



# **Involvement of Gypsy, Roma and Traveller Communities in Health & Social Care Policy & Practice**

**Workshop date  
30 September 2009**

**Venue  
The Resource Centre,  
356 Holloway Road, London N7 6PA**

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## 1. Executive Summary

This report describes the partnership between National Voices, the Irish Traveller Movement in Britain (ITMB) and the Nursing & Midwifery Council (NMC) to look at the experience of Gypsy, Roma and Traveller Communities in getting involved in health and social care policy and practice, as well as to establish how to meaningfully involve them in the work of these three organisations and in a wider context. A one-day workshop was held in London on 30 September 2009 where 20 participants contributed their experiences and views of involvement. The report captures these contributions and situates them within a policy context and literature review.

The workshop covered a wide range of areas, exploring good and bad examples of involvement from the experiences of these communities; the barriers to involving them; and pointers to developing a better way of involving them. A number of key messages emerged on the day and are summarised below.

### Key Messages

- The Department of Health (DH), National Voices and the ITMB should devise informed strategies on actions to be taken to ensure the explicit positive representation and promotion of these communities across all of its work and influence
- Recognise the non-homogenous nature of these communities
- Establish, as far as reasonably possible, opportunities for consultation and involvement of the communities in decision-making processes and structures
- Be clear from the outset about whose interests are really being served by the involvement of the communities – it should be effective partnership, not tick-box
- Establish on-going communication and consultation with these communities on all relevant policy issues, and also liaise with locally-based Gypsy, Roma and Traveller community groups and agencies
- Impact-assess all policies to ensure they promote equality for Gypsy, Roma and Traveller communities
- Work in partnership with other agencies to share good practice learnt from this session

- Ensure there is effective cross-agency working to consider the needs and aspirations of Gypsy, Roma and Traveller communities and individuals in their planning of services
- Assist the communities to challenge negative and inaccurate media coverage
- More work needs to be done to encourage the recruitment of professional staff from Gypsy, Roma and Traveller backgrounds in health and social care
- Policy and practice in health and social care should be reassuring and affirmative of respectful acceptance of Gypsy, Roma and Traveller communities, their culture, history and languages
- Promote positive models and images of Gypsy, Roma and Traveller people and communities

Finally, at the end of the workshop a series of suggestions was made to National Voices and the Nursing & Midwifery Council as to what they could individually do to meaningfully involve these communities in their work. These recommendations can be found at the end of the report.

## **2. Acknowledgement**

As a joint workshop and partnership work between National Voices, the Irish Traveller Movement in Britain (ITMB), and the Nursing & Midwifery Council (NMC), we acknowledge the contributions of the three organisations and most importantly the rich contributions from members of Gypsy, Roma and Traveller communities, from across England, who attended the event.

### **The 20 participants were:**

Brenda, Ann, Lully, Isabel, Susan, Emily, Jayne, Eileen, Martina, Gill, Rosemarie, Anna, Grazyna, Kathleen, Louise, Zoe, Marya, Josey, Teresa, and Julie (who fed into the process by letter)

### **Organisations represented at this workshop were:**

Friends, Families & Travellers  
Society for the Promotion & Advancement of Romany Culture (SPARC)  
Roma Support Group  
City & Hackney PCT

### **Also in attendance were:**

Phil Regan – London Partnership Development Officer, ITMB  
Emily Kessler – Stakeholder Strategy Project Manager, NMC  
Natalie Salmon - Head of Equality & Diversity, NMC  
Andrew Young – Equality & Diversity Co-ordinator, NMC  
Ade Adeagbo – Interim Chief Executive, National Voices  
Lizzy Allen – Involvement Co-ordinator, National Voices

### **3. Background**

This report, which is informed by a literature review and the workshop of 30 September 2009, aims to raise the awareness and stimulate the active involvement of Gypsy, Roma and Traveller communities (for the purposes of this report to be known as “the communities”) in health and social care policy and practice.

National Voices has a strategic commitment to engage with minority ethnic groups and ‘seldom heard’ communities, and organises a programme of events, research and involvement sessions, where appropriate, as a means to achieving this. Current research also identifies that the involvement of Gypsy, Roma and Traveller communities in health and social care policy and practice is limited and not carried out as a matter of routine and practice (Matthews, 2008).

The aims of the workshop and the associated report were to explore;

- Existing literature on involvement theories and practices among Gypsy, Roma and Traveller communities
- Shared experiences and learning from Gypsy, Roma and Traveller communities about their experiences of involvement
- Good examples of involvement from the experiences of these communities
- Barriers to involving these communities
- Pointers to developing a better way of involving these communities
- Suggestions and recommendations that can inform further work on involving these communities in health and social care policy and practice

#### **National Voices**

To support meaningful involvement in health and social care, National Voices has been created to bridge the gap between service users, practitioners and policy-makers. The organisation has a broad and diverse membership of voluntary sector organisations and aims to ensure that the needs and preferences of those affected by government health and social care policy are fully integrated in policy development and implementation.

National Voices believes that user involvement is vital for all modern public services because it provides a key mechanism for holding public services to account, and improvements in health and social care in particular cannot be achieved without a close link between the services provided and the wider lives of the citizens that use the services. Therefore, meaningful service user involvement is the way that public services should seek to achieve that integration.

National Voices believes that an action of service user involvement alone cannot be a measure of success; service users must be involved long-term in order to get a sense of how their involvement is being used, and what expectations they should have for the change that they can achieve by being involved in the development, provision, monitoring and evaluation of health and social care services. Hence, this report and

workshop form part of a wider body of work by National Voices, in its attempt to formulate guidance and explore good practice on effective user involvement for policy-makers and service users in health and social care.

### **Nursing & Midwifery Council (NMC)**

The Nursing & Midwifery Council exists to safeguard the health and wellbeing of the public. It is responsible for registering all nurses and midwives and ensures that they are properly qualified and competent to work in the UK. The NMC sets the standards of education, training and conduct that nurses and midwives need to deliver high quality healthcare consistently throughout their careers, and ensure that nurses and midwives keep their skills and knowledge up to date and uphold the standards of their professional code. The remit of the NMC is set out in the Nursing and Midwifery Order 2001.

For the NMC, this workshop and report form part of the organisation's commitment to engage the wider community and specific communities whose voices are less heard in the process of influencing practice.

### **The Irish Traveller Movement in Britain (ITMB)**

The Irish Traveller Movement (ITMB) is a national policy and voice charity, working to raise the capacity and social inclusion of the Irish Traveller communities of Britain. We were established in 2000 and are a registered Charity and a Company Limited by Guarantee.

The ITMB acts as a bridge-builder, bringing the Traveller communities, service providers and policy-makers together, thereby stimulating debate and promoting forward-looking strategies to promote increased race equality, civic engagement, inclusion, service provision and community cohesion.

The ITMB has an established track record of active policy development, community engagement and social cohesion work. It is a shared custodian of the *Liberty Human Rights Award 2004*.

This event and report supports some of the key aims and objectives of the organisation, which are to promote the social inclusion of Irish Travellers on issues that contribute to their exclusion, promote equality of access to statutory and voluntary services, develop policy models for working with the communities, educate statutory and other services who work with the communities, and build the capacity of the communities to self-advocate and represent themselves.

## 4. Methodology

This study comprised a literature review and a group workshop session of a cross section of members of Gypsy, Roma and Traveller communities, across England, on Wednesday 30 September 2009.

Regarding literature, there are many papers about involving these communities; in particular with reference to housing due to the high profile that settlement as an issue has, among Local Authorities. There are also some papers on education, especially focused on the issues and challenges that children from these communities face, and the general notion and views of the communities towards education. Not a lot of resources that focus on how Gypsy, Roma and Traveller communities interact with the health and social care system were found, and especially not regarding how they are actually involved in policy and practice.

Twenty people – names listed above – participated in the workshop and, notably, all attendees from the communities were female.

Gypsy, Roma and Traveller communities, it was discovered, approach involvement sessions from a different perspective, hence the point of taking part in forums needs to be made clearer (DCLG, 2000). Similarly to other disadvantaged and marginalised communities, there are all sorts of complex reasons why Gypsy, Roma and Traveller communities may be reluctant to get involved in such initiatives.

Some of these are;

- Too busy with work responsibilities, including childcare, to be able to give the time
- The more formal the approach taken, the more difficult it will be to get the members of the communities to join the process or session
- Many have little experience of engaging in formal, bureaucratic meetings and they do not see how they are relevant to the issues they face in their daily lives
- The length of time and discussion it can take for what are perceived as real outcomes to emerge can be frustrating

In a report by the Department of Communities and Local Government (DCLG) in 2006, which looked at developing good practice in tenant participation, it was argued that;

*[Involvement]...is not an objective that can somehow be achieved once and for all. It is an organic process. Policy-makers have to be prepared to review and change structures as the levels of participation change and the individuals involved learn and develop'.*

Therefore, developing meaningful involvement among Gypsy, Roma and Traveller communities does require consultation, creative thinking, commitment from all partners and investment of time. Involvement of these communities can take different forms and the starting points will vary depending on actual levels of trust, dialogue and involvement between the coordinating organisations and agencies and the communities (DCLG, 2006).

One of the key lessons from this workshop was that it is necessary to be clear from the outset about whose interests are really being served by the involvement of the communities. If the motivation comprises merely a tick-box exercise, then this should not be confused with developing effective partnership.

An important question to consider is the incentive; in other words, what is in it for them? One discovers, from this workshop, that any involvement exercise and/or session needs to be about offering real outcomes for the members of these communities that participate – and this will range from the chance to take part, the opportunity to be listened to, an opportunity to influence decisions, training, remuneration for their time, or all of the above.

To address the issues above, as part of the planning processes for this event, we held an initial meeting with the Irish Traveller Movement in Britain, who provided an insight into the communities and positively highlighted the ‘what you need to know’. The ITMB then acted as a conduit in liaising with the communities and identified key individuals who acted as facilitators and key links with the communities.

An initial meeting was held to discuss the agenda, meals and refreshments, incentives, and what the reporting would contain and the purpose of it. The communities’ ‘liaisons’ that attended the meeting were also empowered to be facilitators on the day to ensure that trust can be built around the process and that the familiar faces would enable open and free discussions at the event. All of the statements cited in this report are non-attributable as agreed with participants.

This pre-planning process worked for this event and engendered a positive outcome, as the evaluation and feedback (in chapter 13) highlights.

## 5. Context

In the 2006 comprehensive study of Gypsies and Irish Travellers and equality issues, the Commission for Racial Equality (CRE) concluded that these communities have consistently been left out of corporate strategies of inclusion, equality and regeneration, with the result that they are not getting equal access to basic services and support (CRE, 2006).

The report further argued that this was largely due to little awareness of who these communities are, what their needs and cultural nuances are, coupled with limited knowledge of how they can best be supported. This has then resulted in patterns of systemic exclusion that have been repeated and replicated by policy-makers. This bleak scenario is not meant to deny that there are many examples of good practice shown by individual agents and services working with these communities, but all too often these efforts remain isolated and undervalued in the bigger political picture (ITMB, 2007).

One such example of good practice that it is important to highlight is the Pacesetters programme, which has developed work to specifically address inequalities in health; inequalities that correlate with many of the key messages that came out of this workshop, listed on page 5 of this report. The Pacesetters programme is a partnership programme between local communities, the NHS and the Department of Health. The Equality and Human Rights Group (EHRC) at the Department of Health is working with a number of SHAs to reduce health inequalities as well as promoting working environments that are fair and free of discrimination. There are six equality strands to Pacesetters, of which race equality is one, and the 'core' elements relating to patient care issues include the promotion of dignity and respect and the improvement of the health status of Gypsies and Travellers.

Within this programme there are a number of pilot projects being delivered, one of which is the ITMB's 6 month project with the Royal Free Hospital in London (running until 31 March 2010). The first part of this project involves a number of Traveller women working as part of a steering group set up to oversee the development of appropriate policy and procedures in relation to service delivery in the Royal Free's maternity unit. Part two of the project will see a number of the woman trained up to support professional staff in delivering services, but also to act as support outreach workers to pregnant Traveller women. This programme uses shadowing and knowledge-exchange methods, with both Traveller women and health professionals working in partnership to share cultural understanding and experience to better community engagement. As a result of this participation, the Traveller women will develop portfolios of work and gain a certificate from the Hospital which will be recognised as a valid certificate with all other NHS hospitals.

In addition to the Pacesetters initiative, the Department of Health has initiated other projects to improve the health of Gypsies and Travellers, for example the production of a guide for PCTs – the Primary Care Service Framework for Gypsies and Travellers.

The Department of Health has also recently funded the organisation 'Friends, Families and Travellers' to work within three SHA regions to involve Gypsies and Travellers in Local Involvement Networks (LINKs) and other NHS consultations and fora. Other organisations working in this area include Leeds GATE (Gypsy and Traveller Exchange), which is building a toolkit for participation, and the Race Equality Foundation, which is carrying out BME cultural awareness briefings based on their papers.

However, these examples of good practice aside, the aforementioned patterns of systemic exclusion and inequalities in access to basic services and support do remain a strong barrier for these communities. At the workshop, participants flagged up the issue that Gypsy, Roma and Traveller communities are strongly affected by many factors influencing their health and wellbeing. Particular mention was made of racism, discrimination, myths, stereotyping and the need for better communication, understanding and relationship between the communities and health and social care practitioners.

As some participants explain it;

*Some people just make assumptions*

*There is no encouragement given to Irish Travellers at all*

*Sometimes Travellers complain about treatment thinking it's ethnically based. However, nurses/midwives are bad with all*

*Told to contact police – though not recognising a culture that doesn't trust police and consequences of ringing police*

Some shared their experience of racial abuse,

*I cannot leave after 7pm without being abused*

*Afraid to move in case I move to area where I'll be abused*

Evidence is that access to healthcare and social care is steadily improving (ITMB, 2007) and this was echoed by some of the participants, whilst acknowledging that there is still a long way to go. Attention should now focus on what can be done after the communities have started interacting with health and social care systems, to sustain their engagement.

As expressed by a participant;

*There has been great change with travellers' involvement – largely due to voluntary sector efforts*

This report offers a background to Gypsy, Roma and Traveller communities' views and experiences of involvement in both healthcare policy and practice, whilst also offering some suggestions for ways of reducing the barriers to involvement, as well as suggestions for what could be done to increase the involvement of these communities in policy and decision-making processes. Participants were also asked to share their views on nursing and midwifery services as an example of the health and social care system and were also invited to share their thoughts and judgements on what constitutes good and bad behaviour from nurses and midwives.

Achieving meaningful and effective involvement between policy-makers and the Gypsy, Roma and Traveller communities can be achieved by more interactive sessions, as this workshop demonstrates. These work well when they have become established and have formed relationships with the relevant services. Involvement sessions and events, the communities conclude, are a valuable resource for all partners to build trust and to engender cross-cultural understanding.

As a participant summed it up;

*People need to be worked with over a long period of time, to build up trust and see real progress*

All of these are needed to deal with the unacceptable and systematic social exclusion that Gypsy, Roma and Traveller communities continue to face in the UK (ITMB, 2007).

While the issues raised in this report reflect the experiences of the Gypsy, Roma and Traveller communities in many parts of the country, it is important to remember that these communities, in common with all others, are not homogenous but complex and diverse. The needs of these communities will vary according to criteria such as income, family make up, local context etc. This means there is no one-template-fits-all solution (ITMB, 2007).

Therefore, it is necessary to have a working descriptor(s) for the purpose of this report.

## 6. Descriptors

In the UK the term 'Traveller' is used to collectively describe English, Welsh and Scottish Gypsies, Irish Travellers, Scottish Travellers, Roma – the name given to Gypsies from Eastern Europe, Fairground/ Show people, Circus people and New Travellers (Clark & Greenfields, 2006). This list is not exhaustive.

The collective term above, Matthews (2008) also argues, can be misleading as it suggests a uniform homogenous community rather than a group of communities which share some features and which are not fixed but contested and dynamic like all other communities.

As expressed by a participant;

*It is important to recognise that Travellers are NOT all the same – they are individual communities*

Gypsies, Roma and Travellers of Irish Heritage are identified as racial groups and covered by the Race Relations Acts as legitimate minority ethnic communities. It is important that policy-makers acknowledge this fact. These communities are, therefore, subject to all the rights and protections under the Acts as enjoyed by all other minority ethnic communities. Gypsy, Roma and Traveller communities frequently experience social exclusion and discrimination, which can be intentionally or unintentionally racist in character, on account of the lack of knowledge by the perpetrator(s) of their legal minority ethnic status (Clark & Greenfields, 2006). One of the participants reduced this to 'cultural misunderstandings'.

Some writers define Gypsies, Roma and Travellers of Irish heritage as two distinct ethnic groups. These two groups are defined as follows:

- **Gypsy/Roma** – This category includes people who identify themselves as Gypsies and or Romanies, and or Travellers, and or Traditional Travellers, and or Romanichals, and or Romanichal Gypsies and or Welsh Gypsies/Kaale, and or Scottish Travellers/Gypsies, and or Roma, irrespective of whether they are nomadic, semi nomadic or living in static accommodation (Clark & Greenfields, 2006)
- **Traveller of Irish Heritage** – A range of terminology is also used in relation to Travellers with an Irish heritage. These are either ascribed and or self-ascribed and include: Minceir, Travellers, Travelling People, and Travellers of Irish heritage. Travellers of Irish heritage speak their own language known as Gammon, sometimes referred to as 'Cant' and which is a language with many Romani loan-words, but not thought to be a dialect of Romani itself. (Clark & Greenfields, 2006)

This categorisation does not include Fairground (Showman's) travelling with circuses, or New Travellers or those dwelling on the waterways unless, of course, their ethnicity status is either of that which is mentioned above.

Some writers (Clark & Greenfields, 2006; Matthews, 2008) have argued that society has shunned people from these communities for too long, which in their views, has resulted in their growing mistrust of authority and many generations not receiving good health and social care. Meaningful involvement, however, requires that all cultural backgrounds should be understood and respected. Therefore, it is crucial that policy-makers engage effectively with people from these communities.

An understanding of the history, culture and language of Gypsy, Roma and Traveller communities is the key. Experience to date shows that meaningful inclusion can break down barriers and meaningful involvement is where a community or people can see their identity recognised (Clark & Greenfields, 2006; Matthews, 2008).

This view was echoed by some participants;

*Authority is spiritual, authority is not the Government*

*Travellers have similar roots, just different nationalities*

For the purpose of the 2004 Housing Act, this definition of Gypsies and Travellers was adopted:

*Persons of nomadic habit of life whatever their race or origin, including such persons who on grounds only of their own or their family's or dependants' educational or health needs or old age have ceased to travel temporarily or permanently, and all other persons with a cultural tradition of nomadism and/or caravan dwelling*

(Clark & Greenfields, 2006)

Participants at this event also identify with some of the features of this definition, when they claim that;

*You are born into being a Traveller*

Therefore, this report and the associated workshop recognise the non-uniform and non-homogenous nature of these communities and adapt the descriptor '**Gypsy, Roma and Traveller**', for the purpose of this report.

## 7. Profiling the communities

The starting point, in one's view, in the exploration of how to better involve Gypsy, Roma and Traveller communities, is to acknowledge their existence and aim for a good understanding of these communities as Clark & Greenfields (2006) also argue – that is, what is important to them, what are the unique issues and nuances etc.

For the purpose of analysis, this report adopts the conceptual framework employed by Van Cleemput and Parry (2001).

### ***Identity***

Gypsy, Roma and Traveller communities see themselves primarily as a separate ethnic group beyond their national identity determined by country of origin. This aspect of their identity is viewed as inherited and not chosen. Fear of losing the culture through forced change of lifestyle was evident during the workshop. Cultural 'rules' still exist and are still prominent within these communities.

As expressed by some participants;

*Culture is important*

*Fear of losing our culture, like the Native Americans*

### ***Racism and discrimination***

The experience of negative stereotyping and sometimes racism was mentioned by participants as a key issue. Prior experience and expectation of stereotyping has therefore engendered mistrust and sometimes leads to defensive and hostile behaviour.

As a participant expressed it;

*Gypsy and Roma people feel that the issue of TRUST is very real*

### ***Travelling (nomadism)***

Nomadism was seen as a central feature of the communities' identity and the inability to maintain a travelling lifestyle was frequently mourned. Freedom, choice and socialising were seen as the most important benefits of travelling, but also a necessity for men to obtain employment. Since nomadism is associated with freedom, the sense of a loss of freedom was described as having a profound effect on the psyche of Gypsy, Roma and Traveller communities.

As a participant puts it;

*The removal of the horse has taken the heart out of their life*

### ***Kinship and the family***

Many large Gypsy, Roma and Traveller families are inter-connected by marriage. The value of extended family (particularly kin) is very important to these communities. Participants talked about the accepted responsibility for members of the communities to care for their own family and for this to be shared among family members. Children are extremely important to these communities. There are clearly understood roles in families that are important to display; women should be good mothers and men should be good providers. Respect and regard for older relatives are maintained.

Some participants shared their negative experiences in hospital settings;

*When we have a child, all the family would want to see us. We were told they could not come in*

*When having just given birth, you want to see family*

### ***Self reliance***

This is seen as a key survival principle and there is pride in being resourceful. Men have an independent work ethic – working for themselves rather than being employed by others.

As expressed by some participants;

*Boys get married young because of the need to support their families*

*Traveller boys are meant to be men before their time – they don't go to school after the age of 12 or 13, they learn from their elders and mature before their time*

### ***Education***

A lack of formal education and subsequent illiteracy is common, particularly amongst adults. Reasons given for lack of education were varied, but largely elements of lifestyle (e.g. mobility) and culture (roles within the family), and the reliance on a more than 1,000 year old oral history and oral tradition of learning were cited. Inability to read and write is also often seen as an inevitable consequence of being a Gypsy, Roma or Traveller, but it is important to note that literacy is not seen as the only indicator of intellect and skill, as some of the participants echoed;

*Travellers don't believe in forcing older children into education*

*Education not seen as relevant, Traveller children would like to learn a skill*

*People think that just because you can read and write that makes you cleverer than someone who can't...but actually the person who can't is wise from learning from their elders*

There was concern that the younger generation needed a formal education to 'get on' in a changing world. Some of the participants acknowledged this, when they confirmed that;

*There are no doctors who are from the Travellers' communities, because of lack of educating in the past; education is now improving*

*Previously ended school at an early age, now recognising the importance of education*

*For those adults that struggle with literacy, they can get themselves skilled up*

*Knowledge needed about the steps to get support*

### **Beliefs/faith**

Beliefs appear to be an integral part of the experience of the lives of many Travellers, with prayer and belief in God's intervention being a source of comfort and strength in the face of adversity. Some participants confirmed that;

*Spirituality is important, nature healing, use of plants and old families' remedies*

*It's about God's will for us, living the way He wants us to*

### **Privacy & Confidentiality**

The need for privacy was identified by Travellers as a very important requirement. For women in particular, the need was strongly associated with 'cultural rules' concerning behaviour with the opposite sex. There was concern that non-Travellers did not understand this aspect of Travellers' culture.

Some participants shared their experiences;

*One of the issues is that Traveller women get embarrassed in front of their husbands when they have their medical problems / issues recounted to them without being asked whether this is OK or not*

*They [health workers] need to be more discrete*

*When a Community Member goes to see doctor or goes to hospital, they normally go as a family, and so they don't want a load of questions thrown at them. There must be a more discrete way of collecting this information.*

*Privacy in conversations is crucial*

### **Cleanliness**

The importance of cleanliness and hygiene is a notable feature of Gypsy, Roma and Traveller life. For women, the act of cleaning was an accepted important role. It was considered essential to be seen to have a clean home.

*There are misunderstandings from health workers about rules of cleanliness, rules around women, particularly after birth, they [health workers] sometimes use the wrong basin...health workers are ignorant*

## 8. Participants' Discussions

### 8.1 Experiences of Health and Social Care

This section relates the views of the participants regarding their experiences of, and interaction with, health and social care services, systems and practitioners.

Research indicates that Gypsies, Roma and Travellers experience the poorest health relative to other minority ethnic groups in the UK (Clark, 2006). This can be seen across a range of indicators including the lowest life expectancy and the highest infant mortality rates of any demographic group, as well as high levels of depression, anxiety, and heart disease.

As some participants confirmed;

*This is especially important regarding health, as young boys and girls are normally married by 16, so have kids very young, literally 9 months or thereabouts after marriage, which means that they are not experienced in relationships and there are often difficulties with pregnancies. They are not learning what they need to do with their first born, and are neglecting themselves by not going to antenatal appointments.*

Gypsies and Travellers often have difficulty accessing health care and may have to resort to using Accident & Emergency services for basic health care, with little follow-on continuity of care. Lack of monitoring means that many PCTs remain largely oblivious to healthcare needs of these communities (Clark, 2006).

As a participant claimed;

*We have limited knowledge of local health facilities*

Greenfields in Clark (2006) also identified that;

*'It is incontrovertible that significant numbers of Travellers who move into conventional accommodation experience claustrophobia, depression and mental health problems as a result of the abrupt transition to unsuitable and potentially hostile environments.'*

A participant also confirmed this;

*Making Travellers settle is like putting them into a cage, but you can't change their soul*

It has also been claimed that mental health problems are prominent among these communities (Matthews, 2008) resulting from the pressures that emerge from limited service support, being cut off from family support networks and adjusting to the lack of freedom.

A participant confirmed this;

*Mental health – it's an everyday occurrence...there are lots of issues*

Other research studies (ITMB, 2007) also affirm that many Gypsies, Roma and Travellers face difficulties registering with local GPs, and find information at GP surgeries not accessible, which results in a disproportionate reliance on A & E services.

Some examples cited by a participant;

*At GP surgeries, we are not able to relate to the leaflets...have leaflets that we can understand*

*We have problems with registration [with GPs] and filling forms*

The general mistrust of wider society by Gypsy, Roma and Traveller communities mentioned above also includes health staff, thereby giving rise to low expectations of staff and service provision. The common experience of difficulty in gaining access to GPs and getting registered is frequently attributed to racism, as is poor care.

As mentioned by some participants;

*The trust in doctor/nurse-patient relationships has broken down*

*Access to GPs – Travellers find it difficult to find one, either due to not having a fixed address, or because they can be pushed into housing & moved around the country on short stay leases (second stage/emergency stage housing)*

*Travellers don't like talking about issues with midwives, as they are seen as part of normal society. This means that things like postnatal depression are not recognised*

*Health visitors can often offer to come but then get their visit declined by the community. Or, health visitors can be too scared to go on to sites*

As openly expressed at this session, stories of unpleasant experiences, medical mishaps or adverse outcomes are frequently recounted and so make the incidence of negative events appear higher. Cronin (2003) however argues that the opposite is

probably true with good reputations being well circulated, and also that avoidance behaviour is a common outcome arising from lack of trust.

Cronin (2003) view is that lack of accurate information is compounded by usually poor communication with health staff rather than informed decision-making about health related options and that the most important factor influencing the outcome of health service encounters is whether the person is treated with respect and empathy.

Some participants identified with and confirmed pockets of good experiences in their interaction with the health services and systems. However, there were more examples of poor experiences shared at this event.

As some participants cited;

*Travellers' experience is often that when an ambulance comes to a site it is often accompanied by a police car. This is because if there has been a problem with one particular trailer at that site, the whole site becomes almost blacklisted as a trouble spot...stick with the trailer in question, not the whole site as this is grossly unfair and an example of discrimination*

*I had one child born with a cleft palette, heart & breathing problems. Despite having been in hospital for 3 days with a c-section, being booked in and all the official records in place, I felt complete neglect from staff. My baby was discharged without being checked over. Once home they realised that things were wrong and the baby was not feeding properly, but 3 doctors told me in A&E to go home. It was only when the grandmother took the baby to her local GP that we were referred on to another hospital. We were left to deal with it all on our own, because of preconceived attitudes towards Travellers. I had to leave hospital after one day as I couldn't deal with the attitudes of staff and the unhygienic state of the hospital*

*I have never had a health visitor. I was not visited and not given advice. I felt ignored*

*I have had seven kids and have never had a midwife come to the house. You normally have no option but to go to the hospital*

*I did always have a health visitor and midwife popping out to the site for 3 to 4 days after births. But this is down to the PCT having a known health visitor. This used to be good, but it's a decade ago now. Now health visitors are not coming so much*

*When my sister was having a baby, the midwife had tried to come and see her, but did not know the address to come to as they had moved*

Self-reliance and a cultural pride in being resourceful clearly impact on health beliefs. From the contributions of some participants, there were indications that the communities

have a stoic approach to life and existence. There were generally low expectations of health attainment. There is a strong expectation that the wider family will automatically become involved in caring for and supporting a sick relative in preference to outside support.

As expressed by some participants;

*Understand that travelling communities have a close knit family; they all look after each other*

*Often a grandparent or aunt/uncle will be the person you turn to for advice before a health professional*

Communication difficulties with health staff are common, particularly where the professional does not understand Gypsy, Roma and Traveller cultures. Poor literacy increases the lack of confidence, as a fear of being scorned for ignorance makes it more difficult to ask for clarification when explanations from health professionals are not understood.

Some participants recounted their experiences;

*A fellow Traveller had pneumonia, was taken into hospital, and just because they couldn't spell the previous doctor's name on the form they were asked to fill in they had to go elsewhere, as the receptionist staff wouldn't fill it in for them...not allowed to because of confidentiality and not flexible about this – this can be a major problem as many of the travelling community can't read and write*

*Language is a barrier, particular words used sometimes need repeating*

Family members or a trusted health worker are often brought to act as intermediaries to facilitate understanding in medical consultations. Trust in the health worker has to be earned, as it is an essential prerequisite for engagement. Embarrassment, especially about examination of or discussion about intimate areas of the body or discussion of health concerns relating to sexual health, is a common reason for avoiding access to health care. The need for privacy is important to these communities.

According to a participant;

*Women will not feel comfortable talking in front of male relatives or a male health professional*

*There are certain things Traveller women won't say or do with their husband there. Hospitals often force men to be there in the room with their wives. Hospitals acknowledge Muslim traditions over this, but not Irish Traveller ones*

For most participants, the ability to choose their style of accommodation and to decide for themselves whether, or how, they continue to live a traditional travelling lifestyle is of fundamental importance and crucial to their sense of independence and autonomy. The lack of choice or the intolerable conditions of living at sites, mentioned by the majority of respondents, are an indication to them of the negative way in which they are viewed by the non-Traveller society.

It is this feeling of injustice and persecution that is often forcibly expressed as much as concern about the adverse effects of the conditions per se, Cronin (2003) would argue. One of the most frequently mentioned health benefits, and often the first called to mind by respondents, is the freedom associated with being outdoors.

One participant expressed this;

*Children don't have opportunities to look after horses or chickens, so they don't have anything to engage their minds and their interest in nature*

Participants spoke despairingly of the stress arising from a lack of choice in being able to stay anywhere before they are forcibly moved on and the implication this has on access to health care.

Some participants lamented the inflexibility of the system and inconsistencies in accessing healthcare;

*In Ireland they have a National Health Strategy for Travellers...there is no political will to put targets on the NHS for Travellers*

*There needs to be some joining up – so that there is no postcode lottery, so Travellers can go wherever and expect a particular level of care*

*There needs to be someone to bridge the gap*

Some examples were given of doctors failing to communicate adequately and to give proper attention. People felt that doctors often cannot understand what Travellers are saying; and in turn Travellers cannot understand what doctors say. Stories were told of negative experiences with doctors who treated them dismissively or disrespectfully. Some mentioned instances of midwives and health visitors not wanting to visit a site on their own because they were scared and some would only visit with the police in tow or not at all.

Some participants shared their experiences;

*On calling out a doctor at night for sick child, the doctor was unwilling to visit, and when he visited he was unhappy and unhelpful*

*Families suffer in silence, rarely getting support*

*There are of course regional variations involved in all of this – for example in London, being a very multicultural place, people are more exposed to dealing with people whose first language is not English, and so they are not looked at weirdly or treated badly, in general*

Women felt more able to speak up for others than for themselves, in challenging negative staff attitudes or asking questions if things were unclear.

Another participant expressed;

*When we go into hospital we don't see good examples of things having changed for the positive – doctors, nurses etc. are still not aware of the issues*

*When they heard our accent, no families were allowed in. All together we had to visit two by two*

Below is a copy of a letter written by a member of the community, who could not attend, but wanted her voice heard and contributions noted and recorded.

### TRAVELLERS HEALTH ISSUES

As an Irish Traveller myself I feel there is a great need within my community for health issues because, My community has long lived on Traditional cures for all sickness in the past and even up to this present day. But as always time awaits for no one so the Irish Traveller community's must move along.

My community tend to have a high birth rate and higher mortality rates compared to the settled community families, recent reports have concluded that mental health issues particularly depression and suicide remain a significant health issue for my community throughout the u k.

In addition the barrier posed by low levels of literacy meant that accessing appropriate health care in the first place is a significant difficulty.



Also recently two new Traveller women moved on to our site in Manchester and needed to access a doctor,

When she went down with her very sick child she was told by a member of staff she needed a letter of her landlord to say she had just move into the caravan site! And if she needed a temporary access to medical care she was to ring 999! Now can anyone tell me were do you think this member of staff got her cultural awareness training from?

This is just one of the many issues that my community suffer in every day life,

Julie

## **Some suggestions from participants;**

Health professionals should know;

*If someone is ill, you may want to speak to a Priest; nurses from ethnic minorities or older nurses are more likely to get a Priest for a patient*

*Health professionals don't seem to listen; they are too busy on computers or filling forms - no human touch*

*There is too much form-filling*

*A doctor is seen as an important person but does not often live up to expectations*

Health professionals should;

*Treat people how you want to be treated*

*Listen, learn and build trust and prioritise cases*

*Understand that many women only want to talk in front of women ONLY*

*Less of the Western approach of one symptom, one appointment; care needs to be more holistic*

*We understand doctors and nurses are busy but we are their business*

*Mixed wards not good*

Positive steps to address the issues and problems;

*People from Traveller communities should go into health settings and teach them*

*Learn from other groups who have already got the message across about their culture*

*Traveller communities may not have education but they can talk and express their views*

*Receptionists in healthcare settings need to have training in awareness of Travellers and their culture – Community members can deliver training*

*Set up a dialogue*

*The communities need the Health Service and the PCT behind them or health professionals won't listen*

*Use sensible language*

*It would be great to have someone in hospital to help fill out your form if you can't read or write, instead of being turned away or being told that they aren't allowed to fill it in for you*

*It would be good to have pictures in hospitals and at GP surgeries (e.g. a notice with a picture of a trailer on it), that will bring down barriers straight away and so that Travellers can recognise something familiar straight away and feel at ease*

Messages for health workers;

*Communicate in our language*

*Government and the Authorities don't understand the importance of families*

*Travellers aren't asking anyone to adapt to their culture, why do the Authorities want Travellers to adopt someone else's culture?*

*The system needs to be simplified*

*We can teach them a thing or two as well*

## **8.2 Experiences of involvement**

In this session, participants were asked to share their personal experiences of involvement in health policy and service design. Participants were also asked to indicate if their involvement, where it happened, did make a difference to services? If so how? If not, why not?

Below are some of the views and experiences expressed;

*It has been a very frightening experience over the last 9 years. When I started to get involved, it was only when other Travellers were there that I felt safe. With the right people running the events - who understood – I didn't feel belittled.*

*In my experience they listen more to Roma issues than Irish Traveller issues*

*I have found myself in these PCT meetings being interrupted by people and not given a fair amount of time to express my views and so I have concluded that this is tokenistic involvement*

In relation to Equal Opportunities & Ethnic Monitoring;

*There is no proper ethnic monitoring to understand cultures & backgrounds*

*'White other' written on Equal Opportunities forms can be offensive as this is a crude way of monitoring ethnicity*

*There is variation within PCTs as to whether they do ethnic monitoring or not*

The feeling of being ignored by policy-makers and rarely asked their opinion was also expressed. Some participants had not heard of Local Involvement Networks (LINKs), what they are, why they exist and what could be done through them. In general, people do not know how to make complaints.

Some participants then suggested that;

*The Department of Health should give funding to get Travellers into LINKs etc, in order to help them make complaints and effect change*

*When Travellers do go to LINKs often the people are hostile and biased*

*Training needs to be given to LINKs by Community Members so that they are open to Travellers*

*Service users to be part of the inspection of health and social care settings*

From the shared experiences expressed above, one could conclude that the involvement of the Gypsy, Roma and Traveller communities appears patchy. As Matthews (2008, p.7) also argues;

*In fact, the majority of government initiatives fail to mention the specific needs of Gypsies and Travellers at all: see, for example, DfES (2004), DH (2004a) and Scottish Executive (2006). Although there are references to the needs of BME communities, there is little acknowledgement of the needs of people who live a nomadic lifestyle, either through choice or as a result of enforced evictions. It would appear that government policy, in its failure to acknowledge these needs, reflects the invisibility of Gypsies and Travellers*

Therefore, as mentioned earlier, developing meaningful involvement among Gypsy, Roma and Traveller communities does require consultation, creative thinking, commitment from all partners and investment of time. Involvement of these communities can take different forms and the starting points will vary depending on actual levels of trust, dialogue and involvement between the coordinating organisations and the communities.

From this session, the communities also recognise the need to engage more and be more proactive, as some of them expressed;

*If you don't understand, ask the doctor to repeat!*

*Traveller women need to empower their children to be able to and develop the "I can" mentality*

*Gypsies, Roma and Travellers should aim to have 'one voice'*

### **8.3 Barriers to involvement**

Difficulties in reading and writing are an issue for some in these communities. Only a minority in Gypsy, Roma and Traveller communities finish formal education, which means literacy problems are commonplace (Cronin, 2003).

This was also confirmed by some participants;

*Travellers don't believe in forcing older children into education*

At involvement meetings, some members of these communities may struggle to keep up with agendas and follow minutes which hinders participation and undermines confidence. Apart from this obvious practical issue, there is also the embarrassment of being exposed as lacking those basic skills that are taken for granted in this type of setting (Van Cleemput and Parry, 2001). Participants at the event did confirm that difficulties in reading and writing are sometimes a barrier to involvement in health policy consultations and influencing.

The efforts put into the pre-planning meetings for this session, however, enabled us to manage these barriers.

Equally it is important to note that many mainstream services have a very poor record of engaging with Gypsy, Roma and Traveller communities, owing largely to a complete lack of cultural understanding about these communities. This has often meant that the

attitudes of service staff towards these communities have been informed by societal prejudices and negative stereotypes rather than cultural awareness.

As a participant expressed it;

*It is important for health professionals to listen and learn from different communities*

The upshot has been the build-up of wariness and mistrust on both sides. A traditional fear of agencies, such as social services and the police, for example, means that many Gypsies, Roma and Travellers would feel very uncomfortable at the prospect of sharing information with them.

Some other noted barriers in influencing health policy and service design;

*Pilot projects are there and then dropped. Travellers are quite sensitive and they get tired of repeating themselves again and again*

*It is a shame that pilot projects that work well are not recognised anymore*

*When you do not see improvements when you have got involved it can be really depressing and you feel worthless*

**Some of the key barriers to involving Gypsy, Roma and Traveller communities in health policy and service design are;**

- a. Difficulties in reading and writing
- b. Lack of familiarity with bureaucratic meeting procedures and being intimidated by a formal approach
- c. Meetings can seem irrelevant to issues the communities face in their lives so they do not see the point in attending
- d. Lack of confidence
- e. There may be resistance within the communities to what can be perceived as colluding with mainstream services that are traditionally mistrusted, such as the police and social services
- f. Hierarchical power structures within the communities can mean that women who are interested in getting involved may be prevented from doing so
- g. Unrealistic expectations of what the involvement session can achieve

- h. Disengagement - if there are no changes on the ground after a certain period of time, or projects are cut short before they have the chance to make a difference, patience could be lost with the process

It is important to bear in mind that many of these barriers are complex and long-standing, having developed over generations, and it would be unrealistic to think that they can be done away within a short period of time. However, with some effort, there are practical things that can be done to achieve better and more meaningful involvement of members of these communities.

## 9. Aiming for good practice

This session raised the following questions for participants to address:

- a. What would encourage you and your community to get involved in health and social care policy and practice?
- b. What do we need to avoid and be conscious of when involving you and your community in health and social care policy and practice?

The first step towards engagement with these communities, as earlier cited (Colin, 2003) is to acknowledge their existence and then develop an understanding of the cultural nuances, followed by a profile of needs, before embarking on developing an involvement strategy, which must also be in partnership with the communities.

As a participant described it;

*It is about knowing the community's culture and beliefs*

Also, there is a need for policy-makers and practitioners to be aware of the historic context of disengagement between these communities and official administration systems, as this has given rise to an extreme wariness on both sides, as Matthews (2008) also confirms. The widespread exclusion - through a complex combination of being excluded and self-excluding, that Gypsy, Roma and Traveller communities have experienced from mainstream service provision, means that there is a need to incorporate a realistic set of objectives and timeframe into an involvement strategy.

As some participants explained it;

*The majority of Travellers don't complain too much*

*It is difficult to build up trust with non-Travellers, as they are not in the structure of society*

Setting out a strategy for involving Gypsy, Roma and Traveller communities in health and social care policy processes could also borrow from mainstream practice for working with other BME and under-represented groups and understanding the barriers that impede participation in the first place. Much of this is about following standard principles of community development, i.e. empowerment, consultation and participation.

As expressed by a participant;

*Travellers are like other communities – if we make provision for those whose first language is not English and people with disabilities, why aren't there the provisions for the Traveller community?*

In setting out to meet these communities it is important to clearly explain the point of the consultation, i.e. is the action going to go ahead anyway, or will its progression be based on the outcomes of the consultation. It is also critical to frame the objectives realistically and avoid creating expectations that are over-ambitious and cannot be met. This will be detrimental to the building of trust and future consultation.

There are arguments for and against paying people to take part in a consultation. From the experience of the session, it was recognised that payment can be in the form of expenses such as transport and child minding and/or a fee or voucher for taking part. Those opposed to payment argue that it can compromise the consultation process and motivate people to take part for the wrong reasons. This is a key issue that needs to be framed within a wider discussion of equality and power (Colin, 2003).

Below are further views expressed by participants;

*Awareness-training of all cultures; it should start in schools and the communities need to be involved in delivering training*

*Exercise patience when working with Travellers*

*Use local media, advertise information through radio – use ROOTS FM*

*Remove stigma associated with Gypsies, Roma and Travellers*

*Short-term funding is no good for pieces of research, as once the research gets underway more issues emerge*

*Create a young Gypsy/Traveller helpline that the younger ones can phone – to be manned by a Traveller woman*

*Best consultations should happen on sites, community representatives should be used as conduits*

*Travellers/Gypsy fairs are great way to meet Travellers and gypsies for consultation*

*The Traveller community needs to raise awareness and train people in hospitals*

*All nurses and doctors should have training regarding Travellers, especially as health outcomes are far worse in this group. They get half a day's compulsory training for BME groups, so why not Travellers?*

*We're not different; we just want the same as everyone else  
Instead of 'We will tolerate Travellers', we want to be accepted and recognised in society!*

### **Some suggestions on how to involve the communities in health policy consultations**

In line with Colin's (2003) view, in order for services to carry out effective involvement with Gypsy, Roma and Traveller communities, it is important that participating organisations and agencies address and explore the following:

- a. Partner with existing Gypsy, Roma and Traveller community agencies or organisations. It is vital to have agencies or individuals on board who have the trust of the communities, to broker engagement and lend credibility to the forum, specialist support workers, etc.
- b. Recruit members of the communities as facilitators
- c. Establish a clear agenda with the communities beforehand and ensure that members of the communities are involved in drafting the agenda
- d. Develop a format for the session to ensure that they have a stake in the objectives and that the forum will be relevant to them
- e. Establish a shared understanding of the purpose of the involvement with the communities or communities' lead; it is important not to create false expectations and to explain the type of outcomes that can be hoped for, as well as the uncertainty and potential slowness of the process
- f. Have a clear agreement on how and what will be in the report or be reported

- g. Adopt as informal an approach as possible to the meetings
- h. Arrange for expenses, including travel and childcare, to be covered (and preferably in cash on the day)
- i. Ensure participating staff have a full understanding of the cultural issues
- j. Organise meetings around convenient times and locations
- k. Choose a venue where the participants know and/or are familiar with, preferably a venue already known to them

All the attendees at this event were women, which could make one draw the conclusion that women are generally more willing to engage in involvement processes than men. Therefore, a different tack will be needed to get a group of men together, as effective consultation requires hearing from different voices within the community, including men and women and young and old.

## **10. Nursing & Midwifery Council's (NMC) Session**

This session focused on what the NMC does, their role as a regulator – what it is for, what they do - and what the NMC is going to look like in the future. Emily Kessler (Stakeholder Strategy Project Manager at the NMC), summarised some of the key points in the NMC's Code of conduct for nurses and midwives:

- Make the care of people your first concern, treating them as individuals and respecting their dignity
- Work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community
- Provide a high standard of practice and care at all times
- Be open and honest, act with integrity and uphold the reputation of your profession

Participants were then asked to address the following questions:

- a. What behaviour would you expect from a nurse or midwife, and
- b. What would you do if you did not get it?

<b>Good, expected behaviour</b>
Adapting
Communication
Listening
Meeting individuals' needs
Go the extra mile
Sensitivity
Supporting the whole person
Sensitivity to issues relating to culture and gender
Providing choice
Keeping it simple
Respecting decency
Understanding family history
Explanation of drugs and medication
General advice on conditions, self care, supporting the whole person
Taking a real interest in you
Provisioning for privacy – making sure you have a private space, curtains around – so that you are not walked in on by husbands or other men on the ward (be they staff or the public)
Having the choice of a female assistant or midwife, if possible, but this obviously depends on staffing
Recognising misconduct in colleagues' work, reporting this to senior management and making sure it is acted upon
Very careful about procedure around purity (and cleanliness)
Caring
Sensible
Generous and warm
Honest
Understand when people are loud, they are not being aggressive
Understanding of language and culture
To come without prejudice
Cultural knowledge
Know family history
Gain trust
Patience, sometimes need to explain things over and over

<b>Bad behaviour</b>
Lack of explanation
Not responding to patients' needs
Being rude
Not listening
Being unable to respond
Insecure

Lack of experience
Not realising that others can help
Making assumptions
Being rigid and unhelpful
Ignorance, not interested in learning
Too bureaucratic
Lack of respect
Ignoring the knowledge of the patients
Not respecting your wishes and opinions
Not listening to you or explaining step-by-step what they are wanting to do/how they want to administer drugs (particularly when it is not an emergency situation)
Arrogance with authority (e.g. consultants) – just because of their position/expertise, they should still be respectful and listen to your wishes!
Being hostile to family members visiting or accompanying patients, being the aggressor
Rough-handling (particularly of the elderly or vulnerable ) and not taking notice of family complaints
No feedback given to families with actions being taken following complaints
Poor manners
Patronising

## 11. Nursing Summary of learning for nurses and midwives

From the experiences garnered from participants at this workshop, below is a summary of practical considerations regarding interaction with Gypsy, Roma and Traveller communities in nursing and midwifery contexts.

### **Health professionals need to be accepting and respectful of these communities, their culture, history and languages:**

- In health and social care settings as much as everyday life, these communities often feel that elements of racism and stereotyping adversely affect their lives. Barriers have built up and Travellers often find it hard to talk about issues with health and social care professionals as they are part of ‘normal’ or ‘mainstream’ society. Therefore there is a need for better communication, respect and understanding on both sides between these communities and practitioners in order to develop openness and trust
- Judgements about their communities can engender an idea that Traveller sites are not safe for midwives and health visitors to visit and police escort is needed. Some participants noted that whole sites are blacklisted because of problems with one particular trailer, which is an unfair reaction

- Because of strong family bonds and a culture of self-reliance, there is often an accepted responsibility to care for your own family rather than seek outside support
- If a family member is ill in hospital, the family may want to speak to a Priest. Spiritual needs are sometimes overlooked by nurses
- Gypsy, Roma and Traveller cultural awareness training needs to be built into all nurses', midwives' and frontline admin staff training, preferably delivered by Community members themselves. This training is particularly important given that health outcomes are far worse in these communities compared to wider society
- Travellers are not asking anyone to adopt their culture, so why do the Authorities want Travellers to adopt someone else's culture?

### **Privacy and discretion:**

- It is important to ask Traveller women if they are happy to have their medical issues discussed in front of their husbands and male relatives or not, as lack of discretion with such personal information can be very embarrassing for them.
- When a Community member goes to hospital they normally go as a family unit, and so being asked many personal questions in front of them can be embarrassing – discretion needs to be exercised when collecting personal information
- Traveller women may only be comfortable talking to female health professionals

### **Literacy:**

- Travellers do not believe in forcing older children into education, therefore poor literacy can often be an issue
- There needs to be understanding from practitioners and particularly frontline admin staff regarding poor literacy when it comes to form-filling and reading letters / notes. Participants at this workshop noted times when they had been turned away from services for not being able to fill in forms, and lamented the lack of understanding and support they often have in these situations, which is often justified by confidentiality / data protection reasons.
- Literacy may be an issue, but Travellers can still talk and express their views!
- A fear of being scorned for ignorance makes it more difficult to ask for clarification when explanations from health professionals are not understood
- In health service settings, leaflets and posters they can better understand and relate to would be appreciated – the suggestion of having a picture of a trailer on such materials was a popular one to help bring down barriers straight away

### **Points raised specific to Midwifery:**

- Because young Travellers normally get married and have children at a young age, inexperience and misunderstanding about the importance of antenatal

appointments often means little interaction with health services until the later stages of pregnancy and more complications

- Participants lamented the patchy provision of health visitors and midwives by PCT area, commenting that a decade ago things were better as they saw them more often but this is not the case now
- Rules around cleanliness, especially in the birthing process with the type of basin used, are very important to Traveller women and it is important to check with them first that they are happy with the arrangements in place
- Following childbirth, families are keen to see the new-born and it can be particularly hard if they are not allowed to go as a group to do this, instead only allowed to do so in pairs for example

## 12. Some suggestions for

### 12.1 The Nursing & Midwifery Council

- a. Information needs to be in ALL nurses' and midwives' training about Travellers, Roma and Gypsies and cultural competencies, not just regarding BME groups. Nurses need to have better cultural openness in general – social justice is what they signed up to after all!
- b. In the Code for nurses and midwives it is stated 'A personal commitment to equality and diversity' – this needs to be unpacked – what does it *really* mean?
- c. There could be a column in the NMC magazine, written and contributed by a Traveller – so we are not forgotten
- d. Resources need to be more engaging – e.g. on the NMC website, DVDs, or images in leaflets so that people can connect with it straight away (e.g. with a trailer picture on the front)
- e. You could promote shadowing schemes so people can really understand the other side – there needs to be training on both sides.

### 12.2 National Voices

- a. Introduce subsidised membership rate for 'seldom heard' groups
- b. Promote Traveller communities more
- c. Employ someone from the Traveller community
- d. Set up a panel of Traveller communities
- e. Involve the communities more
- f. Demonstrate the result or you'll lose people's trust!
- g. Those from the session today will be contacted to see if they would like to join the Service User Panel
- h. There could be a Traveller advisory panel at the heart of National Voices for example, to be called upon when drawing up policies

### 13. Conclusion

It needs to be recognised and noted that not everyone is willing or able to get involved in engagement and consultation processes with policy-makers and service providers. It is important therefore, that involvement is not tokenistic and that there is an awareness of barriers that may prevent people from getting involved, for example, in the case of Gypsy, Roma and Traveller communities, a lack of time, confidence, skills, literacy etc. (ITMB, 2007).

There is also a need for a sensitive, clear and carefully thought out approach to involving these communities that acknowledges their existence, the levels of exclusion and the widespread mistrust that have developed towards many services, whilst also recognising that cross-cultural issues need to be given consideration.

Policy-makers, service providers and Gypsy, Roma and Traveller communities all need to make a shift change to ensure that meaningful involvement is achieved.

As some participants summed it up;

*Both sides need training, both talking, both listening*

*No to tolerance; Yes to respect and acceptance*

*This must not just be forgotten, real action must be taken by all of us*

## 14. Evaluation

18 participants completed feedback forms

	Very good	Good	Average	Poor	Very poor
Overall, how would you rate the event?	89%	11%			
Pre-event Information & Administration	67%	28%	5%		
Venue & Catering	72%	22%	6%		
Staff Facilitation of the Event	78%	22%			

	Yes	Not sure	No	No answer
Did you know why you were asked to take part?	83%	11%		6%
Was the information you were given easy to understand?	94%			6%
Were you listened to and respected?	94%			6%
Do you understand what will happen now as a result of the event?	83%	11%		6%
Has taking part changed your view of the NMC & National Voices?	72%	22%		6%

<b>Any other comments or thoughts about the event? How could it be improved?</b>
<ul style="list-style-type: none"> <li>• More meetings need to be arranged. Keep Irish Travellers informed of what is happening after meetings.</li> <li>• I hope it is not just words and something is going to change for Romas, Gypsies and Travellers. Thank you.</li> <li>• Would like more events - I want to be involved. I enjoyed today!</li> </ul>

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