative as well as they can.

These cultural factors combined with environmental factors such as the daily discrimination encountered by Gypsies and Travellers (see Chapter 4 section 4.5.3), the threat to their traditional nomadic lifestyle through constant evictions,

and poor site locations and conditions, result in feelings of helplessness in Gypsies and Travellers, and as a result, the raised levels of mental illness seen in these communities.

The community initiative has provided safe, private place where Gypsies and Travellers can talk about their problems and worries. For many, this has been the first time they have been able to confide in a person who is non-judgmental and understanding. This is the reason Gypsies and Travellers value the good listening skills of the Project Health Worker. The importance of this quality of listening was highlighted in Nehls's (2005) interviews of women who had suffered from domestic violence. They all defined helping as 'hearing my story' and told of the importance of their story being heard by someone who's listening skills were described as 'deferential' and 'engaged'. Once confidence is gained, the Project Health Worker will facilitate involvement of other agencies such as mental health agencies or women's aid. Recognising the great need in these communities, a mental health support worker has now been employed by the project. Partnership working also has a part to play in improving the environmental conditions and raising awareness of discrimination. This is an ongoing remit for the Multi-agency Traveller Forum and the PHW, with her active role in this group contributes to the effort made to improve conditions for Gypsies and Travellers. Also, the PHW has sought to educate health care professionals concerning the culture and lifestyle of Gypsies and Travellers through daily contact and challenging discrimination, teaching sessions with student nurses and conference presentations, both in the health arena and multi-agency.

### 7.4.3 Access to Healthcare, Culture and the CHI

The main aim of the community initiative was to increase access to healthcare for Gypsies and Travellers. As illustrated in table 7.3 below, there are many factors both cultural and environmental that contribute to Gypsies and Travellers having poor access to healthcare.

# Access to Healthcare, Culture and the Initiative

| Cultural Factors | Environmental Factors | Initiative |
|---|---|---|
| - Little or no literacy skills<br>- Nomadic lifestyle, no fixed address<br>- Large families<br>- Past experiences, fear of bad doctors<br>- Illness as weakness<br>- Cultural commitments, visiting sick & dying<br>- Cultural constraints, chaperoning of women<br>- Importance of 'divine intervention'<br>- Lack of cultural understanding, communication problems | - Location of council site<br>- Discrimination & stereotyping<br>- Evictions | - Initial health needs assessment<br>- 'Bridge' between healthcare & Travellers<br>- Facilitates registration with GP<br>- Feedback to GPs<br>- Triage<br>- Facilitates attendance, reads letters, reminder of appointments<br>- Accompanied visits to facilitate communication<br>- Education of health professionals of culture<br>- Development of health passport and leaflets |

*Table 7.3*

The community health initiative has reported success in increasing registration of Gypsies and Travellers with GPs and facilitating the immunisation of children. However, to achieve parity with non-Gypsy/Travellers requires a much more complex set of interventions. The high levels of poor literacy amongst these communities means that filling in forms is an obstacle to registration, reading appointment letters and keeping appointments can also be a challenge, therefore, the Project Health Worker facilitated attendance by assisting Gypsies and Travellers with these tasks and introducing measures to assist, such as calendars for those who can use them. New Gypsies and Travellers to the area will often have unmet health needs, providing a health needs assessment and triage service means those health needs can be dealt with efficiently. As has been discussed, Gypsies and Travellers have different cultural rules and health beliefs than the

general population. They are often wary of health interventions due to negative past experiences and general mistrust. This can result in difficulties in communication on both sides both by Gypsies and Travellers and the medical profession due to a lack of understanding and mistrust. The Project Health Worker has worked as the intermediary between these two, facilitating understanding by written communications with medical professionals, accompanied visits when appropriate and education of health professionals on Gypsy and Traveller culture, lifestyle and health beliefs.

## 7.5 Continuation of community health initiative

### 7.5.1 Service providers' views of continuation

Multi-agency Traveller Forum members, project Steering Group members and local GPs were asked their views concerning the continuation of the community initiative. If they felt there was a need for it to continue and if so, how they thought it should continue. All believed that there was a continuing need for such a service. It was felt that there would be an ongoing need due to the nomadic lifestyle of Gypsies and Travellers which meant that there was always new people arriving in the area who would have unmet health needs and difficulties with access to healthcare. Also, those who were less mobile tended to be those who either couldn't travel due to chronic health problems or alcoholism or age.

*"It won't have done its job (the project) because it's an ongoing thing isn't it. It's going to have to be ongoing because of their culture as well, and how they move around, and lots of families.."*
*(Multi-agency Traveller Forum member)*

*"Their health needs are chronic and enduring. The way that they express their needs is different, and so it takes up a bigger chunk of the resource, so I don't believe the idea that you could provide an advocate and then mainstream everything else and it would work, I think every vulnerable and hard to reach and disadvantage group are more costly in terms of getting equity of provision, and I think we have to take heed of that and I think hopefully with the agreement of the local health boards and the trusts that we can continue a provision of sorts..."* (see mainstreaming of service below)
*(Steering Group Member)*

Other reasons for the continuation of the service included the alienation that would be created through withdrawing the service and the feeling that a lot of the good work that had been done would be undone.

One local GP talked of the potential cost-effectiveness of continuing the project in terms of money saved by lessening inappropriate use of health care services and lessening the results of late treatment.

> *"Well I think there is one other thing and it would be difficult to prove or to quantify this, but I would argue for the cost of (Project Health Worker's) wages, we probably could save a lot of money in terms of inappropriate use of services elsewhere, and I definitely think somewhere along the line its made things more meaningful and smoother."*
>
> *(Local GP)*

### 7.5.1.1 Mainstreaming of Service

Members from both the Steering Group and Traveller Forum believed that for the service to be accepted and taken on board for mainstream funding, it would have to expand. Two alternatives were suggested. One alternative was to spread the service to other communities within the Local Health Board (LHB), this may be to other ethnic minority or disadvantaged groups in Wrexham, such as asylum seekers. This however, would involve either the Project Health Worker expanding her knowledge and expertise to more than one group, or employing another Health Worker with expertise of other groups to work in the health bus. The other alternative is to spread the specialist Gypsy and Traveller service beyond the boundaries of one LHB, possibly to cover two areas. Because the service has been designed to be mobile, this is would be possible. Economically, the cost of the service could be shared between two LHBs. However, this will lead to a drop in the level of service that the Wrexham Gypsies and Travellers receive at present.

> *"I really hope it continues but I think that's a corporate vision, a funding issue, and a willingness and ability on the part of the service commissioners and providers to deliver. I mean the van isn't going to*

*go away and my hope is to see, as part of the exit strategy, is to see if we can't secure continued service provision as an outreach project, but I think it needs to continue beyond Wrexham to be affordable."*

*(Steering Group member)*

### 7.5.1.2 Increased involvement of others

Although, in the interviews in the early stages of the project, members talked of a wish for multi-functional approach with other agencies using the Health Bus, this did not prove to be successful in practice. As mentioned previously, when tried, this resulted in a loss of trust from the Gypsy and Traveller communities. The exception to this is other health workers and social care agencies. Although much work has been done between the Project Health Worker and the primary health team, it was felt that more 'hands on' involvement from the primary health team, for example, GPs or minor illness nurses, or expanding the role of the Project Health Worker was desirable to meet the needs of this group.

> *"I think it's got to change. I think possibly, there's got to be more input from a GP, or expansion of the role into this high flying, minor illness nurse who could prescribe, through my training so far, I couldn't do that. There's a big training element that would be needed in that. But I seem to spend a lot of time triaging people, saying well, I think it's this I think It's that, but I can't give you any treatment, here's a GP appointment."*
>
> *(Project Health Worker)*

It was also felt that a closer working relationship with mental health services would benefit the group. However, an increase in involvement with others needs to be handled carefully, maintaining continuity by commitment from those involved, to ensure it does not become a stream of 'strangers' in the Health Bus, seriously compromising the service. It was also felt that a link worker from within the community was a goal to strive towards for the future. However, this may prove unpopular with Gypsies and Travellers as culturally, members of the community are reluctant to let their extended family know about their health problems, so may be reluctant to confide in an advocate from within their own community rather than someone impartial.

### 7.5.1.3 Focus for the future

It was felt by the members that the focus for the future should remain health, that it was important to retain its identity.

> "I don't see it for the other members, I see it as mainly health, otherwise it may become a place just for interviews or something, and no, to me it's a health bus, you know, everybody must link around it, but no, its a health bus."
>
> (Multi-agency Traveller Forum Member)

It was envisaged that the focus would expand beyond coronary heart disease to one of an enhanced health visiting service, ( Health visiting involving all age groups), however, it was felt important to involve the Gypsy and Traveller communities in any future service, as they would be able to best identify the 'gaps' in the service. Along with a focus on general health, it was believed that another important focus should be in facilitating an increase in Gypsies' and Travellers' own independence in the long term, with the hope of using Gypsy and Traveller advocates to work alongside the health worker who were recruited from the Gypsies and Travellers themselves.

### 7.5.2 Gypsies' and Traveller' views of continuation

The Gypsies and Travellers interviewed were asked how they saw the service developing in the future and whether involving other agencies in the Health Bus was a good idea. The majority did not want any changes and thought it was fine how it was. They did not want other agencies using the Health Bus. Those who did make suggestions, suggested other health professionals, such as a doctor, dentist, dietician or midwife. These views are beginning to change however, as Education and Welfare Rights are now regular visitors on the 'Health Bus' and appear to be well received.

Other suggestions included the use of someone to give general advice and help with form filling in, as the majority of Gypsies and Travellers in the area have poor or no literacy skills. There was also a suggestion from one Traveller for using the

Health Bus for adult literacy when not used for health, by providing a teacher who could teach those who wished to improve their literacy skills.

Another suggestion, which is outside the scope of this project, is for a play bus for the younger children, something that would bring both Gypsy and Traveller children together to increase tolerance of each other. This is at present being piloted through the Wrexham Play Association.

### 7.5.3 Funding structure and CHI's exit strategy

The funding of the community health initiative by the Welsh Assembly's Inequalities in Health Fund has proved to be something of a double edged sword for the service. Without this support, it is unlikely that the service would have started at all. The fund has provided support for this service for the past four years and will have supported it for five years by the time the present commitment has been met. This has given the service time to develop and for partnerships and links to be forged, as discussed in chapter 5, section 5.3.6. This has been one of the strengths of the service. However, the service is funded by 'project' funding which is finite. As discussed earlier in this chapter (section 7.3.2.2) this has impacted on the type of interventions that the Project Lead required to 'sell' the service to future funders. As has been discussed in this section, the belief held by the Project Lead is that the Local Health Board is not able to support this service on its own. The service does not come with any financial support from central funds once the 'project' period ends. Negotiations are underway at present between the Project Lead and both Wrexham LHB and the neighbouring Flintshire LHB. However, this has not proved successful as they are limited in what they feel they are able to support financially. This has led the Project Lead to approach the Local Health Trust which employs the primary health care teams at present including Health Visitors. At present, a new job specification is being drawn up by the Project Lead. The new job specification is believed to be more of a Health Visitor role, with the under fives caseload being transferred back from mainstream services to the community health initiative's Health Worker. In effect the job will revert back to one of a Health Visitor.

The combination of spreading the service to a much larger area and increasing the caseload to include the young children now in mainstream services with support from the Project Health Worker means that the service that the Gypsies and Travellers receive at present will be severely restricted. There will be physically less time to spend with Gypsies and Travellers as the caseload increases and also, the nature of the service will revert to one of child health. There will be less time to assist adults when there are statutory requirements that come with the care of the under five year olds. In effect, although the outreach will remain, the adult health focus of the service will be lost.

## 7.6 Summary

Presented in this chapter was an account of my experiences conducting fieldwork in this evaluation study. Those things that assisted in the fieldwork and some of the difficulties of this fieldwork. Here also, a description of the difficulties encountered reporting the evaluation of the community health initiative to the Welsh Assembly's Inequality in health fund was given. This highlighted the difficulties that can arise if the line between evaluator and project member becomes blurred and the reporting of the evaluation is expected to be done through the actual project management.

My reflections and evaluation of the community health initiatives' strengths and weaknesses were described; reflections of the elements that constituted the strengths of the community health initiative. This was followed by an exploration of the complex interactions between various aspects of Gypsy and Traveller culture, their experiences of healthcare, their health and the community health initiative were investigated. How culture, lifestyle and health beliefs impact on the CHD high risk lifestyle, high levels of mental health problems and problems with access to healthcare found in Gypsies and Travellers in Wrexham and how the community health initiative has sought to improve these, both through direct work with the Gypsy and Traveller communities and through working in partnership with groups such as the Multi-agency Traveller Forum, other healthcare agencies, and other social care and voluntary agencies.

Finally, the continuation of the community health initiative following the end of the 'project' funding period was discussed. Although both service providers and users acknowledge the value of the service and wish it to continue, it appears that the service is now under threat through having to find funding within an already stretched health service. Proposals at present presented to possible future funders of the service present a service that is much less than the Gypsies and Travellers receive at present and run the risk of undoing any long-term improvement in adult health started by this initiative. In effect, the adult service will no longer be provided. This appears to go against the recommendations of the Welsh Assembly's 'Review of Service Provision for Gypsies and Travellers' 2003, which recommends that "*that all Local Health Boards develop and implement strategies that meet the needs of Gypsies and Travellers in their areas, including how they will remove barriers to access to healthcare*". It also states that specialist provision is important, should facilitate access to healthcare and that this provision should not replace mainstream health service provision (see chapter 1 section 1.2.5).

# Chapter 8


# Discussion

## 8.1    Introduction

Due to the complex nature of the intervention and the complexity of the evaluation itself, a brief summary and discussion is provided at the end of each chapter that presents results or outcomes. In this final chapter, the main findings of the evaluation study are discussed. A summary of Gypsy/Traveller culture, lifestyle, health beliefs and experiences of healthcare together with a discussion of how cultural and environmental factors impact on Gypsy/Travellers' access to healthcare and general health is included. The process evaluation and outcomes of the community health initiative are summarised, and the interactions between health, culture, environment, and how the community health initiative has sought to impact on these is also discussed.  Also, comparisons are made with other studies of Gypsies' and Travellers' culture and lifestyle and comparisons made with other reported Gypsy and Traveller initiatives.

The strengths and weaknesses of the evaluation methods used are explored. What worked well, what didn't, and how the evaluation might have been improved. Furthermore, an overall evaluation of the community health initiative is provided, considering its implications and recommendations for future services. Finally, what questions have been left unanswered in this evaluation is discussed and what direction further research should take is considered.

## 8.2    Summary of main findings

### 8.2.1 Culture, lifestyle, health beliefs and experiences of healthcare

The information from participant observations and a series of interviews was described within the framework of 'General Systems Theory', exploring how culture, lifestyle, experience and health beliefs impact at each level or system, from the individual to the societal level, and how society and culture impact on the individual.

Gypsies and Travellers hold a strong sense of cultural identity. Because they also hold a strong sense of 'separateness' from the general population, they are often uncomfortable when they have to deal with 'outsiders'. The limited contact particularly of Gypsy/Traveller women, with non-Gypsy/Travellers can impact on their ability to interact and communicate 'outsiders' and this in turn can affect

access to healthcare. Gypsies and Travellers in this study, when in groups, would frequently talk simultaneously and raise their voices to be heard. This can be mistaken for aggression if experiences in a surgery or A&E department when a parent for example is anxious about the health of a child.

Gypsies and Travellers are heterogeneous groups and to refer to a person by the wrong group can cause offence. In this study, the majority of those we came into contact with the study were Irish Travellers, however, there were also English and Welsh Gypsies represented. There is evidence of a collective identity amongst Gypsy/Travellers. Examples of collective responsibility, decision making and punishment have been witnessed amongst Gypsies and Travellers in this study.

Gypsies' and Travellers' lives are governed by strict rules and cultural expectations. These rules and cultural norms are highly influential in how people live their lives. To break a rule is to risk being ostracised from the community. Rules include: cleanliness rules, different bowls for different jobs; purity rules, women must be virgins when married; gender rules, division of labour between men and women; cultural expectations concerning visiting the sick and dying; and attendance at ceremonies such as weddings and funerals. Many of these cultural rules impact on access to healthcare. If a woman is expected to be a virgin on marriage, there is a reluctance to have a smear test or any internal examinations for fear of this interfering with her virginity. Also, by breaking the rules, offence can be caused and stereotypes of unclean 'Gorgias' confirmed. For example, if a health worker visits a Gypsy or Traveller and washes her hands in a bowl used for dishes, it will be thought of as polluted and thrown away, confirming the unclean behaviour of Gorgias.

The cornerstone of Gypsy and Traveller society is the family, with children being highly prized, and families large. This is not always appreciated by health professionals who might wonder why a woman refuses birth control or seeks help in conceiving after having several children already. For these women, bearing children defines them, and they can feel very empty when that period of their life ends.

Women are homemakers and mothers and men hold the status of the head of the home. For Gypsy and Traveller women, marriage is for life and she is not expected to take another husband, even on the death of a spouse. Domestic violence is experienced by 80% of the Irish Traveller women in this study. Often what is sought by Gypsy/Traveller women is respite when the level of violence becomes too great. Gypsy and Traveller women can be culturally trapped in this cycle of violence and this often leads to depressive illness.

The extended family of parents, sisters, brothers, cousins, provides a source of support with family members looking after their own, this however, can lead to a lack of privacy.

Children are expected to learn the traditional ways, and these are thought more important than academic education, though many now wish their children to read and write. There is a belief that their children need these skills to survive in the modern world. The reality is that many still leave school in their early teens with no or very poor literacy skills. These impact greatly on access to healthcare by creating difficulties with registration, appointments, medication instructions and health information.

Gypsies and Travellers, in this study, were also defined by nomadism. Travelling was seen as the ideal, even if the reality of travelling in the UK today is one fraught with difficulties. This is due to an erosion of traditional stopping places and law resulting in evictions being commonplace. Many do manage to travel, if only for short periods in the summer, or to visit family on other permanent sites. Even if a Gypsy/Traveller is not 'on the road', they will often move on a frequent basis from site to site or to houses and back again. Also, cultural expectations of visiting sick relatives means that Gypsies and Travellers often travel at short notice. This has an impact on attendance at appointments and any arrangements such as regular appointments or any arrangements made on a regular basis.

Religion is very important to many Gypsies and Travellers. Most of the Irish Travellers encountered were Roman Catholic and three of the Gypsy women were 'Born again Christians'. There is a strong belief in the divine power of the

Church and many Irish Travellers will use religious faith healers in addition to conventional medicine. Religion is also used by women to modify their husband's behaviour, usually their drinking behaviour, in the form of 'The Pledge'.

The discrimination experienced by Gypsies and Travellers has been documented in the published literature and confirmed by the observational and interview work carried out in this study. Due to the nomadic lifestyle of Gypsies and Travellers, and the nationwide reporting of 'troubles concerning Gypsies and Travellers', it is reasonable to assume that the discrimination witnessed and reported in this study are not isolated cases but to be found throughout the UK. With this level of discrimination against Gypsies and Travellers, the result is a deep defensive, mistrust of non-Gypsy/Travellers. Ignorance of different cultures contributes to intolerance and stereotyping. This stereotyping extends to both Gypsy/Travellers and non-Gypsy/Travellers who view each other as permissive, dirty, and dangerous. By raising cultural awareness these prejudices can be confronted resulting in better equity of care for Gypsies and Travellers.

The health beliefs and experiences of healthcare were also explored in this thesis. There were two main definitions of good health expressed by the Gypsies and Travellers in this study, an absence of ill-health and lifestyle. Also, cleanliness was associated with good health. There were also contradictions in health beliefs. Many acknowledged that smoking, excess alcohol, poor diet and a lack of exercise caused ill health, but also held a belief that illness was a sign of weakness, especially in men. As mentioned earlier, there is a strong belief in the power of religion to cure, but there was also a fatalistic belief amongst some, that it was a matter of luck and that 'what will be, will be'. Most people interviewed said that they believed they were not in good health. Although those Gypsies and Travellers interviewed suggested that health was a important to them, in practice, immediate needs and environmental concerns come before health. Health is something that comes to the forefront when it becomes an emergency.

Mental illness was seen as a health problem; however, there is a reluctance to seek help from professionals. 'Talking' cures were not seen as helpful as there was a fear that it would make things worse to relive events or recount worries. Distraction was often used by Gypsies and Travellers to help one another. If they did seek help, GPs were preferred. They would accept medication, but there was a fear of addiction and they did not necessarily adhere to the instructions, sometimes only taking a tablet when having a 'bad day' or sharing medication with others. Some chose to conceal their mental health problems or at least the severity, to protect the family from worry or cause shame for showing weakness.

Several factors affect when and how Gypsies and Travellers access healthcare. Gypsy/Travellers may delay seeking help due to the belief they must 'fight' the complaint. A&E may be used in preference to GPs due to the perception of the severity of the complaint and convenience. Some did say they would consult GPs first, but this was moderated by past experiences. Although most Gypsies and Travellers in this study were registered with a GP due to the efforts of the Project Health Worker, many recounted problems registering while travelling due to a lack of a permanent address, literacy difficulties and prejudice. Often Gypsy/Travellers would also experience being taken off GP lists. These negative experiences result in distrust of many GPs, believing that they will get less care than other people. For that reason, when they do find a sympathetic doctor, they are reluctant to lose them and will stay registered even once they have moved from the area.

### 8.2.2 The community health initiative process evaluation

The design of the community health initiative was influenced by two factors. The first was the health needs assessment carried out prior to the development of the project by Health Visitors working with Gypsies and Travellers had a focus of improving access to healthcare and improving general health, the second was the Welsh Assembly Government, Inequality in Health fund's focus on coronary heart disease. These two focuses were combined resulting in the design of a community health initiative with a main aim of increasing access to healthcare for Gypsies and Travellers, but also had an objectives of developing interventions to impact on the coronary health status of this group, and

describing the coronary health status of Gypsies and Travellers (see chapter 2, section 2.1.2 & 2.1.3).

The community health initiative was a dedicated health worker outreach service for Gypsies and Travellers in and around Wrexham. The two main elements of the initiative were the Project Health Worker and the mobile health unit (health bus). The service provided a drop-in service to Gypsies and Travellers on the main council run site three days per week and visits to private sites and housed Gypsies and Travellers.

Although the main aims and objectives of the community health initiative of improving access to healthcare and impacting on the CHD status of Gypsies and Travellers remained constant throughout the first three years of the service, the focus changed with the changing demands from the project and the health and social care demands of the Gypsies and Travellers themselves. The project Health Worker's role was very wide initially. There was a large amount of unmet health and social needs amongst the people. As many of the social care agencies and voluntary sector did not engage with these people, the Project Health Worker dealt with a wide range of adult health and social care needs. She also took on the caseload of the Gypsy and Traveller children as their Health Visitor. This gradually changed as the children were handed back to mainstream services and the Project Health Worker encouraged more engagement from other agencies. The Project Health Worker was instrumental in the collection of the CHD and mental health status data and used the interviews as an opportunity to provide coronary health lifestyle advice to participants, so the data collection became part of the health intervention. The results were also forwarded on to the person's GP and so also increased assess to appropriate healthcare by identifying those who needed treatment.

The 'health bus' provides privacy and a quiet, safe, environment in which to engage with Gypsies and Travellers which would not be possible in their own caravans. It also enabled the data collection for the CHD and mental health status studies as the equipment needed was stored on the 'health bus' and it provided a place for interviews.

Formal health promotion initiatives were initially designed in an attempt to meet the objectives of the community health initiative, it was hoped that they would impact on the CHD health status of Gypsies and Travellers. Several attempts were made to introduce exercise sessions and healthy eating sessions to this group. They all failed after a couple of weeks. There are several reasons for this. They did not fit with the culture and lifestyle of nomadic people. Often people were simply not available at set times and days. Also, priorities of the Gypsies and Travellers did not include healthy lifestyle changes; they had other priorities such as childcare. One to one or small informal opportunistic group discussions of health topics that came up in conversation or were raised as concerns by Gypsies and Travellers themselves were much more effective. Materials such as books and videos were stored in the 'health bus' and used when an opportunity to discuss a health topic arose.

Partnership working was also an important element in the success of the community health initiative. There were strong links with the Multi-agency Traveller Forum (MAF) who were partners in the original bid for funding. And although not all members where 'hands on' in the service provision, the project was supported by MAF and information shared with its members. Concerns that Gypsies and Travellers voiced to project workers were often raised at MAF meetings if it was felt that one of MAF's agencies could help to resolve a problem. Also, partnership working with other health professionals and other agencies outside MAF was crucial. By having a dedicated Health Worker, it was possible to give time to developing these relationships which would not be much more difficult if these people were only a part of a case load.

### 8.2.3 The outcomes of the project

The project has delivered its short and medium term goals and is working well towards meeting its eventual long term goals. Access to appropriate health and social care has improved, acute and chronic health problems have been identified, partnership working has been strengthened, appropriate CHD management and awareness of risk factors has improved and other professionals are now beginning to gain more understanding and have less fear of visiting the Gypsy and Traveller site.

The longer term aims of improving Gypsies' and Travellers general health and the appropriate use of health services by Gypsies and Travellers are more complex problems. Improving general health requires an approach that includes both health and other agencies tackling social, environmental and health problems together. Health promotion can only have limited effect if social and environmental problems go unchecked. The increase in partnership working co-ordinated by the Project Health Worker and the project working alongside the Multi-agency Traveller Forum; has begun to address some of these wider issues. However, if the project hopes to have maximum impact on Gypsies' and Travellers' long term health it must feed into policy development, across all divides; health, social, environmental, and geographical and political.

The coronary and mental health status of Gypsies and Travellers in Wrexham has also been described. This fulfils one of the main objectives of the project and is a component in the overall evaluation of the community health initiative.

Gypsy and Traveller participants in this study participate in higher CHD risk behaviours than the general population. There is a higher prevalence of smoking, particularly in women, poorer diet, lower levels of physical activity, and higher amounts of alcohol consumed amongst men.

Physical measurements show a raised risk of CHD in older (above 45) Gypsies and Travellers with higher rates of raised BMI and Blood Pressure than the general population, also, a much higher rate of low HDL-cholesterol than the general population, rising with age. This may be a reflection of the high CHD risk behaviours identified.

Gypsies and Travellers suffer a higher rate of mental health problems than the general population. Psychosocial well being has been identified as a risk factor in CHD, both in physiological terms and in an increase in high CHD risk behaviours. Contributing factors to high levels of anxiety and depression in this community are complex and interacting (see Chapter 7, section 7.3.2).

The findings of this health status study and the insight gained by the qualitative study into Gypsy and Traveller culture, lifestyle, health beliefs and experiences

of health care provides a better understanding of this community, its needs in terms of health care and enable the design of culturally appropriate health and social care interventions.

### 8.2.4 The Community health initiative's strengths and weaknesses

The strengths and weaknesses of the community health initiative have been considered. The strengths included having a 'dedicated' health worker for Gypsies and Travellers and the qualities that the PHW brought to the role. Another strength was the 'health bus' and the impact that it had in providing the space needed to carry out the work with this group and how that affected the power balance, giving Gypsies and Travellers a choice.

Some of the weaknesses of the community health initiative were also explored, including the professional isolation that the PHW experienced at times during the study and the effect the demands of such a needy group has on the workers involved with their care. Also, the differing perceptions of the PHW's remit were explored, showing the often conflicting pulls in different directions experienced by the PHW from the project management and the Gypsies and Travellers for which the service was designed.

## 8.3    Comparison of findings with previous studies

### 8.3.1 Cultural comparisons

The study of Gypsy and Traveller culture, beliefs and lifestyle in this evaluation has been compared with other studies, both past and present. Two main anthropological studies were carried out in the 1970s. One was a study of Gypsies and Travellers in England by Okely and the other was a study by Gmelch of Irish Travellers (Tinkers) in Ireland. Both anthropologists lived with Gypsy/Travellers in their encampments for over a year, continued to have contact after their studies had finished, and report making lifelong friends in these communities. Okely provides an account from a female perspective and Gmelch from a male perspective. Okely's study was initially policy orientated and Gmelch's study was focused on Irish Traveller's adaptation both economically and socially to urbanisation. Neither study had health as its focus but both give insight into the culture and lifestyle of Gypsy/Travellers which impacts on health and access to healthcare. When considering these studies

conducted over thirty years ago, the most striking finding is their similarity to the culture and lifestyle of Gypsies and Travellers today. Descriptions of Gypsy and Traveller cultural rules such as those concerned with group membership, cleanliness and pollution, purity and division of labour between men and women, marriage rules, and norms such as the value of family and large family size, the importance of 'traditional' self-employment, duties to attend celebrations, visit the sick and dying, and a nomadic way of life, which were given in these previous studies are all described in this present study.

Interestingly, the reporting of relationships between marriage partners is only touched on by Okely when she talks of women being expected to be subordinate to her husband's wishes. Gmelch on the other hand, provided rich description of the dynamics between men and women and the occurrence of domestic violence amongst the Irish Travellers in his study. The volatile and frequently violent nature of marriage relationships amongst Irish Travellers in the 1970s observed by Gmelch, are also a feature of Irish Traveller life in Wales in the 21st century. In the present study, nearly every married woman had experience of domestic abuse and those who were unmarried had experienced the abuse of their mothers. There were differences in interpretation however, Gmelch describes how a large woman would sometimes give as good as she got in terms of violence and describes the occasions when women left their husbands due to abuse in terms of 'abandonment' rather than a need to leave for fear of life and limb or for respite from abuse.

Perhaps the differences that were reported between Gmelch's interpretation of marriage relationships and the interpretations made in the present study were more a product of the time in which they are set or a difference in perceptions due to a difference in gender, rather than differences in the nature of the abuse. As the majority of Gypsy/Travellers observed in this study were Irish Travellers, it is unclear whether the same level of domestic abuse occurs in other Gypsy/Traveller groups, however, domestic abuse was recounted in some of the Romany and Welsh Travellers encountered.

It appears that the culture and lifestyle and values of Gypsies and Travellers have changed little in the past thirty years. From the outside looking in, many of

the rules and norms of Gypsy/Traveller culture appear 'backward' and detrimental to women, however, a Gypsy/Traveller's identity is closely connected with membership of this ethnic group, they are very proud of who they are and as such, the rules and norms of Gypsy/Traveller culture are strongly defended and actively encouraged by both men and women. Testimony to this is the failure of governments throughout the world to assimilate Gypsy/Travellers into mainstream society.

The cultural findings of the present study also support more recent studies of Gypsy and Traveller culture, lifestyle and health beliefs. Margaret Greenfields (Clark & Greenfields 2006) describes how Gypsy/Traveller identity is closely linked to cultural norms and behaviours and the consequence of breaking these cultural rules is weakening of the Gypsy/Traveller identity. She too talks of the risk of bringing 'shame' to the Gypsy/Traveller family by breaking cultural rules and in extreme cases, the risk of the ultimate punishment, expulsion from the community.

Family life and Marriage have also been described in recent studies (Clark & Greenfields 2006, Van Cleemput 2004). Their findings, again, are similar to those found in this study. They found that family life is very important to Gypsies and Travellers, and that marriage is generally young, in the late teens, and for the most part for life. Marriages from inside a group or 'clan' are preferred to marriages to outside groups or non-Gypsy/Travellers. They too, describe the distinct gender roles, with men as the 'head of the home' and women responsible for the home and childcare, the effect death has to family members, the observance of strict moral codes, the importance of religion, a nomadic lifestyle and the importance of flexible non-wage labour, and the importance placed on 'traditional' education.

### 8.3.2 Health status comparison with other studies

Because few studies have been conducted that focus on adult health status of Gypsies and Traveller (Zeman 2003; Hajioff 2000) there is little evidence to provide comparison. However, there are some notable exceptions, including the recent multi-site epidemiological study by Parry (2004) which sought to describe Gypsies' and Travellers' general health in England. Although the focus was not

coronary heart disease, they did gather data on cigarette smoking and also used the Hospital Anxiety and Depression Scale (HADS) to measure mental health. This allowed direct comparison with the present participants of this study. Feder (1994) also described the prevalence of cigarette smoking and blood pressure levels amongst Gypsies and Travellers in East London enabling further comparisons.

The smoking prevalence of Gypsy/Travellers in Wrexham (73%) was found to be higher than both the prevalence found in Gypsy/Travellers in England by Parry (57%) and Feder (63%). Furthermore, the prevalence of women smokers is much higher in the present study (men 58% women 82%) compared to Feder's findings (men 68% women 62%). The Gypsy/Traveller women in the present study also showed higher prevalence of raised levels of anxiety (Welsh 73% English 44%) and depression (Welsh 48% English 27%) compared to those found in women in the English study by Parry.

The reason for these differences in findings is uncertain. The high rates of cigarette smoking are likely to be a reflection of the high levels of anxiety and depression, as many women stated that they smoked to help their 'nerves'. The raised levels of anxiety and depression may be a reflection of the high levels of domestic violence found in this study or it may be a result of the methods used. Close trusting relationships had developed during this study between the Project Health Worker, myself and the Gypsies and Travellers, also the women might have felt more at ease to disclose to us as they were in the privacy of the health bus and therefore less likely to be overheard by family members.

### 8.3.3 Comparison with other health initiatives

Similar to the above section on the health status of Gypsy/Traveller, there are very few evaluations (Fitzpatrick 1997; Feder 1994) of health interventions to make comparisons. However, there is a large literature from nursing professionals describing their service with Gypsy/Travellers. This provides insight into some of the difficulties encountered and cultural differences that need to be considered when providing a service for Gypsies and Travellers. The present evaluation of a community health initiative has found similarities between the initiative being evaluated and other reported initiatives.

Feder's evaluation is the only one found that looked at a dedicated Health Visitor service for Gypsies and Travellers. He found that the service had limited success in increasing immunization and cervical smear test rates due to the large caseload wide role that the Health Visitor needed to adopt due to the unmet need found in this group. This limited her ability to develop the professional networks with other health professional. This wide role of the Project Health Worker has been described in the current study. The difference however, between the two services may be in the size of the caseload that the Health Workers had. In Feder's evaluation, the Health Visitor had a large area of East London with several sites. In contrast, the health initiative in Wrexham consisted of only one large site and a couple of very small private sites, along with housed Gypsy/Travellers. This smaller caseload enabled the Project Health Worker to devote time to developing and sustaining these professional relationships so important in enabling access to healthcare in this group. The importance of partnership working has also been described by other Health Visitors providing services for Gypsies and Travellers (Warriner 2002; Daniels 1999; Matthews 1998; Batestone 1993; Streetly 1987; Peck 1983)

Other key observations made by Health Visitors working with Gypsy/Travellers are the broad role required due to the unmet health needs of Gypsy/Travellers (Daniels 1999; Matthews 1998; Rose 1993; Eckford 1990; Streetly 1987), the importance of cultural sensitivity (Eckford 1990), and the different priorities between health professionals and Gypsy/Travellers when attempting to provide health promotion (Daniel 1999; Fitzpatrick 1997; Rose 1993). All of these have been described in this study and have been found to be important aspects of delivering a service to Gypsies and Traveller.

## 8.4   The Strengths and limitations of the evaluation methods

### 8.4.1 Evaluation of qualitative methods used

Although there is some debate within the field of qualitative research concerning the appropriateness of some methods adopted by researchers to ensure rigour in qualitative research, there is broad agreement that strategies should be adopted to protect against bias and enhance the reliability and validity of findings (Richie & Lewis 2003; Silverman, 2001; Miller & Digwall, 1997; Mays & Pope, 1995b)

Several measures were used to ensure the validity of the research findings and their interpretation in this evaluation. One method was 'Triangulation' of evidence from different people involved in the initiative, such as the Gypsies and Travellers (service users), Steering group members, Multi-agency Traveller Forum members and GPs (service providers). Also, evidence was collected through different methods including participant observations, in-depth semi-structured interviews, review of historical literature and quantitative methods for the investigation of health status.

In addition, respondent validation was sought. In an attempt to reflect the participants' perspectives as accurately as possible, Steering Group members were sent draft copies of the results for comment. This however, lead to difficulties which are discussed fully in Chapter 7, raising the question of the appropriateness of this type of validation method in programme evaluations and the difficulties of providing an evaluation of a service while reporting those findings directly through the management of the service. The findings were also presented to Gypsy and Traveller participants through an open forum where comments were invited and noted.

In this study, I have attempted to describe the culture, lifestyle and health beliefs of Gypsies and Travellers. As a woman, my main contacts were women and children. This was due, in part, to cultural constraints in these communities. Women are not expected to spend time with men unaccompanied. Also, partly due to practicalities; many of the men were not around in the day. Therefore, my observations of the men in these communities was more restricted and from a distance. Much of the information, but not all, concerning men came from the Gypsy and Traveller women and therefore from their perspectives and from my observations and my own perspective as a woman.

The Gypsies and Travellers in this study did become at ease with my presence both in the health bus and accompanying the Project Health Worker to houses, but I was often perceived as part of the service delivery. At times I was referred to by some Gypsies and Travellers as one of the 'nurses' and although I did take great effort to explain who I was and what I was doing, this misconception

may have affected some of the responses, especially to questions concerning the service delivery.

Results from the present study exposed a lack of cultural understanding and discrimination amongst some healthcare workers, both in primary and secondary care. This highlights another limitation of this study which was the limited information gained from healthcare providers other than those already actively engaged with the project or involved with MAF. Due to this, the results only provide a view from one side, those of Gypsies and Travellers and professionals who actively engage with them in their professional lives and who have an interest in their well-being. Members of MAF have a special interest in improving conditions for Gypsies and Travellers and therefore, are not necessarily representative of all professionals.

Furthermore, an economic evaluation of the community initiative was outside the scope of this study due to time, financial and study design constraints. Subsequent evaluations of community initiatives would benefit from this type of evaluation in order to provide a sound economic case for future funding of such initiatives.

## 8.4.2 Evaluation of quantitative study methods

One limitation of this study was the threat to representativeness due to the recruitment method. All adults that engaged with the health initiative were invited to participate in the study, however, 22 declined to be involved in the study and there was a small number of Gypsies and Travellers who chose not to engage with the service and therefore were not asked to participate. Also, men were underrepresented in the study, mainly due to unavailability because they were out working during the day. This may have introduced bias into the sample. However, It was decided that it would be counterproductive to the service to appear too pushy by attempting to recruit people who did not wish to engage with the service.

Data in this study, was collected face to face, due to the high levels of poor literacy skills found, whereas, postal questionnaires were used in general population studies used for comparison. This difference in data extraction

methods may have influenced the results. In phase two of this project, a control group will be recruited, matched for age and gender, and administered face to face to provide a more accurate comparison.

There are also limitations due to the design of the study, it was not designed to describe the general health status of Gypsies and Travellers, but rather concentrated on their CHD health status as this was a primary concern to the project funders and was believed to provide complimentary information to current studies.

Furthermore, a follow up study of the Gypsy and Traveller participants in this study to compare with the CHD and mental health data collected in the present study would be greatly limited by the nomadic nature of the group. By the time the data collection had ended in this study, approximately 40% of the participants had moved to other locations. It would prove difficult if not impossible to trace all of the participants, as some will be 'on the road' and others will be staying unofficially on sites with relatives or on unofficial sites. Many will not be registered with GPs once they have moved on, particularly if there is no Gypsy/Travellers health worker in the new location.

## 8.5 Overall evaluation and recommendations for future services

The project has achieved its main aims and objectives. Access to healthcare for Gypsies and Travellers has improved; the CHD health status and the culture, lifestyle and health beliefs of Gypsies and Travellers have been described; and a culturally acceptable method of service delivery has been developed to impact on the cardiovascular health of Gypsies and Travellers. The short and medium term outcomes identified by the Project Steering Group have been accomplished and inroads are being made into meeting the eventual long term goals.

The evaluation of the community initiative has explored the complex interactions between cultural and environmental factors that influence Gypsy and Traveller health and how the community health initiative has developed approaches to meet the needs of these communities.

The service is valued by the Gypsies and Travellers that it serves. Gypsies and Travellers have expressed a belief that the service is worthwhile and has made a large difference to them and their families. Several mentioned how the Project Health Worker had helped them through a lot. It was felt that life would be much more difficult without her services, that she has provided help for people where there was none before.

Due to this in-depth exploration of Gypsy and Traveller culture and health beliefs over an extended period, the Project Health Worker has acquired 'expert' knowledge in the field of Gypsy and Traveller culture and health which would otherwise not have developed to the same degree. She is therefore better able to identify health care needs and adopt approaches that are culturally appropriate and acceptable. The challenge now is to continue to spread this knowledge to other health professionals. This has done by the liaison work with health professionals in the field, teaching sessions with students and written papers and conference presentations.

Gypsies and Travellers need to be encouraged to find their own voice. Gypsy/Travellers are a proud people, proud of their culture and heritage but they are also marginalised. They are isolated by the greater society and self-isolated as a protection against the discrimination, which has resulted in fear, mistrust and a feeling of powerlessness. Without empowerment, the hope of engaging a Gypsy or Traveller advocate for health to work in their own community has little hope of becoming a reality. The project has taken the first step by showing an interest in this group. The next step may be for the project to work towards exploring and encouraging new possibilities for Gypsies and Travellers to influence their own environment, and therefore their own health, by developing their own community voice. The project in conjunction with the Multi Agency Traveller Forum has been involved in pursuing funding from the 'Fairshare' National Lottery Fund to employ a development worker to address these issues.

Why have other such health initiatives in the past resulted in only limited local success and not been adopted UK wide? It may be that the health status of

Gypsies and Travellers had not been adequately described to date to enable a true recognition of the health needs of this population. The recent results from the large multi-centred study by Parry (2004) commissioned by the Department of Health, and the results of this study, combined with the previous research into Gypsies' and Travellers' health add to the body of knowledge of Gypsy and Traveller health status. Furthermore, politically, the timing may be right. With the advent of the 'Review of Service Provision for Gypsies and Travellers' produced by the Welsh Assembly Government in 2003 and the outcome of the recent 2006 Commission for Racial Equality's 'Scrutiny Project', health providers are becoming more aware of the duty of care to those facing health inequalities.

Finally, there is clear need for this service to continue due to the extreme health needs of this community, many of them severe and enduring. Also, due to the nomadic lifestyle of Gypsies and Travellers, there is a constant turn over, with new families arriving on a regular basis. This initiative has proved to be successful by being adaptive and providing a service that is culturally acceptable and appropriate. Unfortunately, the future of this service, instead of providing a template of good service provision for Gypsies and Travellers to be replicated throughout Wales, runs the risk of being eroded back into a mainstream provision due to the unwillingness or inability of local health authorities to implement the Welsh Assembly's recommendations for the service provision to this group (see chapter 7, section 7.5.1.3).

## 8.6   The direction for future research

The coronary and mental health status of Gypsies and Travellers in Wrexham has been described by comparing the data collected in this evaluation study with data from general population studies. Although socio-economic groups were compared where possible, the present study would be strengthened if compared to a control group from a local socially deprived community. This would enable us to consider the coronary health status of the Gypsies and Travellers in this study in their local context.  Enabling us to address the question of whether the coronary health status of Gypsies and Travellers in this study are worse than those from a socially deprived local community or whether they are comparable to the coronary health status for this area.

Another, important area for future research is in the development and evaluation of cultural awareness raising information materials for health professionals such as doctors and nurses and those who have contact with patients in the NHS, such as receptionists and appointment secretaries. It has been seen from this study that stereotyping and discrimination still exists in the health service and the cultural information from this study could be used to help raise cultural awareness and tolerance if developed into a size and format that is both seen as easily digestible and informative to those who deal with patients and are likely to come into contact with this misunderstood ethnic minority group.

This could be achieved by conducting a qualitative study of the beliefs, knowledge, and experiences of healthcare workers concerning Gypsies and Travellers. The information gained from both the study of Gypsies' and Travellers' health beliefs and experiences of healthcare together with, healthcare professionals' beliefs and experiences could then be used to develop appropriate information materials and/or services to improve access to healthcare for Gypsies and Travellers. This could then be piloted and evaluated for effectiveness and economic evaluations carried out. Depending on the outcome of this further study of healthcare workers' beliefs, knowledge and experiences, materials may also be developed to improve how Gypsies and Travellers engage with healthcare workers by highlighting situations in which healthcare workers have difficulties with Gypsies and Travellers. This would most likely take the form of oral information given to Gypsy/Travellers by Gypsy/Traveller healthcare workers in the field. In essences, the results of the present study and this future study would provide a dialogue on both sides, informing both healthcare professionals and Gypsies and Travellers.

Another direction in which this research may be taken is to determine whether this model of outreach care would be equally as successful for other communities, such as refugees and new economic migrants, where there may be problems in accessing healthcare due to cultural and language difficulties or for other groups in the community who suffer difficulties with access to healthcare such as the homeless or drug users in a community. It may be viable to share the 'health bus' with other agencies and health worker to maximise the

use and lessen the cost of running a mobile health unit. An evaluation of the effectiveness and cost effectiveness of such system would be essential.

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# Appendix 1

## Coronary Heart Disease: Redressing the Balance
### Participant Information Sheet

**What is it all about?**

**Why have I been invited to take part?**
We are asking all adult Travellers in the Wrexham area to take part in this study so that you can give your views. We hope that the information we get will be used to improve health services for Travellers. The same number of 'Country people' (people who are not Travellers) will also be included in the study to see if there is a difference in their health. We will be looking at health and your heart as well as your feelings and emotions.

**What does it involve?**
A 'Health Bus' will visit the Ruthin Road site, private sites and housed Travellers three days per week and provide the normal services of a Health Visitor, including child health checks and immunisations. Also, the health worker will be looking at the health of your heart and will ask questions about your lifestyle and how you are feeling. The Health Worker will take your blood pressure, weigh and measure you, and take a blood test for cholesterol. This information will be used in the study should you agree. Also, the researcher may take notes from conversations in the 'health bus' or may ask direct questions about your health beliefs and way of life.

**How can this study help me?**
You can discuss any health problems with the Health Worker and she will help you get treatment when necessary. She will also give you information on how to improve your health if needed.

**Confidentiality**
All the information used by the study will be treated with the strictest confidence. The information will be used by members of the project only and it will be anonymous. Your name will not be used in any report or publication.

**What if you find I am in poor health?**
If we find that you are in poor health, we will tell you of this and suggest you see a doctor.

**What if I decide not to take part?**
You are completely free not to take part in this study. There is no need to give a reason, and it will not affect your normal care from your GP or Health Worker. You can leave the study at any time.

**Where can I get further information?**
If you want any further information you can contact Janine DeGale (Health Worker) or Helen Lewis (researcher) on 01978 352880 or 07990683668.

# Coronary Heart Disease & Travellers: Redressing the Balance

*Funded by the National Assembly for Wales Inequalities in Health Fund*

## Travellers' Health Project Consent Form

I have read or been given information about the Travellers' health project and I agree to

participate in this study. I understand that I do not have to take part in this study and that

I can withdraw from the study at any time without it affecting my normal health care.

Name: _____

Address: _____

_____

_____

Phone No: _____

Date of Birth: _____

*Signed:* _____

Date: _____

Witness: _____

Date: _____

# Appendix 3

## *Service providers baseline interview Topic Guide*

1. Involvement with the Travellers?

2. Involvement with the Multi-agency Forum?

3. Background to how project developed?

4. Impressions of implementation?

5. What the project is for?

6. Your role in connection with the project?

7. Your agency contribution?

8. What does agency get out of project?

9. Benefit to Travellers of project?

10. Long term benefits of project?

11. Your ideas of success?

12. Design – best/worst aspects of project?

## *Service providers follow up interview topic guide*

1. Background
   a. work
   b. involvement with Gypsies and Travellers
   c. multi-agency?

2. Project involvement
   a. Health worker?
   b. Health Bus?
   c. Other?
3. Design and implementation

4. focus

- what focus
- change

5. Health workers role

6. What worked well, strengths?

7. What didn't work well, weaknesses?

8. What would you change?

9. Difference to Travellers?

10. Changes/improvements in relationships?

11. Changes/ improvements in service?

12. Partnership working?

13. Project continuation

# Appendix 4

## *Gypsy/Traveller interview topic guide*

### 1. Background
- Age, Marital status, Children
- Abode   (caravan, house, council site, private land etc.)
- Travelling status (constant travelling, occasional travelling, settled etc.)
  - Definition of self

    What they call themselves
  - Definition of Traveller

    What makes you a Gypsy/Traveller?


### 2. Understanding of Health
- Definition of health.
- Description of current state of health
- Importance of good health to you
- Explore words associated with 'good health'.
- Explore whether health can be changed, if so by what?
- Definition of 'healthy lifestyle'. What makes up a healthy lifestyle?

                              PROBE:          Smoking
                                              Alcohol /drugs
                                              Exercise
                                              Stress


- Explore ideas about mental health
                              -   Definition of mental health
     -   Acceptability of mental health problems in community
- Definition of old age, when is someone old?


### 3. Experience of Health Care
- How healthcare is got as first port of call. (GP, A&E, other)
                      PROBE FULLY:   Before project began
                                     Now project is running
- If no GP, why?
- Accessing a GP, how easy/difficult? If difficult, what makes it difficult?
- Explore how access could be made better
- Experiences with access to Primary Care
                    PROBE FULLY:   GP registration
                          GP appointments (availability, times etc)
                                Experience of receptionist
                                  Experience of GPs
                                Treatments/ Medications
                            Location of surgery
- Experience with Hospitals
                    PROBE:          A & E
                                    Hospital In-patients
                                    Hospital Out-patients
                                    Visiting

## 4. Understanding and experience of Project
- Understanding of what the project is for
- What is Project Health Worker's role
    - What she does
    - What she doesn't do
- User involvement in designing project
                            - Consulted about needs
    - What information given before project started
- Help received by project Health Worker
                            - for self
                    - for children / other family members
                PROBE:          Kind of assistance
                                    Frequency
                                Usefullness of assistance

## 5. Ideas of success and continuation
- What works well / doesn't work well. How could it be improved?
    - Health Worker
    - Health Bus
    - Healthy living advice
    - Exercise programme
- Benefits for Travellers
    - Short-term
    - Long-term
- Disadvantages for Travellers
    - Short-term
    - Long-term
- Ideas of success

## 6. Continuation of project
- How project should continue
    - Health Worker
    - Health Bus
- Thoughts about other agencies using 'Health Bus'
    - Which agencies
    - Doing what

## 7. Exploration of Culture and Health
- Religion
    - Explore importance of religion
    - What religion if any
    - Thoughts about and use of healers
    - Ill health and punishment
    - Explore understanding and experience of 'The pledge'


- Family life now and how different from parents/children's experiences
    - Childhood experiences

PROBE:        Description of childhood
                   Child rearing
                   Schooling (formal & traveller education)
                   Age of adulthood
                   - Marriage

PROBE:        Age of marriage
                    Choice of partner
                   Where you live
                   Wife's role
                    Husband's role
                   Divorce
                   Domestic violence
         - Family commitments (ceremonies, visiting ill family members in hospital)

- Livelihood
  - how living is made
  - differences from parents/past
  - expectations for children
- Accommodation
  - Experiences of Travelling
  - Accommodation available when travelling
  - Facilities on sites
  - Problems with sites
  - Good things about living on sites
  - Bad things about living on sites
  - Feelings about living in a house
- Experiences of Discrimination
  - How often and what type
  - Who does the discrimination
  - Reporting discrimination
  - Changes in how Travellers are treated

# Appendix 5

## Baseline / Follow-up Interview Participants

|         | Participants/ Organisation | Baseline | Follow up | Comments |
|---------|---------------------------|----------|-----------|----------|
| Int.1   | Steering group/ Project Health Worker | yes | yes | |
| Int.2   | Multi-agency Forum/ Midwife | yes | yes | |
| Int.3   | Steering group / Research advisor & GP | yes | yes | |
| Int.4   | Multi-agency Forum/ Priest | yes | no | Long term sick leave |
| Int.5   | Steering group / Project lead | yes | yes | |
| Int.6   | Multi-agency Forum/ Housing Officer | yes | yes | |
| Int.7   | Multi-agency Forum/ Domestic Abuse Officer | yes | no | Left post no replacement |
| Int.8   | Multi-agency Forum/ Educational Social Worker | yes | yes | |
| Int.9   | Multi-agency Forum/ Traveller Education Officer | yes | no | Left post replaced by int. 10 |
| Int.10  | Multi-agency Forum/ Traveller Education Officer | no | yes | Replacement for Int. 9 |
| Int.11  | GP | no | yes | |

# Appendix 6

## Table of Gypsy and Traveller Respondent Demographics

| Interview no. | Gender | Age group | Cultural Identity |
|---|---|---|---|
| Int. 1 | M | midlife | Traveller |
| Int. 2 | F | young | English Gypsy |
| Int. 3 | F | mature | Traveller |
| Int. 4 | F | midlife | Traveller |
| Int. 5 | F | midlife | English Traveller |
| Int. 6 | M | young | Welsh, Irish Traveller |
| Int. 7 | F | young | Irish Traveller |
| Int. 8 | F | young | Irish Traveller |
| Int. 9 | F | mature | Romany Gypsy |
| Int. 10 | M | young | Irish Traveller |
| Int. 11 | F | midlife | Welsh Traveller |
| Int. 12 | F | young | Irish Traveller |
| Int. 13 | F | young | Traveller |

**Key:**
Gender:  M = Male   F = Female
Age Group:  young = -25 yrs    midlife = 25 yrs – 45 yrs     mature = 45+
Cultural Identity: Self reported

# Appendix 7

# Proposed Traveller Interview Sample Matrix

|  | On Site | Housed | Private land | Total |
|---|---|---|---|---|
| **Age** |  |  |  |  |
| **Under 35 years** | 5+ | 2 – 3 | 2 – 3 | 9+ |
| **35 years and over** | 5+ | 3 - 5 | 3 – 5 | 11+ |
| **Origin** |  |  |  |  |
| **Irish Traveller** | 8 - 10 | 2 - 3 | 2 – 3 | 12+ |
| **English/Welsh Gypsy** | 2 - 3 | 3 - 5 | 3 – 5 | 8+ |
| **Gender** |  |  |  |  |
| **Female** | 6 – 8 | 3 - 5 | 3 – 5 | 12+ |
| **Male** | 4 - 6 | 2 - 3 | 2 - 3 | 8+ |
| **Frequency of use** |  |  |  |  |
| **Frequent user** | 8 - 10 | N/A* | N/A* |  |
| **Occasional user** | 2 - 3 | N/A* | N/A* |  |
| **Total** | 10 + | 5+ | 5+ | 20+ |

- Not applicable as not offered 'drop in' service as site residents are.

# Table of Gypsy and Traveller Interviews Achieved

|  | On Site | Housed | Private land | Total |
|---|---|---|---|---|
| **Age** |  |  |  |  |
| **Under 35 years** | 5 | 1 | 1 | 7 |
| **35 years and over** | 3 | 3 | - | 6 |
| **Origin** |  |  |  |  |
| **Irish Traveller** | 8 | 1 | 1 | 10 |
| **English/Welsh Gypsy** | - | 3 | - | 3 |
| **Gender** |  |  |  |  |
| **Female** | 6 | 3 | 1 | 10 |
| **Male** | 2 | 1 | - | 3 |
| **Frequency of use** |  |  |  |  |
| **Frequent user** | 6 | N/A* | N/A* | 6 |
| **Occasional user** | 2 | N/A* | N/A* | 2 |
| **Total** | 8 | 4 | 1 | 13 |

• Not applicable as not offered 'drop in' service as site residents are.

# Appendix 8

Participant Age Distribution

| Age | Statistic | Std. Error |
|---|---|---|
| Mean | 32.93 | 1.573 |
| 95% Confidence Interval for Mean  Lower Bound | 29.80 | |
| Upper Bound | 36.06 | |
| 5% Trimmed Mean | 31.94 | |
| Median | 30.00 | |
| Variance | 200.419 | |
| Std. Deviation | 14.157 | |
| Minimum | 16 | |
| Maximum | 70 | |
| Range | 54 | |
| Interquartile Range | 22 | |
| Skewness | .847 | .267 |
| Kurtosis | .031 | .529 |

# Appendix 9

## Coronary Heart Status Data Collection

Reference Number:_____

Name:_____

Date of Birth:_____

Address:_____

Gender:   Male θ      Female θ

General Practitioner:_____

Family History:

Mother    Alive    yes θ    No θ    Age at death: _____

History of Coronary Vascular Disease:_____

Father        Alive    yes θ    No θ    Age at death: _____

History of Coronary Vascular Disease:_____

*Cardio Vascular Medical History:*

MI θ        Angina θ      CABG θ      Angioplasty θ    Diabetes θ

    Other Relevant Medical History:_____

_____

Medication:_____

_____

## Lifestyle

| Smoking | Please Tick | Date |
|---|---|---|
| **Never smoked** | | |
| **Light (1 – 9 daily)** | | |
| **Moderate (10 – 19 daily)** | | |
| **Heavy (20+ daily)** | | |
| **Ex smoker Light (1 – 9 daily)** | **Date stopped:** | |

| Ex smoker Moderate (10 – 19 daily) | Date stopped: |  |
|---|---|---|
| Ex smoker Heavy (20+ daily) | Date stopped: |  |

If smoker,

How long have you smoked:_____

Age started smoking:_____

Smoking history:_____

| Alcohol consumption | Daily units |
|---|---|
| Week days |  |
| Week ends |  |
| Celebrations |  |
| Average weekly consumption |  |

|  |  |
|---|---|
| Drank once + last week |  |
| Drank on 5 or more days |  |
| Drank more than 3 units on one day |  |
| Drank more than 4 units on one day |  |
| Drank more than 6 units on one day |  |
| Drank more than 8 units on one day |  |

| Exercise | Please tick | Date |
|---|---|---|
| Physically impossible |  |  |
| Inadequate |  |  |
| Light – normal walking 12 – 20 mins per day X5 |  |  |
| Moderate – brisk walking 30 – 35 mins per day X5 |  |  |
| Heavy – keen sportsperson |  |  |
| Health education advice given |  |  |
| Referred to exercise scheme / group |  |  |

Description of regular exercise:_____

| Diet | Daily | Weekend | Occasionally | Never | Above recommended amount | Below recommended amount |
|---|---|---|---|---|---|---|
| Fruit | | | | | | |
| Vegetables | | | | | | |

| | Measurement | Date | Measurement | Date |
|---|---|---|---|---|
| Weight | | | | |
| Height | | | | |
| BMI | | | | |
| BP | | | | |
| Date Blood taken | | | | |
| Total Cholesterol | mmol/l | | | |
| HDL | mmol/l | | | |
| Glucose | mmol/l | | | |

# Appendix 10

# <u>Hospital Anxiety and Depression Scale</u>

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

**Tick only one box in each section**

**I feel tense or wound up:**
Most of the time
A lot of the time
From time-to-time, Occasionally
Not at all

**I still enjoy the things I used to enjoy:**
Definitely as much
Not quite as much
Only a little
Hardly at all

**I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me
Not at all

**I can laugh and see the funny side of things:**

As much as I always could
Not quite as much now
Definitely not so much now
Not at all

**Worrying thoughts go through my head:**

A great deal of the time
A lot of the time
From time-to-time, but not too often
Only occasionally

**I feel cheerful:**

Not at all
Not often
Sometimes
Most of the time

**I can sit at ease and feel relaxed:**

Definitely
Usually
Not often
Not at all

**I feel as if I am slowed down:**
Nearly all the time
Very often
Sometimes
Not at all

**I get a sort of frightened feeling like 'butterflies' in the stomach:**
Not at all
Occasionally
Quite often
Very often

**I have lost interest in my appearance:**
Definitely
I don't take so much care as I should
I may not take quite as much care
I take just as much care as ever

**I feel restless as if I have to be on the move:**
Very much indeed
Quite a lot
Not very much
Not at all
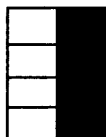
**I look forward with enjoyment to things:**
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

**I get sudden feelings of panic:**
Very often indeed
Quite often
Not very often
Not at all

**I can enjoy a good book or radio or TV programme:**
Often
Sometimes
Not often
Very seldom

# Appendix 11

## NS-SEC (National Statistics Socio-Economic Classification)

The National Statistics Socio-Economic Classification (NS-SEC) was introduced in 2001 for use in official statistics and surveys and is a classification based on occupation. The NS-SEC consists of fourteen categories representing different occupations. There are a further three categories that include full-time students and those who cannot be classified by occupation due to lack of information or other reasons. These categories can be collapsed to eight, five or three categories. The NS=SEC3 (three categories) is the only category assumed to involve a form of hierarchy.

## NS-SEC (8 classes)

Higher managerial and professional

Lower managerial and professional

Intermediate

Small employers and own account

Lower supervisory and technical

Semi-routine

Routine

Never worked or long-term unemployed

## NS-SEC (3 classes)

Managerial and professional

Intermediate

Routine and manual

Never worked or long-term unemployed

# Appendix 12

## Illustration of 1$^{st}$ Double Cousin Marriage
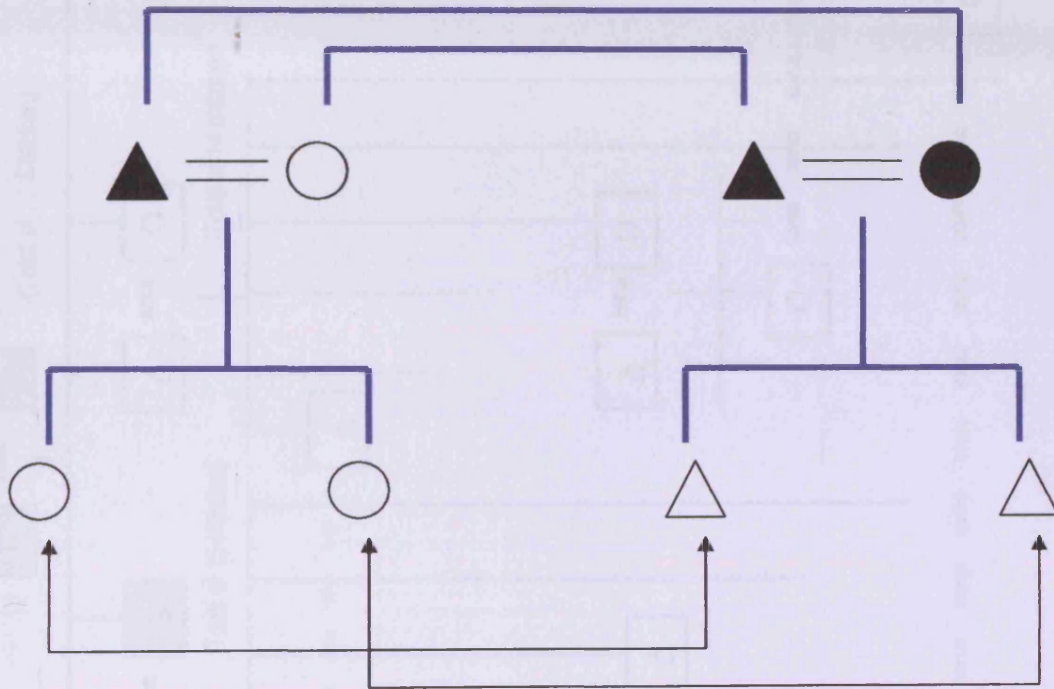


Key:

◯ = Female

△ = Male

▬▬ = Siblings

● / ▲ Deceased

═══ / ⟷ Marriage links

# Genealogy of Wrexham Travellers

(Total of .... Children)

(Total of ... .children)

(Total of 15 children)

(Total of 14 children)

(Total of ... children)

Appendix 13

288

**Key**
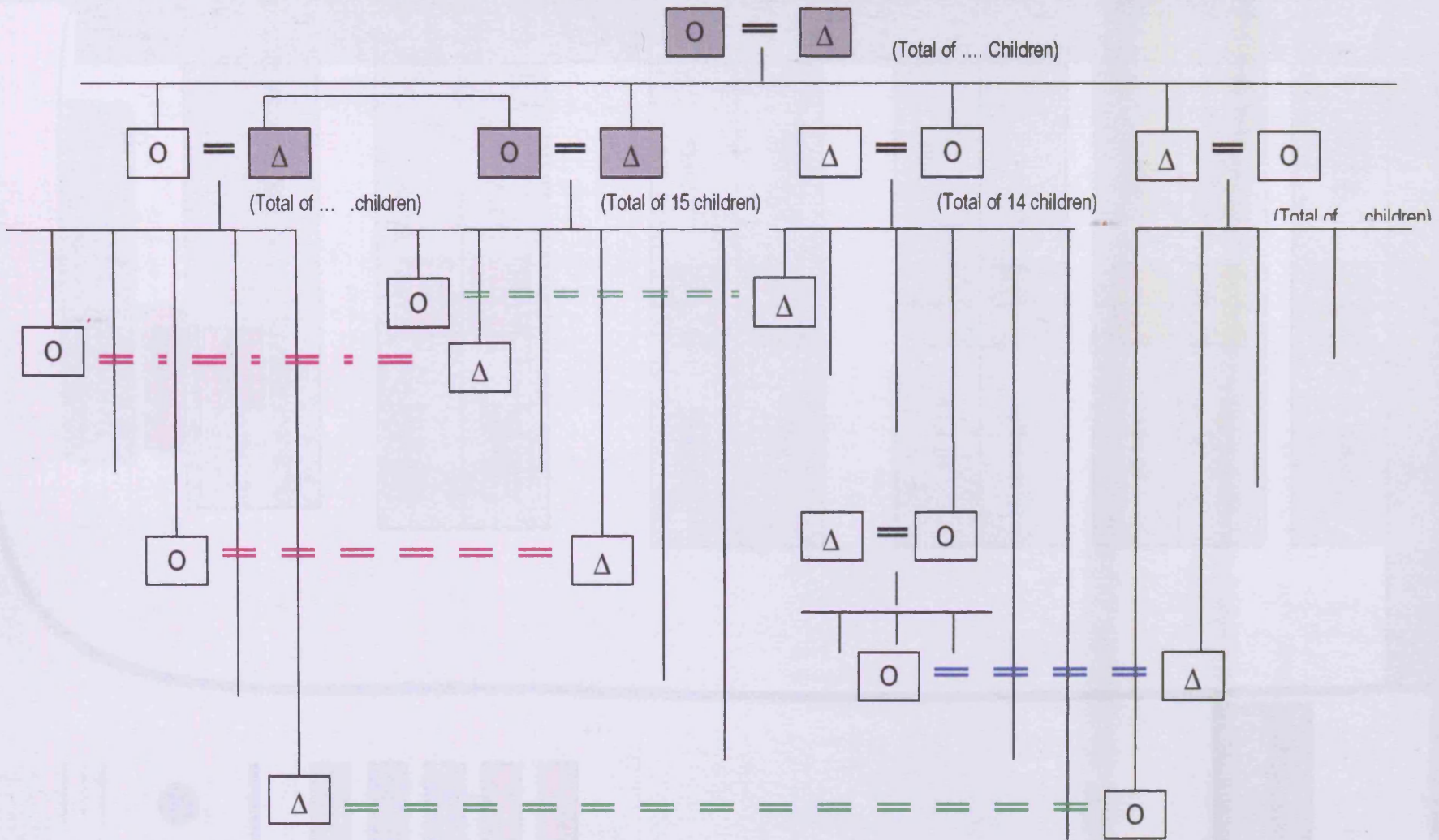
O = Female

O = Female deceased

== = = Marriage

== = : = Cousin marriage

Δ = Male

Δ = Male deceased

== = = 1st Cousin marriage

== = = 1st double cousin marriage
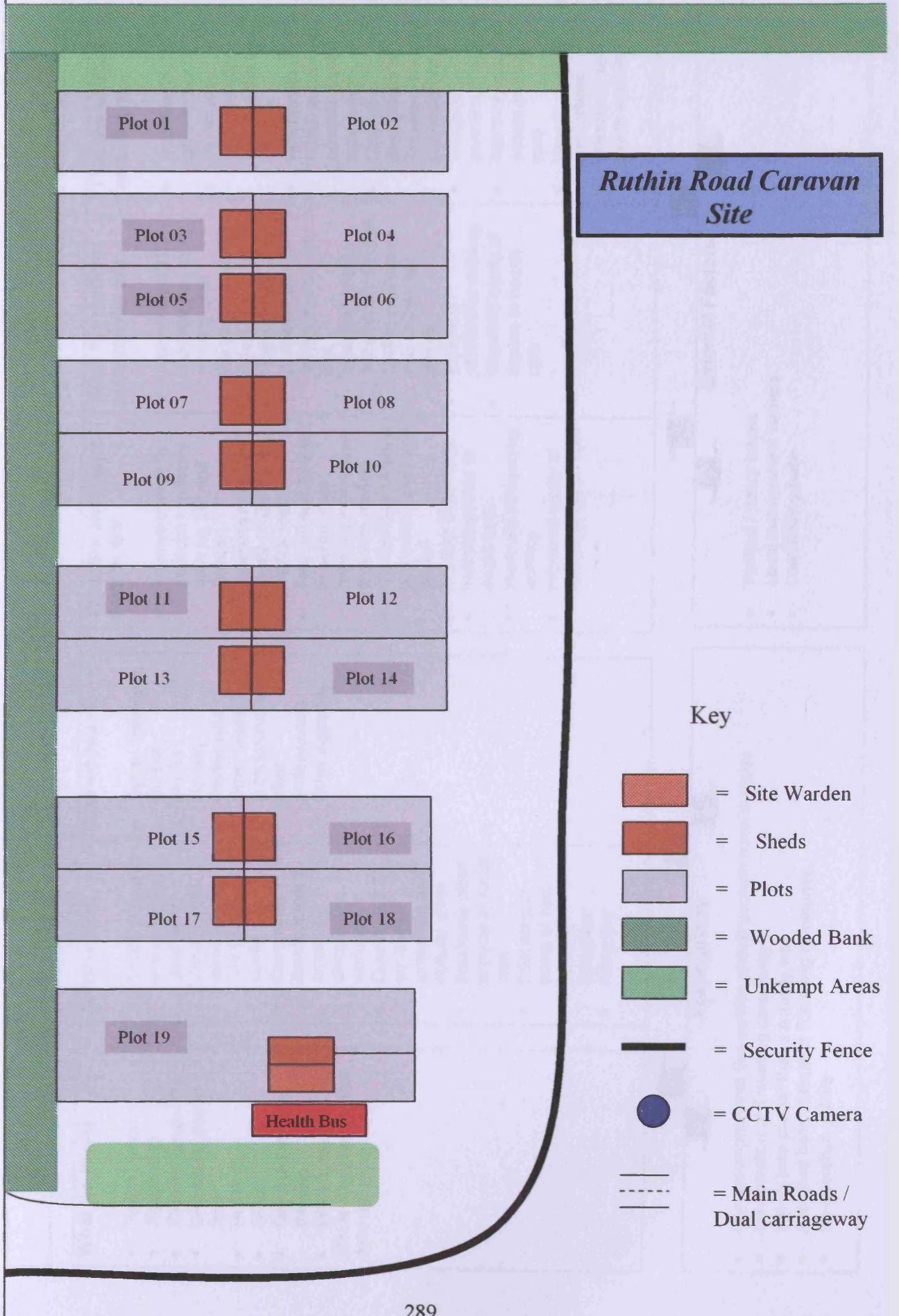
**Ruthin Road Caravan Site**

Plot 01
Plot 02
Plot 03
Plot 04
Plot 05
Plot 06
Plot 07
Plot 08
Plot 09
Plot 10
Plot 11
Plot 12
Plot 13
Plot 14
Plot 15
Plot 16
Plot 17
Plot 18
Plot 19

Health Bus

Key

= Site Warden

= Sheds

= Plots

= Wooded Bank

= Unkempt Areas

= Security Fence

= CCTV Camera

= Main Roads / Dual carriageway

# Logic Model of Coronary Heart Disease and Gypsy/Travellers: Redressing the Balance project

| Inputs | Outputs — Activities | Outputs — Participation | Outcomes – Impact — Short Term | Outcomes – Impact — Medium Term | Outcomes – Impact — Long Term |
|---|---|---|---|---|---|
| **What we invest:**<br><br>• Health Visitor<br>• Researcher<br>• Steering group time<br>• LHB Management time<br>• Health Bus<br>• Skills<br>• Devolved strategic thinking<br>• WAG funding<br>(this is a key service that does not exist) | **What we do:**<br><br>• Enabling access and delivering aspects of primary care services esp. CHD & mental health<br>• Community development & cross disciplinary working<br>• Quantitative & qualitative evaluation and cultural study<br>• Facilitates other aspects of social care<br>• Educating in terms of help seeking behaviour<br>• Advocacy | **Who we reach:**<br><br>• Gypsy Travellers:<br>- On site<br>- Mobile<br>- Housed<br>- Private land<br>• Other health professional and other professionals<br>• Other agencies | **What the short term results are:**<br><br>• Improve access to services in primary care eg. GP and Dentist<br>• Establish morbidity levels of CHD and mental health<br>• First Aid and Triage to appropriate healthcare to relieve pressure on A&E<br>• Recognition of acute problems (health and social)<br>• Number of contacts<br>• Improve access to social care<br>• Improved partnership working<br>• Improved equity of access to health care | **What the medium term results are:**<br><br>• Appropriate CHD management in primary care.<br>• Focus for Traveller forum<br>• Health /other professionals willingness to visit site<br>• Introduce healthy activities for children<br>• Shift in awareness about CHD risk factors<br>• Improved partnership working<br>• Improved equity of access to health care | **That the ultimate results are:**<br><br>• Improvement in general health<br>• Increase in understanding between the two cultures<br>• Appropriate use of health service and compliance with treatments<br>• Changing perceptions of Travellers for other professionals<br>• Improved partnership working<br>• Improved equity of access to health care<br>• Valuing diversity and cultural differences by health workers |

**Assumptions**

- Our assumption that this service should become norm in wales
- Co-operation of Travelling community
- Set up time shorter than it actually was
- Assumed health needs of Travelling community
- Co-operation of GPs

**External Factors**

- Political / policy issues
- Local management barriers
- Low funding base

290

Appendix 15

# Appendix 16 – Prevalence of Smoking

## Prevalence of Smoking by Age Group Compared to Welsh Population

| Age group | Study population in 100s | Welsh* Standard population smokers in 100s | Expected smokers | Number Gypsies & Travellers smoking |
|---|---|---|---|---|
| 16 - 24 | 0.1728395 | 29 | 5.0123455 | 21 |
| 25 - 34 | 0.1975308 | 35 | 6.913578 | 16 |
| 35 - 44 | 0.2345679 | 33 | 7.7407407 | 11 |
| 45 - 54 | 0.2716049 | 28 | 7.6049372 | 6 |
| 55 - 64 | 0.0617283 | 23 | 1.4197509 | 4 |
| 65 -74 | 0.0617283 | 16 | 0.9876528 | 1 |
| Total | | | 29.6790051 | 59 |
| | SSR | 198.7937257 | | |

\* Welsh Health Survey 2003 - 2004

***Table 1***

## Prevalence of Smoking by Gender Compared to Welsh Population

| Gender | Study population in 100s | Welsh population smokers in 100s | Expected smokers | Number Gypsies & Travellers smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 26 | 16.3703696 | 41 |
| Male | 0.3703703 | 27 | 9.9999981 | 18 |
| Total | 0.9999999 | | 26.3703677 | 59 |
| | | | | |
| | SMR | 223.7359777 | | |

\* Welsh Health Survey 2003 - 2004

***Table 2***

## Prevalence of Smoking by Socio-economic Group** and Gender.

| Gender | Study population in 100s | UK population* smokers in 100s | Expected smokers | Number Gypsies & Travellers smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 31 | 19.5185176 | 41 |
| Male | 0.3703703 | 33 | 12.2222199 | 18 |
| Total | 0.9999999 | | 31.7407375 | 59 |
| | SMR | 185.8809991 | | |

\* UK general population data provided by General Household Survey 2003.
\*\* NS-SEC 3 Routine and manual

***Table 3***

# Appendix 17 – Smoking Status

## Light Smokers by Gender compared to UK Population

| Gender | Study population in 100s | UK Standard population smokers in 100s | Expected smokers | Number Gypsies & Travellers smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 18 | 11.3333328 | 28 |
| Male | 0.3703703 | 17 | 6.2962951 | 8 |
| Total | 0.9999999 | | 17.6296279 | 36 |
| | | | | |
| | SSR | 204.2017007 | | |

* UK general population data provided by General Household Survey 2003.
*Table 1*

## Heavy Smokers by Gender compared to UK Population

| Gender | Study population in 100s | UK Standard population smokers in 100s | Expected smokers | Number Gypsies & Travellers smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 7 | 4.4074072 | 14 |
| Male | 0.3703703 | 10 | 3.703703 | 10 |
| Total | 0.9999999 | | 8.1111102 | 24 |
| | | | | |
| | SSR | 295.8904442 | | |

* UK general population data provided by General Household Survey 2003.
*Table 2*

## Ex- Smokers by Gender compared to UK Population

| Gender | Study population in 100s | UK Standard population smokers in 100s | Expected smokers | Number Gypsies & Travellers ex-smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 21 | 13.2222216 | 4 |
| Male | 0.3703703 | 28 | 10.3703684 | 6 |
| Total | 0.9999999 | | 23.59259 | 10 |
| | | | | |
| | SSR | 42.3861899 | | |

* UK general population data provided by General Household Survey 2003.
*Table 3*

# Appendix 17 continued

## None Smokers by Gender compared to UK Population

| Gender | Study population in 100s | UK Standard population smokers in 100s | Expected smokers | Number Gypsies & Travellers non smoking |
|---|---|---|---|---|
| Female | 0.6296296 | 54 | 33.9999984 | 4 |
| Male | 0.3703703 | 46 | 17.0370338 | 7 |
| Total | 0.9999999 | | 51.0370322 | 11 |
| | | | | |
| | SSR | 21.55297737 | | |

* UK general population data provided by General Household Survey 2003.

*Table 4*

# Appendix 18 – Alcohol Consumption

## Weekly Units of Alcohol
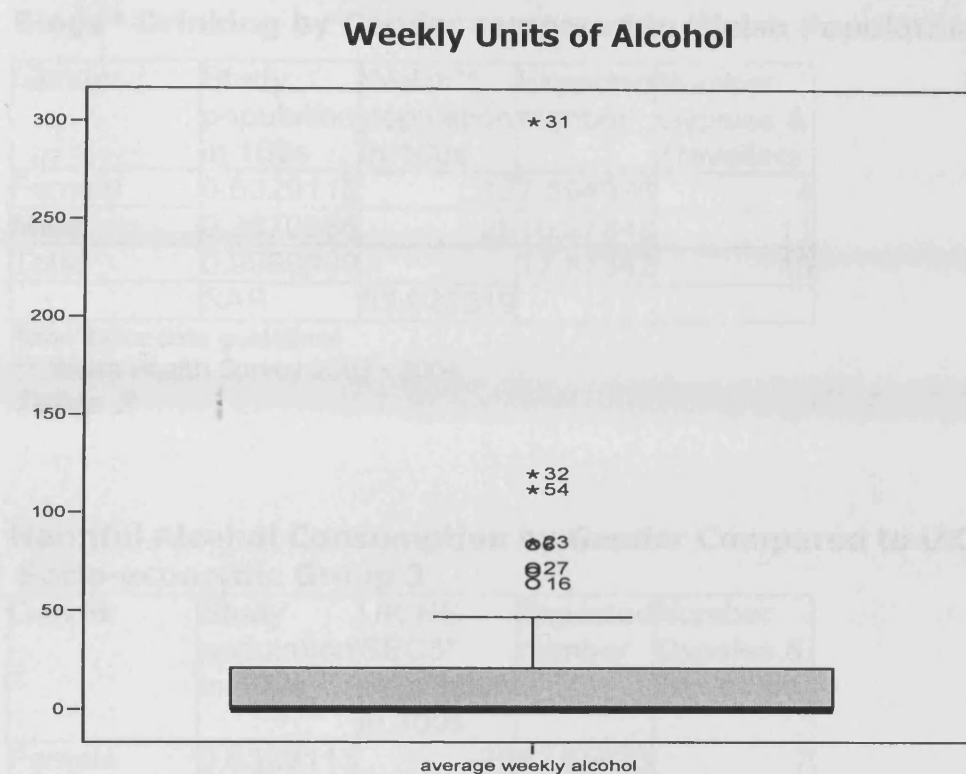


***Figure 1***
The above chart illustrates the large number of non-drinkers (dark bottom, median line) and also a number of 'outliners' with a very high alcohol consumption (these are identified by star and circle symbols. The numbers are arbitrary participant numbers and do not relate to quantity).

## Harmful* Drinking by Gender compared to Welsh Population

| Gender | Study population in 100s | Welsh population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6329113 | 16 | 10.12658 | 7 |
| Male | 0.3670886 | 18 | 6.607595 | 3 |
| Total | 0.9999999 | | 16.73418 | 10 |
| | SAR | 59.757948 | | |

*up to twice safe guidelines
** Welsh Health Survey 2003 - 2004
***Table 1***

# Appendix 18 - continued

## Binge* Drinking by Gender compared to Welsh Population

| Gender | Study population in 100s | Welsh** population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6329113 | 12 | 7.594936 | 4 |
| Male | 0.3670886 | 28 | 10.27848 | 11 |
| Total | 0.9999999 | | 17.87342 | 15 |
| | SAR | 83.923519 | | |

*over twice safe guidelines
** Welsh Health Survey 2003 - 2004
***Table 2***

## Harmful Alcohol Consumption by Gender Compared to UK** Socio-economic Group 3

| Gender | Study population in 100s | UK NS-SEC3* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6329113 | 20 | 12.65823 | 7 |
| Male | 0.3670886 | 38 | 13.94937 | 3 |
| Total | 0.9999999 | | 26.60759 | 10 |
| | SAR | 37.583257 | | |

* NS-SEC 3 is Routine and manual
** General Household Survey 2003
***Table 3***

## Binge Alcohol Consumption by Gender Compared to UK** Socio-economic Group 3

| Gender | Study population in 100s | UK NS-SEC3* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6329113 | 9 | 5.696202 | 4 |
| Male | 0.3670886 | 22 | 8.075949 | 11 |
| Total | 0.9999999 | | 13.77215 | 15 |
| | SAR | 108.91545 | | |

* NS-SEC 3 is Routine and manual
** General Household Survey 2003
***Table 4***

# Appendix 19 – Alcohol Consumption and Marriage Status

**Percentage Alcohol consumption by Marital Status**

|  | single never married | | | | ever married/co-habit | | | |
|---|---|---|---|---|---|---|---|---|
|  | Alcohol none/occ | Alcohol sensible | Alcohol harmful | Alcohol binge | Alcohol none/occ | Alcohol sensible | Alcohol harmful | Alcohol binge |
|  | % | % | % | % | % | % | % | % |
| yes | 75.0 | 7.1 | 10.7 | 7.1 | 52.9 | 7.8 | 13.7 | 25.5 |
| no | 25.0 | 92.9 | 89.3 | 92.9 | 47.1 | 92.2 | 86.3 | 74.5 |

***Table 1***

**Alcohol consumption by Marital Status and Gender**

**Single never married**

|  | male | | | | female | | | |
|---|---|---|---|---|---|---|---|---|
|  | Alcohol none/occ | Alcohol sensible | Alcohol harmful | Alcohol binge | Alcohol none/occ | Alcohol sensible | Alcohol harmful | Alcohol binge |
|  | % | % | % | % | % | % | % | % |
| yes | 26.7 | 3.3 | 10.0 | 6.7 | 26.5 | 2.0 | .0 | .0 |
| no | 20.0% | 43.3 | 36.7 | 40.0 | 2.0 | 26.5 | 28.6 | 28.6 |

***Table 2***

# Appendix 20 – Below Guidelines Fruit and Vegetable Consumption

## No Fruit and Vegetables by Age Compared to Welsh Population

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.3375 | 9 | 3.0375 | 10 |
| 25 - 34 | 0.2625 | 6 | 1.575 | 10 |
| 35 - 44 | 0.2125 | 6 | 1.275 | 7 |
| 45 - 54 | 0.0875 | 4 | 0.35 | 3 |
| 55 - 64 | . 0.05 | 3 | 0.15 | 0 |
| 65 - 74 | 0.05 | 3 | 0.15 | 1 |
| Total | 1 | | 6.5375 | 31 |
| | SSR | 474.1873805 | | |

* Welsh Health Survey 2003 - 2004

**Table 1**

## No Fruit or Vegetables by gender Compared to Welsh Population

| Gender | Study population in 100s | Welsh* Standard population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6375 | 4 | 2.55 | 18 |
| Male | 0.3625 | 6 | 2.175 | 13 |
| Total | 1 | | 4.725 | 31 |
| | | | | |
| | SSR | 656.0846561 | | |

* Welsh Health Survey 2003 - 2004

**Table 2**

# Appendix 21 – On or Above Guidelines Consumption of Fruit and Vegetables

## 5+ Fruit and Vegetables by Gender Compared to Welsh Population

| Gender | Study population in 100s | Welsh Standard population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.6375 | 41 | 26.1375 | 9 |
| Male | 0.3625 | 37 | 13.4125 | 4 |
| Total | 1 | | 39.55 | 13 |
| | SSR | 32.86978508 | | |

* Welsh Health Survey 2003 - 2004

***Table 1***

## 5+ Fruit and Vegetables by Age Compared to Welsh Population

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.3375 | 33 | 11.1375 | 5 |
| 25 - 34 | 0.2625 | 34 | 8.925 | 6 |
| 35 - 44 | 0.2125 | 35 | 7.4375 | 2 |
| 45 - 54 | 0.0875 | 39 | 3.4125 | 0 |
| 55 - 64 | 0.05 | 48 | 2.4 | 0 |
| 65 - 74 | 0.05 | 46 | 2.3 | 0 |
| Total | 1 | | 35.6125 | 13 |
| | SSR | 36.5040365 | | |

* Welsh Health Survey 2003 - 2004

***Table 2***

# Appendix 22 – Physical Activity

## Physical Activity at or Above Guidelines by Age compared to Welsh Population

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.3375 | 80 | 27 | 15 |
| 25 - 34 | 0.2625 | 79 | 20.7375 | 3 |
| 35 - 44 | 0.2125 | 75 | 15.9375 | 4 |
| 45 - 54 | 0.0875 | 66 | 5.775 | 2 |
| 55 - 64 | 0.05 | 60 | 3 | 0 |
| 65 - 74 | 0.05 | 51 | 2.55 | 0 |
| Total | 1 | | 75 | 24 |
| | SR | 32 | | |

* Welsh Health Survey 2003 - 2004
*Table 1*

## Physical Activity at or Above Guidelines by Gender compared to Welsh Population

| Gender | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.625 | 62 | 38.75 | 12 |
| Male | 0.375 | 68 | 25.5 | 12 |
| Total | 1 | | 64.25 | 24 |
| | SR | 37.35409 | | |

* Welsh Health Survey 2003 - 2004
*Table 2*

# Appendix 23 — Body Mass Index
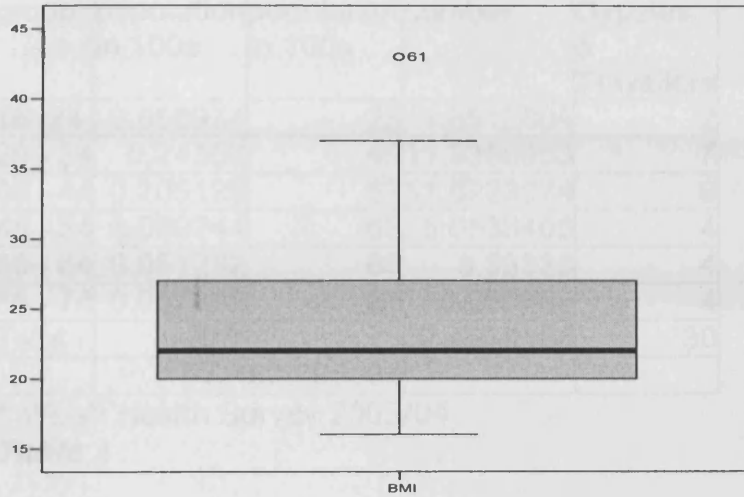
## Mean BMI Score Distribution



*Figure 1*

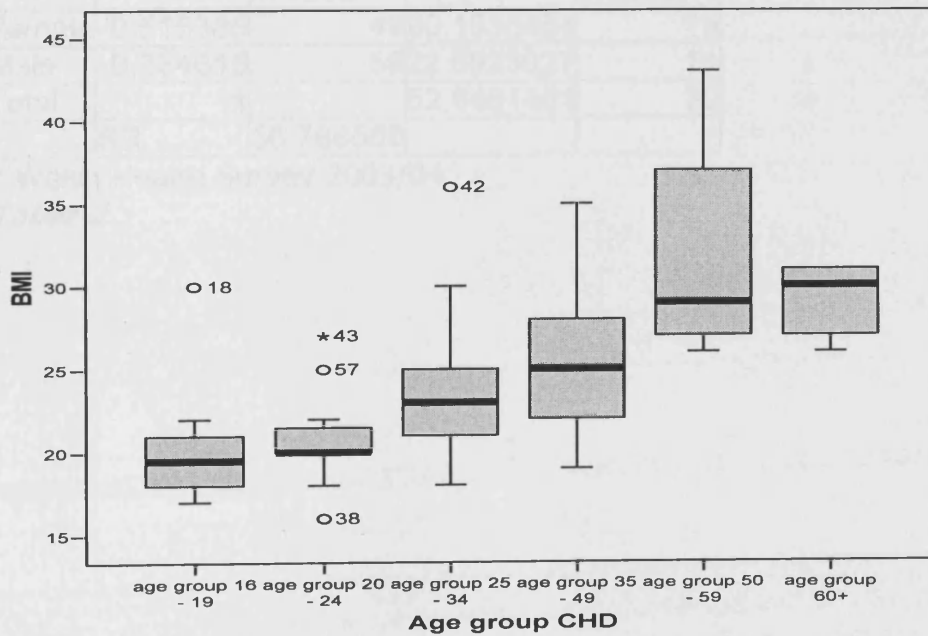## Mean BMI Score Distribution by Age



*Figure 2*

## Appendix 23 - continued

### Overweight and Obese by Age compared to Welsh Population

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.058974 | 28 | 1.6512804 | 2 |
| 25 - 34 | 0.24359 | 49 | 11.9358953 | 7 |
| 35 - 44 | 0.205128 | 57 | 11.6923074 | 9 |
| 45 - 54 | 0.089744 | 63 | 5.6538405 | 4 |
| 55 - 64 | 0.051282 | 65 | 3.33333 | 4 |
| 65 - 74 | 0.051282 | 63 | 3.230766 | 4 |
| Total | 0.7 | | 37.4974196 | 30 |
| | SSR | 80.005505 | | |

\* Welsh Health Survey 2003/04
*Table 1*

### Overweight and Obese by Gender compared to Welsh Population

| Gender | Study population in 100s | Welsh Standard population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.615385 | 49 | 30.1538454 | 19 |
| Male | 0.384615 | 59 | 22.6923027 | 11 |
| Total | 1 | | 52.8461481 | 30 |
| | SR | 56.768565 | | |

\* Welsh Health Survey 2003/04
*Table 2*

# Appendix 24 – Total Cholesterol

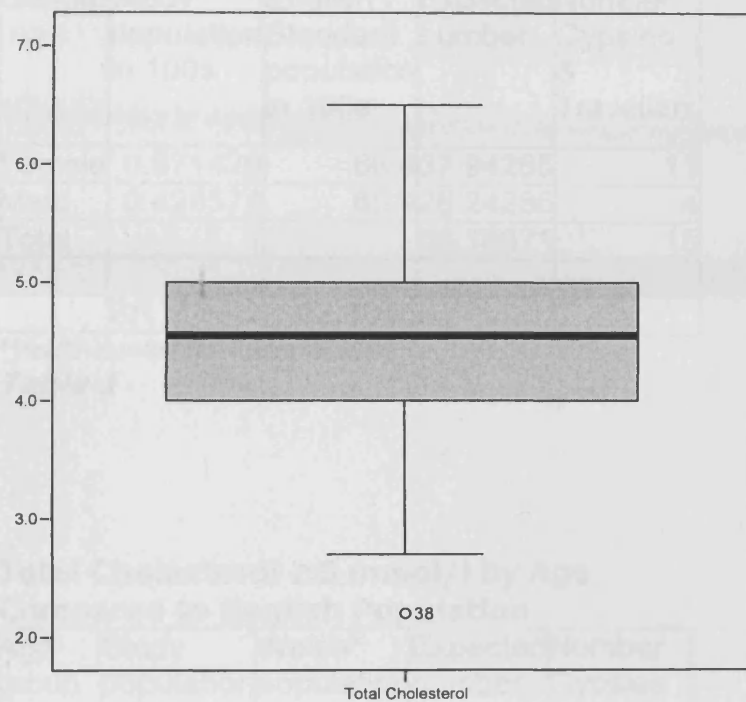## Mean Total cholesterol Distribution
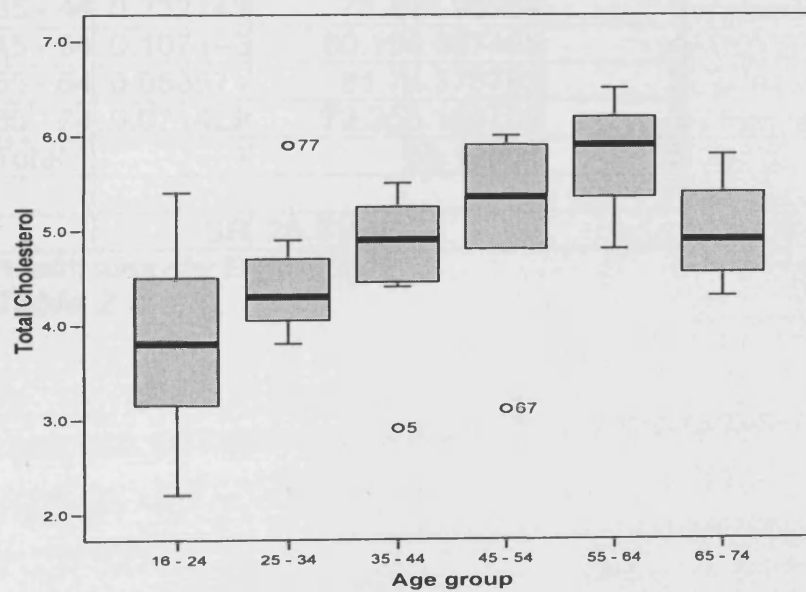


*Figure 1*

## Mean total cholesterol by age



*Figure 2*

# Appendix 25 – Raised Total Cholesterol

**Total Cholesterol ≥5 mmol/l by Gender**
**Compared to English Population**

| Gender | Study population in 100s | English* Standard population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.571429 | 66.4 | 37.94285 | 11 |
| Male | 0.428571 | 65.9 | 28.24286 | 4 |
| Total | 1 | | 66.18571 | 15 |
| | . | | | |
| | SR | 22.6635 | | |

*Health survey for England 2003
*Table 1*

**Total Cholesterol ≥5 mmol/l by Age**
**Compared to English Population**

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.267857 | 28.55 | 7.64732 | 1 |
| 25 - 34 | 0.267857 | 57.35 | 15.3616 | 1 |
| 35 - 44 | 0.232143 | 73.1 | 16.96964 | 5 |
| 45 - 54 | 0.107143 | 80.15 | 8.587495 | 4 |
| 55 - 64 | 0.053571 | 81.7 | 4.376783 | 2 |
| 65 - 74 | 0.071429 | 72.25 | 5.160709 | 2 |
| Total | 1 | | 58.10355 | 15 |
| | | | | |
| | SR | 25.81598 | | |

*Health survey for England 2003
*Table 2*

# Appendix 26 – HDL-Cholesterol

## Mean HDL-Cholesterol Distribution
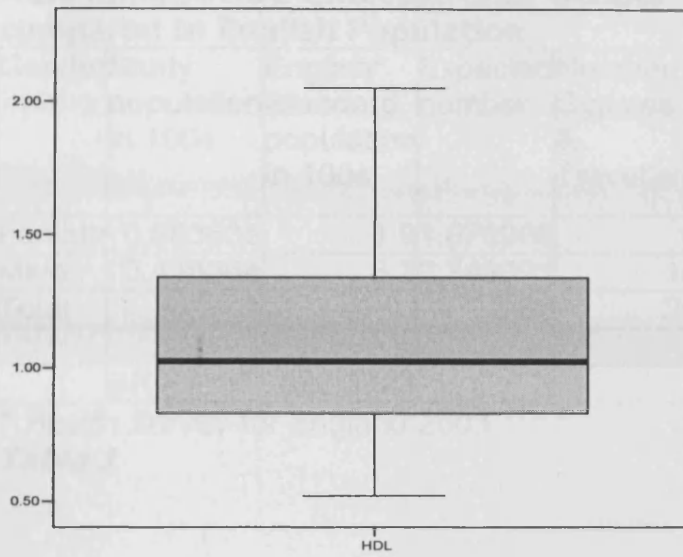

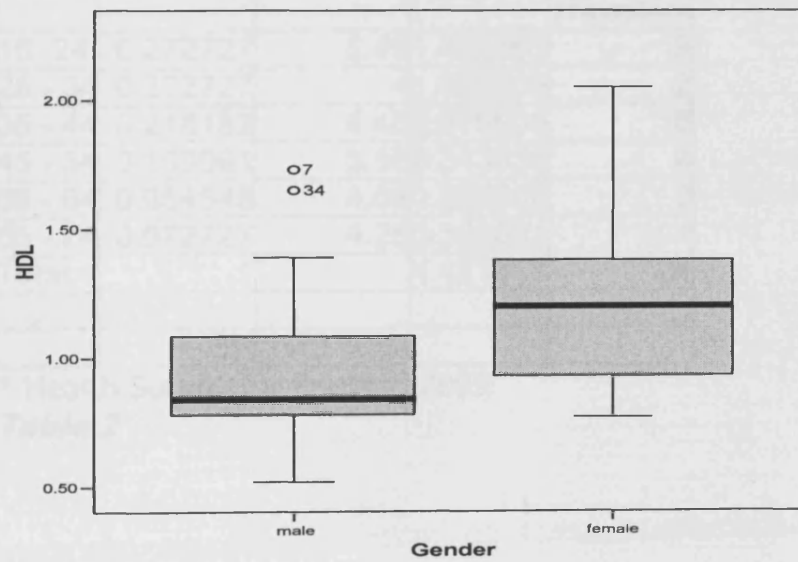
*Figure 1*

## Mean HDL-Cholesterol by Gender



*Figure 2*

# Appendix 27 — Low HDL-Cholesterol

## <1.0 mmol/l HDL-Cholesterol by Gender compared to English Population

| Gender | Study population in 100s | English* Standard population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.563636 | 1.9 | 1.070909 | 9 |
| Male | 0.436364 | 6.3 | 2.749091 | 15 |
| Total | 1 | | 3.82 | 24 |
| | . | | | |
| | SR | 628.2723 | | |

* Health Survey for England 2003
*Table 1*

## <1.0 mmol/l HDL-Cholesterol by Age compared to English Population

| Age group | Study population in 100s | Welsh* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.272727 | 5.45 | 1.486363 | 8 |
| 25 - 34 | 0.272727 | 4 | 1.090909 | 2 |
| 35 - 44 | 0.218182 | 4.45 | 0.970909 | 6 |
| 45 - 54 | 0.109091 | 3.15 | 0.343636 | 4 |
| 55 - 64 | 0.054545 | 4.05 | 0.220909 | 3 |
| 65 - 74 | 0.072727 | 4.25 | 0.309091 | 1 |
| Total | 1 | | 4.421817 | 24 |
| | | | | |
| | SR | 542.7633 | | |

* Health Survey for England 2003
*Table 2*

# Appendix 28 – Mean Blood Pressure

## Systolic BP distribution by Gender



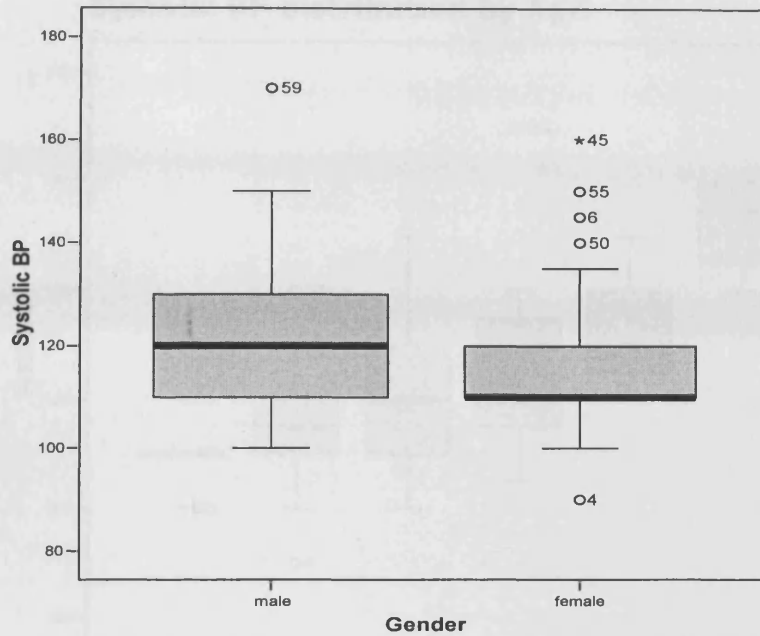**Figure 1**

## Diastolic BP Distribution by Gender



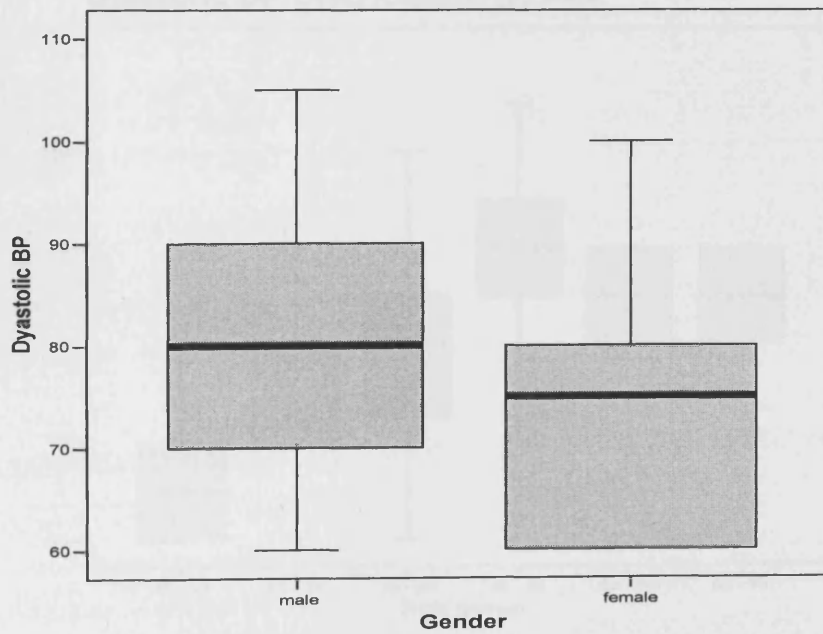**Figure 2**

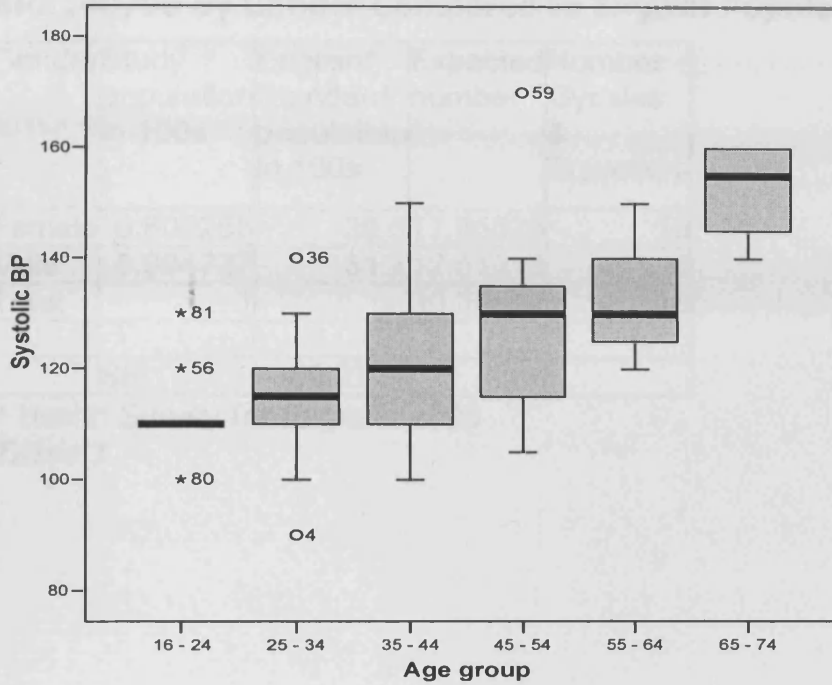## Systolic BP distribution by Age



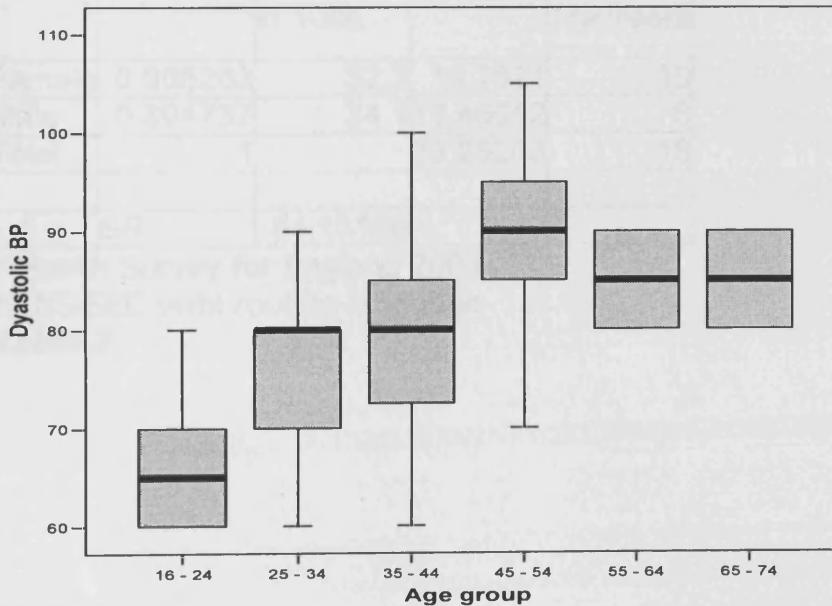*Figure 3*

## Diastolic BP Distribution by Age



*Figure 4*

# Appendix 29 – Raised Blood Pressure

## BP≥140/90 by Gender Compared to English Population

| Gender | Study population in 100s | English* Standard population in 100s | Expected number | Number Gypsies & Travellers |
|--------|--------------------------|--------------------------------------|-----------------|-----------------------------|
| Female | 0.605263 | 29.5 | 17.85526 | 10 |
| Male | 0.394737 | 31.7 | 12.51316 | 8 |
| Total | 1 | | 30.36842 | 18 |
| | | | | |
| | SR | 59.2721 | | |

* Health Survey for England 2003
*Table 1*

## BP≥140/90 by Gender Compared Socio-economic group**

| Gender | Study population in 100s | English* Standard population in 100s | Expected number | Number Gypsies & Travellers |
|--------|--------------------------|--------------------------------------|-----------------|-----------------------------|
| Female | 0.605263 | 32.7 | 19.7921 | 10 |
| Male | 0.394737 | 34.1 | 13.46052 | 8 |
| Total | 1 | | 33.25263 | 18 |
| | | | | |
| | SR | 54.13106 | | |

* Health Survey for England 2003
** NS-SEC semi routine & routine
*Table 2*

# Appendix 29 – continued

## BP≥140/90 by Age Compared to English Population

| Age group | Study population in 100s | English* population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| 16 -24 | 0.342105 | 4.15 | 1.419737 | 0 |
| 25 - 34 | 0.25 | 8.1 | 2.025 | 3 |
| 35 - 44 | 0.210526 | 15.4 | 3.242105 | 4 |
| 45 - 54 | 0.092105 | 29.05 | 2.675656 | 5 |
| 55 - 64 | 0.052632 | 48.55 | 2.555259 | 3 |
| 65 - 74 | 0.052632 | 64.2 | 3.378942 | 3 |
| Total | 1 | | 15.2967 | 18 |
| | | | | |
| | SR | 117.6724 | | |

\* Health Survey for England 2003

*Table 3*

# Appendix 30 - Raised Anxiety and Depression

## Raised Anxiety Compared to English Study

| Gender | Study population in 100s | English Gypsy/Traveller population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.631579 | 44 | 27.78947 | 35 |
| Male | 0.368421 | 30 | 11.05263 | 8 |
| Total | 1 | | 38.8421 | 43 |
| | | | | |
| | SR | 110.7046 | | |

*Figure 1*

## Raised Depression Compared to English Study

| Gender | Study population in 100s | English Gypsy/Traveller population in 100s | Expected number | Number Gypsies & Travellers |
|---|---|---|---|---|
| Female | 0.631579 | 27 | 17.05263 | 23 |
| Male | 0.368421 | 11 | 4.052631 | 3 |
| Total | | | 21.10526 | 26 |
| | | | | |
| | SR | 123.192 | | |

*Figure 2*