

# Gypsy Traveller and Roma Health the current picture

Dr Patrice Van Cleemput  
Research Fellow



**ScHARR**  
SCHOOL OF HEALTH AND  
RELATED RESEARCH

# Overview

- Past evidence and knowledge- recap.
- Barriers to knowledge of current health status
- What is known now - health status
- What is known now - access to health care
- GRT health inequalities – causes of causes
- Ways forward and opportunities

# Health of Gypsies and Travellers 2004

- Department of Health project, began late 2001, final report 2004
- Small scale, localised studies & practitioner account suggested Gypsy Travellers had poorer health than non-Gypsy Travellers
- Reliable evidence was sparse
- We conducted a large-scale study using standardised health status measures
- Supplemented by in-depth interviews to explore health experiences, beliefs and attitudes

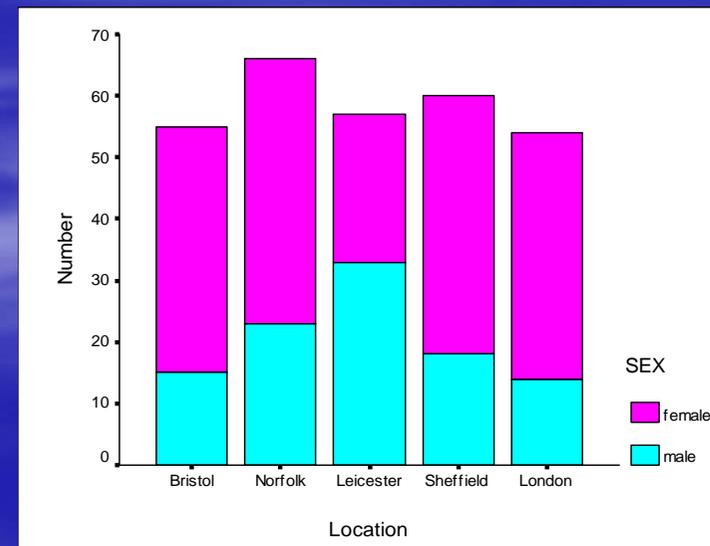
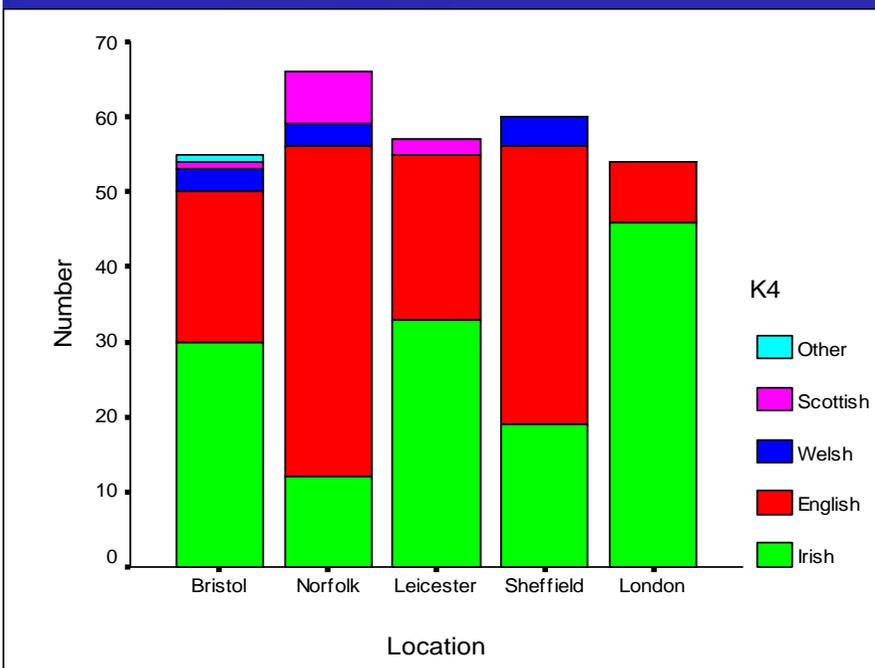
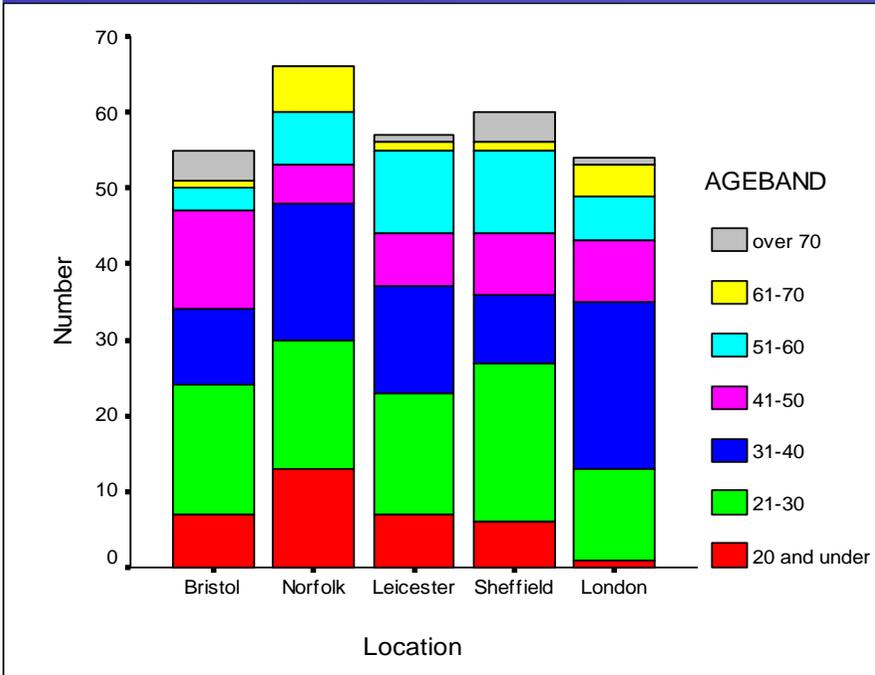
# Sample and methods

- Worked with the Gypsy Council to set up an advisory group, appoint interviewers etc.
- Mixed methods- quantitative and qualitative
- Interviewed Gypsy Travellers in and around Bristol, Sheffield, Leicester, London and Norfolk
- Each one was matched to a comparator of the same age and sex
- Comparators were
  - White people in socially deprived urban areas
  - British Black African-Caribbean people
  - British Pakistani Muslim people
  - Mixed White sample, urban and rural, rich and poor

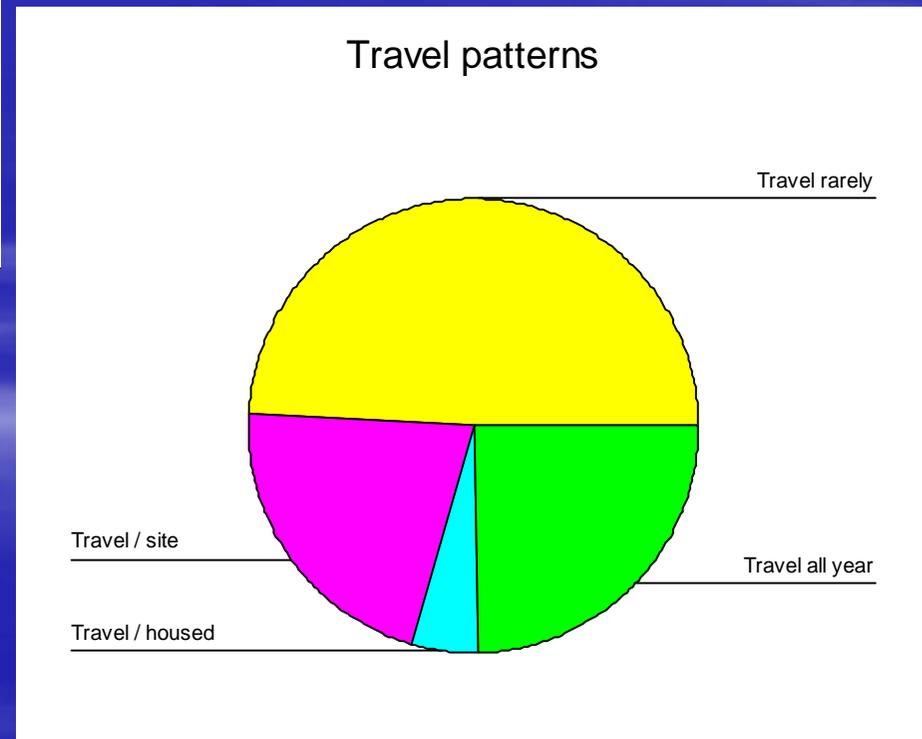
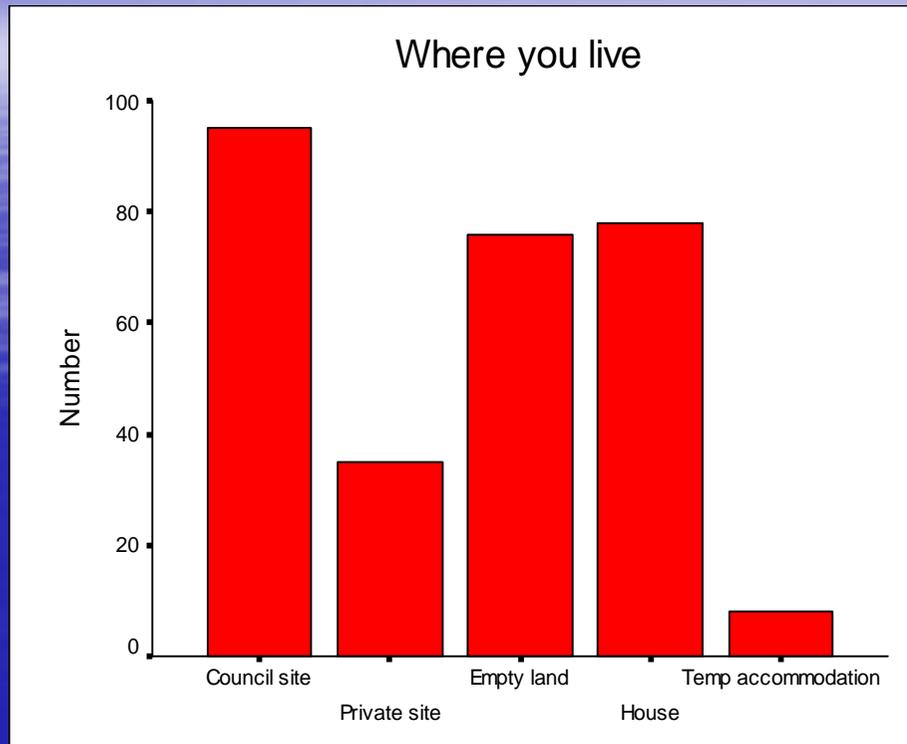
# Demographics

In each location:

- all ages represented (range 16-87)
- each ethnic group present
- 103 men, 190 women (no difference in age distribution)

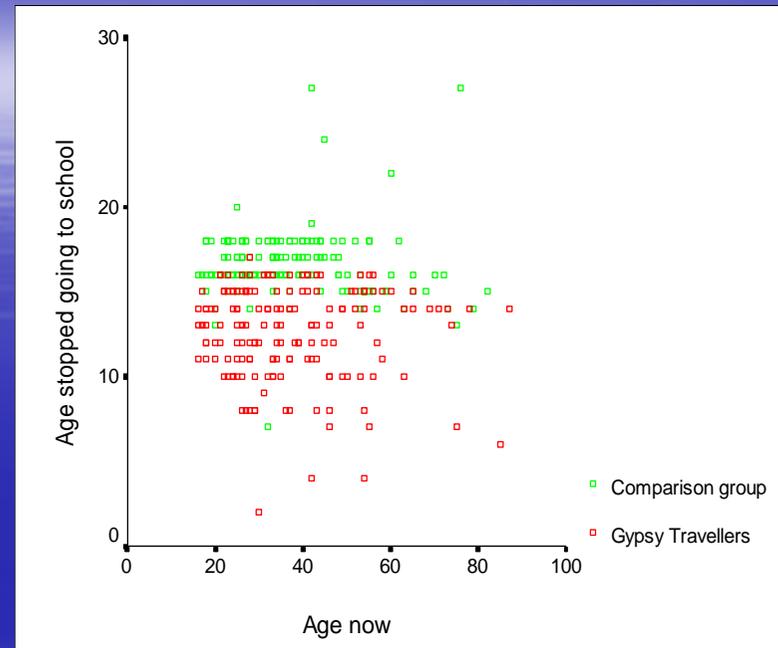


# Gypsy Traveller profile



# Education

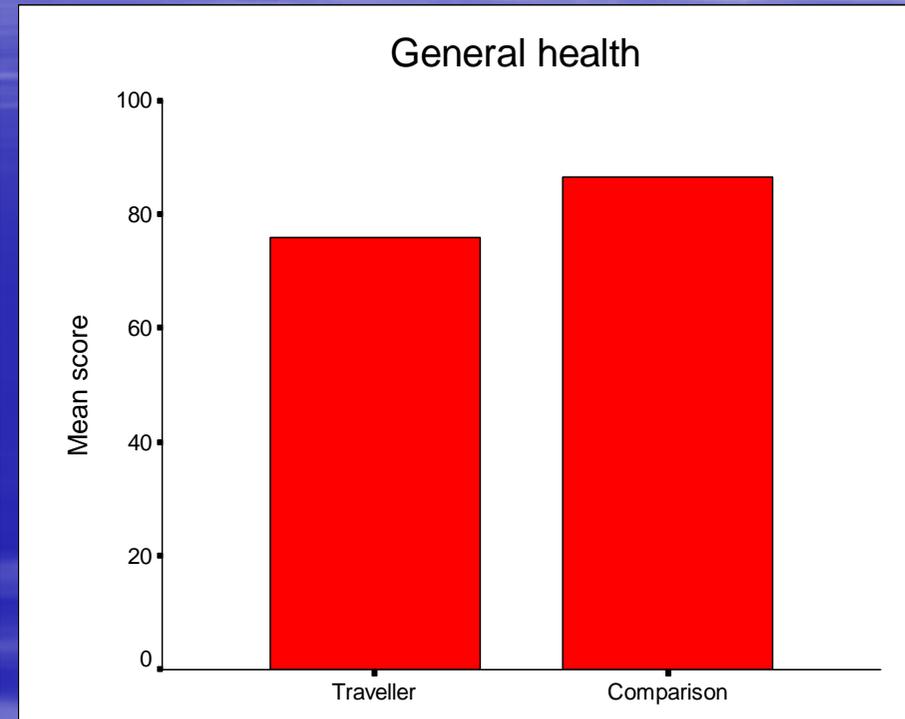
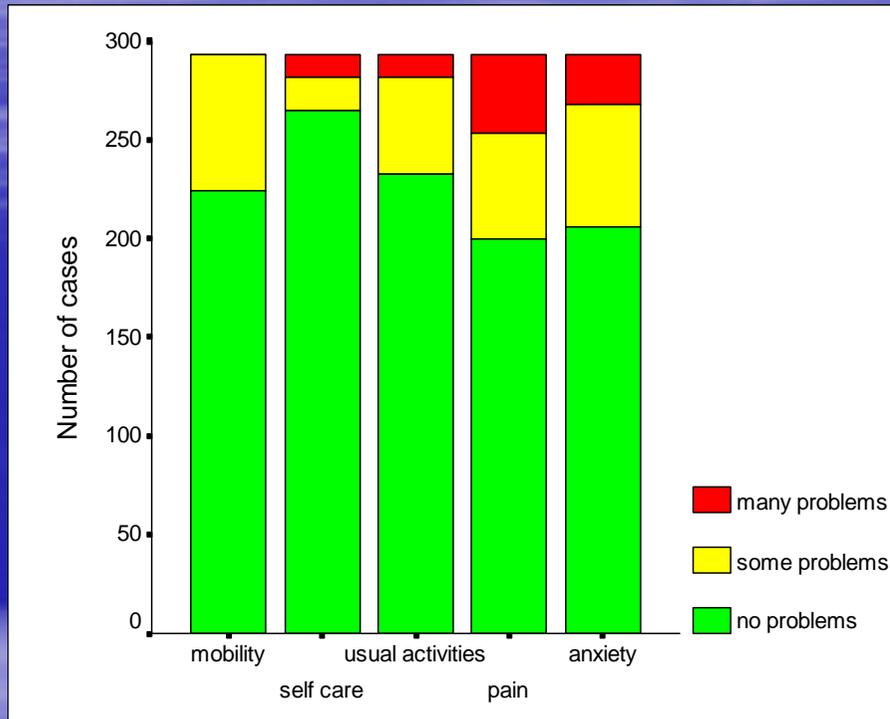
- 66% of Gypsy Travellers went to school, 44% attended regularly vs comparators - 88% and 85%
- Gypsy Travellers left school much earlier than comparators (12.6 vs 16.4 years)
- More of the younger Gypsy Travellers had attended school
- No obvious changes in leaving age over time
- 11 Gypsy Travellers had attended further education vs 164 comparators



## Smoking status (age sex matched group, n=260)

	Gypsy Travellers	Comparators
Current	147	56
Ex	46	59
Never	60	138
	(missing 7)	p<0.001

# Health on day of questionnaire



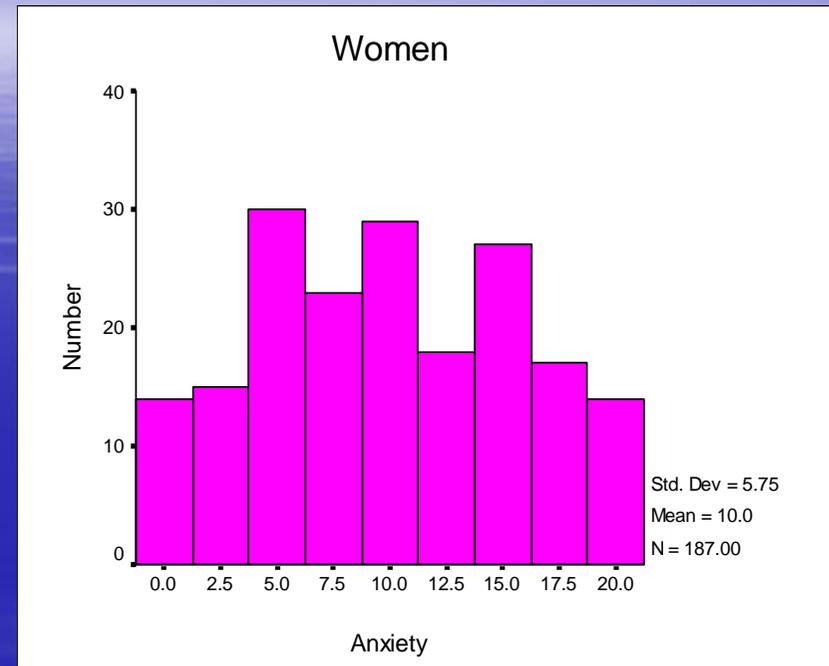
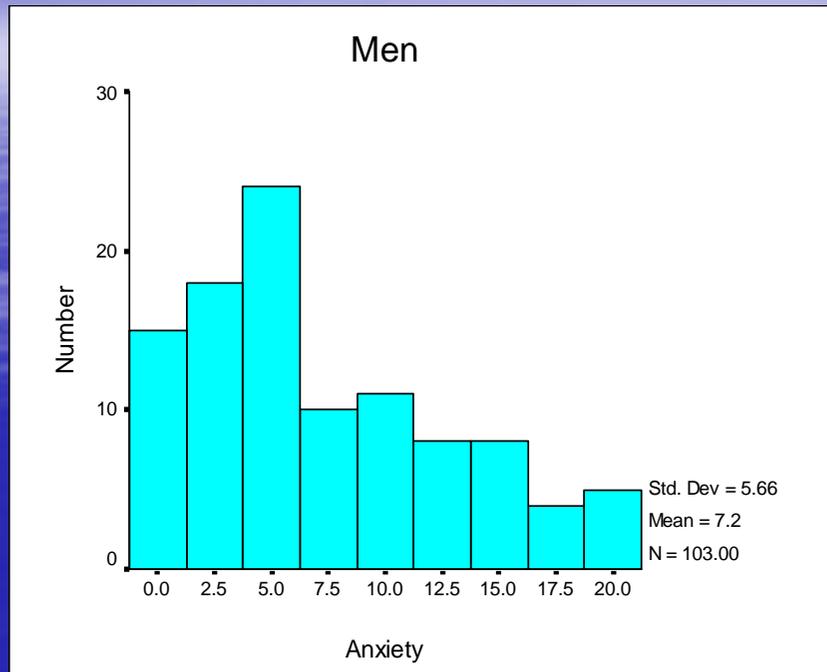
No differences between Gypsy Traveller men and women

Full health = 100  
 Gypsy Travellers mean  $\pm$ SD = 75  $\pm$ 36  
 Comparators = 87  $\pm$ 23  
 p<0.001

# General Health -specific conditions

	<u>Gypsy Travellers</u>	<u>Comparison Group</u>
▪ Nerves	73	10
▪ Arthritis	57	25
▪ Asthma	56	14
▪ Eye problems	28	9
▪ Bronchitis	27	5
▪ Heart disease	20	9
▪ Hearing problems	16	8
▪ Rheumatics	15	3
▪ Diabetes	11	9
▪ Cancer	2	6
▪ Stroke	3	2
<hr/>		
▪ Chest pain	88	57
▪ Bronchitis	107	26
▪ Asthma	168	105

# Anxiety



## Scores

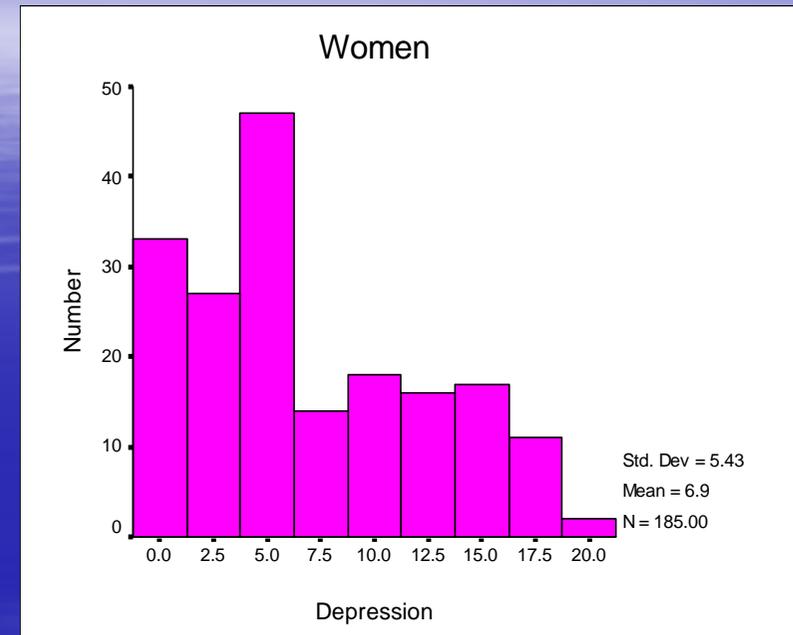
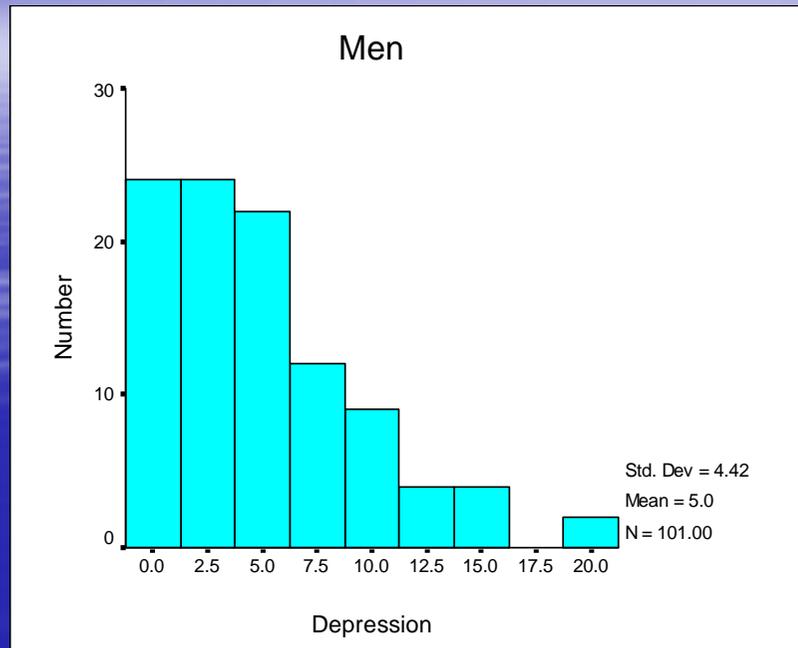
0 = no problems

21 = lots of problems

$\geq 11$  - anxiety

- Significant differences between Gypsy Traveller men (30%) and women (44%)
- Significant differences between Gypsy Travellers (38%) and comparators (13%)

# Depression



## Scores

0 = no problems

21 = lots of problems

≥11 - depression

- Significant differences between Gypsy Traveller men (11%) and women (27%)
- Significant differences between Gypsy Travellers (21%) and comparators (8%)

# Health service use

## Use of facilities

	<u>GT</u>	<u>C</u>
■ A&E in past year	63	38
■ Walk-in centre	13	18
■ NHS Direct	9	32

- Differences between Gypsy Travellers and comparators
- No relationship between Gypsy Traveller use of these and GP registration

## % using services in past year

	<u>GT</u>	<u>C</u>
GP	79	85
Dentist	47	72
Health visitor	48	14
Practice nurse	33	49
Chemist advice	19	33
Midwife	18	12
Optician	14	43
District nurse	10	8
Social worker	8	1
Other healer	8	10
Mental health team	3	2
Counsellor	3	7
Chiropodist	3	9
Alternative therapist	3	18

# Summary of Results

- Gypsy Travellers had significantly poorer health status than comparators.
  - standardised measures (EQ-5D, HADS)
  - self-reported symptoms (chest pain, respiratory problems, arthritis)
- Living in a house was associated with long term illness, poorer health state and anxiety.
- Those who rarely travel had the poorest health.
- Scale of inequality is large, reported problems between twice & five times more prevalent.
- Excess prevalence of miscarriages, stillbirths, neonatal deaths & premature deaths of offspring.

# Associations with ill health

- Health status in Gypsy Traveller group was correlated with age, education and smoking.
- But factors did not fully account for the poorer health status of Gypsy Travellers.
- Gender differences demonstrate that women are twice as likely as men to be anxious, even when education, smoking and carer status are taken into account

# Qualitative study Research Questions

- What are the health beliefs and attitudes of Gypsy Travellers in relation to use of health services?
- What are Gypsy Travellers' experiences in accessing health care and the cultural appropriateness of services provided?

## Key Messages - Cultural

- Gypsy or Traveller identity very important
- Strong feeling of being the most rejected group in society
- Travelling (nomadism) an important feature of identity
- Importance of the family –especially children
- Conflict between desire for close family living and need for privacy
- Self reliance is a fostered cultural trait
- Need to retain element of control is linked to restricted self determination

# Key Messages - Health Related Beliefs & Attitudes

- Pervasive & deep-rooted mistrust of the world (includes health services)
- Stoicism + denial of ill health leads to reluctance to access services (but for children care is sought urgently)
- Family care and support preferred first to social health care provision
- Low expectations of health services but trust in staff who show cultural sensitivity
- Intense fear of terminal illness

# Key messages - health experience

- Chronic ill health ( often with more than one condition) marked but understated
- High burden of stress on carers
- Stress seen as predisposing factor to certain prevalent conditions
- Poor psychological health seen in context of multiple difficulties faced
- Secrecy about depression keeps it hidden and increases the burden
- Bereavement a common precipitating factor of depression
- Alcohol consumption often used as a coping strategy
- Drug use among Traveller youths widely reported and feared
- Cancer is prevalent among families and particularly feared

# Key messages-Environmental Factors

- Lack of choice and freedom to live cultural and chosen lifestyle seen as crucial health factor
- Need to be close to family and community support
- Need freedom to be mobile for cultural, economic and safety reasons
- Safety hazards , security fears and poor access to services are common problems and reasons for desire to move
- Houses are anathema for some and Hobson's choice for many more
- Process of securing appropriate accommodation lengthy and stressful

## Use of Health care services

- Reluctance for GPs to register non-housed Travellers
- Communication difficulties with health staff
- Poor access to and poor experiences of health care led to doctoral study on Communication Barriers between GT and health staff
- Participatory action research (PAR) methods to explore communication processes from the perspective of both staff and Gypsy and Traveller patients.

# Key Messages- Communication (1)

- Experiences of discrimination and racism contribute to sense of devalued identity
- Defensive reactions against shame or humiliation can lead to similar defensive reactions from health staff - mutual mistrust
- Health staff reactions shaped by the broad social climate, and also by role and status, organisational structures, policies and team ethos
- The complexity surrounding the health needs of Gypsies and Travellers also has a major impact on service delivery.

# Key Messages- Communication (2)

- Both parties have internalised stereotypes, which inform their attitudes to each other.
- Each party brings to an encounter their own expectations, based on their personal experience and particular social or cultural context- tensions are then exacerbated
- A reflective and collaborative staff approach based on effective leadership and shared team ethos, can provide the empathic focus needed for trust and effective communication
- There are specific implications of these findings for staff training, in terms of ensuring culturally safe health care for Gypsies and Travellers.
- Cultural competence essential for satisfactory provision of health care services

# Barriers to knowledge of current health status

The current comparative picture is unknown:

- DH not yet committed to including Gypsies and Travellers in the current 16 ethnic minority categories for NHS monitoring
- READ codes are available but rarely used
- Local Health Needs Assessments show lack of improvement in GT health status , but there are acknowledged and inevitable methodological limitations
- Without NHS ethnic monitoring a national picture of health inequalities cannot be updated and used as a baseline for measuring improvement in outcomes.

# What is known now - health status(1)

- The All-Ireland Traveller Health Study ( AIHTHS) 2010 , which includes Northern Ireland, demonstrates continued bleak health status since the national study in 1987. There is nothing to suggest that the picture in the rest of the UK would have altered differently since our 2004 study:

## Life Expectancy

- In 1987 the gap in life expectancy between Traveller women and settled women was 12 years; **the gap in 2008 was 11 years**
- In 1987 the gap in life expectancy between Traveller men and settled men was 10 years; **the gap in 2008 was 15 years**

## Mortality

- Traveller men have four times the mortality rate of the general population.
- Traveller women have three times the mortality rate of the general population
- Suicide is 6 times the rate of general population and accounts for approx 11% of all Traveller deaths

## Morbidity

- Deaths from respiratory diseases, cardiovascular diseases and suicides were more markedly increased in Travellers compared to the general population'

# What is known now - health status(2)

## Localised studies and HNAs

### Life expectancy

Average age of death 65 yrs for Gypsies and Irish Travellers in Bedfordshire compared to UK average of 81.5 yrs ( Beds 2010)

In Leeds it is 50 yrs, with Leeds settled population at 78yrs (Leeds REC, 2005)

### Mental Health

The Bristol MIND study 2008 plus various local HNAs ( Cumbria, Luton 2009, Cambridge, West Sussex 2010, Surrey 2011) all reinforce the findings of poor mental health outcomes of the 2004 Health Status study

## What is known now – access to health care

- Many Gypsies and Travellers still registered only as temporary residents ; many finding difficulty in registering without a permanent address (Cumbria HNA)
- 40% of Gypsies and Travellers were not registered with a dentist in Cumbria HNA.
- More than 50% of Gypsies and Travellers in Cumbria were reluctant to identify their ethnicity when registering with a Doctor for fear of hostility or prejudice.
- Low levels of immunisation uptake identified in several HNAs
-

# GRT health inequalities – causes of causes

- Tackling the wider health determinants are key to improving Gypsy, Traveller and Roma health:

social exclusion

accommodation

discrimination and racism

education

# Ways forward and opportunities

- Inclusion Health- focus on Gypsies and Travellers as one of four most vulnerable groups
- Public health England – opportunity to work with other Local Govt departments to tackle wider health determinants
- Greater use of peer advocacy eg Health Champions, Health Trainers and closer working with Gypsy and Traveller NGOs
- Widen and make mandatory equality and diversity training to improve cultural safety (good examples of practice from Pacesetter Programme in Leicester, Bristol and elsewhere)
- Use Equalities legislation to challenge resource cuts
- Revise data collection to incorporate Gypsies, Roma and Travellers in all health monitoring

