

Fair Access for all?

Gypsies and Travellers
in Sussex, GP Surgeries and
Barriers to Primary Healthcare

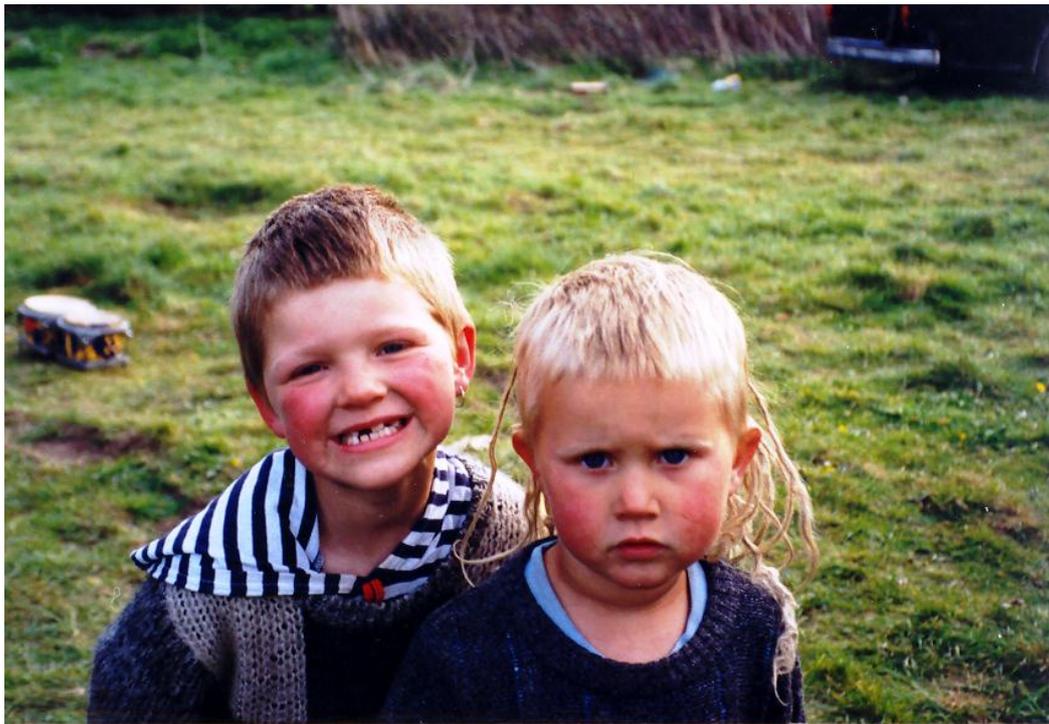


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Introduction

One of the most common and enduring problems Gypsies and Travellers experience in Sussex is a lack of access to primary healthcare, in particular GP Surgeries. Many Gypsies and Travellers face open prejudice and discrimination from GP Surgery staff, including a refusal to register 'Roadsiders'¹ as new patients and a common assumption that Gypsies and Travellers will 'cause trouble' or 'be difficult'.² Such overt discrimination has resulted in many Gypsies and Travellers accessing healthcare only at the point of crisis with large numbers of Gypsies and Travellers receiving primary healthcare through A&E Departments, rather than local GP Surgeries. A&E Departments have been found by many Gypsies and Travellers to be less discriminatory, more accessible and friendlier and with more thorough examinations given.³ It is clear that accessing primary healthcare via A&E Departments is not a good use of resources and results in even more pressure on already overcrowded emergency services. Moreover, accessing primary healthcare only at the point of crisis has a negative impact on people's health and can be extremely dangerous as conditions such as diabetes, asthma and bladder infections can develop serious complications if not treated early.

This report argues that a number of GP Surgeries across Sussex have not adhered to the 2010 NHS Constitution by 'refusing access on unreasonable grounds' and through 'unlawful discrimination...on the grounds of race.'⁴ Through the examination of social and cultural barriers to Gypsies and Travellers accessing healthcare and use of case studies this report will also argue that the majority of GP Surgeries throughout Sussex have little or no understanding of the complex needs and experiences of Gypsies and Travellers. Finally, this report will highlight how the complex needs of Gypsies and Travellers can be addressed through the use of Good Practise Examples and Recommendations.

Context

This report is based on findings made by the Friends, Families and Travellers (FFT) Sussex Outreach Team, part of the Sussex Traveller Health Project and work carried out between November 2009 and August 2010. The FFT Sussex Outreach Team is made up of 2 Wellbeing Community Development Workers and 5 Outreach Support Workers who provide support, advice and signposting to around 500 Gypsies and Travellers each year across Sussex.⁵ Gypsies and Travellers are supported in a number of areas including housing, welfare, health, wellbeing, adult social care, families and young people, work, education and community engagement.

Barriers to Healthcare

There are a number of complex and diverse social, cultural and environmental barriers that prevent many Gypsies and Travellers accessing essential health care services across Sussex and throughout England.



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Racism

Gypsies and Travellers experience the highest levels of racial abuse of any ethnic group in the UK with 63% of young Travellers bullied or attacked⁶ and 35% of people admitting to racism towards Gypsies and Travellers.⁷ Such abuse is so deeply imbedded in society that can be seen as the 'last bastion of racism'.⁸ Racism towards Gypsies and Travellers can be found openly expressed in the media with headlines such as 'Stamp on the Camps'⁹ and names like 'chav' being used in a derogatory way in television soaps and on comedy shows. It can be argued that '...extreme levels of public hostility towards Gypsies and Travellers are fuelled in part by an irresponsible media reporting of the kind that would be met with outrage if it was targeted at any other ethnic group'¹⁰. How many other ethnic groups in the UK experience frequent and apparently acceptable, racial abuse across the media; in newspaper articles, blogs and in television dramas? The devastating impact such high levels of racism towards Gypsies and Travellers affects and often shapes Gypsies and Travellers confidence, self worth and self esteem at fundamental levels.

There is an expectation from many Gypsies and Travellers that they will experience racism and prejudice in even the most subtle form, which has developed from past experience and generations of social tension. Such negative interactions ultimately obstruct people's use of community facilities and access to local services. In short many Gypsies and Travellers avoid particular services if they, or their family, have been ill-treated there in the past. For example, between November 2009 and August 2010 five racist incidents between GP Surgery staff and Gypsies and Travellers in Sussex were reported to the FFT Outreach team.¹¹ Such incidents have involved refusal of registration for having a common Irish Traveller name, living on a Local Authority site and for having no proof of address, all of which are unlawful reasons to prevent an individual accessing NHS healthcare. Furthermore, the impact these incidents have had on individuals involved has exacerbated the levels of distrust many Gypsies and Travellers have towards Statutory Services in Sussex, particularly the NHS. These incidents have also caused distress to victims and have put each individuals health at risk as they all resulted in patients being delayed healthcare and/or refused registration.

Cultural Barriers

From research carried out by the FFT Outreach Team, supporting Gypsies and Travellers to access primary care it is clear that the majority of GP Surgery staff across Sussex have very little knowledge or awareness of Gypsy and Traveller culture and how this impacts on access to primary care services. For example, within the majority of Gypsy Traveller families there is a strong gender divide where it is inappropriate to discuss health issues with strangers or with members of the opposite sex. Therefore, a Gypsy Traveller might not wish to disclose why they want an appointment with their GP to a receptionist and may alternatively access primary care through A&E Departments because they feel that treatment in the A&E Department is better than that provided by their GP.¹²



Photo Chris Thomas www.miltoncontact.co.uk

Within Gypsy Traveller communities there are high levels of stigma and fear around mental health. Mental health is commonly viewed in terms of psychosis by Gypsies and Travellers, whereas stress, anxiety and depression are generally seen as having 'bad nerves', which is often part of every day life and something many people 'learn to live with'.¹³ Therefore, many Gypsies and Travellers would not consider approaching their GP for support with mental ill health as they might not be aware of the support available and may not want to be associated with 'mental health', as it might be viewed, in terms of heavily stigmatised psychosis. Historically Gypsies and Travellers have had negative experiences with the Statutory Services in the UK; with night raids carried out by the Police, Roadside evictions from Local Authorities and families being added to Child Protection Registers simply for being Travellers.¹⁴ This has resulted in many Gypsies and Travellers not accessing support for fear of being 'put on record' as mentally unstable. Stoicism and self-reliance are specific values intrinsic to Gypsies and Traveller identity, born out of living within, or on the fringes of, a hostile society and seen as a necessary development for survival.¹⁵

The Role of the Family



Photo FFT

Healthcare in many Gypsy and Traveller families is largely kept within the domestic realm and managed by mothers and daughters, with men and boys often receiving healthcare advice and appointments organised by their wives, mothers and daughters. Going 'outside' of the family unit for support with health is a relatively new thing for many families to whom 'looking after their own' is part of familial duties and not the role of health professionals. Furthermore, when a person is sick or in need of care their whole family will usually be involved, at some

level, in supporting and administrating the care. This raises a number of issues, not least that of the large number of unofficial carers, many of who are children, but also of the lack of privacy individuals may have to discuss personal health with a health professional should they need to. On a practical level this lack of privacy may make it difficult for outreach health Practitioners to work with individuals in their homes and may also mean that whole families may attend GP appointments with individual family members. This can sometimes present a challenge to the GP or health Practitioner if they are not used to this cultural practice.

Inadequate Health Service Provision



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Many statutory institutions including the NHS inadvertently exclude Gypsies and Travellers from accessing basic health services by not providing adequate information and services that meet the diverse and complex needs of Gypsies and Travellers. Furthermore, some Gypsies and Travellers may struggle to understand the language health Practitioners use.

There is an estimated 62% percent illiteracy rate amongst groups of Gypsies and Travellers within the UK.¹⁶ This means that a proportionally large percentage of Gypsies and Travellers within Sussex may have little or no knowledge of primary care services that are available as these are almost always advertised in written format - on posters and flyers. This results in many services going unnoticed by Gypsies and Travellers including vital mobile and static health services including cervical screening, diabetes check-ups, mental health services and peri-natal care. Furthermore, it has been reported to the FFT Outreach Team on a

number of occasions that patients have not had prescriptions explained to them by GPs as the assumption is usually made that patients can read. This has resulted in many families regularly misusing medications including taking preventative medications such as anti-depressants only when feeling unwell and sharing medications between family members for a number of different ailments and complaints.¹⁷

No Fixed Abode?

It is estimated that there are between 200,000 and 300,000 Gypsies and Travellers living in the UK.¹⁸ Two thirds of Gypsies and Travellers live in houses and a third either in Local Authority (LA) Traveller Sites, on their own land or on unofficial encampments. There is a huge shortage of LA Sites and even less transit sites which has left over 25,000 people displaced and with nowhere to stop legally or safely. Such people are usually forced to stop on common land or on roadsides, most of which are without sanitation, rubbish collection, clean drinking water or electricity. Furthermore, being forced onto inappropriate stopping places usually creates social tension between local people and Gypsies and Travellers, with Roadsiders often being blamed for an increase of crime and fly-tipping. However, it is worth noting that statistics show that overall crime does not increase when Gypsies and Travellers move into an area.¹⁹



Photo Eva Sajovic

Roadsiders have great difficulty accessing primary health care and it is almost impossible for people to access secondary care without a referral from a GP. Many Roadsiders will only access health care at the point of crisis as homeless services are heavily over-subscribed and waiting times can be extremely long. This results in an over-dependence on A&E Departments with many people opting to use these instead of crowded and sometimes culturally inappropriate Walk in Health Centres.²⁰ At A&E departments people know that they will not have to explain their housing situation, will be guaranteed to be seen that day or at least within a few hours and will generally receive a good level of care. It must be stressed however that this is not an 'easy option' for many Gypsies and Travellers, but one taken by many because they feel they have no other choice.



Photo FFT

There are only four Walk in Centres in Sussex; in Eastbourne, Hastings, Brighton, and Crawley, all of which are located in urban centres. There are no Walk in Centres in rural Sussex and only one in the whole of West Sussex. This is clearly insufficient compared to need reported by the FFT Outreach Support Team.²¹ Furthermore, this highlights the lack of knowledge the NHS has of rural communities who may have no fixed abode or are Roadsiders and rely heavily on the services Walk in Health Centres provide. For example, many Roadsiders, move across the country throughout the year meeting seasonal work commitments on farms and visiting extended family members. This results in individuals and often whole families being forced to use A&E departments to access primary care when away from their registered GP, if they have been refused short term registration at a local GP Surgery or do not have access to a Walk in Health Centre.

Case Studies

Case Study A

'A' is a 15 year old New Traveller girl who lives on an encampment in Brighton. 'A' visited her local GP Surgery in Brighton in April 2010, a surgery where her sister and step-father are registered. 'A' was registered with this surgery the previous year, but moved briefly to live with her father in Bristol after the sudden death of her mother. Upon her return to Brighton 'A' discovered she had a bladder infection and attempted to re-register with her old surgery for treatment.

'A' visited the surgery with an Outreach Support Worker from FFT. 'A' was told she would be able receive treatment once, but was not allowed to register as a temporary patient. 'A' was told that she could not register as a permanent patient either, as she had no proof of address and was told by the receptionist to "contact [her] PCT to be assigned a GP." 'A' did not understand what the receptionist said and did not know what a 'PCT' was and was left very confused about how to go about finding a new GP.

Case Study B

'Mrs B' is a housed English Gypsy from West Sussex who has a history of drug and alcohol abuse and mental health problems and has relied on Rehabilitation Centres and CMHTs for support in the past. 'Mrs B' appeared to be developing psychosis when her FFT Outreach Support Worker visited her in November 2009. This was also confirmed by 'Mrs B's' family who raised their concern to 'Mrs B's' FFT Outreach Support Worker. 'Mrs B' attended an appointment at her local GP Surgery in West Sussex for stomach pain she was experiencing. 'Mrs B' did not see her normal GP but had been registered with her GP Surgery for 12 years, however during her appointment 'Mrs B' was not asked by the GP about her drug history and prescribed a potentially addictive drug for back pain. During the appointment 'Mrs B's' GP also failed to recognise the early signs of psychosis, nor questioned Mrs B about her mental health and wellbeing, which indicates that 'Mrs B's' health records were not read by the GP before her appointment. Within 2 days of this visit to her GP 'Mrs B's' mental health had deteriorated so badly her FFT Outreach Support Worker had to call 'Mrs B's' GP twice to request an emergency CMHT referral.

Case Study C

Mr and Mrs C are English Gypsies who live on a Local Authority Traveller site in Mid Sussex. In June 2010, 'Mr and Mrs C' attempted to register with their local GP Surgery upon moving into the area. 'Mr and Mrs C' visited the surgery and spoke to the receptionist who confirmed that they had room for new patients and gave 'Mr and Mrs C' a registration form to fill out. 'Mr and Mrs C' returned the registration form at a later date and were refused registration at the Surgery when the receptionist saw 'Mr and Mrs C's' address and said "We've had problems before with you lot from the site." 'Mr and Mrs C' were very upset by the open racism they received and left to register at another surgery over a mile away from their home, one which they have to use their car to get to, rather than walk across the road to their local surgery.

Case Study D

In July 2010 'D' called her local GP Surgery in Crawley and asked if it was possible to register there. 'D' was told that the Surgery was taking patients and could register at her convenience. Upon her arrival at the surgery the first receptionist collected the registration paperwork, but shortly after this a second receptionist intervened and said that the surgery was not taking on any more patients. When 'D's' FFT Outreach Support Worker explained 'D' had spoken to someone the previous week on the telephone and had been told that the surgery was taking on new patients the receptionist replied that they were not taking on any more 'Maughans', stating 'D's' family name. The assistant manager then added that he could not disclose any information but that the surgery had had a "lot of trouble with other Maughans." 'A' explained that Maughan is an extremely common name within the Irish Traveller community and could be compared to the 'Patel' within Asian communities. The Assistant Manager responded that the West Sussex PCT had permitted them to refuse to register any more patients with the surname Maughan.

What can we learn from these Case Studies?

The 2010 NHS Constitution states that 'No one can deny you the right to access these services because of your race'. It also states that 'Reasonable Grounds to refuse access to the NHS include violent or abusive behaviour by the patient'. This clearly shows that each patient should be considered as an individual and should not be discriminated against because of a family name that affiliates them with an ethnic group. Given our experiences, we think it important for GP surgery staff

to be monitored and held accountable for the way in which they treat members of Gypsy and Traveller communities.

It is also clear that the majority of GPs and Surgery staff need comprehensive training in mental health awareness and recognition of the early signs and symptoms of mental health distress. This can be emphasised by the recent survey carried out by the mental health charity Rethink where it was discovered that only 31% of GPs feel equipped to take on the role for mental health. While three quarters of GPs say they can take responsibility for diabetes and asthma services, less than a third felt the same for mental illness.

Paul Jenkins, Chief Executive of Rethink, said: "GPs with a real interest in mental health can play an invaluable role in supporting more than a million and a half people with severe mental illness. But we often hear from people with mental illness, that GPs don't understand mental health and want to quickly refer them on to specialists. Now GPs themselves are telling us that they have concerns too.

"The proposals expected in the white paper can work, but only if GPs are given proper training and support to understand the needs of people with severe mental illnesses such as schizophrenia and bipolar disorder. If they are to be given responsibility for deciding what happens to people with severe mental illness, then they also have the right to get properly trained up first".²²

A Good Practice?



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Morley Street Walk in Centre, Brighton

What works

- ✓ Patients are given very thorough examinations and the time to discuss symptoms

- ✓ Staff show an understanding of drug and alcohol misuse, homelessness and mental health
- ✓ People report very good treatment by the GP
- ✓ Excellent reception staff

Crawley Walk in Centre

What works

- ✓ Friendly, informative reception staff
- ✓ Patients offered help with filling out paperwork
- ✓ Welcoming atmosphere

Eastbourne Outreach Team

What works

- ✓ GP and nurse visiting Traveller Sites and encampments to offer immunisation against measles
- ✓ Gypsy Chair of the Steering Group enabled an invitation for midwives to visit a Traveller site in Eastbourne

Recommendations



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1. GP Consortiums to introduce equal opportunity and cultural capability training and support for GP Surgery and Health Centre Staff with a rigorous monitoring and evaluation system in place the measure Practice development.
2. All GP Surgery staff and visiting Practitioners in areas with a significant Gypsy and Traveller population to undertake Gypsy and Traveller Cultural Awareness Training with Friends, Families and Travellers or awareness training with a similar specialist Gypsy Traveller organisation.

3. Each Surgery and Walk in Centre to use current ethnic monitoring forms effectively or if necessary update ethnic monitoring forms to include Irish Travellers, English Gypsies and Scottish Travellers, all of which are distinct ethnic groups under the Race Relations (Amendment) Act 2000.
4. GP Surgeries, Walk in Centres and Outreach Teams in Sussex to engage with Friends, Families and Travellers Outreach Support Staff and similar specialist support services to strengthen links and build trust between Primary Care Services and Gypsies and Travellers.
5. GP Consortiums to promote a family and community approach to delivering services to Gypsies and Travellers which would provide an opportunity to work with the whole community on health promotion activities.
6. GP Consortiums to recognise and value the role the extended family plays within an individual's health and recovery and to utilise the often strong and caring familial support networks available, where this is appropriate.
7. GP Consortiums to monitor and evaluate ethnic monitoring and establish service development action plans to reflect the needs of the local community.
8. Each surgery to treat all temporary and registered patients with dignity and respect as stated in the NHS constitution 2010. Furthermore, Practise Managers to challenge staff racism and prejudice directed at Gypsies and Travellers, and recognise that it can, at times, be subtle and not recognised as prejudice by staff.
9. GP Consortiums to promote awareness of the Patient Advisory Liaison Service (PALS) complaints system and seek ways to provide advocacy to support patients to access and utilise the complaints procedure.
10. Each surgery to respect the culture, rights of privacy and confidentiality of Gypsies and Travellers and for reception staff not to ask inappropriate personal questions regarding personal health on the telephone or in front of other patients and for these questions to remain confidential between patient and GP. Where this is not possible it is recommended that reception staff be discreet when asking personal questions and always consider cultural restrictions when doing so.

11. Each Surgery to pro-actively increase their knowledge of local Gypsy and Traveller communities and develop or adapt services to reflect local need, as stated in the NHS Constitution 2010.²³
12. Each Surgery to meet their statutory duty under the Race Relations (Amendment) Act 2000.²⁴
13. GP Consortiums to ensure that all Gypsy and Traveller groups are fairly represented in their area by holding appropriate and accessible consultations and involving Gypsies and Travellers in the evaluation and design of local services.
14. GP Consortiums across Sussex to increase Gypsy and Traveller knowledge of local services by using creative ways of disseminating information that do not rely on the written word. To develop and use pictorial cards to explain pathways to care and instructions for medication. To share service information by word-of-mouth from GP to patient and by the discreet and culturally appropriate use of mobile health centres and other outreach services.
15. GP Consortiums to roll out mental health training to GPs, practitioners and Surgery staff, with a particular emphasis on recognising the early signs of mental health distress and being given guidance on what steps to take to support patients who are becoming mentally unwell.
16. All GP Surgery and Walk in Centre staff to adhere to NHS Constitution 2010 where all patients have the right to choose their GP Practice and not to be refused access on unlawful or unreasonable grounds. It is reminded that entitlement to NHS care in the UK is based on residency, rather than having a permanent address and thus it is unlawful to discriminate against Gypsies and Travellers who have no proof of address.²⁵
17. To ensure that once GPs take over Commissioning that they do not 'exclude' so called 'hard to reach' people, who may not be regarded as 'cost effective', as GP Practices run on a business model.

¹ The term Roadsiders is used here to describe Gypsies and Travellers who have nowhere legally to stop and end up stopping by the roadside or living on unofficial encampments. It is estimated there are currently 25,000 Roadsiders living in the UK. Friends, Families and Travellers (2010).

² A number of case studies and anecdotal evidence reveal that Gypsies and Travellers across Sussex have been openly discriminated against by GP Surgery

staff as a result of having no proof of address, sharing a common Traveller name or living on Local Authority sites with a 'bad reputation'. Friends, Families and Travellers (2010).

³ Gypsies and Travellers' experience of using urgent care services within NHS Brighton and Hove boundaries, Prof V Hall, M Sadouni, A Fuller. Friends, Families and Travellers, University of Brighton, NHS Brighton and Hove (2009)

⁴ Handbook NHS Constitution (March 2010)

⁵ Around 500 Gypsies and Travellers, from all ethnic groups and backgrounds including New Travellers are given support and advice by the Sussex Outreach Support Team every year. Friends, Families and Travellers (2010)

⁶ Children's Society Report (2007)

⁷ Profiles of Prejudice Mori & Stonewall (2003)

⁸ Trevor Phillips Gypsy and Traveller Law Ed. C Johnson, M Willers (2007)

⁹ The Sun Newspaper (2005)

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CRE Launch of Consultation Strategy for Gypsies and Travellers (2003)

¹¹ Five incidents involving GP Surgeries were reported to Outreach Support Staff from November 2009-August 2010. However, racist incidents are common and largely underreported within Gypsy Traveller communities due to a common perception that reporting racist incidents won't change anything. There is also a lack of understanding and support for Gypsies and Travellers to report racist incidents, particularly to the police. Therefore, it can be estimated that the number of racist incidents that occur is much higher than those reported, both within statutory organisations and between individuals. Friends, Families and Travellers (2009)

¹² Gypsies and Travellers' experience of using urgent care services within NHS Brighton and Hove boundaries, Prof V Hall, M Sadouni, A Fuller. Friends, Families and Travellers, University of Brighton, NHS Brighton and Hove (2009)

¹³ Anecdotal evidence suggests that many Gypsies and Travellers have a low expectation of health and 'put up' with poor health to a large degree often seeking healthcare and support much later than other communities. Such can be attributed to a lack of awareness of health care support available and of a culture of stoicism and self-reliance. Friends, Families and Travellers (2010)

¹⁴ Anecdotal evidence of many Gypsies and Travellers, in particular Roadsiders, highlight negative experiences of Statutory Services. Friends, Families and Travellers (2010)

¹⁵ Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study. Ed. P Van Cleemput, et al. University of Sheffield (2006)

¹⁶ Dorset Traveller Needs Assessment Anglia Ruskin University (2007)

¹⁷ Anecdotal evidence highlights the urgent need for health services and medical instructions to be given face-to-face or by other means which do not rely on literacy. Friends, Families and Travellers (2010). Also Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study. Ed. P Van Cleempt, et al. Universtiy of Sheffield (2006)

¹⁸ Common Ground Commission for Racial Equality (2006). This figure differs from official Government statistics as these are based on Gypsies and Travellers living in caravans on Local Authority Traveller Sites and do not include Gypsies and Travellers living in houses and by the roadside. Furthermore, the UK Census does not have, until 2011, an ethnicity box for Gypsies and Travellers where people can disclose their ethnicity, therefore the numbers of Gypsies and Travellers in the UK is largely under recorded.

¹⁹ Joseph Rowntree Foundation (1996) Office of the Deputy Prime Minister News Release (2006)

²⁰ Contrary to popular myth, the large majority of unmarried Gypsy and Traveller girls and women are shielded from involvement with the opposite sex and sexualised behaviour with someone other than one's husband is seen as shameful within traditional Gypsy and Traveller communities. Walk in Health Centre waiting rooms are often frequented by homeless young men with alcohol and drug problems and mental health problems, which can be very daunting and uncomfortable for Gypsy and Traveller girls and women. Many young women from strict and traditional Gypsy and Traveller families do not spend time with young men outside of their family without a chaperone. Therefore, such women and girls are less likely to be exposed to men with mental health problems who may also have drug and alcohol problems and thus may be intimidated or frightened by the behaviour displayed by men managing chaotic lifestyles, poor mental health and addiction. Friends, Families and Travellers (2010).

²¹ Many Gypsies and Travellers have reported problems registering as a temporary patient with local GP Surgeries and some have reported racism and prejudice directed at them, which leads many people being forced to travel to A&E Departments and Walk in Centres in urban areas or register with a GP Surgery further away from their home. This highlights the need for more Walk in Centres across Sussex, in particular rural Sussex, and improved access to GP Surgeries that currently exist. Friends, Families and Travellers (2010)

²² 251 GPs were interviewed online by ICM Research on behalf of Rethink in June 2010. Interviewees were selected at random from ICM's nationally representative panel of GPs. Rethink (July 2010)

²³ Handbook NHS Constitution (March 2010)

²⁴ The Race Relations (Amendment) Act 2000 prohibits discrimination on grounds of race, colour, nationality, ethnic and national origin in employment, education and provision of goods and services.

²⁵ NHS Primary Care Service Framework: Gypsies and Traveller Communities (2009)