



Pacesetters Programme
Gypsy, Roma and Traveller core strand

Evaluation Report
for the
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Patrice Van Cleemput
Paul Bissell
Janet Harris

Public Health Section
ScHARR
The University of Sheffield

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Executive Summary

Background

This report presents the findings from an evaluation of the core Gypsy & Traveller health strand of the Pacesetters Programme, a partnership between local communities who experience health inequalities, the NHS and the Department of Health, launched in March 2008. The Equality and Human Rights Group (EHRG) of DH worked with six Strategic Health Authorities (SHAs) and 18 participating Trusts to deliver equality and diversity improvements and innovations which aimed to enhance patient and public involvement in the design and delivery of services.

The motto “Nothing about us without us” was used to emphasise the importance of community members’ involvement as equal partners in Pacesetters. In order to underline the commitment to this motto, a Quality Assurance Group (QAG) was formed. It comprised two invited community members from each SHA region and first met together in January 2009. An intended outcome of QAG involvement in Pacesetters was that they would feel valued by the Department of Health and the participating SHAs and Trusts, and play an important role in advising on the work of Pacesetters.

Aim of the Evaluation

The aim of the evaluation was to assess the strengths and weaknesses of the Pacesetters initiatives and the feasibility of scaling up the successful improvement strategies across a wider network of NHS Trusts.

Evaluation Methods

The evaluation used a mixed methods approach to assess the process and (wherever possible) the outcomes of the Pacesetters Programme. The evaluation commenced in April 2009 and six projects representing a range of service improvement themes were selected as case studies. Methods included activity data collection, evaluation questionnaires, focus groups and individual interviews with key stakeholders. Each SHA was represented by the selected projects. Each of the eighteen Trust leads were also advised on determining feasible objectives, documenting activity data and measurement or assessment of outputs and outcomes for their own local evaluations.

Evaluation Findings

a) Community Member Quality Assurance Group (QAG)

Although no explicit terms of reference for the QAG were identified, QAG members were enthusiastic and viewed their role seriously, valuing this unique opportunity for involvement in the Pacesetters Programme. They experienced a sense of worth and achievement in being facilitated to interview and appoint the evaluator (PVC). They also valued the opportunity to meet as a 'mixed' group and to critique the Pacesetters projects. In the absence of an opportunity for dialogue and contextual information, the feedback sent to Pacesetters project leads was felt in some cases to be inappropriate. Community members had no remit regarding engagement in their local projects and there was a clear lack of clarity for both QAG members and the project teams about the role of the QAG. QAG members were remunerated centrally and at a higher rate than peers who were steering group members or advisors on local projects. These factors combined to compromise relationships between QAG members and the local Pacesetter teams.

Staff changes in the Department and an unfilled vacancy for a QAG coordinator resulted in a break in continuity in their involvement. Although QAG members valued the two convened meetings during the 2-year period and felt an initial sense of worth, the raised expectations of a final meeting that was not fulfilled and the paucity of feedback on their contribution diminished the overall sense of being valued and involved.

b) Individual case study projects

i. EAST MIDLANDS SHA: 'Health Ambassadors'

Three Trusts concentrated their resources to deliver this project. Thirty community members were trained as health ambassadors to raise awareness of the culture and health needs of Gypsy & Traveller communities, to break down barriers and encourage trust and dialogue with healthcare staff. The Ambassadors have delivered over 60 training sessions to approximately 800 staff from various disciplines across the region. Staff evaluations were positive, indicating achievement of the aims. Identified changes to staff practice included improved communication skills, resulting from improved awareness and understanding, alongside practical changes such as texting

reminders for appointments. In one of the few GP surgeries where training has been delivered, community members are now feeling much less reluctant to attend. Ambassadors demonstrated increased confidence in communicating with health staff and now feel more willing to ask questions about their care and treatment. There are plans to sustain the work, with a waiting list of further Ambassadors wishing to be trained and existing Ambassadors wishing to develop their role further

ii. WEST MIDLANDS SHA AND SOUTH EAST COAST SHA – Patient Adult Health Record

Five Trusts in these two regions worked with community members to design a hand held health record and to pilot its use in supporting access to healthcare and facilitating continuity of care. A staff training programme was commissioned with trainers and community members delivering twenty sessions, reaching 229 staff across the two regions. GP practices are also receiving separate training. The training was evaluated positively with particular reference to the opportunity to learn directly from community members. Records distribution and completion of baseline health information is in progress and there are plans to monitor use. At least one other Pacesetter site (Bristol) has expressed interest in using the records in their area.

iii. SOUTH WEST SHA – Staff cultural awareness raising and Directory of local services for the community

NHS Bristol synthesised all Gypsy and Traveller work across the greater Bristol sub-region for maximum benefit. Staff awareness training regarding culture and health needs resulted in a two-stage project with five community members recruited by a peer community development worker to a ‘Confident to Present’ training course. Initial staff training sessions to be delivered by the community educators are planned. A directory of resources was produced in consultation with community members and through multi agency collaboration. This set out to increase awareness of local services, support access to health care and to serve as a health promotion tool. Distribution of the directory is in progress. Review and update of the directory and provision of further staff training sessions will be facilitated through the continued involvement of the community development worker and health visitor.

iv. YORKSHIRE & HUMBER SHA – Raising awareness among Gypsy and Traveller communities and staff cultural awareness raising.

Activities to increase community participation and health awareness culminated in commissioning an Introduction to Community Development and Health (ICDH) course in order to support community members to further develop their skills and become active within their community on health projects. A core group of 4- 5 community members attended for the first term, but crucially, interest was not sustained. Lessons were learned that more time was required and a number of variables to be addressed to develop capacity in a divided community, with a regional approach involving other established community support agencies. A celebration event was held with invited speakers from neighbouring Gypsy and Traveller communities to heighten awareness of opportunities for personal development; these included health ambassadors from East Midlands.

A neighbouring community members association was also commissioned to deliver staff awareness sessions. 55 staff from various agencies attended the three sessions. The input from community members had the most immediate impact on participants and most evaluated the training well, highlighting this important aspect.

v. LONDON SHA

Increase GP registration amongst Newham's Roma community.

To raise awareness of mental health issues amongst Newham's Roma community.

NHS Newham and East London Foundation Trust (mental health) (ELFT) worked closely together on their separate projects to increase staff awareness and improve access to services for Newham's Roma population.

NHS Newham developed a staff-training programme in collaboration with a project Roma support worker. The two pilot sessions at GP practice lunchtime meetings were well evaluated and the allocated time was extended to accommodate the interest and need for information by staff.

A health event was organised to raise awareness of health services among community members and held at the Roma Support Group, with support from Roma volunteers. Presentations were delivered on three health topics and health checks were available to the audience of approximately 60 Roma men and women. Uptake was high and was

successful in raising awareness and identifying unmet need for referrals to GPs and community care navigators.

ELFT worked in partnership with the Roma Support Group to research, develop and produce a theatre drama production to address the key issues of mental health in relation to the Roma community. The production of the play has already been successful in addressing some taboos so that more timely support and intervention can take place. A DVD of the play and also containing further information on improving mental health and access to support, aims to consolidate this success and will be made available on request for community members,

ELFT worked with NHS Newham to produce respective training packages for their Trusts. ELFT will be piloting the training package for mental health practitioners as part of the wider cultural competence training for staff after it has been piloted.

Cross cutting themes across Community Engagement

In this section we highlight some of the key themes that emerged in relation to community involvement in the Pacesetters Programme.

§ Community Engagement as a key emphasis ('Nothing About us without Us') – with directives to SHAs/Trusts

-Community members need to be consulted at outset on priorities for action.

§ Fluctuating commitment to community involvement centrally

- Trust is hard won and fragile and can be lost if community member involvement is seen to be tokenistic through their voice not 'counting' or if expectations are raised and then not matched. Promises of action should be followed through or explanations given if there is good reason that they cannot be.
- Continuity and good communication with a trusted person is important.

§ Different understanding and experiences of community involvement

- Community engagement should not be seen as a 'quick fix' and requires time and sustained effort.
- Each Trust had varying experiences and were at different starting points on the ladder of engagement.
- Representation regarding community members needs to be transparent.

§ Different levels of community involvement locally

- The need for and development of a project must be decided with community members and they must take ownership of it or champion it for it to succeed.
- Involvement through communication should be maintained through all stages of the project.
- Flexibility is essential to allow for effective community involvement.
- Confidence and trust are core issues.
- Facilitation through a trusted link person should be provided to overcome barriers to participation.
- The remit of community members as advisors or decision makers should be clear
- Time and costs of community involvement need to be built in to local budgets.

Cross cutting themes across Projects

- § Process was as important as outputs in developing lasting collaborations, confidence and increased skills among community members, and increased awareness of health services.
- § Staff changes within Pacesetter teams and also in the Department of Health were numerous, leading to communication breakdown and loss in continuity with a negative impact on project delivery.
- § Two years is insufficient time for embedding real change, particularly for Trusts that are at a low starting point in relation to community engagement. Bureaucratic delays in the release of funding and setting up service level agreements delayed the start of several projects.
- § Evaluation needs to be built in and independent evaluators appointed before the start of the projects for appropriate systems for data collection to be put in place and to ensure baseline data collection.

- § Sufficient dedicated time and administrative support is required for project delivery staff if they are also combining the work with a permanent service delivery role with community members.

- § Remit and remuneration of community members must be agreed at the outset of the projects

- § Pacesetter projects are much easier to deliver in Primary Care Trusts where key professionals are more easily identified.

Chapter 1

Gypsy, Roma and Traveller health inequality: contextual background to inclusion as a core change strand of Pacesetters

Although health policy had particular emphasis on reducing inequalities in health and targeting socially excluded groups (Acheson D 1998; Department of Health 1999b) for several years prior to the inception of the Pacesetters Programme, the health needs of Gypsy Travellers were not referred to, even in a 1999 policy document, *Reducing Health Inequalities: an Action Report* (Department of Health 1999a), thus demonstrating the extent of their social exclusion.

A report by the South West Public Health Observatory in 2002 ((Doyal L et al. 2002) highlighted the need for further research to inform work to reduce their health disadvantage. In the foreword to this report Dr Gabriel Scally, Regional Director of Public health stated

There is no other group in our population that is so marginalised and disadvantaged as Travellers. Their culture and lifestyle is often at variance with that of the settled population amongst whom they live. This can sometimes create tension and misunderstanding.

There is no doubt however that, whilst the health of the population as a whole continues to improve, the health of Travellers remains a major concern...Health inequalities, quite rightly, is at the very top of the health agenda and there can surely be few other groups whose needs require such urgent attention.

The report highlighted the “*the comparative poverty of research on their health experience*”, and the need to improve the evidence base in order to work with Travellers to improve their health experience. In the same year, research, commissioned by the Department of Health, was being undertaken to address this need by identifying the inequalities in health status between Gypsies and Travellers and non-Gypsy Traveller populations and exploring their perceived barriers to service access or use (Parry G et al. 2007). The results showed striking inequalities in the health of Gypsies and Travellers, even when compared with people from other ethnic minorities or from socio-economically deprived white UK groups and demonstrated the long-term health impact associated with a history of persecution, social

pathologisation and social exclusion of Gypsies and Travellers. A society that has demonstrated entrenched and widespread hostility towards Gypsies and Travellers has contributed to wariness about trust in outsiders and contributes to the communication barriers with health staff that are implicated in their poor access to healthcare. The report identified that cultural insensitivity, whether arising from ignorance or from racist attitudes, was a strong feature in accounts of compromised communication (Van Cleemput P et al. 2007).

This has important implications for use of health services and helps to account for the inverse relationship between health needs and service use found in the health status study (Parry G et al. 2007). Although several respondents in the study described positive experiences of health services, these were often depicted as exceptions to the norm

It was in response to the research findings that the Department of Health engaged with Gypsy and Traveller community members, organisations that represent them, and NHS organisations to discuss appropriate action. At this time the Pacesetters Programme was being designed by the Equality and Human Rights team at the Department of Health as a partnership between them, the local communities who experience health inequalities and the NHS. This was the ideal opportunity to address the serious health inequalities between Gypsy and Traveller groups and others in the UK and to improve their access to health care, with its overall aim of delivering equality and diversity improvements and innovations resulting in patient and public involvement in the design and delivery of services, reduced health inequalities for patients and service users; and working environments that are fair and free of discrimination. Ethnic group was one of six equality strands in the Programme, but to ensure that participating Trusts and SHAs did not avoid the more challenging choice of focussing on Gypsy, Roma and Traveller communities, improving the health status of Gypsies and Travellers was made a core change that every participating Trust had to address.

However, many NHS organisations and staff are confused about who is covered by the terms Gypsies and Travellers. There is particular uncertainty over the fact that approximately one third of the population of Gypsies and Travellers in the British Isles now live all or some of the time in housing.

In the UK, distinct groups, commonly known as English Gypsies, Welsh Gypsies, Irish Travellers, Scottish Gypsy Travellers and also more recent arrivals of Roma from various countries in mainland Europe, have been identified – and have identified themselves – as having different languages, beliefs and certain different cultural traditions but also many common features of lifestyle and culture that unite them collectively as distinct from the rest of UK society. They are all recognised as ethnic groupings under the Race Relations Act 1976 (Home Office 2000). Other groups of Travellers include Show-people and New Age Travellers (who now prefer to be called New Travellers).

Although Gypsy and Traveller communities are poorly captured in most national datasets, Communities and Local Government estimates that they represent 0.6% (c.368, 000) of the total UK population. (Cabinet Office 2010).

The core Gypsy and Traveller change strand of the Pacesetter Programme coincided with, and was supported by, the publication of the Primary Care Service Framework: Gypsy & Traveller Communities (NHS PCC 2009). Each primary care service framework (PCSF) is a generic, comprehensive and enhanced service specification for PCT commissioners and practice-based commissioners. The specific purpose of the PCSF for Gypsies and Travellers is to: ‘equip PCT commissioners with the necessary background knowledge, service and implementation details to work with providers and practitioners to deliver accessible primary care services, over and above mainstream services, for Gypsy and Traveller communities and to improve Gypsy and Traveller health and quality of life by providing effective, appropriate, ongoing support.’

An indication of the pathologisation of Gypsies and Travellers in society can be detected in criticisms of the PCSF published in various newspapers and other forms of media. This illustrates the size of the challenge faced by those seeking to reduce health inequalities as it highlights limited understanding of the concept of health equity. The PCSF points out that this policy is concerned with health equity by stating that it is “not about providing different or separate services for Gypsies and Travellers; rather, it is about ensuring that these communities can access the same high quality, mainstream primary care services as everyone else”. This was the aim for participating Trusts in the Pacesetters Programme.

Chapter 2

Improving the health status of Gypsies, Roma and Travellers: core strand. Pacesetters brief

Following initial planning meetings between 2005 and 2007, a priorities planning workshop was organised to help Pacesetters sites prioritise the Gypsy & Traveller health core changes that they will work on. The event was to be attended by community members, and run along the lines of a community engagement event. At the meetings in the previous years community members and other stakeholders discussed the most pressing issues relating to improving the health of Gypsies and Travellers and reviewed schemes and initiatives that were already in place to identify what works and where the DH Pacesetters Programme could focus its attention through participating SHAs. At this stage there was cross-departmental collaboration with the Gypsy and Traveller Unit at the ODPM (since replaced by the CLG) and acknowledgment that greater collaboration is also required at local level between local councils and PCTs, particularly with regard to addressing accommodation issues. Several priorities were outlined for consideration at the end of the initial meeting, some of which were subsequently identified as possible change ideas for the Pacesetter Programme. Other suggestions were also subsequently adopted that would complement the Pacesetters work; for example funding voluntary organisations with innovative and nationally significant schemes for improving NHS access and outcomes for Gypsies and Travellers through the Section 64 General Scheme of Grants (S64 of the Health Services and Public Health Act 1968)

Before the meeting in March 2008 a proposed work plan with short listed change ideas that had been identified from the discussions at the previous meetings was circulated to the participating SHAs prior to their attendance. They were briefed to work singly or together within or beyond their SHA areas, commit themselves to a programme of local awareness raising and address one or more of the other issues described below as part of the core work on improving the health status of Gypsies and Travellers.

What Trusts would take on, and how they chose to work, was to be determined by results of their engagement with local Gypsy & Traveller communities and in the light

of local priorities. The SHAs were also made aware of the DH Community Engagement Guide, A Dialogue of Equals (Department of Health 2008) to assist them. The change ideas themes that they could choose to work on were:

Raising awareness

Pacesetter sites were asked to explore different ways of raising awareness within both health and Gypsy & Traveller communities. Approaches could range from public health campaigns on sites, better training for NHS staff, with training being led by community members, through to appointing “health ambassadors” from within Gypsy & Traveller communities to bridge the gap between the NHS and those communities. All Pacesetter sites were actively encouraged to adopt the Leicester PCT Health ambassadors’ model that was about to be implemented, or to explore other ways of raising awareness.

GP registration and better access to the NHS

Pacesetter sites were asked to consider ways to improve GP registration, thereby improving access to NHS services in general

Better sharing of personal health information

SHAs were reminded of the problems of recording, updating and sharing of personal health information for Gypsy, Roma & Traveller communities. They were informed of two examples of health records, completed by NHS and health staff, and owned and kept by community members, that had been developed to address this issue.

Hastings and Rother PCT, a participating Trust, had worked with local communities to develop a local hand-held record. NHS Scotland had also introduced nationwide hand held record.

Pacesetter sites were asked to consider how they might improve the recording and use of personal health information, possibly following the lead of Hastings and Rother PCT or in other ways.

Other important health matters

Pacesetter sites were advised that ideally, the core work should be focused on the above themes in order to give the work a sharp and coherent focus, but that in exceptional circumstances, in addition to, or instead of, work on improving GP

registration or personal health information, they may work on other important health matters if agreed with local communities as the best course of action.

Finalising and submitting plans

Following discussion and work in their SHA groups, the eighteen participating Trusts had all identified change ideas that they wished to work on. Some of these Trusts had made their decisions without any of their own community members present, but the community members who did attend the meeting from other regions were asked to divide themselves so that the Trusts in each SHA group had community members working with them.

It was agreed that the Trusts, with their local community members, should subsequently review the outcomes of the 10th March workshop, and confirm the change ideas that they would like to work on by June 2008. Those Trusts who were unable to involve community members in the workshop, were asked to secure that involvement before proceeding to confirm their proposed change ideas.

Chapter 3
Outline overview of Pacesetter sites:
Gypsy and Traveller core change project plans

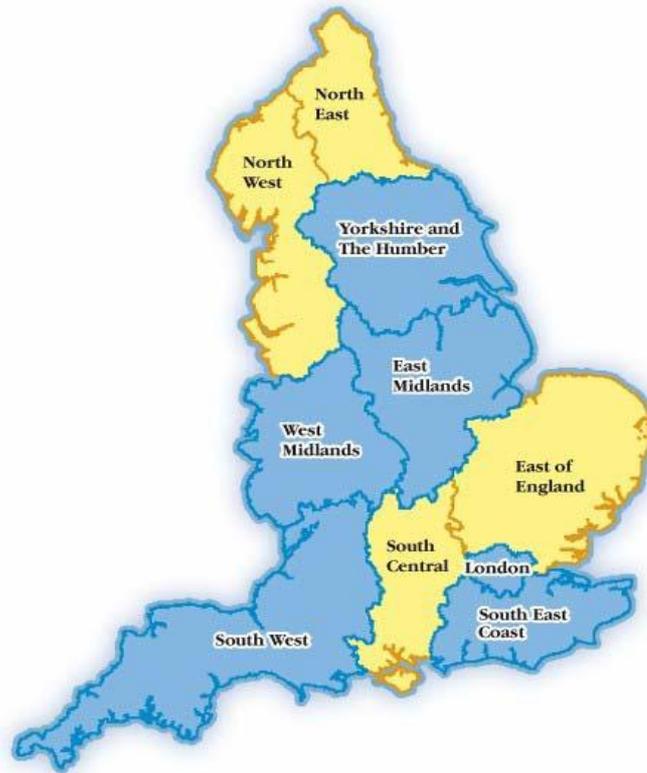


Figure 1 Map showing areas covered by Pacesetter sites

YORKSHIRE AND THE HUMBER SHA

Programme Manager - Janet Smith

Leeds Mental Health - Teaching NHS Trust ¹

- 1. Respect for Communities
 - Staff Cultural Awareness raising

NHS Sheffield

- 2. Tackling health Inequalities in the Gypsy and Traveller Communities
 - Raising awareness among Gypsy and Traveller Communities
 - Staff Cultural Awareness raising

¹ The Gypsy and Traveller project in Leeds PFT was their core change project in Wave 1 and was completed before the evaluation of the Gypsy and Traveller core change projects commenced.

Yorkshire Ambulance Service NHS Trust

3. Gypsy and Traveller community first responder and health education scheme
Raising awareness among Gypsy and Traveller Communities

EAST MIDLANDS SHA

Programme Manager – Leon Chariker

Leicester City PCT

4. Gypsy and Travellers Health Ambassadors Programme
Staff Cultural Awareness raising
Raising awareness among Gypsy and Traveller Communities

University Hospitals of Leicester*

East Midlands Ambulance Service NHS Trust*

* These two Trusts combined with Leicester City PCT to participate in the Health Ambassadors programme

WEST MIDLANDS SHA

Programme Manager – Balraj Rai

5. Development and piloting of Personal Adult Health Record for Gypsy and Traveller Communities (PAHR) ²

Walsall Integrated Learning Disability Service (NHS Walsall)

6. Gypsy and Traveller community healthcare needs
Raising awareness among Gypsy and Traveller Communities

Wolverhampton City PCT

7. Implementing of Gypsy and Traveller service delivery framework for the PCT
Improve access to health services – improving ethnic monitoring

LONDON SHA

Programme Manager – Maria Kyriacou

NHS Newham

8. Increase GP registration amongst Newham's Roma community
Increasing GP registration
Staff Cultural Awareness raising
Raising awareness among Gypsy and Traveller Communities

² The PAHR project was a joint project between the 5 participating Trusts in the West Midlands and South East Coast Regions

East London & City Mental Health Trust

9. To raise awareness of mental health issues amongst the Newham's Roma community

- Raising awareness among Gypsy and Traveller Communities
- Staff Cultural Awareness raising

The Royal Free Hampstead NHS Trust

10. Improving access to maternity services for Travellers at The Royal Free Hampstead NHS Trust

- Staff Cultural Awareness raising
- Raising awareness among Gypsy and Traveller Communities

SOUTH EAST COAST SHA

Programme Manager – Jonathan McInerny

5. (see West Midlands) Development and piloting of Personal Adult Health Record for Gypsy and Traveller Communities

- all three Trusts are involved in the PAHR project

Surrey & Borders Partnership NHS Trust

11. Awareness raising of Gypsies and Travellers health needs

- Staff Cultural Awareness raising

Hastings & Rother PCT

12. Improving the health status of Gypsies and Travellers; Health resource for 0-2 year olds.

- Staff Cultural Awareness raising
- Raising awareness among Gypsy and Traveller Communities

East Kent Hospitals NHS Trust

SOUTH WEST SHA

Programme Manager – Michail Sanidas

Bristol PCT

13. Improve Gypsy and Travellers access to local services

- Staff Cultural Awareness raising
- Raising awareness among Gypsy and Traveller Communities

South Western Ambulance Service NHS Trust

14. Develop a model of Gypsy and Traveller Participation in the promotion of health and well being

- Raising awareness among Gypsy and Traveller Communities

Chapter 4

Evaluation Methods

The evaluation used a mixed methods approach to assess the process and (wherever possible) the outcomes of the Pacesetters Programme. The evaluation commenced in April 2009 and six projects representing a range of service improvement themes were finally selected as case studies.

The external evaluation team worked with participating Trusts to identify feasible objectives and to consider the evaluation tools they required to measure process, progress and success in achieving those objectives. There was agreement that Pacesetter sites would collect activity data, and ideas were discussed and suggestions made so that there was shared understanding of the baseline audit data and ongoing activity data that would be required for the external evaluation of the case study sites. The sites that were not included for an in depth case study evaluation were also encouraged to collect and document their activity data and to measure their outputs and outcomes in the same way.

Methods for evaluating the process and outputs of projects, and the short term outcomes, included data collection from minutes and reports of meetings or events forwarded by Pacesetter leads, participant observation of steering group meetings and project activities such as training sessions and health awareness events, interviews with delivery leads and project managers, evaluation questionnaires, telephone interviews, and focus groups and individual interviews with key stakeholders. Methods for evaluating process and success of the core principle of community involvement included participant observation at meetings and focus group and individual interviews with community members and coordinators.

Challenges to data collection

Projects were at various stages at the start of the external evaluation, with some projects still in the process of engaging with the communities to decide on their change ideas, but most had agreed on these and had identified and /or commenced work on the key project tasks and activities. Two Trusts who commenced early with the wider Wave 1 local change ideas had already completed their projects.

A range of staff were involved in project delivery in various Pacesetter sites. Where project activity data collection was carried out by staff who were employed to work

with the community or by other workers commissioned to undertake project work, and not by the Pacesetter managers or leads who were responsible for completing the documentation, there was sometimes difficulty in obtaining the required activity data. It was too late for many projects to collect baseline data or other activity data that had not originally been documented.

In many Pacesetter sites there were staff changes at Programme manager or project lead delivery level during the course of the projects that led to discontinuity and to difficulties in maintaining clear communication about the evaluation process. Staff changes also occurred within the central Pacesetter team in the Department of Health.

The main challenge to data collection was the limited time scale in which to collect and analyse sufficient data across six project sites in order to measure outcomes. Most projects experienced unavoidable delays to their proposed timetables and were unable to complete the projects in sufficient time for long-term outcomes to be achievable and for short-term outcomes to be evaluated from all perspectives.

One valuable lesson from the evaluation is that measurable objective setting and evaluation methods need to be considered at the planning stages of any service delivery change programme and for all staff to understand the importance of data collection, monitoring, and accurate and retrievable methods of documentation. Plans need to be in place to capture baseline data for evaluation of short and long-term outcomes and for staff to be identified and budgeted for to continue monitoring and evaluation after project completion in order to evaluate long-term outcomes. Evaluators need to be appointed at the start of a programme to facilitate work with teams to facilitate this process.

Chapter 5

Specific challenges facing Trusts

There were many particular challenges to be faced by Trusts seeking to improve the health of Gypsies and Travellers and to improve their access to health care. To achieve these aims there is particular need for an associated improved effort at all levels to seriously tackle the wider determinants of health, including societal attitudes towards Gypsies and Travellers, as well as focussing on delivery of health services. The extreme pathologisation of Gypsies, Roma and Travellers (GRT) in wider society is also evident among the UK's largest workforce, the NHS, and its staff can, and need, to play a key part as role models in challenging prejudice and discrimination. This background to GRT groups' position in society presents various challenges.

Varied baseline engagement with G&T community

Many Primary Care Trusts have poor knowledge of, and history of engagement with, their GRT communities (Parry G et al. 2004). Among other Trusts there is even less of a culture of community engagement and much less likelihood that there will have been any engagement with GRT communities. Some Trusts had no prior knowledge of how to seek the whereabouts of their GRT communities before they could even begin to start to engage with them. The amount of time required for this is was underestimated, although indicated in the Community Engagement Guide, A Dialogue of Equals (Department of Health 2008): *We believe that, to create a dialogue of equals, professionals will need to understand how to engage emotionally as well as intellectually to understand and appreciate better the needs of all the communities they serve ... emotional engagement is about having an understanding and appreciation of the lives, needs and circumstances of the group(s) targeted by the engagement. This appreciation has to extend beyond the issue/subject/strand that is being consulted upon* (p5).

This led to very varied lengths of time required by Trusts to decide with communities what their core change ideas would be and how to design them. This variation was increased by the variations inexperience of staff appointed to be delivery managers of their Pacesetter Programmes. Whereas many staff had a background in equality and diversity roles, only few had specific prior engagement with and knowledge of their

GRT communities. Those Trusts that did have that experience in their teams, such as East Midlands PCT, had a time advantage in commencing their activities and being able to complete the work within the short timeframe. However, there was also a counter to this advantage with a time management conflict as many of these staff were trying to deliver the Pacesetter work within their wider roles of working with the GRT communities. Both aspects of their work were found to increase without the extra required time costed in.

Lack of ethnicity data

The social exclusion of Gypsies and Travellers is compounded by the lack of acknowledgement of their ethnic minority status. This results in their exclusion from ethnic profiling in the pursuit of health equity. Gypsies, Roma and Irish Travellers are routinely overlooked on ethnic monitoring forms that are derived from categories used in the 2001 census form. For example, the Mental Health and Ethnicity Census (Count Me In)(Commission for Healthcare Audit and Inspection 2005) failed to include categories for GRTs. Although this omission from routine ethnic monitoring will be redressed with their inclusion as ethnic categories in the 2011 census, the challenges in acquiring baseline data for monitoring the effectiveness of their interventions, for example on access to health care, have exercised the Pacesetters sites. The EHRG were fully aware of these barriers and in the PCSF they advise GP practices to “use a special flag to identify Gypsy and Traveller records, and apply Read Codes to all identified Gypsies and Travellers” (NHS PCC 2009). Nevertheless, even where this practiced is in place, challenges remain, as many Gypsies, Roma and Travellers may conceal their ethnic identities because of concerns over discriminatory views and so would be recorded among White British or White other.

Diversity of Gypsy, Roma and Traveller groups

In seeking to work with Gypsy, Roma and Traveller communities to identify priorities, most Trusts have been less aware of the needs of Roma groups in their communities and have worked solely with Gypsies and Irish Travellers.

In common with all the projects, and in the baseline documents from the Department of Health, references are always made to ‘Gypsies and Travellers’. Although Roma are included under the heading of Gypsies and Travellers and this is clearly stated in the Primary Care Service Framework for Gypsy and Traveller communities 2009,

their separate ethnic identities should be recognised within the Gypsy and Traveller umbrella. Their specific needs and circumstances may easily be otherwise overlooked and they rightly prefer to be separately identified as Roma in health policies and needs assessments as in other policy areas. Hence they are now more usually identified separately, as in the Gypsy, Roma and Traveller Achievement Service, provided by local authorities in fulfilment of their responsibilities to Gypsy, Roma and Traveller pupils. They are also separately identified and recognised in the annual Gypsy, Roma and Traveller History month, endorsed by Lord Adonis in 2008 (Department for Children 2008).

The variable demography of different groups of GRT communities has influenced the decisions about which groups the Trusts would work with. For example, Irish Travellers predominate in the Royal Free Hampstead catchment area and their Irish Traveller organisation, situated in the vicinity, were appropriate partners for the Royal Free to work with. This is not to suggest that the needs of Gypsies and Roma would be overlooked in their work; many of the needs would be met for all groups to some extent by the initiatives, for example raising staff awareness, or increasing GP registration. However, in most areas Gypsy and Irish Traveller groups have not worked together with Roma and have had little association with them on a regular basis. This posed some difficulties in deciding priorities where community engagement had to take place separately and where choices had to be made. For example, in NHS Sheffield there was an identified need to address the access to primary health care for Roma, highlighted by their high attendance in Accident and Emergency departments, in addition to the other more longstanding identified needs among the Gypsy and Irish communities. In contrast, NHS Newham has one of the largest Roma populations in the country and they, along with ELFT, focussed on this community. It is not known how Gypsy and Irish communities in the area received this decision or the extent to which they were aware of it. However, one of the outcomes of the work in Newham with the Roma Support Group was a conference where the Pacesetter work was presented and there was an opportunity for networking between Roma, NHS staff and other Gypsy and Irish Traveller groups who were invited and attended. Potential closer links were also fostered through diversity of representation on the Quality Assurance Group, although this was limited by the infrequency of their meetings.

Despite these specific barriers and the very short time scale in which to operate, taking into account the community engagement process, fourteen of the eighteen original Trusts continued to work on one or more core changes to improve the health care experience of Gypsies, Roma and Travellers and at least some of these Trusts have been able to find means of embedding their work in mainstream practice.

Chapter 6

Gypsy, Roma and Traveller community members' involvement

Community engagement and involvement was a central feature of the Pacesetters Programme and of the Gypsy and Traveller core strand in particular, with the motto adopted by the Department of “ Nothing about us without us.” This chapter is divided into two sections. The first describes the context and central process of involving community members. The emerging issues relating to community engagement are then explored.

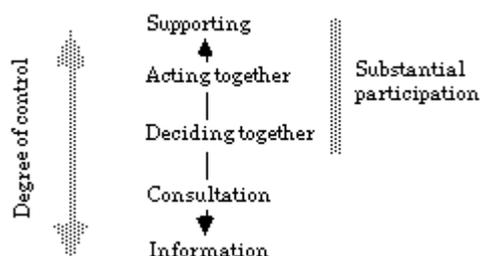
Community Engagement process

Background context and process

In 2005 the Department of Health began a series of workshops to confirm the most pressing issues relating to the health status of Gypsies and Travellers that stem from social exclusion and discrimination, to explore how the NHS can best address the health inequalities experienced, to explore current initiatives, and to discuss how to involve the Gypsy and Traveller community.

There was commitment from the outset to involve Gypsy, Roma and Traveller community members at a collaborative, or ‘acting together’ level (see figure 1), with identified community members and representatives of Gypsy and Traveller support groups invited to join key figures from the NHS, academia and Government departments with an interest and knowledge of the health of these communities.

Figure 2. A 'ladder of participation' model to describe different levels of involvement. adapted by David Wilcox From Sherry Arnstein's ladder (Wilcox D 1994)



Wilcox describes these levels of involvement:

Information

The least you can do is tell people what is planned.

Consultation

You offer a number of options and listen to the feedback you get.

Deciding together

You encourage others to provide some additional ideas and options, and join in deciding the best way forward.

Acting together

Not only do different interests decide together what is best, but they form a partnership to carry it out.

Supporting independent community initiatives

You help others do what they want - perhaps within a framework of grants, advice and support provided by the resource holder.

The Department also demonstrated its commitment to full participation by community members, in all elements of the Pacesetters Programme, by producing a document, 'Dialogue of Equals', to support staff *"to understand better how to identify and create opportunities for engaging with seldom-heard communities or marginalised groups"*

A national workshop followed in March 2008 when the six SHAs signed up to participate were invited to plan and prioritise the Gypsy & Traveller health core changes that they would work on. It was emphasised that community engagement was essential to the work, and SHAs and their participating Trusts were asked to bring community members to the event. Several community members did attend, although not all sites were represented. Participants were invited to work initially in their different SHA groups to discuss the different change ideas, but instead of being included in their SHA groups, the community members were invited to gather separately as one group for the initial session. The intention had been to give the community members an opportunity to discuss the change ideas in their own terms, with peer support, rather than to participate from the start with the staff they had accompanied to the meeting.

The community members joined the SHA groups for the subsequent workshop session to plan how to take their ideas forward.

One method for involving Gypsies and Travellers centrally was to invite them to form a group to provide overall quality assurance for the Pacesetters work on improving the health status of Gypsies, Roma & Travellers. This required planning, coordination and management. Evaluation of the planning process, formation, and outcomes of the quality assurance group (QAG) is described in the remainder of this section.

Context for the QAG

The decision for community members to be invited to form the QAG was taken at the priorities planning workshop in March 2008. Those community members who attended the workshop were asked by the Department of Health lead for Gypsy and Traveller health to volunteer to form a group for the purpose of quality assurance and five of them volunteered. It was agreed that HJ, the director of Leeds Gypsy and Traveller Exchange (GATE), a community members association, would chair the QAG.

No clear mandate for the group and no criteria for wider membership was agreed at this stage, but by the end of the year HJ was invited to tender for an initial 3-month contract to organise, chair and administer a QAG.

QAG formation

The QAG was to comprise community members drawn from the regions taking part in the Pacesetters programme, but although one of the stated aims was to ensure that they made a significant input to various elements of work across the 18 participating Trusts, there were to be just two members from each of the six regions with representation of Gypsy, Roma and Irish Traveller community members. These criteria automatically excluded at least one of three members from the same region who had initially been asked and had volunteered in March. There were no other stated criteria for membership and at this stage the remit for the group was to meet either physically or virtually to comment on updates on the work of the 18 participating Trusts and to select an evaluator and keep an active interest in the progress of the evaluation. Although the criteria were seemingly straightforward there were considerable challenges beyond the usual barriers to community engagement, and a subsequent significant time commitment to form a QAG across such a wide geographical area to

work together to deliver the required outcomes. It was also a considerable time lag between the initial meeting in March when the first members had been approached and the first meeting that eventually took place nearly a year later in January 2009.

HJ had to consider many factors before any approaches were made to individuals. She wanted the QAG to reflect the range of experiences and capacity within the wider Gypsy, Roma and Traveller communities and so tried to include a range among the 12 members of those who were actively involved in working with their communities such as community development workers, and those who were inexperienced, those who were literate and those who weren't and those from different home environments. It was also considered important to have two community members from each region that knew each other, could support each other and were in a position to travel together to meetings, which in some cases would necessitate overnight stays.

HJ used her knowledge of individuals in different regions to approach potential members rather than work through the SHAs. It was important for each person who was approached to fully understand what he or she were being asked to do and to have the Pacesetter programme explained to them. This was always going to be difficult when the initial contact is not face-to-face. It would be much more difficult if an unknown or untrusted person was making the initial contact.

HJ phoned potential candidates to promote the QAG and to invite them to attend an initial 2-day meeting in Leeds at her office base. She emphasised the opportunity for people who do not normally meet to get together and enjoy each other's company while doing valuable paid work for the Department of Health in giving their opinions on what the different Trusts are doing to improve the health of their communities.

Initial 2-day meeting and QAG members' impressions of their role

Eight community members representing four SHAs attended the two-day meeting. At this stage, despite efforts through a Roma community organisation, it had not been possible to recruit any Roma representatives. Although the two members from South East Coast SHA were not able to attend, they were included by phone and email afterwards and able to contribute to the review of the Pacesetter project updates. During the two days they learnt about the interviewing process and equal opportunities and then had the opportunity to interview candidates and select the evaluator for the Gypsy and Traveller strand of the Pacesetter programme.

The QAG members were also invited to critique the projects in the 18 Trusts from submitted reports and were able to make useful suggestions for improvement in the structure of future reports and for additional questions. Their comments were collated and reported back to the participating Trusts and a full report sent to the Department (Jones HJ).

Finally at this 2-day meeting the QAG members were also asked to conduct a review of exhibition material that was to be used in the Pacesetter Programme and they made many relevant suggestions improvements to the draft material.

Suspension of QAG role and final meeting

The role of QAG coordinator had only been funded for 3 months and although it was intended that there would be a further tender for a coordinator to be appointed in the longer term, this did not happen, and the change of plan left the QAG in limbo. Staff changes in the Department contributed to the lack of continuity. It was to be another eight months before the group met again, and in the intervening period there was no direction for the group or impetus or facilitation for them to remain engaged as a central group. The QAG met on only one more occasion for one day in London at the Department of Health. On this occasion a second coordinator, LH one of the Pacesetter project delivery leads, was seconded to organise and facilitate the day with support from the Department lead. The aim of the day was to do some initial team building prior to a review of project report updates that had been summarised for the purpose by the Department.

QAG members were told of an intention for a further meeting to review the Pacesetter programme overall and to contribute to the evaluation. It was suggested that this could be a celebration event when they could meet together and receive acknowledgement of their contribution. The constraints within the Department that culminated in bringing forward the date for the final evaluation prevented this from taking place.

Emerging issues in relation to community involvement

Since the second, and last, meeting of the QAG group, nine QAG members were separately interviewed in their own locations, apart from the East Midlands members

who were interviewed as a group of three³. HJ, the initial QAG coordinator was also interviewed. Interviews and attendance at steering group meetings in local projects also inform this evaluation. The following key themes emerged.

Fluctuating commitment to community involvement

By trying to ensure collaboration at the outset, through SHAs bringing community members to the priorities and planning workshop, the Department demonstrated its commitment to an inclusive approach, but the community members remembered feeling excluded by this process by initially being grouped together separately from the SHA groups. Their perception of being segregated fuelled a latent distrust in health staff. The following quotes highlight this perception:

as community members we all had to go into another room...why did they segregate?
(AC).

I felt that we were excluded from things that was going on (EL).

I found that very strange that we had to be separated when we were all invited to the one meeting... nothing about us without us, that is our motto in our team you know? You get use to people talk about you rather than to you and I thought perhaps they have got something we are not going to be part of or they need to talk about us without us being actually in the room (AW).

The above example illustrates the varying level of community participation within and outside the Department and reinforces the need to ensure shared understanding and shared aims by briefing community members fully and then consulting, listening and acknowledging them as equal partners.

Although most of those who were present at the initial workshop mainly remembered the 'segregation', another member, who had a good experience of being fully involved in her SHA workshop later in the day, felt more positive about the overall outcome of the event and the ultimate goal.

³ Three different QAG members were given an opportunity to represent East Midlands; all three were Health Ambassadors on their local project.

It was good because there was a lot of community members there and also a lot of organisations and they were saying to improve the health of Gypsies and Travellers they needed to work together (AC).

QAG members felt particularly involved at their first 2-day meeting by being given the opportunity to be included in the interview process for the evaluator. This was a valued and empowering process:

The two-day meeting that we had it was absolutely fantastic because we interviewed people to do the evaluation and because they put us in charge of that and it was fantastic because they involved us every step of the way, they actually involved us in that decision-making. (AC)

This practical task, conducted over two days, also gave an opportunity for the group to develop as a team and to experience a sense of worth and achievement.

As a quality assurance group, we made the decisions, it was put in our hands to do that and it was brilliant because we took leadership to do it and it empowered us even further to say well, you know, we've achieved this and we've achieved that and you know if it was a year ago we hadn't achieved nothing but now we've achieved this that and the other and we've also employed somebody. (AC)

This level of engagement, at the higher rung of the 'ladder of participation' achieved in part the stated outcome 'that members of the QAG will feel valued and are valued by the Department and the participating SHAs and Trusts'.

However, the level of engagement was not consistent with regard to their role in quality assurance of the different Pacesetter projects. QAG members were enthusiastic about the role as they perceived it initially. When they were recruited they felt valued

I understood then that my opinion would be valued about what each region and or each group were hoping to achieve, I could look at it realistically and give my opinion in a quite honest way and in what they were doing, and is it going to benefit the Gypsies and Travellers and so this is why I agreed to do it (AW)

Despite some QAG members being prevented from attending one or either of the two meetings they also felt included by the coordinator's efforts to keep them informed to play an important part

it was quite lengthy obviously, but I did it by email so that I was still involved and I was very pleased that even though I was unable to attend... she still forwarded me the minutes , notes and things that were spoken about what was expected, so it was much a clearer picture in what I needed to do. (AW)

The level of involvement fluctuated with regard to lack of acknowledgement and feedback after they had reviewed and made constructive comments or asked questions about the content in the project reports. This initial delay in receiving feedback following the first meeting inevitably resulted partly from the gap in continuity during staff changes in the Department, but there was also absence of feedback after the subsequent meeting in September, which turned out to be the final meeting. Receiving feedback on work carried out is an important indication of the level of participation and involvement and accordingly an indicator of the value placed on the work and the workers.

Not getting the feedback, it's alright a person having the opinion and giving the opinion, but it's nice to know if it's done anything. (SW)

Yes, whether it's done anything or not. It's like when you're cleaning you stand back and say ' done a good job there'! (JP)

Say for instance we give our opinion on the assessment or something we thought needed changing or something that maybe needed improving on...Its going to take a few weeks a few months or something, but it would have been nice for a little bit more feedback to say yeah they thought that was a good idea and they did change it (LG)

The lack of feedback and acknowledgement compromised the desired outcome of community members "feeling and being valued by the Department, and participating Trusts". Its absence appeared to fuel mistrust and reinforce a default perception by community members that they were not truly valued and that their involvement was only at a superficial level.

Because at the end of the day we don't even know if they're twisting our words on paper you know. We don't know if anything was useful that day do we? (JP)

Some aspects of fluctuating commitment to community involvement arose from lack of clear guidance and clarity about the remit of a quality assurance group and how it would fit with local community engagement.

Experience and Understanding of the process of involvement and QAG role

The mistrust that was spoken of in relation to feeling 'segregated' at the initial workshop meeting was intensified by lack of prior understanding of the purpose and their role in the meeting, and by awareness of previous experiences of apparent 'tokenism' with no ensuing action following engagement.

*Because I didn't know nothing about it, to me it was just another meeting. (BJ).
I was thinking when I went 'now what's it all about? Is it just going to be another talking session with nothing happening or do we get some action from it?' (LG).
She (local Trust lead) didn't explain it very much ... she said it might be important because part of my role in my day job is with health with Gypsies and Travellers, ...I was a bit wary actually, because I wasn't sure... it wasn't made that clear what they intended to do. (AW)*

Subsequently, despite the format of the reports being revised by the Department of Health, in accordance with their suggested headings at the original 2 day meeting, community members felt that there was still insufficient information on which to assess the quality of the projects, and lack of clarity about the information that the Department required for them to carry out their role.

The reason for the quality assurance group was the questions were asking how they were going to do it, how many people were going to be involved ... I suppose what they wanted to know was, was that value for money. So there was the few missing gaps but I think from what I could see of it, what the Pacesetters wanted to know was not the questions they'd actually asked the Trusts... so when the PCTs were asked to write up their report of their actions, what they were going to do, they did that, but then

afterwards when we looked at that, then the Pacesetters wanted to know stuff that wasn't asked in the first place. (AC)

QAG members recognised the inadequacy of the report process and identified improvements to make their role more relevant.

when you read the report and went through everything it would be nice for somebody maybe from the area to have stood up and said a few things as well, because to hear somebody say it is different from reading it. (LG)

This lack of clarity about their role and direction from the Department, compromised the potential working relationship between QAG members and their local Pacesetter teams as these concerns were mirrored by them. Attitudes towards the concept and role of the QAG varied among participating Trusts. Some felt frustrated by the QAG's comments on their project updates which indicated a lack of understanding of the local issues, and they questioned the Department lead on the need for a QAG to review their projects when they had their local community members involved who could do this. One programme manager pointed out that the QAG was asking inappropriate questions about their work because they didn't have all the facts. Another programme manager echoed this concern and felt that the way in which the feedback from QAG members on their reports was communicated back to project leads was insensitive and without context, thus contributing to confusion about the QAG role.

The PAHR steering group proposed some bridge building to facilitate the process by offering to give a presentation to the QAG so that they could make informed comments and ask appropriate questions. This offer was not taken up as the future of the QAG was in limbo at this time.

Some participating sites appeared to misunderstand and in cases mistrust the QAG role, adding to the difficulties that some QAG members experienced locally

I actually felt a little bit awkward when I went to the (local project steering group meeting) when they knew that I was on the QAG group... I felt a bit uncomfortable...it was as if I was there to spy you know... it had only backed up my suspicion about what was going on and I thought, 'well if they haven't got anything to hide ...why are they worried that sick?' (AW)

QAG members did not have a remit to be actively engaged in their local projects and the extent of their involvement was not a factor in their selection as QAG members. One of the major difficulties in achieving effective community engagement across all the different sites is that each site is starting from a different history or level of community development and participatory working. There was wide variation among the members, with some being on their local Pacesetter steering groups and active participants in their local projects, and others playing little or no active part. QAG members agreed that there should be a requirement for their involvement in their local projects despite this being problematic for some who felt excluded locally.

Oh definitely, because they want to be involved in the achievements, it's like a trail isn't it? As you're going along you want to see the process. If something's coming back then you want to know why it's coming back. If there's any room for improvement you can improve it (AC)

Where there was a local conflict and disappointment from a QAG member about not feeling involved locally, it was not clear, in the absence of an identified coordinator, who had responsibility for mediating and supporting the QAG member concerned. The member concerned felt let down that promises of intervention had not resulted in her being contacted *because of the way I was treated (SW)*. There was also a feeling among other members that QAG members needed support to be involved locally if there was a problem.

Them high up people were letting the QAG reps down if they weren't getting involved (EL)

Staff changes in the Department and resource constraints, resulting in an unfilled vacancy for a QAG coordinator with overall responsibility for supporting the QAG, contributed to the lack of continuity and sense of feeling 'let down.' The loss of contact with a known and trusted person was keenly felt, as would be expected among community members who, given their experiences, take time to build trust. This also affected the level of involvement, in respect of an eight month gap between meetings and no-one having responsibility for keeping the group connected and involved

if there's no communication how's anything supposed to be started how's anything supposed to work.... the regular meetings are so so important (JP)
A lot of them (us) felt that they were let down. They were hoping for a lot more things to happen. (EL)

The evaluator and HJ did attempt to fill this gap with members and keep them informed both proactively and reactively; the former by phoning each contact to update them and HJ by responding to need as it arose.

I phoned Helen, and sort of said to her, you know, what's actually going on, then she started sending me some emails back and saying so and so has taken over this area, so and so has taken over that area. I was saying well how come my area doesn't know nothing about it? (BJ)

I think inevitably I had to support QAG members to deal with their local politics and what the impact was (HJ)

One of the tensions between the unclear central QAG role and the role of community members involved in their local projects was the considerable difference in their remuneration, with the former being funded centrally and the local participants receiving funding from local budgets. This led to resentment between community members who were involved locally but played no part in the QAG, both in terms of equitable remuneration and in terms of 'opportunity' to play a seemingly more prestigious role. This was a particular problem in one region where the local community members were selected democratically by their community organisation to represent them on the local steering group but two other members of the same organisation had already been recruited by HJ as QAG members and were known to receive significantly greater remuneration. It has not been possible to contact the two QAG members after the initial 2-day meeting and the conflict also resulted in resignation of one member from her local steering group.

There was potential for resentment among community members in other regions where the same two members were attended QAG meetings. To avoid this, LH the project lead from East Midlands, who undertook the role of co coordinating the one-day meeting in September, felt it important to give an additional community member

an opportunity to attend the QAG. This was in agreement with, and in place of, one of the original two members.

Although there was uncertainty about the QAG role and unfulfilled expectations of their level of community involvement the QAG members had several ideas about how they could have been used more effectively and involved at a more participatory level.

QAG members' views and suggestions on community involvement

The concept of a QAG was valued. QAG members all clearly took their role seriously and felt considerable responsibility for their input. They had particularly valued the opportunity to meet as a group, and to work together to give opinions on projects and their progress.

It's a good place to integrate with the rest of the other Travellers what they've come up with, a good idea of what they were going to do in their areas. If you agree with something that's brilliant; if you've got something that you don't agree with then you have to come to a solution together because sometimes what you think is best might not be best. So it's about doing the decision making together, you know, this is why people work together, it's not just communication but it's a way of team building teamwork. (AC)

Value was placed on meeting together and on the opportunity of meeting members of other groups and gaining strength from unity. Many had little previous experience of working together and this was an opportunity to break down some of the barriers that are present through lack of direct contact with each other and lack of awareness of each other's situations

We met the Roma gypsy didn't we? And it was good to know that they was involved that we was involved with something with the Roma. At first you might feel like you're fighting on your own (SW)

Irma says that she really likes the fact that she can meet other Travellers and Gypsies. They have different lifestyles because Roma don't travel but their problems are similar and it was really good that they can come together and we can do something together (interpreter for I)

They felt though that there had to be greater understanding and recognition of constraints that sometimes prevented members from attending meetings , with plans put in place to make sure they were still included, as had happened with the two members in the far south after the initial two-day meeting in Leeds.

I think straight after a meeting for the people that can't get there I think if the information is actually sent to them what was actually spoke about and saying well do you agree do you disagree and then you still feel a part of the group because then your information is going back again, and I think for the last 18 months I haven't done a great deal; maybe people probably thought at the time is not to put any pressure on me because my son had killed himself (BJ)

This last quote raises the difficult question of continuity within the QAG and whether absent members should be replaced. It also highlights the importance of group support and team building. BJ clearly wished to stay involved despite her incapacity to attend meetings as a result of her bereavement. There was differentiation however between incapacity and lack of interest among QAG members. Some warned against keeping QAG members involved who were identified as being unmotivated by genuine interest in the project

“in the middle of that time don't be afraid to discard that person if you think they're not interested. Because at the end of the day they're wasting your time, don't invite them” (SW, LG)

This warning was given with reference to their experience of past observations on local projects

a lot of people just come for the food, ... Or if there's money involved...and if it was local they'd just come and sit for that hour for the money. (JP, SW)

However, an unsuitable venue was also identified as a barrier to attendance at meetings. Although there was only one further meeting after the initial 2-day meeting, the decision to hold it in London was unpopular even by those who were relatively local. Though the QAG members weren't penalised financially they considered the costs of meeting in London.

*I think London's the worst place in the world for it...Its like in Sheffield we can drive instead of jumping on a train, but if you've got to go on the train and its so expensive to get there...and when you get there the taxis seem to be double the money (LG, JP)
I know London is the capital and for us it is quite convenient but we are quite spread out across the whole country. It could be in the Midlands somewhere... it would be available to a lot more people (AW)*

A one day meeting was also considered too short a time for a meeting when allowing for travel time, particularly where there was limited information beforehand of what would be expected of them on the day

The day went a bit quick didn't it? It could have done with a bit longer and we discuss it a bit more (JP, SW)

For me on the day it would be having a bit more information about what to expect when we got there (JP)

The QAG members also required more information from the projects on the day to inform their discussions, particularly as they were reading reports about projects that they were not involved in.

some of them was alright but not a lot of them because there was 'where's this going?' and 'why hasn't this been put on ? ... they were shortened weren't they and they'd made some of them a little bit confusing. (JP, LG, SW)

QAG members have identified ways in which they could have been utilised more effectively both as a group and as advisors to local project teams. The group concept is important; for many community members, it is still a daunting prospect to be one or two 'community voices' in the absence of existing trusting relationships. However, QAG members could have played a role in helping their local community members to engage with the Pacesetter teams and to help to forge initial links. More continuity was felt necessary, but a suggestion was made that the QAG reps could be on hand at given times as advisors to the local projects

So if you are on hand as an advisory, well I think perhaps you could have prevented some of the mistakes that happened. If you were involved beforehand instead of just getting the report and the mistakes have already been made. I don't see why not, cause it would probably be only one day out or the odd day out to meet with people, yes I think that would have been important. (AW)

Most QAG members wished for a greater role and for continued involvement as a group between meetings and would have liked the opportunity to occasionally visit each other's projects. One also suggested that a newsletter would have been a good way of being kept informed in between meetings. This less formal method of project update would have been more acceptable and had been used for example as an additional method of communication in the Gypsy and Traveller health status study to keep steering group members informed between meetings. Most were uneasy with the suggestion of keeping in contact by phone; although with greater team building this may have been different.

I'm very sceptical who I give my phone number to so on that basis no, I don't know each other enough to exchange phone numbers (JP)

I think perhaps if there was just a meeting midway somewhere in between doing the actual reporting it would have been nice so that you've got an idea of what other members feel and think about things as well (AW)

Community involvement required flexibility and continuity with trusted facilitators. Where this was successful the community members did feel valued. We saw this very clearly where there was existing trust in LH from the Health Ambassadors. There are also other examples where a trusted project manager has worked with community members and they have felt valued, despite not necessarily feeling that their local leads have engaged as effectively. For example one community member who had attended the PAHR record design meeting said

I thought to myself well that is actually a fantastic idea plus at the meetings they allowed you whether it be right or wrong what you're saying, they still allowed you to say your opinion, which many many meetings I have been to (they don't) and I've been

to so many ... it was so open no matter whether people were against the project or with the project (BJ)

For any group to come together to fulfil a role together there has to be an element of team building. It is also an important aspect of involvement to receive the necessary development for capacity to fulfil the role. QAG members recognised this and felt that there was a need to meet on some occasions without a formal agenda, in order to build together as a team, and that this would also be a useful way that they could achieve much by way of informal communication with each other to discover how local projects are working.

its very very important as far as I'm concerned that at least twice a year, all those members should meet up, not for a meeting but on their own, so, have hotels booked so they don't have to worry about it , the petrol and bit of food going down there is paid for, and all meet up and find out how things are going in every single area. Because everybody knows, right it hasn't worked in this area, then they can sit down all the other areas and say well if its worked in yours what are we doing wrong in our area? Well this is what we're doing in our area so maybe if you take a leaf out of this book and try that. But if information's not being linked from everybody then what's the point of having this big organisation that nobody knows who's in it. (BJ)

Although the QAG members were unable to reach their potential and achieve the desired level of involvement through lack of resources to facilitate more meetings and lack of a clear remit and direction for work between meetings, they did feel that they had made some worthwhile input into the Pacesetters programme.

A significant number of community members in different projects have been valued and felt valued for their significant contribution to their projects and have been empowered in the process. This alone is an important outcome of the Pacesetter Programme and is well articulated by a 'thank you' in an email from one of the Pacesetter project workers employed to work with Roma community members

"The Roma voluntaries (volunteers) representation on the RG&T Pacesetters Meetings and The National Voice meeting in September - empowered them - they said even with their health problems), they never are going to be the same - because they

know they (sic) rights now and that change their confidence in their personal lives and their health improve as well... Roma knows, that they (sic) involvement can change the situation between them and clinician."

Lessons: could anything have been done differently?

The Pacesetters Programme was groundbreaking in its commitment to inclusion and genuine involvement of Gypsies and Travellers at the design stages. By seeking out and inviting a small number Gypsies and Traveller who were known to have a keen interest in health and were known to the health professionals who also attended, the Department of Health demonstrated its commitment to inclusion at the preliminary meetings, and this in itself is a significant achievement. . Those community members who were consulted at the earliest stages did not continue in the role as advisors, and there was a missed opportunity to involve them in planning for the priority-planning workshop with the participating SHAs in 2008 and consulting them at an early stage on the formation of a quality assurance group. They could have formed part of an ongoing advisory group to the Department to ensure that central Pacesetter plans were considered in terms of the impact on community members.

It is clear that there are no shortcuts or 'quick fixes' to community engagement and it was ambitious to expect each participating SHA group to bring community members to the priority planning meeting, in London, and at fairly short notice. Whereas it was important that those SHAs who were already engaged with their local Gypsy and Traveller communities did bring along community members, it would have been helpful for SHAs to have had more advance notice of the meeting and the emphasis on community participation so that there was an opportunity to engage locally at an earlier stage.

One of the barriers to effective community engagement is resources. The time required is both underestimated and undercosted. The remuneration for community members' time and expenses to attend meetings is only one part of the cost; but the costs required for team building and capacity building are also important and should be budgeted for from the outset. An equitable remuneration across the programme needs also to be agreed. It is also important to decide how many community members should be involved and to agree the extent of any remit beyond the attendance at meetings that also needs costing. There have been examples where a community member representative has been asked to 'bring as many members as possible' to a

meeting, with little apparent consideration of the implications. On one occasion, after such a request had been made and several community members had been approached there was a realisation and change of plan; the representative was then given the embarrassing task of going back to community members to say that only two were required. Clear planning and discussion with community representatives on an advisory group could ensure that such costly actions in terms of credibility and respect commitment are avoided.

Community engagement must take place from the beginning and should be facilitated through a link person who is adequately skilled in participatory working and can help community members to negotiate the barriers to their participation. Continuity is also important so that trust can be developed and dialogue maintained. A shared understanding and agreement of the level of participation and the aims of involvement is essential. Clarity is necessary in a clear 'terms of reference'.

The need and idea for a project must be decided with community members and they must have ownership of it if it is to succeed, and their involvement must be maintained through all stages of the project. When they are asked to contribute to decisions during the project, such as design of a record, it must be made clear whether they are being asked to advise or to decide and who has the authority to make changes after decisions have been agreed, and to ensure that community members are listened to rather than attempting to 'bring them along with us' in what has been pre-decided.

Trust is very fragile and can easily be lost if community member involvement is seen to be tokenistic through their voice not 'counting' Wherever possible, raising of unrealistic expectations should also be avoided and communication be maintained to avoid disillusionment and default expectations of 'talk and no action'.

Seeking quality assurance through brief structured reports alone may not have been the best way for the QAG to achieve the desired outcome of making a significant input to various elements of the Gypsy and Traveller work across the 18 NHS organisations. Resources might have been identified for more meaningful engagement with their local projects before they were required to comment centrally as a group. If QAG members had been introduced to their local delivery leads and project managers initially it could have ensured that there was shared understanding of their role and of the projects that they were having input into and thus avoided misunderstandings.

The costs incurred in coordinating community engagement are particularly underestimated. It is often forgotten that community members are not employed staff who can ring fence their diary commitments to attend meetings, but are people who face frequent disruptions in their lives and often cannot avoid last minute changes. The time and commitment involved in coordinating, organising and planning meetings to bring community members together is considerable and requires much more dialogue than might be appreciated by staff who are used to having an administrator to book meetings. To many community members formal meetings are unfamiliar territory and it is important to give adequate explanation of the purpose and what is expected from their attendance.

Community outreach is an important aspect of community engagement. Some community members, who in one project were visited by Trust staff in their own homes by prior agreement and arrangement, appreciated the opportunity to inform teams in this way. It also demonstrates respect from staff who are willing to come to them 'for a change'. As one community member commented “ *it would be a step forward.*”

Community members require support and personal development. Although they may be keen to have a voice and participate and may do so quite confidently on a one to one basis with trusted staff, it is much more difficult to have a voice in a wider forum. Practical support to build confidence and to make the experience enjoyable is also important. A flexible and enabling approach is also required to facilitate engagement and to overcome some of the potential obstacles such as non-literacy.

Feedback and acknowledgement of the contribution of community members is essential. On occasions where their contribution is sought and is then not used, for example when QAG members spent time commenting on an exhibition material that was not revised in light of their advice, it is essential to give explanations. Feedback is essential at all stages of community involvement but also needs to be followed through in the dissemination and evaluation of a project. The perspectives of community members are an essential element of the evaluation and can help to ensure that future projects build on lessons learned in community engagement.

Community members have reviewed this report on community involvement and their comments have been acknowledged.

The QAG members names are listed in the acknowledgements section for their contribution to the Pacesetter Programme and, where applicable, in its evaluation.

(see acknowledgements)

Chapter 8a
East Midlands SHA
Health Ambassadors project

The project is a collaboration between all three participating Trusts: University Hospitals of Leicester, East Midlands Ambulance Service, and NHS Leicester City. This arrangement has the potential benefit of pooling the financial resources to support development of the project across the service throughout the city and county.

Gypsy and Traveller population in Leicestershire

Leicestershire has a large population of Gypsy and Traveller families, living in a mixture of accommodation. The recent accommodation needs assessment reported 42 pitches on socially rented sites, 210 pitches on authorised private sites and approximately 32 families on tolerated but unauthorised sites and a minimum of 185 families in housed accommodation. This equates to an estimated 650 families at any one time, in addition to an average of 86 unauthorised encampments per year of 5-7 caravans staying for up to 6-7 weeks. Approximately 20% are Irish Travellers with the majority of the remainder classing themselves as Romany or English Gypsy or Traveller.

Leicestershire has provided dedicated health care to this community since 1995 through the Travelling Families Service. The need for this service was identified in research on the Health Needs of Travellers in Leicester, conducted by Liz Anderson, a Research Health Visitor (Anderson E 1997). She reported on their poor uptake of preventative services, and community members spoke to her of their need and desire for a dedicated service.

This outreach service for Travellers covers Leicester city and county, and Rutland. The primary aim of the team is to visit all Gypsies and Travellers to help them access health care and to give advice and support in health related matters. The team comprises a specialist nurse/health visitor manager, a health visitor, a nurse auxiliary and a secretary. This team was therefore well placed to work closely with the community to decide on a relevant Pacesetters project and to implement it with them in close partnership.

Project origins

The health visitor for Travelling families, Lynne, has worked for 15 years with the Gypsies and Travellers in Leicestershire and is highly respected by them. A strong mutual trust has been established between them over this period. Prior to the inception of Pacesetters, various Gypsies and Travellers had worked with Lynne and some of them had been involved in research studies conducted with them in Leicester on the Dept of Health commissioned health status of Gypsies and Travellers and their access to and use of health care and so already had a keen interest in health improvement for their community (Parry G et al. 2007; Van Cleemput P et al. 2007).

Following attendance by Lynne and two community representatives at the Pacesetters planning meeting in at the Department of Health in March 2008, Lynne held an open exploratory meeting in April for any Gypsies and Travellers who might be interested in taking forward the ideas for a project to improve their access to health care.

She initially approached fifty community members but all Gypsies and Travellers were encouraged to attend and not to be deterred by any issues such as poor literacy, or living on the roadside. The thirty community members who did attend the April meeting were asked to suggest some ideas for projects that they thought would be most useful. A further twenty community members discussed the issues in their homes.

Between them, they identified problems that each of them and their families experience when attempting to access and use the services of various agencies, including health services. There was general discussion and they vaguely identified the project as one that would address the need for services to understand the culture and needs of Gypsies and Travellers, as well as Gypsies' and Travellers' need to understand health services and the difficulties that staff can encounter with Gypsy and Traveller patients. For example, Lynne addressed the question of why health services need dates of birth and detailed spelling of names as she explained how the same person could end up having three different health records because at different times they have given different name spellings or dates of birth.

Similar issues had previously been acknowledged and work had taken place by some community members in research on identifying contributory factors to communication barriers between Gypsies and Travellers and health staff (Van Cleemput P 2008). As they discussed this further with Lynne, at and following the open meeting, the idea of Gypsies and Travellers being trained by her to deliver cultural awareness training to staff from different agencies was formulated and jointly agreed with Pacesetters leads. The first official meeting with these thirty community members resulted in them each signing up to participate.

From the issues that they highlighted through talking about good experiences and bad experiences of health service provision they decided on the aims of the project and on the format of the training that they wished to deliver. They chose the name Health Ambassadors from a range of their suggested titles for the role.

Motivation for community member's involvement in the Health Ambassador project

The trust invested in Lynne and her team by the Gypsies and Travellers in Leicester, and the prior experience of several of them in other projects that she had helped to develop were factors in their motivation to participate. Many had not only been participants in the Health Status Study, but had also had the experience of participating in the validation forums to comment on the preliminary findings, and attending the dissemination conference for Gypsies and Travellers where the issues were presented and then discussed in workshops and where various initiatives in other countries were presented.

Thus several important elements were in place before this project commenced:

- recognition and understanding of the health inequalities and a belief that action was possible from a widened knowledge of initiatives in other areas.
“before even before Lynne started we wanted to do something ourselves, we wanted to change things ourselves”.
- history of Gypsies and Travellers in Leicester working together in groups and an increasing confidence to develop further
“I know before few of us were doing life support, we were all doing that as a group I think it went from there onto this, then we heard about this and all just joined up”.

- complete trust in the person who was leading the project and that she would consulted them fully and involve them completely in the process
“she came up with different ideas and then we suggested and came up with different ideas ourselves”.

Project Aims

LH and the aspirant Gypsy and Traveller Health Ambassadors jointly identified the following project aims:

- to raise awareness among healthcare staff of the culture and health needs of Gypsy and Traveller communities.
- to train people from Gypsy and Traveller communities to deliver training to:
 - a) break down barriers
 - b) help staff understand cultural context
 - c) help staff make informed decisions re health care
- to encourage trust and dialogue between Gypsy Traveller and healthcare communities
- for each group to develop a genuine understanding and appreciation of the cultural and organisational constraints that impinge on each other.

These aims build on the previous work research where Gypsies and Travellers and health staff shared their perceptions of communication barriers, and they are notable for recognition and acknowledgment of the need for dialogue and two-way learning and understanding. This was apparent later into the project in a focus group discussion around what to them had been the essential aim:

“ Communication between both sides...definitely... more understanding of each other”

“the main point was to get people to listen and to understand our culture because they still don’t understand it”

“and it was for us to learn about them wasn’t it? To learn more about when you go to the doctors, about the secretaries”

One important aspect of learning about the health services that emerged in this discussion with the ambassadors was for Gypsies and Travellers to understand their rights:

“ and to learn about your rights as well. Cause some of them would just fob us off”

Despite the recognition of the need for understanding on both sides, when the group spoke of their initial hopes and expectations of outcomes from the project their main focus was on the need for staff to respect and acknowledge them as part of the wider community and not to scapegoat them as a group:

“that people would learn that not all Gypsies and Travellers are bad and that there’s good and bad in everyone. More or less understanding one another. And to let people know that what they read in the paper isn’t necessarily true. Cause you never see any good things about Gypsies and Travellers, you only see bad things about them.”

“For them to understand us a bit more instead of looking down on us really”

“it would be nice to walk into a doctor or an hospital ... and know you are going to be treated the same as everybody else”

Project Management

Lynne manages the project within her wider role as SHV for Travelling families. This has some advantages in that Lynne is already known and well trusted by the community members and she knows and understands the issues.

In theory, she is given some dedicated time for this role resourced from the Pacesetter budget. In reality, as appears to be the case with all projects where the project manager is carrying out the role of a Pacesetter lead within her wider role, there is an underestimate of the extra amount of work that is generated and the difficulties in accounting for the separation between ‘Pacesetters work’ and everyday work. A vast amount of ‘everyday work’ has the potential to turn into Pacesetter work, and equally a contact about Pacesetters frequently generates more ‘everyday work’.

A steering group was convened to oversee and support the project with her and to consider its direction. In addition to Lynne and six health ambassadors, the steering group includes the programme manager, the equality lead and representatives from the University Hospital Trust, Leicester Traveller Education service and a Gypsy and Traveller organisation (DGLG). There have been three meetings in the past year.

Other community members' views of the project

The decision to choose the Health Ambassador project was unanimous among the fifty community members who were consulted. Later, two young daughters of one of the ambassadors also attended one of the health ambassadors' focus groups. The youngest, expressed a view indicating that she perceived the health ambassadors project as reinforcing their 'otherness' and that there should be no need for special training solely about Gypsy and Traveller culture. Her older sister explained how she had felt the same but now understood it differently:

yeah I know what you are saying cause I thought like that. But why they need to know we should be treated different rather than all the same, we are different. We've got different beliefs and that.

Other ambassadors tried to explain that they were aiming to ensure that their beliefs were understood and respected rather than seeking special treatment. The discussion continued and they agreed eventually that there was a generational difference in expectations of racism and in the ability to stand up against it.

I think it is good for the people like my granny and my mum because they are from a completely different generation. And my granny and my mum, when they got into hospitals, they did get that sort of racism. I have been there when my little brother been in hospital and I have seen that racism she is got and I have seen how wound up she got and arguing with them

There was an agreement that until a Gypsy or Traveller became a parent and had to make a stand on behalf of their child they didn't truly experience the full extent of discrimination, because up until that point they had been protected from it to a certain extent:

"you see she has not had a child yet and once she had a child she'll have to put herself forward, she always been pushed behind mammy's skirt, if you know what I mean" .

"you have to be heard now that you are the mom"

Towards the end of the focus group discussion the younger daughter became convinced that the Health Ambassador project was worthwhile.

Following the initial meeting in April 2008 to identify and set up the Health Ambassadors project, Lynne designed a day-long programme to train the community members to become ambassadors.

Training to become a Health Ambassador

Following the initial exploratory meeting, the next time that they met was their official training day in May 2008.

The thirty community members who were initially keen to become involved all attended and the training took place over a full day.

The morning was spent looking at experiences, and flip charts with pictorial headings were used, on which those who were literate helped those who weren't, to jot down key points to the following questions that they were asked to consider:

- What did the health service providers need to know about the community that would make the difference to their health and health care?
- How would we promote that?
- What are the good and the bad experiences of health provision that we have experienced?
- What are the myths about Gypsies and Travellers that we need to address?
- What's important to say?
- What lessons had we already learnt?
- What did we need to learn from them?

In the afternoon they considered how they were going to deliver the training and the issues that needed to be covered. These included confidentiality, who should be trained, where should training sessions be delivered, and a discussion of general issues that could be raised by those attending their training sessions.

Among the 'important things to say' that they identified, besides cultural information, were key issues of equality "*they need to listen to us*" and "*treat us like an equal.*" They were also fully aware of the various negative myths that are circulated about Gypsies and Travellers and identified many that they wished to address such as:

"They... are thieves, think we are all related, have a hidden agenda, can't manage in a trailer, steal babies, are forceful, and get everything free"

Feedback from Health ambassadors about their training was very positive. They were asked to jot down their thoughts and views on post-its and these were collated. The only negative comment was that it was a long day. Although 10 am to 3.30pm may not seem too long for those who are used to training, this was very new experience for all of the Gypsies and Travellers, and although they enjoyed it they did find it very tiring.

They have remained positive about the training now that most of them have been involved in delivering at least one session. They felt that they were being consulted and drawn out about what they already knew rather being instructed on how to deliver training:

“we did learn about confidentiality and things like that) but “basically it was talking about how we live”

“well really it is our own training we did our own talking, that is what the training was because we know what to say. Lynne would like basically tell us “ talk to each other about ...”, that was our training. Lynne said she can’t train us cause you already know what you are doing”

“ yeah so you finished up and you knew how to go and ask. And it was things you wanted to ask them”

When asked if there was anything that they were particularly apprehensive prior to delivering their first session, a typical answer was *“how they would react to us”*

However, such an encouraging approach to training that inspired self-belief in their ability, rather than instilling great apprehension, led to optimistic expectations of the outcomes of their delivery of training sessions.

The ambassadors took the training seriously and recognition of their work was accorded with a certificate ceremony to which Pacesetter leads, other PCT staff and other community members were invited. One Ambassador, aged 63 years revealed her pride in this achievement

“ It’s the first certificate, apart from my birth certificate, I’ve ever had”

A Health Ambassador logo was also designed and the community members were given a badge with this logo to wear when they delivered their training sessions.



Figure 1. Health Ambassador logo



Figure 2. LH and some of the Health Ambassadors with their certificates

Health Ambassador staff training sessions - structure and content.

The first training session was offered in May 2008. The number of participants in each group has varied, as have the size of the venues. Each session is slightly different, but all comprise an agenda to inform them of what will be covered in the sessions, although this is tailored to each different staff discipline group. They are given a scenario specific to their role with suggested points to consider regarding how

access to their service is affected. They are also given a Gypsy and Traveller information pack containing factual information about the Travelling Families health service, information about different groups of Gypsies and Travellers, useful contacts and a suggested reading list.

Initially the training sessions were small in size and ambassadors often did the sessions in mother/daughter pairs, although sometimes a Gypsy and an Irish Traveller would work as a pair.

A typical training session commences with Lynne giving an introduction of her service and of the health ambassadors and their roles. She summarises the purpose of the session and what will be covered i.e. relevant information about Gypsy and Traveller culture and how it impacts on their service, myths surrounding Gypsies and Travellers, and service providers' expectations. She also explains that they will be given an opportunity to ask freely about anything concerning Gypsies and Travellers and their situation, emphasising that the health ambassadors have been trained and will not be offended at any questions.

Lynne hands out a pre-evaluation form prior to the presentation which asks about each attendee's previous first hand experience of Gypsies and Travellers and in what capacity, whether they have had any work related previous cultural awareness training with this group or with any other ethnic groups, whether they feel it is important to understand cultural differences and whether Gypsies and Irish Travellers are recognised ethnic minorities. They are asked to complete this before a 'quick quiz' is read out. The quiz consists of seven factual questions about Gypsies and Travellers with the aim of stimulating discussion as Lynne then gives out the answers.

A scenario situation is then presented which varies according to the staff group discipline receiving the training and the attendees are asked to consider the issues for their discipline, and to consider how the health ambassadors may be able to help.

They are then invited to ask questions. The health ambassadors lead this part of the session but have Lynne at hand if they need her support.

To begin with and at an observed session in June, the health ambassadors delivered approximately 65 % of the content but Lynne has worked to increase the confidence of the ambassadors so that they can deliver a greater part of the session.

Ambassador training sessions- staff uptake

Up until December 2009, 59 training sessions had been delivered by 28 of the 30 trained ambassadors. Although on some occasions evaluation forms were not given out and in several cases forms were not collected back from all those who did receive them, Lynne knows that approximately 800 people attended these sessions in total as she was given the numbers who were expected to attend each session in order to plan a ratio of one ambassador to approximately 10 participants.

450 participants have returned their completed evaluation questionnaires, of which 253 were from staff or students working in community or hospital healthcare.

In addition to staff group sessions the ambassadors have also given presentations at the Involve conference 2008 in Nottingham and the NACTO 2008 conference in Warwick.

Mixed discipline groups

The sessions have been delivered to a wide range of disciplines in primary and acute health care and in other agencies and voluntary sector groups.

In addition to specific requests from various staff groups for sessions to be delivered to their staff or student group, there were also some mixed groups.

These additional mixed group sessions were held as a result of an enthusiastic participant who felt that there should be wider knowledge of the sessions and wished to help with recruitment by designing the poster to advertise the sessions. The poster was distributed very widely by email attachment and as a hard copy through the voluntary sector, statutory services, and through the PCT.

Four or five of these mixed sessions were held and participants in each group came from a range of agencies or services including Police, academics, council equality staff, PCT commissioner, education, youth offending services, probation officers, finance managers, physiotherapist, support workers, domestic violence refuge workers etc.

Although this demonstrates a wide-ranging need for such sessions among the range of organisations that Gypsies and Travellers may encounter, the health ambassadors found it quite difficult to deal with such a varied group in one session. Lynne also felt that these sessions tended to be dominated by one or two strong voices who wanted to focus on certain issues, and possibly at the expense of others who may have had different questions related to their specific services. However, when participants were asked to evaluate their experience of mixed group sessions they responded positively

as they found it useful to hear answers to questions that they may not have thought of asking.

Lynne responded to the challenges that mixed groups posed for the health ambassadors by identifying these mixed groups as taster sessions. She suggested to the participants that they return to their organisations and invite them to request a further session for their specific staff group. Some groups, for example probation officers, did follow with a request for a specific staff group session as a result of one of their members having attended a taster session.

Health and social care staff

The majority of sessions have been delivered to a range of staff in the NHS: Health visitors, district nurses, student nurses, student midwives, hospital matrons, hospital safeguarding teams, palliative care staff, and GPs and their staff (including receptionists) and to social workers and students.

Only four GP practices were targeted to date, and have requested sessions, but these were much more difficult to organise than for other professional groups due to limited opportunities for all staff to be available and for enough time to be set aside. Lynne feels that more GPs would like to have a training session for their practices, as is indicated by those few individual GPs who attended taster sessions but that there are too many other demands on their time. Those that have requested or attended a session have usually been prompted reactively following an incident or fracas in their practice.

Monitoring progress of Ambassador training sessions

Over the eighteen months since the health ambassador sessions have been delivered Lynne has held five review sessions with the ambassadors where they have analysed their progress and made some changes to the format of the training. For example, breaking into smaller groups after the initial introduction and quiz. At each of these review sessions Lynne has invited a speaker on a topic chosen by the ambassadors. These have included smoking cessation, caravan fire safety, First Aid and the new hpv vaccine

Health Ambassadors – their experience of delivering staff training sessions

Lynne has sought ongoing evaluation of the health ambassadors' experiences at the review sessions. They have been consistently enthusiastic about their role and the

reception they have received from participants at the sessions. Typical comments included:

“ It’s the best thing I’ve ever done ”

“I’m buzzing after a session ”

“ I don’t want the sessions to end; I enjoy them so much ”

“I never thought the nurses/ doctors/ staff would be so interested in what I had to say”

“I really feel that we can make a difference”

The ambassadors showed that they had also gained knowledge about the service provision of participants who attended their session.

“ I’ve learned so much from listening to the hospital’s issues too ”

“Why didn’t staff explain those things to me before, then I would have understood”.

However, the first six months were a steep learning curve for both Lynne and the ambassadors. Various issues arose:

- Lynne soon realised that if mother and daughter pairings were used that the daughter would defer and tend to let the mother speak for both of them.
- There was also some discomfort on the part of Lynne and the ambassadors at sitting at the front of a group “on show as if on a stage”.
- As would be expected, some health ambassadors found it easier to deliver the sessions and respond to the questions than others and were more proficient and confident at doing so.
- In some sessions the questions lead to a situation where it widens into a general and deeper discussion on a particular topic and on occasions this has resulted in not all of the agenda being covered.

To resolve these issues it was agreed that where the venue was suitable, future sessions would be delivered in small groups with a health ambassador to each group. Each group would be covering the same agenda. Lynne would still deliver the first part of the session (as preferred by the health ambassadors), but would then circulate and be at hand for support where needed.

Where certain ambassadors struggled, or were unable to give clear answers to the questions, Lynne would tactfully contribute to the discussion and ask further questions to enable the ambassador in question to clarify her response.

Lynne also gave careful consideration to the type of group that was to be trained and which health ambassadors were best suited to that group. For example she would ask the more confident articulate or experienced health ambassadors to deliver a session to a group of GPs whose questions may include more specific medical issues than general ones related to culture.

Some health ambassadors also had preferences about who they did or did not wish to work with, and these preferences were also taken into account.

Achievement of Aims: Health Ambassadors perspective.

Two focus groups were held with health ambassadors, with fourteen attending in total (including two relatives who were not trained). One focus group was held with five women in a market town where they live and where they all attend the town's only health centre and the other was held in Leicester city. (see Appendix 3: Health Ambassadors who took part in the focus groups):

Health Ambassadors' evaluation of their delivery of training

One of the aims of the project was to train the ambassadors to deliver training so as to break down barriers. In respect of existing barriers, the ambassadors were nervous beforehand as would be expected; as much about how they would be accepted than about their own abilities:

...meeting a lot of people and wondering how they would react to us

However, most of the Ambassadors overcame their nerves quite quickly, as soon as the initial barriers on both sides were overcome.

At first there was some that was a bit funny, and then perhaps we were a bit funny to them, but then when we all started talking different questions started coming out and answers, and we got to understand each other and it was better, and we thought they are not as bad as we thought and they were probably thinking the same about us; because at first there's a barrier - "oh Gypsies, /Gorgers" but it come down and you could sit and chat with them.

The comment above illustrated the point made in a study *Understanding Prejudice: attitudes towards minorities* (Valentine G & McDonald I 2004), that lack of personal contact and awareness of groups who are perceived to be different is one of the reasons for prejudicial attitudes towards them. However, increasing positive personal contact alone does not necessarily change negative opinions; the same study also suggests that although “ in negative encounters minority individuals are perceived to represent members of a social group, in positive encounters minority individuals are read only as individuals and not as members of a group” (p18)

The ambassadors grew in confidence as they discovered that most participants attending the sessions were genuinely interested in learning about them and about their culture and as they recognised that they, as ambassadors, were viewed as having something to offer.

It was good; once I got up there and I started chatting they couldn't shut me up

we are all learning now that we are equal

This increased self-confidence surprised the ambassadors themselves, as many had appeared to internalise the perceived view of Gorgers that “*they think you're ignorant anyway*”. It was apparent that they had rarely, if ever, had previous opportunities to discover their talents for expressing themselves in public and to see that they were as able as others in doing so.

“you surprise yourself how much you do know. When you come out you think “ oh God I didn't know I knew that” It is surprising what you do know and you kept it inside and then when you learn you can open your mouth and you ain't got to be ... it is surprising where it comes from”

Breaking down defences

One of the key aims of the project was to break down barriers, and the ambassadors acknowledged from the start that this needed to happen on both sides. Another likely reason that the ambassadors felt enabled to deal with any perceived or actual challenges from participants who attended their sessions was their increased ability to

let down their defences so that they could hear and understand more easily what lay behind some of the questions

“your ears are open more you listen to what they are saying to you and they listen to you because you haven’t got your back up and so you talk, instead of (roaring) “ I am a Gypsy, listen to me!”

The aim of breaking down barriers was clearly achieved within the confines of the training session. This was despite the occasional difficulties that the ambassadors encountered with some participants who they perceived had attended the sessions with an agenda of challenging the ambassadors over issues related to their negative prejudices, rather than seeking to understand and learn.

It is likely to be a combination of the training they received and the confidence they gained from being respected by the majority of participants, which has enabled the ambassadors to deal with such challenges in the adept manner they describe, as opposed to being unwittingly drawn into contentious arguments.

there is an odd one or two in a group, they’ll ask you their questions like ‘do Travellers leave rubbish?’ and you answer the question and you can see that they just switch off and they are not interested in anything else...you just ignore them and answer the rest of the questions and talk to the rest of the group, you can just see somebody who is just not interested.

The ambassadors also developed the confidence to ask some questions of the staff groups when they were delivering training to them. For example one ambassador was able to get a satisfactory explanation to her question about why health staff would have asked about the likelihood of pregnancy when she had taken her young daughter for an appointment. She explained how this had made her see the consultation in a different light:

“I never thought of it that way. So you learn different things of them.

Common gaps in staff awareness and knowledge

The ambassadors spoke about the common questions that frequently arise in relation to provision of health care, such as:

doctors in hospitals, first question, “ why do you come in groups?” immediately that is the first question

*Like in hospital they ask why your partner doesn't come in with you with the baby?
Why don't we like the doctors asking young girls personal questions?*

why when you go to a site do all the children run round the car...you know what I mean, a lot of children and a lot of dogs

However, a far greater number of questions are concerned with a genuine interest in wanting to understand their culture and ‘how they live.’ The ambassadors expressed genuine surprise and satisfaction that that they have been able to help to ‘open the eyes’ of staff to a different level of understanding, even though they are often surprised, and on many occasions amused, at the lack of knowledge about their lives and culture

“ when you go to these meetings (training sessions) they don't just ask you health issues and things.....they don't understand us at all, they don't know nothing about us ...near enough all the time it goes on to personal questions. And to us that's not so important and we think why are you asking us that?”

Although they joked among themselves over some of the questions and found them amusing there was also a touch of disbelief, bordering on disdain at some extreme levels of apparent ignorance

I was asked where I shop by a bunch of midwives...where do you buy your groceries and I said “Asda” and they said “Asda???”

“ how do yous communicate with one another?”

another thing they ask you ...(laughs) who is the chief?

However, one ambassador summed up how ‘othered’ they are as Gypsies and Travellers

“to them we are not like them at all”

Whereas they were able to spot those attendees who had come with a personal agenda to challenge the ambassadors over issues such as ‘leaving rubbish behind them’ and not rise to a challenge to argue with them, they appeared equally able to dispel similar stereotypical views held by those who were more prepared to listen and understand

“you can pick people out when you go in a big meeting who genuinely wants to ask questions because they are interested and people who got their own grudge against Travellers cause you are answering the question but that is not the answer they want to hear.”

Changes in experience of health services

As very few GP practices had requested training sessions and relatively few practice staff attended the mixed discipline session it was not possible for many of the women to have detected any changes in staff attitudes or behaviour at their GP practices. Several of the women observed that they had detected no change in apparent discriminatory or dismissive staff attitudes

“I still don’t see any difference in accidents and emergency (even though they may have had some training) ...just in the way that they talk to you, like you are rubbish and ringing social services to you.... some of them in casualty have had training; it is probably not all of them is it...”

The ambassadors were philosophical about the lack of change and observed that it would take a long time and many more training sessions for widespread changes to take place

“... it is not going to be that quick to get it through to a full hospital. We haven’t been doing it that long really.”

“ At the end of the day it’s going to get us years to get through everybody”

“ cause you can’t guarantee that the people that are there are the ones you have trained.”

There was also a concern that those who attended the training sessions might not translate their learning into action:

“because we haven’t seen any responses...it would be good to go back to someone we’ve trained and to ask them what difference did it make”

“because some of them on the day said that there was some definite things they were going to change, I’d like to go back and see did they.”

“ yes to see if our work, meeting all these nurses and doctors ...has it made any difference to them, has it changed anything?”

However, the women in the smaller focus group, who all attended the same practice that had attended their training sessions, had noticed changes:

“Since we have been doing the meetings and we have been doing the meetings at the surgery, there’s been a lot of difference with the receptionists, because before they wouldn’t give you the time of day.”

“They’ll see you now wont they?”

“They’ll speak to you; if you are on the telephone they will have a civil conversation whereas before when you’d ring they’d try and diagnose you over the telephone and they are not even doctors, that doesn’t happen anymore.”

“ it is a pleasure to go into the doctor now”

“yeah cause they know you now, so it really has been a turning point”.

An important outcome of this change in attitude is that community members are now feeling less reluctant to attend the surgery when they have a health problem

“before if you had to go to the doctor you’d think, “ oh I can’t go I can’t go””

“ yeah it was a chore to go to the doctor; they are all going to stare at you.”

PVC: so you'd find easier to go to the doctor now; what about your family & friends?

“ yeah everybody has noticed the difference.”

PVC: so they are busier now then?

“ yeah (laughs) so we are just hoping now that the health of the Travellers is going to last a bit longer, they are going to be a bit more healthier because they are more comfortable going.”

Although many of the ambassadors had not yet been able to detect changes in their experiences of health care in their GP practices, or in some cases in hospital departments, there were examples of changes in other health services. Ambassadors described some specific changes they had observed in staff attitudes and awareness that resulted in adapted practice changes at a local pharmacy

“ ... before they just hand you out your medication and that was the end of it. Now before you actually take it, they'll ask “ do you know how many times a day you have to take this? and you must store it in the fridge...” Before that I used to push it in the cupboard, I didn't know it had to be in the fridge.”

“ My mum she is old, she can't read and write and they write it down now and they put a little moon or something for the night- time and a sun for the day time”.

Reciprocal Changes

As the ambassadors discussed their increased ability to listen undefensively and to understand the staff who attended their training sessions, they were able to transfer this learning to their own encounters with health staff outside of the training sessions.

“ it is bred into you to think that way so you automatically think they are going to be against you before you go anywhere”

“ you'd think they don't want to see you because you are a Traveller”

“you understand it now”

“ you'd think why they are asking all this instead of seeing my kids? but it doesn't be like that.”

“ it's things like that we are more wise to now.”

Although the ambassadors recognised that attitudinal change was two directional, they found it hard to disentangle the reciprocal influence of their less defensive attitude on the attitude of health staff. They recognised that they were more able to listen but found it harder to perceive that their attitude shaped the attitude of health staff and vice versa. Indeed it is not possible to say to what extent any change of attitudes by health staff is due to the increased understanding and awareness that they have gained from attending these sessions and how much is a result of them feeling less need to be defensive in response to perceived demands or hostility from Gypsy and Traveller patients. There is a strong likelihood that both explanations are applicable.

“you do not get upset now”

“you can talk to the doctors more”

The increased confidence that they would be given more time to be listened to and understood enabled them to ask the health care provider to speak in more straightforward language so that they could understand

“Before these sessions, they didn’t quite understand it but now they have had the sessions they are more understanding and they take the time. Like I am thick sometimes and I can’t get my words out, they’ll take the time to listen and for me to explain it so they do understand it. So they are talking in their high words and I say “woh wait a minute doctor, I am not being ignorant but I haven’t got a clue what you are on about”.”

One of the added benefits of the increased confidence of health ambassadors in their confidence and ability to communicate with health staff is that they report an increased willingness to ask questions. This can lead to increased understanding about their care and treatment.

“Cause some of them would just fob us off and we’d think that they are not interested and that is it, but ... a lot of the Travellers think “they are not listening so that is it... before we’d go and let them look at you and give you a prescription. You wouldn’t ask

the in and out of everything. Where as now I feel more comfortable and I will ask them all the questions under the sun if I think I need to.”

Additional benefits of becoming a Health Ambassador – capacity building

The increased self-confidence that ambassadors have reported in their encounters with health staff and other agencies as a result of the training sessions has extended to other areas of their lives. Several spoke of feeling more capable and less in awe of people who they had previously felt inferior to

“Because people that you see who have a job and are well to do and are well educated...you think they are going to be a lot brainier than you but they are not... you realise that you are all really on the same wavelength. They have got a lot of knowledge because in what they do but we’ve also got experience.”

This has increased self-belief has given one ambassador the confidence to get involved in wider local community projects

I have done a lot more since I started coming to this, like organising things for the kids ... Nobody organised me I just decided to get up and go to this meeting at New Parks, I was organising loads of things, I got grants given to me and all these schemes going for the kids

Being a health ambassador has given the women a feeling of status that has enabled them to use the title with confidence. One woman explained how she used this to good effect when she was receiving poor care on her granddaughter’s discharge from hospital.

“I said” wait a minute I am an ambassador for the NHS ... which I wouldn’t have reported her but I said “ I want your name” and she entirely changed and I thought ohhh , this is a discovery and I wished I’d got my badge (with me)”

Another women had discovered an increased ability to explain her cultural beliefs to staff at her child’s nursery when they failed to understand why she had asked them not to explain where babies really come from if he spoke about her pregnancy

“she said “why?” and I said “ you know what you need...you need a session with me” One of the days I said, I’ll come in and I’ll sit down and explain everything to you”

Importantly the ambassadors are developing the confidence to share their newly acquired knowledge and understanding with others in their community

“ you know what you are entitled to and what you can do”.

“ we are trying to learn it to other Travellers I think we are more confident to go and help other Travellers.”

Achievement of Aims: staff perspective

Of the estimated 800 staff who have attended sessions up until December 2009 there were 450 completed questionnaires returned. Of these 253 were from staff or students in hospital or community health care settings.

The need for cultural awareness was evident from the responses to the pre-awareness questions. Only 14% of staff or students were aware of any prior contact with Gypsies or Travellers outside of their work experience and only 43% of health staff or students had any direct prior contact with them at all. Although most who attended the sessions, apart from the students, had chosen to attend, there was a 100% agreement in the importance of understanding the cultural differences. Only 34% of the health staff had any received any previous cultural awareness training and only 14% of these had received any with reference to Gypsies and Travellers.

The evaluation of the training was extremely positive with 99% of respondents giving the highest scores of 4 or 5 on the extent to which the training had achieved its aim and the same percentage attaching great importance to community members delivering the sessions.

93% felt that the training had enhanced their skills to work with Gypsies and Travellers but there were no questions to discover what this may mean in practice or to discover what changes in practice were intended as a result. However, the

responses gave some indication of attitudinal change, and therefore a likelihood of improvement in practice, with 87% of health staff reporting that their prior perceptions of Gypsies and Travellers had been altered. This percentage has to be viewed with some caution though as there is no indication of what their prior perceptions were. It is possible that some of those whose perceptions were not altered did not have any negative perceptions at the outset.

Although the evaluation of the training was extremely positive and had achieved the aim of raising awareness of the culture and health needs of Gypsies and Travellers it is not possible from the questionnaires alone to gauge the effectiveness of the training in improving their health care experience. Attendees were invited to leave their details for further contact to monitor effectiveness and 42% did so.

Between December and February attempts were made to contact a random cross section of these from the different staff groups for an evaluation telephone interview. Although this was very time consuming with many failed attempts to reach the staff members in question, the fourteen staff from varied disciplines who were interviewed all gave very similar types of responses to the questions, which indicated that the training had been extremely successful in changing attitudes and practice.

The interviewees identified a wide range of issues that they and their colleagues had experienced in providing care to Gypsies and Travellers. Many of these issues related to non-compliance, such as *'missed appointments, making appointment for one person and three turning up, not very willing to leave much information about themselves, their lack of co-operation with information, reluctant to breast feed.'*

They also identified issues related to communication difficulties and the sense of urgency on the part of Gypsies and Travellers: *'they speak very quickly, some accents difficult to understand, they are quite impatient when they can't get through to a member of staff first time round, they need to be seen immediately, when sometimes it is inappropriate.'*

The training had reportedly made a difference to interviewees in respect of greater understanding of these identified issues. Typical responses included

“It’s had a huge impact. We know respect and understand why they react the way they do.”

“It put things into context; made me realise how invasive my questions had been; why I had not got answers, why I need to ask questions in a different way.”

The importance of the health ambassadors delivering the training was emphasised and responses indicate that this is the most effective way to dispel myths and negative prejudice. Most interviewees had cascaded their learning at some level to colleagues and had experienced some success at doing so, but others had more difficulty:

“staff and friends I tried to discuss it with did not believe me. They were really blinkered and yet they had no real experience, it made me realise how difficult it must be for Travellers”

“One or two colleagues doubted some information that was given and we had an interesting debate. It is difficult to change very fixed views.”

Staff also revealed the reciprocal impact of the training in the same way that this had been identified in the focus group interviews with the health ambassadors. Several staff recognised that each party had defensive expectations and that with each being more aware and less defensive as a result of the training they were able to understand each other better and achieve improved dialogue.

“I had very biased ideas - not based on fact. I think I had been intimidated by them.”

“The few I have met since seem more relaxed and confident. I am not sure if this is because I am better equipped to help them, or they understand my service; I guess its both “

“they are less confrontational, more relaxed and at ease. They are also less challenging, more understanding of what I can actually provided and more willing to listen and to work with”

The importance of dialogue and mutual understanding was also noted in response to the question concerning the aspect of the training that had the most impact

“Being able to speak freely to them and their honesty. That I would now be more confident when talking to a Traveller & hopefully more able to put them at ease.”

“Getting to know the issues for the clients & in turn them understanding our difficulties”

The interviews revealed that staff had been able to make significant changes to practice as a result of the training. Many of the identified changes were simply improved skills in communication, based on their improved awareness and understanding, but there were also practical changes

“I take more time, explain why I need to ask certain questions”

“ring or text to remind them of appointments”

“make sure that they have community Midwives – name clearly identified.”

In summary the evaluation of the staff perspective complemented the perspective of the health ambassadors; this is encapsulated in a comment by one staff interviewee

“We have learnt so much, we now feel we can begin to work alongside the client at their level and pace, understanding what’s behind some of their reasons for not participating and cooperating etc. We now have a mutual understanding of each other.”

Current status of health ambassador training sessions and future plans

Lynne feels that that health ambassadors are now requiring a refresher training session and there is a need to update her database of trained ambassadors to discover who wishes to remain on the list.

There is also a need to train further ambassadors from the waiting list that includes four Gypsy Traveller men.

Some health ambassadors feel ready to take on the initial part of the delivery concerning an introduction to the local Gypsy and Traveller community, who is included and where they are, and to talk about the role of the Travelling families health team. One Ambassador suggested that they could take on more of Lynne's administrative work in booking ambassadors to deliver the sessions.

Those who do feel ready for this also have identified a need for training and practice before doing so. There is also enthusiasm among the ambassadors to expand their roles and develop more of a liaison role.

“we were on about getting cards to give out with our contact details and phone numbers on and what we do that they can then contact us. They still have to go through Lynn to organise it if they wanted to but if they wanted to contact us with any questions they didn't ask at the meetings they can always ask one of us.”

Others wanted to go further and be on standby as an advocate and discussed various areas where they could work in this way such as in care homes or prisons, but they also identified some of the considerations such as issues of confidentiality and family members not wanting them to be involved in 'other Travellers business'.

There are plans for a DVD to be made which is intended to be a compilation of the different aspects of the cultural awareness sessions.

Lynne also intends to support the Ambassadors in their wish to write a book about their experiences

Some of the practical challenges require decisions and action before many of these developments can take place

Summary of strengths of the project

The project lead was well known, trusted and respected by the community and this enabled effective engagement with a wide section of the community at the inception of the Pacesetter programme. Community members were therefore fully involved in the choice of project and had complete ownership throughout. They were consulted at every stage and generated their own ideas so that the project was community led.

All three Trusts supported this one project so that there was a concentrated focus. There has been a strong commitment and enthusiasm for the project from all the Ambassadors, coupled with extreme dedication by Lynne, the project lead and the Travelling families team to maintaining this enthusiasm through regular reviews and consultation.

By starting this project at an early stage because of effective early engagement Lynne has been able to refine and develop the project over a 2 year period and learn from early experiences. There has also been adequate time to celebrate the success of the project with the Ambassadors and enable them to share the credit for its success at a celebration event.

Summary of challenges

Co-ordinators role.

LH carried out the coordinator role as part of her wider role as specialist health visitor for Travelling families. It was envisaged that this would require four hours per week of her time and this was funded accordingly. In practice the project demands very much more of her time. This includes the consultation time with Gypsies and Travellers and recruiting to the project, designing the training of the health ambassadors and ongoing review sessions with them, coordinating the requests for sessions and designing the tailored sessions for each group, contacting and recruiting ambassadors to deliver each session and arranging the practical issues of transport and reimbursement, evaluating the sessions, responding to issues that arise and reporting on and promoting the health ambassador sessions and bringing community members with her to various Pacesetter or PCT events both nationally and locally.

She estimates that a minimum of two days a week is required to take the project forward to deliver more sessions and to develop them in the light of experience and to train further ambassadors whose names are on a waiting list.

Status - volunteers or sessional workers.

At present the Health Ambassadors are reimbursed for any travelling and out of pocket expenses they incur in the delivery of the sessions, or in connection with any training review sessions they attend. The administration of this arrangement is extremely cumbersome and in line with future aspirations for the project, to

eventually become self-funding. Lynne is currently working with the Trust to develop a more commercial approach.

Summary of lessons learned and important components of success

A project must be discussed with many community members, rather than selecting one or two who may not be representative of the general community

The project idea must come from the community in order for them to take ownership.

Community members must be involved at all levels and remunerated for their time and expertise. This requires accurate costing and support from finance officers to cost projects accurately and time must be factored in for effective evaluation and dissemination of information learnt.

Community members need to be given support to continue their self-development so that the project does not become an end in itself.

Community members need to be given adequate recognition for their contribution and achievements.

Chapter 8b
West Midlands and South East Coast SHAs
Personal Adult Health Record Project

Objective. To design, develop and implement a Personal Adult Health Record (PAHR) for adult Gypsies and Travellers in selected sites in two strategic health authorities that would be owned by the individual Gypsy or Traveller and shared with relevant health professionals wherever they travel to.

Context

Various versions of Patient Held Records had been in existence in individual Trusts over the past couple of decades, but there has been little evidence of project management of their implementation or evaluation of their use and effectiveness. In 2003/4 a literature review of appropriate health care interventions to enhance the health promotion evidence base on Gypsy Travellers, as well as other ethnic minority and marginalised groups, explored a range of generic interventions, including hand held records (Aspinall 2005). Although many studies were found to have recommended the use of hand held records, there were few descriptions of pilot schemes to implement the intervention and a dearth of formal evaluations. Although there were reports of effective pilots of a system of patient held records for use by Traveller families in the UK, no evaluations of these pilot schemes were identified. The report noted however that there was strong support for the practice across many statutory and other agencies, which suggested that it is an effective intervention. It referred to a research review of the practical problems surrounding patient-held records and ethical arguments for and against them that concluded that 'there are no substantial practical drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical records' (Gilhooly & McGhee 1991). At this time the National Association of Health Workers with Travellers (NAHWT) had collected various examples of records in use for Gypsies and Travellers around the country to utilise the best components and formats for a national record. They produced a sample record that they wished to pilot but did not receive the necessary backing to implement it.

More recently a personal health record had been developed and implemented across the whole of Scotland by the Scottish Executive Health Department in 2005.

Guidance was issued to Chief Executives of NHS Boards on the implementation, with information about training that was to be integral to the rollout and directed at Gypsy Traveller users and health professionals.

In October 2005 the Department of Health (DH) held the first Stakeholder Meeting on Improving the Health Status of Gypsies and Travellers and the decision was announced that addressing Gypsy and Traveller health would be a core element of the proposed Pacesetters Programme. It was envisaged at this time that participating SHAs, with support of the DH, would be asked to develop a national person-held record similar to the one developed in Scotland. Rafeek Gardee from NHS Scotland attended the second meeting in 2006 and spoke about the development and implementation of the person-held record for Gypsy Travellers in Scotland.

Community involvement in project identification

Community members and health staff initially discussed the proposal at the Department of Health Stakeholders meeting in February 2007, as one of several possible change ideas for the Pacesetters Programme. There were mixed reactions to the idea, with some community members seeing the potential benefits of ownership and of ready access to their health information when they were travelling. However, reservations were also raised about the potential likelihood that GPs would not complete it, the possible stigmatising effect of carrying a record and the need for it to be kept updated. There were also concerns about indifferent feedback following the introduction of a Scottish PAHR in 2004. Other alternatives to a PAHR were discussed as possible solutions to improving the collection and sharing of personal health details, including GP summary sheets and the use of SMART cards. A key benefit to the PAHR raised by the community itself was that if they had a medical condition and were on an unauthorised encampment the PAHR would be evidence for the ranger/ police not to move them on until their healthcare needs had been met during that stay.

During 2007, both housed and travelling Gypsies in Hastings and Rother/East Sussex Downs and Weald (HR/ESDWPCT) had been consulted and had supported the development of a PAHR, in addition to the local voluntary organisation, Friends and Families of Travellers (FFT). The proposal, and then later the draft document, was shared with individual Gypsies, a women's health group and with national members at

the Sussex Traveller forum. Community members were keen to see this idea taken forward.

In March 2008 Hastings and Rother PCT gave a presentation of their draft record at the Pacesetters Programme event in London, which was attended by community members. The community members who attended the workshop felt that hand held records were a good idea in theory but were not needed for all Gypsies and Travellers, and that more work would be needed with community members if they were to be effective in practice. Some reservations expressed by the community were that it was a way of Government agencies monitoring them and that their confidentiality may be at risk.

By the end of the workshop the SHA leads from West Midlands and from South East Coast SHAs and their community representatives agreed that they would work jointly on this project and that they would meet together the following month with the DH Pacesetter Lead, RW and community members to consider the best way forward.

Process and activities

Project management

The geography and diversity among the six Trusts involved made this a complex project to manage and coordinate, in addition to two being secondary and tertiary care trusts. At a joint meeting in June 2008, following local regional meetings, a draft project governance structure was finally agreed and a decision taken to employ a full time equivalent project manager, or two half time managers, to work across the two regions.

The post was advertised nationally and two community members were involved in the recruitment and selection process.

A steering group was set up jointly by the Programme managers from West Midlands SHA and SE Coast SHAs and was made up of health professionals and community members in the two regions.

The aims of the PAHR would be to:

- § facilitate continuity of care
- § minimise the need for individuals to repeatedly provide their medical history
- § minimise the likelihood of inaccurate or incomplete medical history
- § provide up to date, accurate information regarding treatment and medication

- § allow more informed engagement between Gypsy/Traveller and health professionals
- § support access to appropriate healthcare at the point of need.
- § allow for some proactive lifestyle interventions from primary care and community health care staff

The project manager, Hilary Williams (HW), took up post in February 2009.

Community members' involvement

In West Midlands SHA a consultation meeting was held in May 2008, facilitated by New Deal for Communities, which supports the Walsall Gypsy and Traveller Forum. 12-15 Gypsies and Travellers, predominantly from Walsall, but including two from Wolverhampton, attended the consultation event with leads from all three participating Trusts (Walsall PCT, Heart of England Foundation Trust and Wolves PCT), Paul Jeff from DH Pacesetters team.

Community members were enthusiastic about PAHR and two community members were nominated by the Walsall Gypsy and Traveller Forum at one of their meetings to be on the bi-regional PAHR steering group. These were different community members to the two QAG representatives for the West Midlands region. At this meeting some clear direction was given on the content and structure of a record.

In South East Coast SHA there was more variable involvement from community members from the three different Trusts, which differ much more in terms of geography, the services provided, and the populations that they serve.

In Surrey & Borders Partnership NHS Foundation Trust (SABP) (Mental Health Trust) there are close links with community members who are employed as community development workers by Surrey Community Action and who attended the DH workshop event in March 08. These community members were invited to sit on the bi-regional steering group.

In Hastings and Rother (East Sussex) PCT the Pacesetter lead (FE) has very close links with the Gypsy and Traveller community across East Sussex and a strong trust has been established between them

In East Kent Hospitals Trust (Canterbury etc) there is less local involvement with the Gypsy and Traveller communities and no apparent links with the established Gypsy

and Traveller forums existing in Kent, although one of the community members who is the leader of one of these groups attended some of the design workshops.

Lessons from the Scottish model

At the inaugural bi-regional steering group in June 2008, when a number of different existing records were considered, a teleconference call was made to key staff responsible for the implementation the Scottish Patient Record of Personal Health (PRPH) to discover any lessons learned.

One key positive aspect of the implementation of the PRPH was the capacity building element where Gypsy Traveller Community members co-designed and co-delivered the training attached to the roll out of the record. They received Train the Trainers Training as an integral part of this approach.

Another positive aspect was the support and ownership of the record among health visitors. This was important for implementation and driving demand for the record.

Important messages from the Scottish experience included:

- § the need for endorsement from GPs to inspire other GPs to engage, accompanied by a training package and awareness raising about relevant issues.
- § any training delivery around cultural competency should be through and with the community and Train the Trainers must be included to ensure added value for the community.
- § active involvement and engagement of the Gypsy and Traveller community is instrumental in the development and implementation after a pilot phase.
- § the project should be rolled out in 'bite sized' chunks (the whole of Scotland was deemed too big to target and manage at once)
- § evaluation should be built into the process from the very early stages so that ongoing learning results.

Following this consultation concerns were identified about the size of the available budget and whether it would be sufficient to roll the project out across two regions. It was noted at the meeting that significant funding would be required to pay for training of NHS and Gypsy and Traveller community members in addition to paying for Training the Trainers. It is unclear how much bearing this had on subsequent decisions on implementation.

A decision was reached to produce a discussion paper of three options for developing the PAHR, which identified the benefits and disadvantages of each option:

- § to pilot the existing records from Hastings and Rother and Walsall separately and simultaneously in their respective regions.
- § to pilot the Scottish HHR (with permission), in the two regions.
- § to develop and pilot a new HHR in the two regions.

The decision was made to follow the last option and learn the lessons from previous work by others. This option also gave the Gypsies and Travellers an opportunity to have their views taken into account on the design. In choosing this option the steering group recognised that the project would take longer and that the costs would be greater.

Design of the record

Twelve community members from the two regions attended a design day held at the DH in December 2008. An external design team was appointed to undertake the design using the ideas put forward by community members.

Two alternative versions were brought to the bi- regional steering group meeting in January 2009 and were taken to each region for wider consultation with community members. It was agreed that the involvement of GPs and other clinicians were a key factor in ensuring success and that their feedback on content was vital. A pdf version was also produced for distribution to facilitate local consultation with GPs and other clinical leads.

The timescales for consultation over such wide geographical areas and across different groups was a tight one, with the original deadline of end of February for a final print ready document. However, there were inevitable delays with such a range of contributions and suggestions to be considered.

Additions and other changes were still being considered at the bi regional steering group meetings in March, and in April when there were issues over project ownership and responsibility for decision-making. This took place in the context of a debate on use of specific imagery that had been agreed by community members. A compromise was eventually reached that the record would be piloted as it stood, with the possibility of finding an alternative image to be raised during training sessions.

The final edition was approved and printed by May 2009. The following month the record was taken for wider consultation to Appleby Fair, the venue for one of the largest annual gatherings of Gypsies and Travellers in the UK, where HW received positive informal feedback from community members who viewed the record.

Training for staff and community groups

Initial considerations

Key questions were considered by the steering group: who the training should be aimed at, who should deliver the training and how, and what were the necessary training outcomes.

They agreed that a wide range of health staff should receive the training, including all GPs and community based health providers with Gypsy and Traveller contact, and that there should be a high level of community input into both the development and delivery of training.

At subsequent meetings there were pertinent questions raised about targeting training at those 'with Gypsy and Traveller contact' with the point made that those who did not have contact may well be those who most needed training.

The steering group recognised that the task of attempting to train a vast number and range of staff identified as requiring it across the disparate Trusts in two regions was unrealistic in a relatively short time scale.

Selection of trainers

Although one of the key messages from the initial consultation over the implementation of the Scottish record was that 'Train the Trainers must be included to ensure added value for the community', this was not included in the Pacesetters project. The extra costs and required time were likely to have been prohibitive but it is not clear what discussions took place around ensuring that in an alternative model 'any training delivery around cultural competency should be through and with the community'.

Steering group members were given a short time scale to recommend trainers so that a tender document could be distributed to suggested and interested training providers the following week. Although there are community members in the UK who have experience in delivering training on cultural awareness it is not known if steering group members were aware of these. Three suggested training providers were

interviewed. The successful candidate had been recommended by a community member, based on her experience of attending one of their courses.

Voscur trainers

Voluntary and Community Sector (Voscur) training providers, based in Bristol, were awarded the contract. They are experienced in delivering programmes to equip groups and communities to find ways in which equalities issues are better promoted to service providers and the wider community. They have a focus on peer educators and have worked with Gypsy and Traveller community members through their 'Confident to Present' training programme (see Bristol project chapter).

Proposed training content and community involvement

Voscur attended the April bi-monthly steering group and gave a short presentation to steering group members, who were then asked to contribute their views and ideas in preparation for their meeting to design the training package.

None of the four community members of the bi regional steering group were present at this first meeting with Voscur. Although it was agreed that there should be a high level of community input into the development as well as into the delivery of training none were reportedly invited to participate in the initial training package preparation.

Agreement was reached in prior discussions at the steering group meetings that the training needed to highlight the health and cultural needs of Gypsies and Travellers and the need for 2- way learning between Gypsies and Travellers to learn from each other. There was also an agreement that GP practices should receive one to one training rather than participate in wider staff group training because of their unique role, and that Voscur would only be involved in the wider staff group training.

The training package developed in time for the June bi-regional steering group meeting when the four community members were present included:

- § Exercises, a health and culture quiz and presentation- to impart knowledge
- § Scenarios and role play to illustrate myths and typical situations
- § Community member 'Q&A' session
- § The PAHR- why is it being introduced (piloted) and how to use it
- § Action planning
- § Monitoring and evaluation

In addition to the training session there was also to be a resource package, including a CD, to be made available on request for those wishing to cascade training.

Several further suggestions were made to refine the package before the programme was finalised.

One of the heeded suggestions was that delivery of the training sessions should be postponed until September to avoid school holidays and to give staff more notice to attend.

GP practice training programme

HW consulted practice managers in two practices in the West Midlands on the optimum methods for delivering training to GP practice staff.

The time constraints for practice staff to be released for training were identified, and ensured that the only availability would be at a lunchtime hour. It was also suggested that the training should be delivered separately but simultaneously to GPs and practice nurses in one group, and administrative and front of house-staff in the other group.

The rationale for this suggestion was that role specific content would differ and that the presentation style should also differ. For example it was suggested that GPs and practice nurses training should have a strong clinical focus with statistical facts and information about lifestyle issues, whereas front of house staff should have a focus on registration, confidentiality and should deal with the reported prejudice that “some feel that health issues in the Gypsy and Traveller community are largely self-inflicted due to lifestyle”. There was some clear stereotyping in these discussions with the suggestion that the presentations to GPs and practice nurses should be professional, with “no attempt to be touchy-feely” and that it should be more relaxed with the front of house staff group. It suggests that there are quite clear divisions between the two groups in the practices that were consulted as opposed to a non-hierarchical and supportive team ethos.

However, the lack of availability of trainers was a key factor in the eventual decision to deliver one session per practice. The sessions were made available to all practice staff, but as many clerical staff are part time or sessional there were inevitably a greater number of clinicians than front of house staff able to attend.

In Sussex, the Pacesetter project lead will deliver a condensed version of Voscur training package to clinical staff, discussing cultural and common clinical conditions,

while a project officer will deliver training to non-clinical practice staff, covering ethics, stereotyping, the Race Relations Act, belief systems etc.

These sessions will be delivered in a 90-minute slot over a lunchtime period. Training has already been delivered to Practice nurse forums and GP / primary care forums and are also planned for practice manager meetings. The training will be piloted in GP practices already engaged and working with the Gypsy and Traveller community, and refined if needs be thereafter.

Group staff training programme

The training programme of 20 sessions was to have commenced in July with three sessions to be delivered in each of the five⁴ participating Trusts, plus one further 'mop-up session' in each SHA. Two community members were to be present at each training session. Voscur paid the community members directly for their involvement. The proposed arrangement to involve local community members was more difficult to organise in non PCT Trusts such as Kent where it has been much harder to coordinate and identify key managers and health professionals. Coordinators have struggled to develop the networks and these are only just starting to be developed. Community representatives and local coordinators on the bi -regional steering group were asked for their advice on community members that would be interested, and to forward any names to the project manager. Voscur, with community members, delivered a total of 14 sessions, in five Trusts in the two regions during September and October 2009. (see appendix 2 for Trainer session plan).

Distribution of records- who and how

Training was to take place prior to the distribution of records. The timing and methods of distribution have varied due to the diversity of the Trusts participating in the PAHR project. In the West Midlands the distribution of records in Wolverhampton and Walsall has been via SHVs and CDWs as originally proposed, and records have started to be issued to Gypsies and Travellers. In Hastings and Rother PCT the distribution has been through training - once staff have received training they have been issued with a sequentially numbered box of records and have had to sign for them. Staff must then record each record they issue and the name of the Gypsy or

⁴ Heart of England NHS Trust had withdrawn from the project as the local SHV had identified that there were no mobile Gypsies or Travellers in that pilot area

Traveller who received it. To date no records have been issued In East Kent, and in Surrey there have been delays in distribution, although distribution is now underway. Both of these Trusts have had to find distribution routes via their community trusts. There are no documented criteria or explicit statements about the selection of adults to be offered a record, although there was a general understanding that they should be targeted at mobile Travellers. Some criteria would ideally be specified as different people could interpret the definition of mobile Travellers in different ways. For example, some Travellers are mobile by virtue of having no permanent fixed address either on a site or in a house. Others may live at a fixed address on a site all year round but travel in the summer months. It is not clear whether a fixed address or whether permanent or temporary GP registration were criteria that local CDWs or SHVs used, or indeed whether a request from community members was also a permitted route to being offered a record. The latter might arise if a community member had a chronic health condition and wished to carry their own record. Whether each Trust made their own decisions and the extent to which community representatives had input to the distribution criteria is not certain. In Sussex a decision was made that any adult from the Gypsy and Traveller community would be eligible to receive a record.

Evaluation of the use and effectiveness of the records is to some extent dependent on the situation of those who use it and the extent to which they need it if they use different GPs or health care providers outside of their usual area of residence.

Monitoring the distribution of records

An important aspect of the evaluation is to be able to assess the level of initial uptake and use, both by Gypsies and Travellers in bringing them to consultations, and by health staff in using them and completing relevant sections. It is therefore essential for a recording and monitoring system to be in place and for an agreed means of contacting the record holders at defined points in time in order to be able to evaluate their use of the record.

Monitoring systems were discussed in June 2009. As it was not feasible for the project manager to manage and monitor distribution in all six Trusts, it was proposed that staff in each Trust would be asked to keep a record of who had received a record and that information would be kept with the Pacesetter project lead in each Trust, even after the programme comes to an end. The person responsible for issuing the

record would also be responsible for filling in the initial history at the same time.

Again, monitoring systems would be easier for Pacesetter sites whose Trusts were directly responsible for the staff who were distributing the records.

The use of the records was to be monitored by opportunistic enquiry from health care staff when they met a mobile Gypsy or Traveller. Staff were expected to enquire whether they were in possession of a record and whether or to what extent it was being used. It was also suggested that reminders would be generated to ask staff to remember to enquire about PAHRs and their use, and to arrange a follow up telephone call to community members who had been issued with a record.

Emphasis was placed on flexibility in approach as no two sites had the same staff disciplines working with the community or attending the training. Where there were HVs identified as working with the community, as in Wolverhampton, these were the key professionals, whereas in Walsall the key professionals were CDWs. In Surrey the local delivery lead undertook to email an electronic copy of the PHAR to all the Practice Managers to familiarise and raise awareness of these records. They were requested to acknowledge the email as evidence and in the hope that the GPs will request records if required. The aim was to ensure that health professionals based in Surrey and Borders Partnership Trust (SABP) were aware of the records, and a record would be introduced at the induction course for new staff. The in house trainer had attended one of the training workshops.

Since then the Pacesetter Coordinator at SABP has identified and made contact with the GP who carries out training for all GPs in Surrey and will ensure that training for GPs on the Patient held records will be accomplished within the year.

As very few records have yet been distributed to Gypsies and Travellers in most areas there has been little opportunity to evaluate how well monitoring systems are working.

Evaluation of staff training

Voscur group training sessions

229 staff from a range of disciplines attended the fourteen training sessions delivered by Voscur and the community members. 142 of these attended the eight sessions in SEC region and 87 attended the six sessions in the West Midlands.

Numbers attending each session ranged from as few as four to as many as 35

The original evaluation sheet underwent a few changes in response to the suggestions made to capture the extent to which learning outcomes were achieved. The learning outcomes of the training were identified on the evaluation sheets that attendees were asked to complete. (see appendix 5 for evaluation form) .

215 evaluation questionnaires were returned. All but 19 of the attendees scored 4-5 on the likert scale indicating the extent to which the training had achieved the learning outcomes.

Voscur amalgamated the responses to the specific questions from the evaluation questionnaires into summaries of key positives, key learning points, and subheadings giving an overall perspective. The summaries indicate a very positive response to the training with many examples of improved understanding and awareness, plus many examples of intentions to cascade the learning either formally or informally amongst colleagues. The most detailed summaries in terms of participant reflections are the amalgamated verbal responses to the additional questions that trainers asked respondents to consider at the end of each session:

- How will you use the learning from today to address attitudes and prejudices in your staff team / departments?
- What have you got out of the session?

These questions were asked to give an opportunity to cover what they learned as well as to consider how the session could address attitudes at workplaces.

The combined summaries of verbal reflections and the responses to specific questions on the evaluation forms assist the evaluation of effectiveness of the following short term learning outcomes:

Improved awareness and understanding of Gypsy and Traveller ethnic identities

Although not all comments indicated that this specific learning outcome was achieved, many respondents reported some level of increased understanding and awareness that suggested that this too was part of their new understanding. For example:

“Learning that the terms G&T are not specifically one type of person”

“Being really enlightened! Wasn’t sure if we had had clients from G&T community”

Improved awareness of specific health inequalities and health needs

Despite few references to health inequalities, there was much evidence to support that the training helped staff to realise the specific health needs of Gypsies and Travellers. This is reflected in comments such as

“the role play opened up my eyes, made me more aware of G&T needs”

“Awareness of acute issues and acute needs – it can be forgotten if we do not have this sort of training and awareness.”

Understanding of the specific barriers for Gypsies and Travellers in accessing and using health services appropriately

The vast majority of responses indicated that the training was highly successful in raising understanding of the barriers in access to health needs, and importantly in demonstrating how these could be overcome. Many respondents referred to an increased understanding of the prejudice and discrimination encountered by Gypsies and Travellers and also to lack of cultural competence in staff practice. For example

I will change how I perceive G&T communities and biases and the need to work with them in a non- judgemental way – improve the way we work.

We have always felt the need to do it the ‘NHS way’ and now realise that is not right.

Use of the Personal Adult Health Record

The overall response was very receptive; there was much enthusiasm once participants had received the training and were able to realise the necessity and value of the PAHRs. There seemed to be a lot of willingness to use them and encourage colleagues to use them and many people saw how it could be rolled out to other marginalised communities who lacked full access to health services.

Evaluation of the Training sessions

The summary of reflections contained only positive comments. This may well reflect the majority of responses, but we do know, from Voscur's evaluation summary of 'activities- what could have been improved', that the trainers did not manage to get through all the activities in all of the sessions and they felt that " *this impacted on the feedback... It meant that the training may not have met all the intended ' what you hope to get out of the training' for some participants' "*

Voscur reported that participants most valued the opportunity for a question and answer sessions with the community members, and this appears to be a common finding with all projects that included this in their awareness raising. The participants clearly learned a great deal from the questions and answer sessions and also from the action planning activity that was carried out towards the end of each session. Many reported that they had not only acquired new relevant information and understanding but that it helped them to realise the extent of their previous lack of awareness:

"Now realise that G&T awareness wasn't even on my radar; it's been a complete eye opener."

"Had my own awareness raised; it has made me realise, and challenge, my assumptions"

Participants were particularly keen to share this understanding with colleagues both informally and by means of formal cascading using the Trainers pack. This was evident from their action plans; for example

I will:

"Go back and find out what other people know; what their assumptions are and challenge them."

"I want to incorporate it into core training to team and take to wider lifestyle services team. We need to cascade to all!"

Evaluation of wider objectives

One of the training objectives, in addition to increasing knowledge and raising awareness, appears to be a longer-term objective of improving patient interactions through attitudinal change. This is indicated by the question 'Have your views changed

as a result of the training, and if so, how? ' Responses and intended actions gave some insight to the initial impact of the training:

Having not worked with G&T can now take away understanding of the level of discrimination towards them, am absolutely shocked at the level. My attitude, perception and way I will interact will change!

Realise a lot of work still needs to be done, need to encourage both sides, G&T and health professionals, to engage more. Build relationships and trust more, need to adapt our service.

Although improving patient interaction is a longer-term objective and it will be necessary to review whether staff have actually put their plans into action at a later date, the vehemence of these responses are a promising indication that attitudinal change may be sustained with positive results. Post training questionnaires to assess the longer-term impact have now been distributed but the data is not yet available. However, correspondence from the project manager from the head of IM&T strategy and development, after he had attended training, shows a positive outcome of the training in modifying practice at policy level:

"I'd never realised the implication of not being able to send an appointment letter (via Royal Mail) to a transient population. We are currently in the process (budget constraints permitting) of deploying a solution that will send SMS text reminders to patients of up and coming appointments. I can't see why we couldn't use this technology to send SMS texts for other correspondence to certain groups."

GP practice training

GP practice staff training has commenced in the West Midlands region but has not yet started in South East coast regions.

PAHR use and impact.

By February 2010 there was a variation in numbers of records distributed to Gypsies and Travellers in different Trusts. Most Trusts had not yet distributed any records, but where this has commenced, for example in Walsall, there are reports that Gypsies and

Travellers have produced them at GP practices. There has not yet been an audit of record use in terms of baseline information entered in the records or level of use by health professionals. It is therefore too early to evaluate the use and impact of the PAHR.

Community member engagement

This project had good community engagement at different levels throughout the different stages. However the level of engagement varied among the six Trusts and was greatest where the engagement was already in place- in Sussex, Wolverhampton and Walsall. There was a strong commitment to community engagement through initial consultation at the stakeholder meeting in 2008 and through community membership on the steering group. However, it has not been possible to interview a wide enough sample of community members to evaluate the extent to which they were satisfied with the level of engagement and to discover whether their perceptions of engagement matched the perceptions of the project staff. Two community members who were also QAG members, one from Kent and the other who was also a steering group member from Surrey, and another community member who worked closely as a Gypsy liaison person for the Pacesetter project lead in Hastings and Rother PCT were all interviewed and had different perspectives.

The steering group community member from Surrey was first introduced to the idea of the PAHR at the stakeholder meeting in March 2008 and did not feel enthusiastic about it, citing the fact that in her area there were very few mobile Travellers, and also

“they already tested it in Scotland and from what I’d heard it failed, so I couldn’t understand why they were taking it up again to repeat something that had already failed”

She felt that her voice had not been heard:” I didn’t feel valued for my opinion anyway and I was just there to tick the boxes ... to be honest with you I felt as if that they’d only made their minds up ...that they’d already decided what they were going to do”

Although she subsequently agreed to be on the steering group, further disillusionment led her and her fellow member to stop attending. On the other hand the community

members in West Midlands did continue to attend the meetings and continued to play a role in the staff training sessions.

The community member from Kent was very enthusiastic about the concept and potential of the records

“It’s easy to go to them and say this is going to help you and your family, this is nothing to do with the police, this is nothing to do with social services this is to do with you, if you or if your children is poorly this is all you have to do take to a doctor and if you do travel somewhere else again you can take that to a new doctor. And he will know what pills your baby’s on so he don’t give your baby the wrong pills.”

However, despite being the head of a Traveller organisation in Kent she seemed completely unaware of what was happening locally with the PAHR project:

“I was saying (to the QAG organiser) well how come my area doesn’t know nothing about it? ... I think this is the thing what’s sort of bad cause if there’s a project that’s actually going on in the area and if there is a big organisation in the area that knows most what’s going on anyway then I thought the wisest thing would have been come to the group, you know, or at least speak to the head of the group”

The community member who had been involved in the local project, before the Pacesetter project had evolved, felt both included and enthusiastic about the PAHR and the project in general. There was already a strong trusting relationship in place and she felt that her views were heard and respected. She was enthusiastic about PAHR and explained how she perceived the benefits to her and the wider community she had consulted:

“Give them better health support and give all them that is travelling, and them on sites that go off to visit family, a bit of independence...so they don’t have to worry about “ well if I go there I won’t be able to get a GP, I’ll have to come all the way back.” It’s a bit of a lifeline for them if you know what I mean. They are starting to see this as a lifeline and a bridge between our community and the GP’s, the hospitals...so it is like a bridge that is being built”

This small range of views and experiences cannot be viewed as representative, but they do indicate the scale of difference between Trusts where there is a strong history of community engagement and those where much more time is required to network and engage and to build trust with community members.

The team have disseminated the pilot record by presenting it at other national community gatherings. Some community members expressed interest in the record when it was presented at the Irish Travellers Movement conference and took copies to share more widely.

Summary of strengths of the PAHR project

There was a high level of community member input into the design of the pilot record, and the eventual production was well received by community members outside of the project Trusts. At least one other Trust has expressed an interest in purchasing the record for their use.

The staff training has been successful in raising awareness of Gypsy and Traveller needs, with strong appreciation of the community members' presence and input in the training delivery. In primary care trusts the project has been easier to implement and the training has been particularly meaningful to the community staff. In these Trusts, where it is easier to facilitate, there has been strong community engagement and key professionals were more easily identified.

Summary of challenges

There were problems with community member representation on the steering groups. The felt need for consistency of representation on the steering groups led to some resentment by those who have not been selected, despite the selection being made by the local Gypsy and Traveller forum. This resentment was intensified when other members of the same forum were recruited by another route to be QAG members and it was known that they received different level of payment. This local conflict became a significant issue and at one point there were plans for mediation from the DH to resolve it. There were similar conflicts concerning the different expectations and role uncertainties of QAG and community members on local project steering groups. These issues were explored further in chapter six.

There was a further challenge in the broader context of ownership and deciding who had the authority to veto any agreed decisions by community members on the record content.

The timescales for a project to be managed over two large and separated regions were unrealistic and also incurred extra costs and resources through being project managed by one person. In sites in the non primary care trusts the tight timescales for a short-term project of this scale are reflected in the lengthy process of identifying key staff in the community for local responsibility for project delivery and monitoring. The diversity in the participating Trusts meant that different Trusts were operating to different timescales and to differing modes of distribution and monitoring systems. Staff changes in six different Trusts also had an impact on the continuity of the project.

The use and effectiveness of the record and the project as a whole cannot be fully evaluated within the project lifetime.

Summary of lessons learned

It is complex to manage a project as one entity over two separate regions. The extra resources and time required need to be costed accordingly. Local project managers are preferable both from that aspect and also because of the value in building up a more extensive knowledge of local networks and intelligence.

Evaluation, including agreement on criteria for distribution of records and monitoring their use, needs to be built into the project at the beginning, as does the appointment of a project manager. The project was heavily reliant on the goodwill of some participants.

Community involvement and representation over such large geographical areas needs careful consideration as local representation has resulted in greater challenges for community members who have been required to travel to London for steering group meetings. In the case of South East Coast SHA two of them are responsible for representing community members in three large counties. Time needs to be given to wider community consultation at the start of the project so that there is wider ownership among community members in all six Trusts

Roles need to be made clear about the authority for decision-making.

Chapter 8c

NHS Bristol

Raising staff awareness about Traveller culture and health needs and producing a directory of local services for the community

Gypsy and Traveller population in Bristol and south Gloucestershire

The estimated Gypsy/Traveller population of Bristol City is 460-480 individuals, mainly living in houses, with only 5% in caravans.

South Gloucestershire has the largest percentage of the Gypsy and Traveller population living in caravans in West England with an estimated total population of 250 families. (Greenfield et al 2007)

Project context

In 2007, Bristol Mind conducted a local study (Bristol Mind 2008), which identified some key issues for Gypsy and Traveller community members around prejudice and discrimination that they experienced both in everyday settings and within the health service. These findings built on the findings already identified in the larger health status study in which Bristol had been a study site.

Annie (AC) , a community member employed as a community development worker by Bristol City Council Gypsy and Traveller team, attended the Pacesetters planning workshop with the Trust representatives in March 2008 and was able to contribute to decisions about the way forward for NHS Bristol Trust. They felt that it was important to explore the potential of the East Midlands approach in training community members to be Health Ambassadors but agreed that different solutions may be required for different areas. They concluded their discussions with a decision that Annie would engage with local Gypsy & Traveller communities to discover their health issues and how satisfied they were with their local services and then determine priorities for action.

While consulting with local communities, Annie became aware that one Gypsy had experienced problems obtaining appropriate services for her leg ulcer. She referred this problem to CG, the Pacesetter lead, who is also the Associate Director of Public Health and lead for Equality and Inclusion.

An idea was then mooted that there was an identified need to set up a leg ulcer service for Gypsies and Travellers and that this could be a suitable Pacesetters project. The Quality Assurance Group reviewed the proposed service, and their comments in addition to the results of Annie's continued engagement with the community, led to rejection of this proposed project idea in May 2009. It was felt that focusing specifically on leg ulcer services would not have the biggest impact on addressing health inequalities. Nevertheless, the idea did not lead the Pacesetters team down a blind avenue, because the consultation process indicated that Gypsies and Travellers knew very little about their local service provision. Their lack of awareness was further revealed when PCT staff did an organised 'walkabout' and met various members of the Gypsy and Traveller community in their own homes. A decision was made therefore to produce a resource directory designed with and specifically for local Gypsies and Travellers to increase their awareness of local services.

This was in addition to the original decision to focus on improving staff awareness through sessions with community members. A decision was also made to provide community members with capacity training to build their confidence and improve their presentation skills. As a result the trained community members would then be equipped to deliver cultural awareness training to NHS staff.

After a lengthy and thorough consultation process, the following project aims were identified:

Awareness sessions for NHS staff (delivered by peer educators)

- § to involve Gypsies and Travellers in all aspects of the project;
- § to ensure that NHS Bristol provides a service that is culturally appropriate to the Gypsy and Traveller community;
- § to eliminate any discriminatory practices, ignorance and prejudice by the health care community;
- § to foster further the trust of the community in the local NHS.

Directory of local services

- § to increase Gypsies and Travellers' awareness and knowledge of local services;
- § to disseminate healthy living information to Gypsy and Travellers;
- § to support Gypsies and Travellers in gaining access to health care.

Project activities

To obtain maximum effect for the Gypsy and Traveller community, NHS Bristol synthesised all Gypsy and Traveller work across the greater Bristol sub region. This includes the Pacesetters as well as other initiatives like the implementation of the Developing Race Equality (DRE) programme.

Annie, as the CDW in the Gypsy and Traveller team, is an essential member of the local Pacesetter team and is also the Pacesetters QAG rep for the South West Region. Children's services, managed by North Bristol Trust, employ a specialist health visiting service for the Traveller families. Linda (LV), the specialist health visitor, works closely with the Bristol City Council Gypsy and Traveller team. This project work focuses particularly on Bristol and South Gloucestershire. Pacesetter funds paid for the development of the resource and the training programme. Annie and Linda's posts are permanent posts funded by NHS Bristol

Awareness sessions for NHS staff

The awareness training for staff is necessarily a two-stage project, with the first crucial stage being to train the peer educators.

Peer educators training

The project team were influenced initially by the East Midlands Pacesetters proposal to train community members as Health Ambassadors to deliver staff awareness training, and they decided to work on similar lines.

At the beginning they identified several potential risks that may need addressing. These mostly centred around the training content and its ability to reach the correct level for the participants and to achieve its aims in addressing discrimination and ignorance of Gypsies and Travellers needs within the healthcare system. There was an additional concern about recruiting sufficient community members, maintaining their enthusiasm and managing their expectations.

A year previously Annie, another Gypsy woman and two Gypsy men attended a training course for people from BME groups, called 'Confident to Present'. Their previous participation in this training, provided by Voscur, led to a decision to commission Voscur to train community members to enable them to deliver cultural awareness training to a wide range of professionals. They would deliver two 2-day training sessions in December 2009 and January 2010.

The agreed aims of the training were:

- to build confidence in the Gypsy and Traveller community.
- to deliver training to health providers about their traditions and culture.
- to improve communication skills.
- to empower the community to be pro-active.

To achieve the objectives of:

- Services becoming more culturally aware and sensitive to needs.
- Delivering Race equality.
- Increasing service satisfaction from the Gypsy and Traveller community.

Recruitment of community members to train as peer educators

Annie recruited community members through written letters and telephone. Two Gypsy and three Irish Traveller women attended the two sessions, with one attending both sets of sessions. Several more expressed a commitment to attend, but some dropped out at the last minute. A variety of reasons were given, such as lack of trust and misgivings about what would happen to the information they might share, childcare issues, and some just simply forgot about the training.

Training content

Trainers focused first on developing a relationship with participants so they felt comfortable and confident to discuss issues, and personal experiences.

The training was delivered in an engaging manner so that participants were given plenty of opportunities to practise presentation skills. During the course of each session, there were at least six opportunities for participants to practise delivering presentations.

The training content included opportunities to practise:

- Structuring a talk
- Body language and voice
- How presenters might talk about their own personal experiences, and the experiences of wider G&T communities.
- Using resources and images
- Dealing with difficult audiences
- Presenting to specific types of audience

- Managing questions and answers

A certificate was awarded to participants on completion of the training.



Photo 3. Community members doing group work in Confident to Present training

Evaluation of training

The trainers used their own observations to evaluate the sessions. All of the participants said that they were nervous to begin with, and “Confidence levels were noted by trainers at the beginning and end of sessions through body language, verbal feedback from participants, and willingness to stand and present. Their confidence grew, and by the end of day one all were keen to stand up and present.”

The trainers observed that participants had increased their awareness of:

- experiences of discrimination
- their specific gender roles within their communities
- a need for further support and training in areas such as literacy and computer skills
- a greater need to be listened to by service providers – this was noted when they were giving presentations and participants identified which audiences they wanted to aim their talks at.

The participants also completed evaluation forms and identified that they had hoped to improve their skills, gain more confidence and gain better understanding of the subject. All reported that these expectations had been met and that their overall experience of the course was excellent.

All expressed an interest in attending and presenting at events, and two of the women have already agreed to attend an event for health students at a local university (UWE)

Some of their comments about the course included:

Brilliant 2 day session. It's been very useful.”

I've learned so much how to put things in order.”

I've laughed and cried and I didn't realise how much we have been persecuted over the years.”

When talking of experiences it can be emotional, that makes us stronger.”



Photo 4. Community member presenting her work

Linda has noticed the increased confidence in some of the women who attended the course and reported that one of the women has asked to attend the sub - regional steering group for Traveller Health to be able to present her point of view directly to the 'people in positions of power'.

The impact of the training is best illustrated by one course member's story.

Hannah's⁵ story

Hannah is a member of the Irish Traveller community. She had expressed an eagerness to attend the Pacesetter 'Confident to Present' training in order to increase her confidence levels. When she arrived at the training in December Hannah was extremely reticent about standing up in front of a small group. She had also recently experienced a personal bereavement so was still in mourning. Despite this she committed herself to the training.

⁵ Hannah is a pseudonym

Hannah had never spoken in public before; indeed, she revealed at the start of the training that she was a long-standing member of a group at her church but that she never contributed to group discussions due to her lack of confidence.

The Pacesetter's training course enabled Hannah to explore issues for herself and her community and to practise preparing and giving presentations. She expressed that through completing the training activities her confidence levels had been greatly boosted and that she came to realise how under-valued she felt regarding her life in general.

Hannah returned with her daughter for the second set of training as she felt this would be beneficial to her daughter who was lacking in confidence. Hannah also explained that since completing the first round of training, she had made a public speech at a memorial event for her son. She said that all her family were stunned when she got up and gave the impromptu talk.

Towards the end of the training, participants were asked if they would be willing to give a presentation about Gypsy and Traveller awareness to trainee health workers. Hannah immediately and enthusiastically volunteered. Hannah was sufficiently stimulated by this course that she also expressed a determination to sign up for a range of other courses, including literacy courses, and took home leaflets with the aim of pursuing these ambitions. Since this training, Hannah has been invited to give presentations in front of service providers and it has enabled her to grow in confidence to achieve this. She now gives regular twice-weekly talks to an organisation that works to combat race discrimination. She has also been empowered to do more awareness raising for more organisations.

Raising staff cultural awareness

Voscur and Linda have been trying to arrange training events with health or social care staff in the near future, because it is important for the women to build on the confidence they have gained. Despite initial enthusiasm from staff concerned, there have been difficulties because in the current economic climate staff must attend training in their own time. However, 20 minute taster sessions are in the process of being confirmed and dates set for staff at a walk in centre and at a GP practice, with the hope or expectation of being invited to give full presentations at later dates.

Two half-day training sessions for health service providers have also been arranged in May and June 2010

There is an intention to produce a DVD so that if no community members are available for particular training sessions there will be an opportunity to hear the 'real voice' of Gypsies and Travellers.

Directory of local services

The initial idea of producing a directory of services for Gypsies and Travellers was aimed at increasing their awareness of services and supporting them in gaining access to health care. However, it was quickly seen by the Pacesetter team as also an opportunity to disseminate health promotion advice and this suggestion was put to Anne, who agreed on behalf of the Gypsies and Travellers she consulted.

Linda and Annie collaborated on producing the directory. Linda assembled the draft health information, using her health visiting expertise in working with Gypsies and Travellers and her close working relationship with Annie. She consulted health promotion and relevant agencies, such as domestic violence support, for their advice on specific content related to their specialities. Annie and her CDW colleague made helpful comments on successive drafts of the content. Annie, and a consultant on the use of plain English, gave advice to make the content accessible.

Putting together the draft directory was a multi-agency operation as the directory was to include information about education, and other council services as well as health.

There was an intention to invite community members to a lunch for a full consultation on a final draft copy prior to sending the final agreed version to the printers. However, it was not possible to organise an event on this scale. This was partly due to staff sickness, with funding not able to be released and facilitation unavailable, but also because it was felt that individual consultations may be better due to conflict between community members on one of the sites

Linda and a student were able to visit a Gypsy site and spend dedicated time consulting the residents. They received positive feedback from all those that they consulted.

A surprise finding was that the residents they consulted preferred a pocket-sized leaflet to the draft A4 sized version. This was contrary to the format envisaged by Annie, but the decision was made, based on this consultation, to print 200 copies of a small leaflet, contrary to the perceived wisdom and advice to produce a larger version with bigger font. The directory leaflet would fit in the sleeve of the PAHR records, should Bristol pursue a tentative decision to purchase these.

Prior to the availability of the printed copies some new residents arrived on a site and commented to Linda that they would have appreciated a copy of the leaflet as they had needed information on local health services.

Final Directory Content

The final copy covered the following broad headings:

Healthy Living

Education

Places To Live

Work, Money And Benefits

Other Help And Support

Your Own Useful Numbers

The Healthy living section covered smoking, exercise, eating for health, alcohol, family violence, family planning, drugs, safety at home, poisoning, burns and scalds, and fire safety. Relevant phone numbers were included in these sections where appropriate.

In the health section photographs of hospitals were included with the contact details.

Planned distribution of the printed directory

The site manager will give a copy of the directory to current residents on Gypsy sites and new residents will be given one when all initial documentation for living on the site is completed.

Linda and members of the Travellers education service will distribute copies to housed Gypsies and Travellers. Linda will also disseminate information to GP practices, health visiting teams and other agencies who may have initial contact with Gypsies and Travellers so that records may be requested.

Evaluation of the impact of the directory

Plans have not yet been agreed on evaluation of the leaflet or decisions made about how and when it will be reviewed/ updated or how and when an audio version might be produced and made available, but the ongoing involvement of Annie as a CDW ensures that this is likely to be followed through.

Effectiveness in meeting the project objectives

The project has been successful in involving community members in all aspects of the project, and in training some community members to become peer educators.

The aim of eliminating discriminatory practices, ignorance and prejudice by the health care community, and ensure that NHS Bristol provides a service that is culturally appropriate has yet to be realised until the training can be put in place. However there is now an increased potential to meet this objective as training sessions are arranged.

The aim of increasing Gypsies and Travellers' awareness and knowledge of local services, disseminating healthy living information and supporting them in gaining access to health care is also likely to be realised through the successful production of the directory. However, it is too early to assess the effectiveness until the directory has been launched and its use evaluated.

Strengths of the projects

The results of this project stemmed from good collaborative multi agency work and the willingness to be flexible in approach. This included close support from the regional Programme manager, MS, who worked closely with Linda and Annie to support their activity, and met regularly with Linda to support her with the project management side of the directory. This also enabled some pooling of resources and increases the likelihood that updates and further developments can take place to sustain the initiatives. There was thorough consultation with community members on areas of need, and the initial project ideas, based on identified needs, were revised to take account of community feedback.

The directory has a dual purpose of simultaneously raising awareness of services and being a health promotion tool. It is likely to be used positively as a health promotion tool as this aspect was included following consultation with community members.

Some Gypsies and Travellers are now trained and confident to deliver cultural awareness training to staff. This capacity building has given community members the confidence to have a 'voice' in other forums with potential for a positive impact on serviced delivery. Their success and the spread of it by word of mouth increases the potential for other community members to become involved.

Challenges

There have been are conflicts of time with fitting in Pacesetter work around other work. This challenge is common to projects where frontline staff are delivering the Pacesetter tasks in the context of their other work. The level of work involved in convening meetings, consultation and liaison was underestimated. There were also practical problems such as limited access to printing facilities for production of draft copies of the directory and costs have also risen since the project began.

There were difficulties in recruiting sufficient participants for the ‘Confident to Present’ course and it was not known until the day of the training the exact number who would be attending. Even though more community members had expressed a commitment to attend, people dropped out the last minute.

Summary of lessons learned and important components of success

Community members have been consulted at all stages of the project and this is important for them to take ownership.

Greater time and preparation is required to recruit community members as participants for training and to anticipate and address identified obstacles to attendance at training sessions.

Community members have a key role in ensuring that resources are produced in accessible formats and plain English and assisting professionals in this important skill. Collaborative multi agency work has some disadvantages, in respect of time spent through layers of consultation and liaison in a time limited project, but closer working with shared goals also increases the available resources and gives greater opportunity to maximise the impact of joint initiatives.

Chapter 8d

NHS Sheffield

Tackling health inequalities in the Gypsy and Traveller Communities

Background to Sheffield Gypsy and Traveller communities

Sheffield's Gypsy and Traveller population is around 340 people (100 households) who live on the two long-term council sites at opposite ends of the city (eleven miles apart) or in permanent housing throughout different parts of the city.

Project origins:

ICHD project

Although the specialist HV (JC) and the local Community Health Improvement Practitioner (LB) had invited Gypsies and Travellers to attend the initial Pacesetter planning workshops, none were willing to attend. In early discussions about possible projects, those working with the community identified the need for community empowerment and for community members to increase their awareness of their own health needs, knowledge of services available and to increase their confidence.

A Health Information Day was held in March 2007 and included various activities such as reflexology, head massage etc. The aim of the event was to increase participation, have discussions on health and to bring two distinct Gypsy and Traveller communities in Sheffield together and improve relations between them. Tutors from an Introduction to Community Development and Health (ICDH) Course had a stall at this event and generated some interest from approximately a third of the 30 community members who attended.

Following this initial interest some taster sessions for community engagement were held (range of activities requested by and enjoyed by Gypsies and Travellers with and without children), and a decision was made to continue to run a regular weekly group as a Gypsy and Traveller Women and Health Group. A subsequent aim was to promote and deliver the Introduction to Community Development and Health (ICDH) course. It was planned to include use of ICDH Tutors to work with the group. The ICDH programme is based on using people's life experiences to identify their own health needs and then to look at processes and actions that could make a difference.

The course was to be based on active participation that included work to explore with the participants their experience and understanding of what health means to them, the factors that impact on their health, identifying and priorities for action and how needs can best be met. The course would aim to work with course participants to build confidence and communication skills.

Following on from the ICDH Course, it was envisaged that participants would be supported to further develop their skills and to become active within their community on health projects and achieve the following objectives:

- To create dialogue between PCT and community as a group.
- For Gypsies and Travellers to communicate as empowered individuals and gain confidence to sit on working groups across the city.
- To engage with members of the Sheffield Gypsy and Traveller communities and to create dialogue between health professionals and other organisations and agencies working with Gypsies and Travellers to result in a better understanding of cultural issues and ultimately better service delivery

At the first session the women who attended had discussed some of the activities they would like to see. These ranged from specific health related topics such as child ailments, first aid, and cooking / healthy eating to more wellbeing activities such as Pampering (Eyes, Facials, Reflexology, Nails, Massage, Make-up), Arts & Crafts and cycling or health walk and picnic. The organisers agreed to try and have a taster of some of these suggestions in the first six weeks.

The group ran for seven weeks, although no community members attended two of the sessions. Transport was provided, and a crèche was available at the venue that Gypsy and Traveller women had used on other occasions. For most sessions only a core group of four to five women attended, despite more having expressed an intention to attend but failing to attend on the day. However, all the women who attended expressed enthusiasm and appreciation of the group. This included appreciation of the opportunity to get off the site/away from the house. The opportunity to meet with each other was felt by JC to be a significant motivating factor to attend the sessions, particularly since the Sheffield Gypsy and Traveller Support Group (SG&TSG) no

longer existed to provide such a meeting place, and those that did attend were those who rarely took part in any activities outside of their homes.

However by the end of the first set of sessions the numbers attending had already significantly decreased to two, who became less satisfied with the sessions. The second course of sessions planned for October/December would have focussed more on health and lifestyles, discussion, and practical sessions but for some of the people attending, this was seen as too many 'questions and talking' and they felt more comfortable with practical activities e.g. Cook and Eat. Following a meeting and discussion with the remaining two group members in October it was decided to end the sessions.

Evaluation of the ICDH course

The Pacesetter team identified several factors that were implicated in the failure of the ICDH course. Some of the difficulties were in the mismatched expectations and motivations of the group members. It was recognised that in the few sessions that were held some productive work was achieved, for example on factors that affected their health, on cooking, and working together as a small group. However, the two remaining women on the course saw no need for increasing their skills or being supported to be a voice for their community and wanted only to continue to have an opportunity for more leisure activities. One of the key learning points was that the team needed to work much more slowly and not be too ambitious in their aims. The team learnt that community development approaches are not a quick fix and as with many communities it would take a number of variables and a length of time to develop the type of capacity in the community within the required time period of the Pacesetter programme. The Gypsy and Traveller communities in Sheffield remain separate and divided both geographically and socially, and the Pacesetter team continue to experience difficulty in engaging with community members as a group. Many community members are living in houses and are not in contact with specialist services or do not identify as Gypsies and Travellers. The team have identified a need to seek out and support potential community leaders and to develop closer links with larger Gypsy and Traveller communities in neighbouring towns and cities in South Yorkshire.

QAG members acknowledged the difficulties the team had identified in their feedback on the project report and paid recognition to their efforts to bring two communities

together. The team considered various ideas to address some of the identified needs for a place to meet and for increased opportunity for social activities.

Change of project direction

Following the termination of the ICDH course it was agreed that more capacity building was required in the Sheffield Gypsy and Traveller community and that a new focus was required for the Pacesetter project. Through discussions in Public Health- it was identified that there was poor awareness by clinicians of Gypsy and Traveller needs. At the DH Pacesetter planning workshop in March 2008 it was decided that all three Trusts in Yorkshire and Humber SHA would focus on awareness raising and that a champion would be identified to drive the work forward. A further need was identified to improve GP registration among Sheffield's Roma population as they had a disproportionate use of accident and emergency services. It was decided that this need would be addressed within current public health work and health visitor roles. Rather than to include it as part of the Sheffield Pacesetter project.

Leeds GATE were commissioned to champion the cultural awareness training on the basis that they had already well established community engagement, had delivered training in Leeds, and would involve their community members in delivery of cultural awareness training in Sheffield. The original aspiration of the Sheffield Pacesetter team was to train Sheffield Gypsies and Travellers to deliver the training by inviting Gypsies and Travellers from other areas in South Yorkshire with expertise to act as mentors. The plan was to hold an open day for Gypsies and Travellers with the outside mentors to gauge interest. This would be followed by a training day for outside mentors, followed by a launch event to recruit Sheffield G&Ts mentees and then hold three training sessions for mentees. However Leeds GATE had already been commissioned to deliver training sessions, adapted to meet Sheffield needs, and the above plan was felt to be too ambitious and not within their scope of work. Following subsequent local meetings, a decision was made to focus on raising awareness with frontline clinicians and the public sector regarding the health and social needs of Gypsies and Travellers and on developing an understanding of communication with a socially excluded and disadvantaged community.

A further meeting was planned to re-engage the previous ICDH course participants on this work and to invite them to attend some sessions. There was an original intention

among the Sheffield team to use Leeds GATE experience to develop the capacity of the Sheffield community members so that they could be supported to deliver future training sessions. However this idea was not supported due to lack of remaining resources, and instead local community members were invited to attend the local sessions delivered by Leeds GATE

Cultural awareness raising with frontline clinicians and the public sector

A Protected Learning Initiative (PLI) for GP out-of-hour services was proposed for February 2009. However despite major efforts at advertising the event there was insufficient interest in uptake and the event could not take place. This experience taught the team that the demand for GP and practice nurse time is high and there are many other essential training needs that have to be covered in their limited availability of PLI sessions.

The team decided therefore to run three cultural awareness sessions in different areas of the city where Gypsy and Traveller community members are living. These sessions were to last for two hours and were open to health professionals, staff from other services and agencies, and workers from the community/voluntary/faith sectors interested in improving and enhancing their understanding of the Gypsy and Traveller community. They were advertised as an open invitation by means of flyers and emails distributed via various mailing lists, including the city council multi agency group. Leeds Gate met with the Sheffield Pacesetter team to discuss their proposed training plan and some changes were made before a pilot session was delivered. This was attended by four Sheffield community members and LB, JC, Traveller Education staff and a Police training organiser from the multi agency group.

Aims of awareness sessions

- § To improve awareness of the specific health inequalities and health needs of Gypsies and Travellers
- § To gain an improved awareness and understanding of the ethnic identities of Gypsies and Travellers and the health impact of the racialisation of those identities
- § To understand the specific barriers for Gypsies and Travellers in accessing and using health services appropriately

- § For staff teams or workers from different agencies who are working with the community to understand the different ways in which Gypsy and Traveller patients impact differently on each other's role and to give team members an opportunity to listen to each other and understand the issues from everyone's perspective.
- § For staff teams or workers from different agencies who are working with the community to identify the possible reasons for such impacts and to identify the specific issues that need addressing to improve their access and use of services.
- § To learn from examples of good practice and identify specific actions you propose to take following this training to improve the access to health care for Gypsy and Travellers.

Training content and delivery

The first training session was observed by the evaluator, and commenced with an introduction by LB explaining why there is a need for cultural awareness raising to tackle health inequalities. An advocacy development officer from Leeds GATE delivered the rest of the session with a Leeds community member who answered questions about Gypsy and Traveller culture, and a student social worker on placement at Leeds GATE who delivered the health status aspect of the presentation. The first hour of the session was spent on verbal presentation of cultural information, mainly covering ethnic group status, discrimination, accommodation issues and various aspects of cultural identity. Questions were invited and were mainly directed at, and answered by, the community member. The three Sheffield Gypsies who were in the audience as observers contributed minimally when questions were asked. In the second half of the session participants were invited to take part in two exercises. These were designed to illustrate the experience of negative stereotyping by the media, and lack of accommodation choices open to a family who is living on the road, respectively. The exercises and feedback took most of the remainder of the two-hour session, leaving five minutes for the presentation on health status and health inequalities. At the start of the session participants had been asked to write on post- its the issues that they wished to see covered in the session; a further five minutes was left to cover these and were inevitably covered superficially or not at all.

Evaluation of cultural awareness training sessions

A total of 55 staff from various agencies attended the three sessions. Of these only 24 were from health and social care and five were from primary care.

The majority of participants found that the course met their expectations and they evaluated the content and training delivery as either excellent or very good. Most participants identified many aspects of Gypsy and Traveller culture that was new to them and found the most useful part of the session was the opportunity to hear directly from a community member. Typical responses to the question about the most useful part of the training included:

“Being able to talk to Eileen about her experiences / culture”

“ Eileen’s contribution, giving real insight”

As with cultural awareness sessions in other Pacesetter projects it is the input from community members that had the most immediate impact on participants. Responses to questions asking about intentions to change practice reflected the raised awareness gained from the training:

“Being open and asking questions so as not to offend anyone during my visit”

“ Be aware of literacy issues”

It was less possible to assess the extent to which the training had informed attitudes but some responses indicated that this was the case:

“To be more open to necessary referrals from Gypsy and Traveller community”

The stated aims of the session had a strong focus on health inequalities and the health impact of their situation, although in the one observed session very little space was given to the stated aim of informing about health inequalities and accessing health care or examples of good practice. This may have partly reflected the needs of the multi disciplinary audience, but for those who had attended to learn more about health related issues, the imbalance was reflected in some comments relating to the need for further information, for example

“I didn’t think there was enough focus on the health of this community that I expected and although the information on offer about the way the community is perceived and treated was useful it didn’t tell me anything I didn’t know.”

“would have liked to have seen more about mental health”

Conversely, other respondents in the same session felt that one of the most useful aspects of the training was learning about health and the barriers in access to services. As with other projects where cultural and health awareness training has been delivered it is harder to meet the wider range of learning needs of a multi agency audience. This requires prior consideration when the training aims are agreed and when allowing time for questions at the end

Although questionnaires were sent out to most of the 55 participants approximately 3 months after their training only nine were returned. Of these nine respondents, six stated that they had used the information in their work and had passed material on to other staff but there was very limited response to the questions concerning changes that have been made to practice or detection of changes in working relationships with Gypsy and Traveller community members. Most responses referred to sharing information with other staff or with students. The most encouraging response that suggests attitudinal change was:

“It has given my practice a different outlook when dealing with the Gypsy and Travellers community”

However, although the evaluation forms have yielded minimal information to gauge the impact of the training, JC has had first hand experience of an apparent change in attitude in the district nursing service where a team member had to visit a patient on one of the sites regularly to do her dressings and had been well received by the Gypsy patient. JC suspected that the nurse in question had attended one of the training sessions and felt more inclined, or less apprehensive, about visiting the site as a result. Another positive outcome from the sessions was that the Head of the Podiatry attended one of the sessions and as a result of his increased awareness of need the podiatry team have now set up a mobile clinic service for Gypsies and Travellers.

Additional short-term gains and strengths of the project

The Sheffield Pacesetter team has been ambitious in trying to build confidence and capacity among community members and bring people together from a divided Gypsy and Traveller community within the project time frame. Although their initial

attempts to devise a tailored course in conjunction with community members eventually had to be terminated after seven sessions they identified needs for a permanent meeting place and possible future activities that could be arranged and supported by existing PCT staff.

A Sheffield Gypsy and Traveller Action group was also formed which includes members of the Gypsy and Traveller community alongside professionals from several different agencies who are working with the community. This includes staff from Sheffield Homes, who manage the Gypsy and Traveller site accommodation in Sheffield; some of whom also attended cultural awareness training sessions. They are working to support community engagement and multi-agency working.

Although this group too is facing difficulties from working with a divided community the members are continuing to work together and meet under the name of GIFT. A visit to Leeds GATE was being planned for community members by the end of January 2010 and discussion is taking place with the group and community members who, with support and training, would like to get involved in awareness training.

The first activity for the action group was to jointly plan a celebration event that was originally proposed as part of the Pacesetters programme. Through this joint working a successful event was held in November 2009 where invited speakers provided examples from elsewhere about their work with Gypsies and Travellers and spoke about the importance of community engagement and voice. Speakers included a team from the Health Ambassadors Pacesetters project in East Midlands, Barnsley Gypsy and Traveller Health Trainers and Leeds GATE. There were eighteen stalls providing information from different agencies, organisations and NHS departments, ranging from the BME Community Mental Health Team, Bookstart, Community Police, DAAT: Drugs and Alcohol Information to NHS Sheffield/PALS / City Centre GP Led Service Consultation. Transport was provided from the two sites and eighteen community members from Sheffield attended the event and gave positive informal feedback

The 'spinoffs' arising from this event and previous health event days have been the dual effect of community members being made more aware of local services and meeting the staff on an informal basis, and of staff meeting community members and gaining more insight into their needs.

The Pacesetter Programme has raised the profile of Gypsy and Traveller health needs within public health and NHS Sheffield to a new level. There are also now intentions to secure funding to recruit Gypsy and Traveller health champions and a Gypsy and Traveller health trainer.

Their needs are now more readily considered in other initiatives, with other sources of funding more readily accessible. For example, funding was made available and permission granted by the city council for a Gypsy caravan and exhibition in the city centre to highlight Gypsy, Roma and Traveller history month in June 2009. The team are confident that the raised profile as a result of the Pacesetter programme was at least partly responsible for this support. Such events do much to counter the negative stereotypes of Gypsies and Travellers that are more familiar to the general public.

Summary of challenges

The wide health and welfare needs of Sheffield's Gypsy and Traveller communities were recognised and campaigned for since the 1970s, both in the statutory and the voluntary sector. A dedicated post of health visitor for Gypsies and Travellers was established in the early 1980s. A Sheffield Gypsy and Traveller Support Group (SG&TSG) was also formed at this time to campaign for adequate and sufficient accommodation, provide welfare and educational services and develop the response of the statutory services to the needs of Gypsies and Travellers. Over its approximate 30-year existence it achieved the former part of this aim with provision of a wide range of services and was a recognised central space for Gypsies and Travellers, being used by many outside of the city as well as local Gypsies and Travellers. This group has now ceased to exist.

It might be assumed that a population who have long been used to such a high level of dedicated service provision might be sufficiently engaged and empowered to be readily involved in the Pacesetter project. However, although it was no longer in existence at the start of the Pacesetter project, the historical existence of the SG&TSG may partly help to explain the difficulties identified by the Pacesetter team in engaging with community members. It could be significant that many of the Sheffield Gypsy and Traveller families and individuals have been able to rely on services being provided and that most have had little experience of working together to achieve the changes that they have required. It is possible that such provision inadvertently had fostered a dependency culture, and lack of belief in their own ability

to influence change. Although there was encouragement for Gypsies and Travellers to be involved in the management of the SG&TSG, very few played any active part. There is no evidence of a reduction in health inequalities for Sheffield Gypsies and Travellers associated with their long history of dedicated service provision. Sheffield was one of the areas where the Gypsies and Travellers participated in the health status study, which revealed the extent of their health inequalities. The significant prevalence of anxiety and depression in the population may also be a factor that militates against their capacity to engage at the consultation stage of the project. There are other factors associated with the demographics of the Sheffield population and the divisions between some of the different families that render it problematic for them to come together for a common purpose or in being willing to engage on behalf of the wider 'Gypsy and Traveller community'. The concept of one Gypsy and Traveller community either in Sheffield or in other locations is one that requires careful consideration. Although Gypsies and Travellers may readily define themselves collectively as distinct from the rest of UK society to the extent that they have a different collective term for all those who are not a Gypsy, Roma or a Traveller and they will gravitate to other Gypsies, Roma and Travellers whenever they may meet each other, this does not define them as a community. In Sheffield there are particular long-standing divisions between family groups who live in diverse and scattered locations.

All attempts at fostering community participation to contribute to the choice and design of the Pacesetter project involved a lot of preliminary individual contacts on the part of JC in the course of her normal work and LB, as there was no forum or group where they could be consulted together initially. The divisions between different members of the Sheffield Gypsy and Traveller communities have influenced the degree to which some members will participate in any events or activities. The cultural awareness sessions only reached a relatively small number of health professionals and because an outside body was commissioned to run these there are no plans for these to continue or to be embedded in local diversity training programmes. The original plan to reach far more primary health care staff was a particular challenge given the priority placed on pressing clinical issues for their protected learning sessions.

Summary of lessons learned and important components of success

The overwhelming lesson learned from these projects is to ‘think small’ and build from strong foundations. The particular divisions from within Sheffield’s Gypsy and Traveller communities have militated against the success of any major initiatives aimed at bringing them together. The importance of understanding the motives for attending a course has been learnt and therefore to meet the expressed needs appropriately. Providing a meeting place where people can socialise and reduce their isolation is more important to some of those who attended the ICDH course than the course itself.

In retrospect the Pacesetter team would have preferred to build capacity among a small cohort of Sheffield Gypsies and Travellers who have expressed interest through local mentoring from Gypsies and Travellers with experience from nearby areas in South Yorkshire. These links have now been made through inviting them to speak at the celebration event and can be fostered through the newly formed action group. Bringing community members together with professionals from various different agencies at a celebration event was an effective useful way to begin to break down barriers and foster mutual understanding. These links can be fostered and sustained as the professionals involved reported that they found it very useful to make informal contact in this way and learn more about the situation and needs of the Gypsy and Travellers. This experience has informed the decision to continue to take a more regional approach to link with other established agencies and communities to support the development of the relatively small groups of Sheffield Gypsy and Traveller communities and to learn from them about what works and what doesn’t.

The team have realised that it is more productive to do targeted pieces of work with individual GP practices and, with community members, to offer tailored cultural awareness training to them, at a time convenient to them, rather than expect to avail of a whole protected learning initiative. JC is taking these opportunities when she liaises with them over particular patients. One major component of the success of the Sheffield projects has been their successful and sustained efforts at raising the profile and awareness of the Gypsy and Travellers communities in the PCT and among other agencies, and therefore increasing the likelihood of future willingness to commit resources to address their unmet needs. By also linking with other agencies and organisations on a regional basis and pursuing options such as health champions and

health trainers that are already in existence within the wider region, NHS Sheffield is already building on the foundations of this Pacesetter project.

Chapter 8e

NHS London

East London Foundation Trust and NHS Newham

Projects to reduce health inequalities in the Roma population in East London:

These two Trusts both decided to focus on the Roma community in the London Borough of Newham as their services both experienced difficulties in providing optimum health care to their uniquely large population of Roma people. They worked closely together as they were working with many of the same people from the Roma communities that they served.

Roma communities in East London

The London Borough of Newham has a population of 246,000⁶ of which 62% are from non-white ethnic minorities. As with other Gypsy and Traveller ethnic groups, the exact size of the Roma population in the borough is unknown. Estimates vary widely, but in the nearest official count as is possible, given the lack of reliable data, the estimated number for Newham borough is 20,000. This figure was obtained using the pupil level annual school census in a nationwide survey of local authorities in England, commissioned and funded by the Department for Children, Schools and Families (Fremlova 2010).

The Roma support group (RSG), a 3rd sector organisation based in Canning Town in the London Borough of Newham, has been offering assistance and support to Roma refugee and migrant community in London since 1998, which corresponded in time with the arrival of significant numbers of Roma asylum seekers from Eastern European countries, mainly Poland, Czech Republic, Slovakia, Romania and former Yugoslavia.

The RSG is the only known organisation in London and in the UK focusing on working with and for the Roma community. It offers support to over 870 families, or approximately 4,350 individuals in London, but mainly in the borough of Newham,

⁶ There are significant variations between GLA and ONS population estimates. Whilst the ONS data estimates the population of Newham to be 247,600, collation of data from NHS Newham GP lists indicates a registered population of 342,000. Commissioning Strategy Plan 2010 – 2015 8 Newham population projections, GLA and ONS, 2009 – 2031. Source: 2006 ONS pop projection and 2008 GLA pop projection

East London. This number equates to approximately 1.75% of the total population of the borough of Newham. They facilitate the integration of Roma refugees and migrants into their host communities and support them to overcome prejudice and social exclusion by: advice/ advocacy on welfare, debt, housing and employment matters, general health and mental health advocacy and social inclusion schemes for Roma children and young people. (Ingmire 2009 personal communication).

Roma Pacesetter projects steering group

As the two Trusts are working with the same populations and working closely with the Roma support group they are both represented on one single steering group. The steering group is made up of one or two community members (attendance varies), Roma Support Group representatives, Children's Society (Roma Project worker), Newham PCT, Newham University Hospital, East London Foundation trust (mental health trust for Newham), London Borough of Newham Travellers Education Lead.

NHS NEWHAM

NHS Newham serves the community of the London Borough of Newham, employing around 1,050 staff and encompassing 64 GP practices, 63 pharmacists, 22 optometrists and 30 dentist sites in the borough. The community is culturally the most diverse of all London boroughs, with over one hundred different languages spoken, and almost half of the population under twenty-five. Newham Borough has the youngest population and highest birth rate in England (currently 6000 per annum). It has one of the fastest growing populations in London, with 20% of the population changing each year and is the sixth most deprived local authority area in England. Newham faces all the health issues that go with this position, high mortality, low life expectancy and high levels of chronic illness. The latest statistics show GP access survey results showing a satisfaction rate of 68% compared to an England average of 77%

Community involvement in project identification

The final project aims were identified through close consultation with Roma representation on the steering group.

Objective - To improve GP registration of Roma community members.

It was envisaged that the aim of improving GP registration would be achieved through its wider awareness raising process objective.

Resources

A part time Roma Health Communication Worker, Grazyna, was employed to provide practical support to Roma people wishing to register with local GPs, to discover the extent of the issues involved. She was to work to increase awareness of health and health services among the Roma community and of the Roma community among health staff. Grazyna is integrated in the Roma community and has worked closely with Gaba, the mental health project worker from RSG who worked with ELFT to develop the aims of their project.

Context

There was already evidence from the health status study (Van Cleemput 2007) and other research to indicate that GPs and health professionals have a poor understanding of the cultural needs of Gypsy, Roma & Traveller communities. Local evidence from consultation meetings with the Roma Support Group and from Newham's Patient Advice and Liaison Service (PALS) data also suggested that members of the Roma community often do not know how to access NHS services, register with GPs, or understand how the system works. The project lead for Pacesetter project was also the PALS lead and initiated the PALS Volunteer link Scheme with RSG and is therefore aware of these issues. They have already trained three volunteers within the Roma Support Group to take concerns from the community and bring to regular structured meetings. The concerns are then dealt with, resolution obtained, and PALS provides regular reports to GPs. Services within the PCT have complained of low screening rates, low immunisation rates, inadequate documentation required for registering, and poor interaction with staff.

Anecdotal evidence from these meetings suggested that GP practice have their own barriers to the registration of Roma patients. For example, community members spoke of their requirements for translation services but that practices do not always call interpreting services and send people away unregistered. There was also a perceived lack of will to register members of the Roma community because of their reluctance to undergo screening and the effect this would have on their practice targets.

Health is a taboo subject for the Roma and this is linked to a well-founded lack of trust in health services. Since the 1950s most of Eastern European countries adopted a practice of placing all Roma children in Special Needs Schools for mentally ill. These practices were wide spread and affected nearly all Roma children throughout post-war history of Eastern Europe, making Roma ethnicity the only criteria for this

discriminatory and damaging policy. As a result of this, many of their Roma clients express their fear and mistrust towards the medical establishment (Ingmire 2009 personal communication).

Activities

It was envisaged the awareness raising would improve GP registration. The following activities were planned:

1. A DVD had been produced in another Pacesetter project which informed migrants how to register with a GP, and when and how to access Accident and Emergency departments, pharmacists and the PALS service. Grazyna translated this into a Roma dialect and loaded it onto You Tube for wider access by the Roma as well as other migrants.

2. Staff awareness would be raised of health inequalities experienced by the community and their cultural and specific health needs

A variety of approaches were planned including a staff quiz, articles in the in-house publications, displays and lunchtime seminars /discussions included with Equality & Diversity staff training.

3. A staff-training programme was prepared with the following aims

- § To introduce the history, culture and language of Roma people
- § To inform on health-related issues, customs and taboos
- § To improve communication skills with Roma people

The structure of the training programme was deliberately short to accommodate the limited time available at staff lunchtime meetings. Fifteen minutes was devoted to MZ, who was familiar to staff, giving an introduction and explanation for the training and Grazyna sharing information, with the aid of a power point presentation and a further fifteen minutes left for a questions and answer session.

4. Awareness would be raised amongst the Roma community of NHS services available to them.

The Roma support group, through their work with the Roma community, had identified a need for a health event to be organised for Roma to inform them and raise

their awareness of health services and for this event to be filmed for a DVD to be made available in the community languages.

The event was held at the Roma Support Group AGM in order to attract community members. NHS Newham provided speakers, with an interpreter translating the presentations as they were delivered, on the following health topics and with associated information on accessing appropriate services:

1. Heart disease and how to recognise angina or a heart attack and what to action to take if such suspected events occurred.
2. The Smoking Cessation Service and advice on how help to stop smoking can be obtained.
3. The Child Immunisation Programme



Photo 6. Presenting ‘The Healthy Heart’ with an interpreter

Community member volunteers, Irma, Danuta and Anita played an important role in advising the presenters on how to make their presentations culturally acceptable and relevant. For example to use pictures but not to use pictures depicting the body, not to

promote exercise such as jogging but suggest dance or walking which are more acceptable.

Following the presentations the community members were invited to visit stalls which were being manned by PCT staff in order to avail of smoking cessation advice on a one- to -one basis and to have access to freely available smoking cessation resources. Other resources on healthy eating and exercise were also available.



Photo 7. Roma women visiting the Smoking cessation stall

Community Care Navigators⁷ were available to offer MOT health checks that included weight and BMI measurement, blood pressure measurement and blood glucose levels.



Photo 8 . MOT health checks

A conference for staff and community members organised by the Roma support group and held in February 2010 to raise awareness of the services available to Roma people and raising awareness of the Roma people and their needs among a wide range of conference delegates from different organisation in the statutory and voluntary sector. The Pacesetter project workers jointly delivered health workshop presentation with two of the Roma women volunteers, Anna and Danuta.

⁷ Community care navigators work in the community with people who are at risk of or who have long term conditions to help them to navigate services that are available to them and to offer them support in management of their conditions.



Photo 9. Grazyna and Gaba with Anna and Danuta presenting health workshop

Impact -Staff Awareness raising activities

A wide range of staff were reached, from all levels of clinical staff to senior management and commissioners. Their awareness of the needs of the Roma community were raised through staff quizzes, articles published in staff magazines and bulletins, and delivery of a number of presentations and displays at various staff group meetings, including the Primary Care Access Group and the practice nurses forum. A presentation was also given to 200-300 staff at a local Equality & Diversity Conference and displays were mounted at the annual staff conference with 500 staff in attendance.

The project update became standing item every month at the Primary Care Access Group.

Two pilot sessions of Roma Cultural Awareness Programme was delivered in November and December 2009 at staff team meetings at one of the Transitional team practices. Thirteen different staff members attended the two sessions: the practice manager, two benefits advisors, a practice development nurse, four practice nurses, homelessness nurse, three receptionists and one GP.

Although only half an hour was scheduled for the training the staff were so engaged and interested that the discussion and questions were allowed to continue for 45 minutes, thus taking up the entire staff meeting.

Two-way sharing of information occurred. For example, sharing information about child immunisation and the differences in different countries. Grazyna was able to explain why the Roma had expectations of a child development check at the immunisation appointment, based on their experiences in Poland. MZ was also able to answer the more strategic questions, such as the possibility of providing a drop in service for childhood immunisations

The questions informed the pilot and were used to produce a longer version of the presentation for other occasions.

Outcomes

Staff outreach.

A useful discussion took place on how to encourage Roma to bring their children for immunisation and how this could be made a more positive experience and a nurse was invited to come to the proposed Roma Health event later that month to give a presentation on child immunisation.

Trust and dialogue encouraged.

Evaluation of the event showed 100% agreement that the training had encouraged trust and dialogue with the Roma community, with people saying that they had a '*better understanding*', '*raised awareness*', and improved knowledge of the situation: knowing *the customs and traditions is a great help*" and "*I understand their culture better*". There was also specific learning around issues such '*not using juniors (children) to translate*'.

Intention to manage interaction differently.

Staff stated that what they would do differently as a result of the training. These intentions included "*being aware and confident with patients*" "*to approach them and understand them*", "*to improve communication skills with Roma people*", "*to try to build trust and understand them better*" "*to support them at any length when in contact with them*" and "*be more sensitive to the needs of this population.*"

It is too early to evaluate the extent to which these intentions are put into practice but a nurse at the second session who had also attended the previous session was able to

give a first hand account of one specific positive outcome of the learning and increased awareness she had gained:

A Roma man attended with his family, including their young baby. The nurse realised that he was Roma and asked him outright if this was the case. She realised that he was probably unfamiliar with the UK childhood immunisation programme and spent time explaining it to him in much greater detail. As well as then immunising their baby she realised that their child of about 5 years had not had his pre-school booster and this was given also. The rapport was such that she was able to enquire about the child's schooling and then inform the man that the child was old enough to attend school and explain how he should proceed to enrol him. The family returned for the baby's second vaccination and expressed their gratitude to the nurse, explaining also that the child was now enrolled at a local school.

Impact of Health event to increase awareness amongst the Roma community



Photo 10. Interest in MOT checks

The event was well advertised among the Roma community and a minimum of 60 Roma men and women attended, including about 10 to 15 children. The presentations held the attention of the audience and their interest was evident by the numbers who eagerly visited the stalls for further information.

The popularity of the MOTS was evident by the crowd of men and women around the stand taking their turns to have the checks. The community care navigators collected data on 23 participants who ranged in age between 18 years and 62 years. Of these, 11 were women and 12 were men. All of them were registered with GPs in Newham.

Outcomes of Health event to increase awareness

Raising awareness of services

Evaluation forms completed with 16 heads of family showed that the event fulfilled an unmet need. The event as a whole and each of the individual presentations were rated as very useful with most respondents giving a maximum score. There was a 100% agreement on the usefulness of the MOT checks with two respondents wanting to score 20 out of 10.

Meeting unmet health needs and raising health awareness

As a result of the MOTs six people were taken on as clients for the community care navigators. These were people who had already diagnosed chronic conditions, which included chronic heart disease (2), hypertension (2), previous stroke (3), angina (1), and arthritis (1).

There were also people who had health checks who did not have previously diagnosed condition and those with above normal scores were referred to their GP. Those with borderline scores were given relevant advice about lifestyle.

Informal feedback to Grazyna and the organisers was that more health presentations and more events where MOT health checks would be available would be welcomed. The DVD will help to meet the need for more awareness of health services, as it will be available to the community for them to watch at home. Two community members told their stories and explained why the event was so important.⁸

⁸ The names used are pseudonyms

Rosa

Rosa is a 45-year-old Roma lady who, with her husband Karol, a musician, their young baby and four other children between 4 and 11 years old sought asylum in the UK from Poland in 1998.

Prior to their arrival in the UK, Karol was under the care of doctors in Poland for a stomach ulcer. They spoke no English and on arrival in the UK they struggled to understand the systems and were returned to Poland between five and six times. The asylum process was extremely stressful. At times police would arrive in the early hours of the morning and take them to the airport for deportation without any explanation. For Roma the connotations with World War 11 when Roma were rounded up and taken to death camps such as Auschwitz were very real and affected them severely. In 2001 Karol suffered severe depression and Rosa also started to have panic attacks. These were exacerbated by the fears each time a letter arrived and she also began to suffer from depression.

In 2004 they were given the decision that they could remain in the UK but their health problems persisted. Rosa continued to suffer from anxiety and depression and lost weight but could not obtain the help she required from doctors in England for some time. She is now under the care of a psychologist.

Karol developed a serious eye condition in 2005. He continues to suffer from depression and some days his bouts of depression are so severe that he doesn't want to get out of bed or to touch the violin that gave him so much pleasure in the past. However, Karol is finding some solace through giving music lessons to Roma children and he has been training them to play in a performance for the health event. On the day Rosa had difficulty in persuading him to come to the event because he had been so depressed during the previous days. However, he came and he gave a solo violin performance as well as performing with other musicians in a band. The children he had trained also performed, encouraged by Karol, to a highly appreciative audience. Rosa had a MOT health check at the event and was surprised to learn that that her weight was above normal. As a result of the advice she received she has decided to make some dietary changes. She persuaded her wider family that health checks are a good idea and they would like more health events in the future. She has noticed changes since the start of these projects in the way that the health taboos are lessening “ *something is changing*”.

Tomasz

Tomasz is now aged 60 years and was builder in Poland. He was under the care of a doctor for heart problems before he came to the UK seeking asylum with his wife and disabled daughter in 1998. He found the asylum process extremely stressful and suffered a heart attack during this 3-year period. His wife left him and her daughter, as she too was no longer able to cope with the stress. The Home Office then sent them back to Poland and he returned again in 2005. Tomasz remains separated from his wife and lives here with his disabled daughter aged 29 years and his 19-year-old son. He also has a married elder daughter.

Tomasz came to the health event and had his health check and persuaded his family of the benefits. He said he was not surprised that his results were bad but he now checks his blood pressure and blood sugar daily. Although he was not surprised by his results, he knew that others were surprised by their results. The event has made him think more about his children's health and he wants to help them to stop smoking. He feels that such events are very important for Roma and hopes that the health presentations will help others to avoid the heart problems that he has suffered.

Summary of effectiveness in meeting the objective

As with all Gypsy, Roma and Traveller groups, their exclusion from ethnic monitoring on most GP practice databases makes a baseline impossible and renders it difficult to monitor GP registration. The nature of the GP practices in NHS Newham also militates against measuring success as they have two Transitional Teams who register people who have no proof of residence (a particular problem for Roma people in London) and a drop-in GP practice, open 8am until 8pm, where people do not have to register. The exact number of Roma in the area is also difficult to quantify and will fluctuate. However the Roma support group do keep records of those Roma who access their services and are able to monitor some level of progress through their records and demonstrate an increase in GP registration. Although it is not possible to verify the extent of this success statistically anecdotally we know that Grazyna, the Roma Health Communication worker has been successful in disseminating information to the community about how to register with a GP.

NHS Newham has been very successful in increasing awareness of health within the community and increasing staff awareness with increased trust and dialogue with the

Roma community. The level of awareness has been raised beyond the initial aims and expectations of the project and has had a positive impact on the use of health services as well as an increase in GP registrations.

Unexpected positive outcomes included the trust invested in the staff member who presented the 'healthy heart' awareness session at the Health Event, through the important preparation work she did with the Roma volunteers. This has both increased the women's ability to trust health staff and increased their desire to have the same presenter to do further work with them in the future.

Individual Roma volunteers who had a voice on the steering group felt empowered by their experiences and have developed more confidence in their personal lives as well as gaining health benefit from participation and recognition of their contribution to the success of the project.

Summary of strengths of the project

NHS Newham's existing links with the Roma Support Group and its subsequent partnership with them from the inception of the Pacesetter project was a considerable strength of this project. The community engagement throughout the project has been essential to its success and the trust that already existed between RSG and the PALS lead, who is now also the Pacesetter project lead, has been strengthened further. Her enabling support gave Grazyna the confidence to deliver presentations and to organise the health awareness event, but also gave her increased confidence to raise health issues on behalf of the Roma at an NHS Diversity and Equality conference.

The increased health awareness in the community which culminated in the health awareness event at their AGM and then the health conference led to a positive press coverage for Roma community which was previously unheard of. The project has encouraged greater community participation in health and fostered sufficient trust to make the Roma voice heard and their needs recognised.

As well as improving the health awareness of the Roma community, an essential element of the project has been to build the knowledge and understanding of the NHS staff so that they can address the particular needs and challenges of the Roma community effectively and with sensitivity.

The raising of awareness has also led to the NHS Newham Project lead becoming involved in encouraging and drafting a script for a scene, which includes a Roma

patient, and Roma issues in a customer care/access DVD to be produced by DH for all practices in England.

The project has been so successful that it was included as a promising practice model in the study document, Inclusion Health (Cabinet Office 2010) which outlines how improvements in health care for the most excluded groups in society can be accelerated to ensure high quality services are available to all.

Summary of challenges

The project Lead at NHS Newham has only able to dedicate one day a week to the project. This also raises difficulties in sustaining the work when the funding ends and the project workers post finishes.

EAST LONDON FOUNDATION TRUST (ELFT)

ELFT is a mental health trust that provides local services to the City of London and Hackney, Tower Hamlets and Newham and also provides specialist services to a wider population.

Objective -to raise awareness of mental health issues amongst the Gypsy and Traveller communities

Resources

A project worker, Gaba, was appointed to facilitate awareness raising of mental health with community members and to put together a staff training package. She had already been working for the Roma Support Group Mental Health advocacy project and was therefore well trusted by the community

Context

In addition to physical health status data that reveals widespread morbidity from a range of serious chronic illnesses and conditions, the RSG has collected statistical data that indicates poor mental health amongst high numbers of service users accessing their Health Project. Approximately 50% of over 300 clients suffer are reported to be

suffering mental health problems, including depression, personality disorder, dementia, learning disability, suicidal tendencies, self-abuse, dependency/ misuse of drugs, etc. Figures collected by the RSG in 2004-2006 also indicate that over 80% of adult service users did not complete their primary education

The high number of Roma clients suffering mental health problems can be attributed to a variety of possible reasons including recent traumatic life events (war, racist attacks, pogroms, bullying, frequent incidents of rape, etc.), which forced them to leave their home countries to seek asylum in the UK; systematic discrimination and marginalisation; social exclusion as Gypsies and refugees; insecurity related to their former status as asylum seekers; individual and/ or family experience of detention centres; pressure to conceal their Roma identity in schools and work places due to wide spread anti-Gypsy prejudice and discrimination. (Ingmire 2009)

As highlighted earlier, mental health is a taboo subject within the Roma community and they are often very reserved towards discussing mental health issues with healthcare professionals.

Activities

The change idea was to involve local Roma in producing a script and acting in a play aimed at raising the profile of the issues facing their communities and to raise the profile of mental health services. The agreed activities and aims were:

1. To research, develop and produce a theatre drama production, produced in partnership with the Roma Support Group and a theatre company, which will address the key issues of mental health in relation to the Roma community and be aimed at the Roma community and staff.

Careful planning was required for the theatre project due to the cultural issues associated with mental health. Gaba was therefore well placed to organise focus group meetings with the Roma community members and the project partners to discuss the rationale, content, creative approaches and outcomes of the theatre/ play project.

2. To develop and deliver a specialist high quality training programme for mental health practitioners to equip them with adequate information for deepen their personal insight into understanding the health needs of Polish Roma Communities.

The training programme was to specifically address the community's traditional cultural practices, customs, lifestyle and history and how they relate to mental health and access to services.

ELFT worked with NHS Newham, who were simultaneously working with RSG to design a training package for their Trust staff, that would be culturally sensitive and responsive to the needs of the community. The project Task group produced a set of slides that were available for both Trusts to include in their respective training packages.

Impact - the theatre drama production

Gaba engaged many Roma who had attended her mental health advocacy project to participate in all aspects of the production from script writing to performance. The Forum theatre company, commissioned to produce the play, worked well with the Roma community members and coached Gaba.

Numbers participating have fluctuated but the script and format have been loose, and the preparation very relaxed and informal, in order to facilitate engagement and to give members space and opportunity to express their feelings. The Roma women used their experiences of mental health problems to generate the ideas for the performance and these were a fulfilling and cathartic form of self-expression.

The first public performance was held in February 2010 at the end of the RSG conference. A recording was made of the performance that will be edited for a DVD to be made available on request for community members. The Roma women had been very nervous about performing the play and so a recording was made for the DVD at a rehearsal in case some of the women failed to turn up. However, they did turn up and performed confidently. They participants appeared to enjoy performing as much as the audience appreciated the performance.

Outcomes- the theatre drama production

“ the best thing about the play is how we got there ” (Gaba , the project worker)

Breaking down a mental health taboo among participants

One of the most important outcomes was in the planning process as so many community members began to talk about the mental health issues in the focus group

meetings. This was already breaking down a strong taboo before the play was produced.

Increasing awareness of mental health among the wider Roma community

The enthusiasm about the play from the Roma community was surprising led to 75 Roma had signed up to attend the performance within the first week of it being advertised.



Photo 11. Scene in the play

The DVD will also contain further information aimed at improving mental health and access to support. The performance by the Roma has demonstrated that the taboos about mental health are being eroded and should give confidence and permission for others to open up about their own or their family's mental health problems and assist them in both giving support to others and seeking earlier intervention



Photos 12 and 13. Further scenes in the play.

Impact- training programme for mental health practitioners

The final version of the ELFT package contains much of the same material as that produced for Newham PCT but with extra slides that focus on the mental health issues.

ELFT will be piloting their package now that they have successfully completed their theatre drama production. ELFT plan eventually to mainstream the training package as part of the wider cultural competence training for staff and are arranging the training with the Community Development Lead in City & Hackney PCT.

The training package will be given, on request, to staff at induction training as part of the mainstreaming plans.

Summary of effectiveness in meeting objectives

The project has been successful in addressing the key issues of mental health in relation to the Roma community and assisted in breaking down the taboos so that more timely support and intervention can take place.

The project has also met the aim of producing a specialist high quality training programme for mental health practitioners to equip them with adequate information for deepening their personal insight into understanding the health needs of Roma c, although this has yet to be piloted.

Summary of strengths of the project

As with NHS Newham, the quality and level of community engagement was a particular strength of this project. The project manager worked closely with the project lead who was already employed as a mental health advocacy worker in the RSG and well trusted by the community. By building on existing work and links with the RSG the project was able to meet its aims whilst also supporting an important community resource that will continue to be available after the project has finished.

Summary of challenges

There was considerable delay to the start of the programme due to staff turnover delay in recruitment to the post of Pacesetter manager and then a long period of notice before the manager could commence. The bureaucratic process involved in drawing up service level agreements also led to considerable delay before work could commence on the project. These delays and breaks in continuity had the potential to compromise the engagement with the Roma Support Group and result in loss of momentum. This risk was reduced because ELFT had a standing item on the joint steering group agenda. However, the timescale for project delivery was therefore very short and resulted in delay in piloting the training programme.

Financial barriers were also identified with insufficient resources to produce a second DVD aimed at staff as originally intended.

There are challenges related to mainstreaming the projects as there was insufficient time and resources to consolidate the work for it to be sustained.

Summary of lessons learned and important components of success from both projects

Building trust is the key to working successfully with the community and this takes time.

Partnership with a grassroots organisation has been key to the success of both projects. Realistic expectations are an important component so as not to disappoint, but equally it was important to have open discussion and consideration of all possibilities. Without the enthusiasm and commitment to try the seemingly impossible, knowing the extreme taboo about mental health, Gaba the project worker would not have responded positively to the suggestion of working with the Roma to produce a drama performance.

Enthusiasm and commitment among the Pacesetter lead, Gaba and the women from RSG was another key component of the success of these projects so that the various elements of the programme were not conducted as a tick box exercise but were a result of healthy working relationships with shared goals.

Chapter 8

SUMMARY OF LESSONS LEARNED FROM AWARENESS RAISING

Staff Awareness Raising and cultural competence

Awareness raising was the core change that was expected of every participating Trust in the Pacesetters Programme. It is also recommended in the Primary Care Service Framework: Gypsy and Traveller communities (EHRG 2009) that all doctors and practice-based staff should receive mandatory cultural awareness training. However the brief for Pacesetter sites on the change idea of awareness raising has undergone modification through the consultation stages. The original version of the change idea was to 'Improve staff attitudes and behaviours through education and awareness of the community's healthcare needs and circumstances'. At this stage the stakeholder meeting included the concept of increasing staff cultural competence. This change idea was subsequently redrafted to 'cultural and awareness raising of NHS and GP practice staff so that the needs and circumstances of Gypsies and Travellers are better understood, accompanied by active health promotion campaigns among Gypsy and Traveller communities'. This is an apparently subtle but significant change from the wider concept of improving cultural competence, so that by the time the Pacesetter sites were asked to consider how they would work on the core change ideas they were only briefed to explore 'different ways of raising awareness within both health and Gypsy and Traveller communities'. The essential difference is that various definitions of cultural competence emphasise effectiveness in working with or communicating with people from different cultural backgrounds whereas cultural awareness is just one element in the pathway towards achieving cultural competence (Bhui et al 2002). The Medical Council of New Zealand highlights this difference in its definition:

"Cultural competence requires an awareness of cultural diversity and the ability to function effectively, and respectfully, when working with and treating people of different cultural backgrounds. Cultural competence means a doctor has the attitudes, skills and knowledge needed to achieve this." (MCNZ 2006)

Although cultural awareness does not by definition imply the requirement for attitudinal change to achieve effectiveness, community members indicated their hopes

and expectations that this outcome would be achieved as they discussed their aspirations for training that they would deliver, as in the case of these Health Ambassadors:

“For them to understand us a bit more instead of looking down on us really”

“it would be nice to walk into a doctor or an hospital ... and know you are going to be treated the same as everybody else”

Many of the stated objectives in staff awareness training to health staff delivered by different pacesetter teams or their subcontracted organisations referred to increased understanding as well as increased awareness. Although not always specifically stated, there was an implicit expectation that this would inform attitudes and by progression would lead to behavioural change among staff who received the training.

For example, Voscur who delivered the training in conjunction with community members to staff in West Midlands and South east Coast Pacesetter sites asked

“How will you use the learning from today to address attitudes and prejudices in your staff team / departments?”

To evaluate the success of any training it is therefore essential to be very clear about the intended outcomes and to set measurable objectives to achieve them. The above question illustrates an objective and the answers to the question will inform any potential progress towards achieving the objective.

Attitudinal change

There are a wide range of models and current approaches to training, and the underpinning philosophy is crucial to determining the approach used. In response to a review of the impact and effectiveness of training across all agencies in the public sector, the Home Office produced a best practice guide. This states that training aims and objectives need to be specific with trainers being clear whether to focus on giving information, raising awareness, or to go further in changing attitudes, behaviour, or the organisational culture (Home Office 2002). Approaches also depend on whether training is targeted at individuals, groups, organisations or sectors.

The Stonewall study on attitudes towards minorities found that: *‘informing people about minority groups and their culture can help reduce prejudice but can also risk fostering resentment’* (Valentine 2004). Coxhead, in work on anti racism training strategies for the Police service, has also identified the need for a greater understanding of the phenomena of prejudice towards Gypsies and Travellers and for tailoring training accordingly (Coxhead 2004). He points to the distinction between stereotypes and prejudice, referring to Reich and Adcock (1986) who identified values, attitudes and behaviour change, as inherent factors that may predispose an individual towards prejudice. He states that if stereotypes were the fundamental problem, simple corrections through trainer intervention, would extinguish the problem, as a form of ‘reality correction’. But if participants rejected trainer interventions based on their own ‘evidence’ then there would be a need to target prejudicial values. A study by the author has also shown that raising awareness is insufficient to achieve attitudinal and behavioural change and can sometimes strengthen a defensive polarisation of positions (Van Cleemput 2008). Community members have recognised those participants who are resistant to changing their negative prejudices and for whom cultural awareness training may not result in the desired outcomes of attitudinal and behavioural change: *“you can pick people out when you go in a big meeting who genuinely wants to ask questions because they are interested and people who got their own grudge against Travellers, ‘cause you are answering the question but that is not the answer they want to hear.”*

Although there is infrequent reporting of such resistant prejudicial attitudes towards Gypsies and Travellers from Pacesetter teams who delivered the awareness raising training, it is important to consider the extent to which self completed evaluation questionnaires would reveal evidence of successful achievement of outcomes aimed at reducing such prejudice. It is also important that trainers are trained to deal appropriately with resistant prejudice that may be revealed or become apparent during such events. As Coxhead points out in his paper on Gypsy and Traveller training strategies, in the context of training trainers:

“It is imperative that issues being raised in training are dealt with. Where appropriate challenge does not take place where it is needed, messages of tacit ‘acceptability’ follow.”

Methods of delivering cultural awareness training

Staff awareness training was delivered in a variety of settings depending on whether it was targeted to specific organisations or groups such as staff in a GP practice, student nurses in training, or multi disciplinary and/ or multi agency groups. The size of groups participating in the training also varied from as few as four to as many as thirty-five or more. It was not always possible for trainers to know in advance how many would attend, but it is ideal to be able to target the training to the specific audience and also plan training delivery methods according to the size as well as to the requirements of the group. If small group discussions are to be used it is necessary to have sufficient community members involved.

Although community members were involved to some extent in all the different awareness raising sessions, the extent of their input into the content and into the delivery varied. All were involved in opportunities for questions and answer sessions for participants. In some sessions this was a time set aside for an open question and answer session, whilst in others it was preceded by a presentation, a quiz or by a scenario specifically presented to stimulate discussion of relevant issues. In some session participants were encouraged to identify questions that they may wish to ask or areas they would want to see covered in the training so that any gaps or deficits would be addressed at the end.

A systematic review of cultural competence in mental health care that included evaluated models of professional education has shown that there is little evidence on the effectiveness of cultural awareness training and equally there is limited evidence of the effectiveness of the different components. (Bhui et al 2007) Overwhelmingly in the training delivered in Pacesetter sites, it was the opportunity to meet with community members and to have question and answer sessions with them that was considered by participants to be the most useful aspect of training. This illustrated the extent of identified need for knowledge of these communities and the lack of awareness of their culture and their specific health needs that exists among staff. However, as identified by some community members, for example, the Health Ambassadors in East Midlands, there was also a need for health professionals to support community members in training delivery and also to address issues more strategic questions and issues related to service delivery. The importance of community member involvement in planning the training and in its delivery cannot be overestimated. One example of a thought provoking method employed in training, that

was reported to have a strong impact on participants, was conceived by and described by a community member who delivers cultural awareness raising sessions as part of her role as a community development worker. She used her own experience of being afforded little respect to create a real situation within her training sessions where this could be demonstrated and which would also directly affect the participants.⁹ The analogy of this common experience of Gypsies and Travellers provoked strong reactions of empathy. This particular community member was not involved in local Pacesetter awareness raising training, but this example illustrates the power of individual experience in devising innovative and effective methods of communicating and stimulating awareness and reflection on identifying need for attitudinal change.

Limitations and pitfalls of awareness raising training

It is important to recognise the limitations of what training can achieve in isolation to achieve the aim of improving access to health care through changing the culture and attitudes of staff in a workplace setting. Unless individual staff have the remit or authority to influence the ethos in the workplace the training of individual staff members will have limited success. Where training can be delivered to workplace groups as part of team development there is an increased opportunity for this to be developed.

Training has limitations in enabling individual health staff to deliver culturally competent care without a long-term approach to develop communication skills, focussing on personal qualities, beliefs and attitudes. Training must also avoid “pigeonholing” of Gypsies and Travellers by simply about giving information on Gypsy and Traveller culture, hence the need for training be delivered from a Gypsy or Traveller perspective that aims to assist health staff to be able ‘to put themselves in another person’s shoes’ whatever their culture. As Papadopoulos recommends, there needs to be an emphasis on the impact of social divisions in the wider context that covers and challenges forms of discriminatory thinking such as essentialism, ethnocentrism, and racism (Papadopoulos 2006).

The other important factor in effective communication between community members and health staff is the reciprocal nature of communication. We saw clearly in the evaluation of the health ambassadors training sessions the importance of two-way

⁹ The community member has specifically requested that I do not publish the exact details of this example as she wishes to retain the effective surprise element in her training sessions

learning and the need for facilitation for community members to be given an opportunity and confidence to ask questions of health staff.

One of the obstacles to effective delivery of cultural awareness training for staff is in having the requisite amount of time for them to attend. In GP practices in particular most training sessions were limited to a one hour lunchtime session. Where staff do have the opportunity to attend longer structured sessions it is usually by choice and this raises the possibility or likelihood that those who are most need in need of awareness raising may not necessarily be those who attend. Unless there is a self driven need for change it will not occur.

Evaluation of awareness raising

It is crucial that any training is rigorously evaluated. Within the time frame of the Pacesetters Programme most training has only been evaluated by means of individual evaluation questionnaires completed at the time of training and in some cases by post training evaluation questionnaires sent by post a few months later. The design of evaluation questions is important to be able elicit the extent to which participants feel that the training aims have been achieved. In some cases, where questionnaires had already been designed before the evaluator was in post, the training aims were not stated and there were more frequent questions concerned with satisfaction of venue, content, delivery etc rather than extent of learning outcomes. However most local trainers did adapt their forms to evaluate level of increased knowledge and potential effectiveness in changing views and practice by asking participants questions such as

- What did you hope to achieve from the training?
- Highlight 3 most important things you achieved from the training
- Have my views changed as a result of the training; if so, how?
- What do I intend to do differently?

The response rate to postal questionnaires sent several months after training is likely to be low, especially without reminders and follow up. In the few examples where postal questionnaires had been sent very few had been returned from the one initial mail out. However, to have any chance of evaluating the effectiveness in achieving objectives of improving service delivery through awareness raising it is necessary to attempt to discover what changes have been made in practice. One method is to ask specific

questions of the participants about what they have done / how they have used the training, either by postal questionnaires, or more ideally through qualitative enquiry by means of individual telephone interviews. Both methods were used with some success in identifying positive changes in practice, mainly in respect of improved communication.

The other more effective, but necessarily longer term method is to evaluate the outcomes in terms of the community members' experience. However much participants report changes in their practice, the real evidence of achievement is in the extent to which the change impacts on the experience of the community members. However it is too early for these long-term outcomes to be evaluated in most of the awareness raising initiatives in the Pacesetter sites. The one exception is where a focus group was conducted with health ambassadors who all attended one practice where the staff had received training and were able to report a change in attitudes and behaviour. It was also notable that they identified the reciprocal nature of these changes through effective breaking down of defences.

There are many lessons learned from the Pacesetter delivery of staff cultural awareness raising, but of all of these perhaps the most important is that much time and planning with community members must be allowed for determining the aims and objectives, appropriate delivery and effective evaluation of outcomes.

Chapter 9

SUMMARY OF LESSONS LEARNED FROM COMMUNITY ENGAGEMENT

Community Engagement as a key emphasis ('Nothing About us without Us')

This principle of community engagement being a crucial and essential component of any initiatives to improve health and access to health care among Gypsies, Roma and Travellers needs to be emphasised, as it was with the Pacesetter Programme, with specific directives to SHAs/Trusts. However, it is also essential that community members are consulted at the outset on priorities for action.

Commitment to community involvement

There was fluctuating commitment to community involvement centrally. Continuity and good communication with a trusted person is important. An important lesson learned was that trust is hard won and fragile and can be lost if community member involvement is seen to be tokenistic through their voice not 'counting' or if expectations are raised and then not matched. Promises of action should be followed through or explanations given if there is good reason that they cannot be fulfilled. Representation regarding community members needs to be transparent.

It was apparent that there were different levels of understanding of community involvement among different Trust and members of Pacesetter teams. Each Trust had varying experiences and were at different starting points on the ladder of engagement. Community engagement should not be seen as a 'quick fix' and requires time and sustained effort. It is an important lesson that sufficient time is allowed for community engagement when project funding is allocated and timescales are decided. Time and costs of community involvement need to be built in to local budgets.

Levels of engagement

A consequence of the different levels of understanding and different starting points of the ladder of engagement was the different levels of local community involvement. Facilitation through a trusted link person should be provided to overcome barriers to participation, as confidence and trust are core issues.

The need for and development of a project must be decided with community members and they must take ownership of it or champion it for it to succeed. Involvement through communication should be maintained through all stages of the project and the remit of community members as advisors or decision makers should be clear

Flexibility is essential to allow for effective community involvement.

Chapter 10

SUMMARY OF LESSONS LEARNED FROM PROJECTS

- § Process was as important as outputs in developing lasting collaborations, confidence and increased skills among community members, and increased awareness of health services.

- § Staff changes within Pacesetter teams and also in the Department of Health were numerous, sometimes leading to communication breakdown and loss in continuity with a negative impact on project delivery .

- § Two years is insufficient time for embedding real change, particularly for Trusts that are at a low starting point in relation to community engagement. Bureaucratic delays in the release of funding and setting up service level agreements delayed the start of several projects.

- § Evaluation needs to be built in and independent evaluators appointed before the start of the projects for appropriate systems for data collection to be put in place and to ensure baseline data collection.

- § Sufficient dedicated time and administrative support is required for project delivery staff if they are also combining the work with a permanent service delivery role with community members.

- § Remit and remuneration of community members must be agreed at the outset of the projects.

- § Pacesetter projects are much easier to deliver in Primary Care Trusts where key professionals are more easily identified.

Chapter 11

Overall evaluation findings – short term gains

‘The best thing is how we got there’

Whilst it is clearly premature to evaluate the long- term health (and social) gains accruing from outcomes of the Gypsy and Traveller core strand of the Pacesetter Programme, it is possible to identify some short-term gains. Many of these gains have been made in the process of involvement.

1. The core principle of full involvement with community members at Department of Health level has been established even if the levels of engagement have been variable over the lifetime of the programme. Community members have had an important role and voice in identifying the most pressing issues related to improving the health of Gypsies, Roma and Travellers and helping to decide what core areas of change should be prioritised. Important lessons have been learnt that will enable future involvement to be deeper, strengthened and sustained and more effectively embedded in community networks. At the same time, the firm commitment to improving the health of Gypsies, Roma and Travellers has been acknowledged by the Department of Health and this has raised the profile of the health needs of these groups at both a local and a national level, so that their voice is more likely to be sought and their needs are more likely to be included in future initiatives aimed at reducing health inequalities for minority communities.

2. Trusts have also made important links with community members and are continuing to consult with them after the projects have ended, indicating that the Pacesetters projects may result in important synergies. In some cases new forums have been established and further initiatives will be developed in collaboration with community members.

3. Some short-term gains have been identified in each of the main themes of change ideas. Several Trusts have worked with community members to develop cultural awareness training programmes for their staff. In many Trusts where these have been successfully piloted and evaluated, they are being mainstreamed as part of wider cultural competence training for Trust staff.

4. Community members who have been trained to deliver training have been empowered by the process and have developed confidence in accessing health care, with increased capacity for dialogue. This has led to increased levels of trust in some health staff and the potential for earlier presentation and diagnosis of symptoms and for improving understanding and concordance with prescribed treatment. Some community members have increased levels of self-belief and self-efficacy resulting from their success in delivering training and the (deserved) recognition for their contribution in this area. In a number of cases, this increased self-belief has enabled community members to become more involved in wider community projects. This increased community involvement has the potential to reduce the isolation of Gypsies, Roma and Travellers and reduce the propensity for the wider community to 'otherise' and stereotype them.

5. Increased awareness of health needs and health services among local Gypsies, Roma and Travellers represent important short-term gains in several Trusts. In many cases, it should be stressed that it has been the process of involvement that has been as important as the outcomes. Some of the initiatives to increase awareness have been innovative and successful in eroding previous taboos in discussing health matters, particularly those surrounding mental health issues. Community members involved in such initiatives have felt empowered and have in some cases have experienced an improvement in their health as a result. In addition, some successful initiatives have been recorded as audiovisual resources for wider distribution amongst the communities involved. In one case a resource has been uploaded onto You Tube to maximise the opportunities for communities to access the resource.

6. Whilst it needs to be stressed that many of the short term gains listed here may be seen as relatively small and localised, the most important gain is potentially very far reaching in that the principle of 'nothing about us without us' has been established and the profile of Gypsy, Roma and Traveller health needs has been raised so that they are now firmly on the radar of commissioners, providers and policy makers.

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Appendix 1: Health Ambassadors who took part in the focus groups:

Linda McCann

Lucy Scott

Bridget Reid

Lena Price

Nan McCann

Star Winter

Lizzy Squires

Maggie Smith

Neesha Price

Charmaine Cater

Mary Casey

Mary Ann Smith

Julie Price

Lil Gaskin

Appendix 2 Voscur Trainer Session Plan for PAHR training

| Section | Example Time | Content and objectives | Teacher Activity | Learner Activity | Resources |
|----------|--------------|--|---|---|--|
| A | 9.30 | Welcome and introductions | <p>Give introduction, outline aims and objectives and highlight ground rules</p> <p>If time facilitate a warm up activity.</p> | Participation Q&As | <p>Trainer notes (A1)</p> <p>Trainers notes (A2)</p> <p>Trainer notes (A7)</p> <p>‘Outline of session’ handout (A3)</p> <p>‘Ground rules’ handout (A4)</p> <p>‘Warm up’ activities (A5 and / or A6, if time)</p> <p>Flip chart and paper</p> <p>Flip chart sheets with pre-written ‘introductory and ‘warm up’ question</p> |
| B | 9.40 | Distinguishing G&T communities – Matching exercise and legislation (Objective: 2) | <p>Distribute ‘Matching Exercise’ activity sheet (B2) ask participants to match statements with group types</p> <p>Distribute handout B3 at end of activity</p> | <p>Work in pairs to complete activity sheet B2</p> <p>Participate in discussion</p> | <p>Trainer notes (B1)</p> <p>‘Matching Exercise’ activity sheet (B2)</p> <p>‘Matching Exercise’ handout (B3)</p> |
| C | 9.50 | Quiz and presentation, G&T health and cultural awareness (Objectives: 1, 3) | <p>Distribute ‘G&T Quiz questions’ activity sheet (C2) and ‘G&T quiz sources’ handout (C3).</p> <p>Give group 7 minutes to answer questions</p> <p>Feedback answers using PowerPoint presentation (C4) to highlight points</p> <p>Facilitate discussion</p> <p>Distribute handouts C5, C6 and C7 at end of activity</p> | <p>Small groups, complete activity sheet C2 and feedback.</p> <p>Group discussion, participate and feedback</p> | <p>Trainer notes (C1)</p> <p>‘G&T Quiz questions’ activity sheet (C2)</p> <p>‘G&T Quiz sources’ handout (C3)</p> <p>PowerPoint presentation with quiz answers and additional information (C4) – on laptop or memory stick</p> <p>‘G&T Quiz answers and information’ handout (C5)</p> <p>‘Relevant Legislation’ handout (C6)</p> <p>‘G&T Sites and data’ handout (C7)</p> <p>Laptop and Projector, (or Smart Board)</p> |
| D | 10.30 | Role-play focusing on G&T | <p><u>Role-play exercise</u></p> <p>Choose 2 participants to</p> | Observe and take notes on activity sheet | <p>Trainer notes (D1)</p> <p>Trainer support notes ‘Role Play outline’ (D2)</p> |

| Section | Example Time | Content and objectives | Teacher Activity | Learner Activity | Resources |
|----------|--------------|--|---|--|--|
| | | awareness covering perceptions and attitudes (Objectives: 1, 4,) | read 'Role-play script' (D4) Distribute 'Role-play observation questions' activity sheet (D5) before start of role-play; ask participants to answer questions while observing Facilitate discussion | D5 Participate in discussion | Trainer support notes 'Role-play background' 'Role-play script' (D4) 'Role-play observation questions' activity sheet Flip chart paper |
| E | 10.50 | Talk, questions and answers with representative from G&T community – discussing health issues for G&T communities (Objectives: 1, 3, 4) | G&T Rep talk for 10 minutes. After talk ask participants to write questions on post-it notes Facilitate Q&A Distribute handouts E4 and E5 at end of activity | Q&A | Trainer notes (E1) 'Gypsy and Traveller organisations and other useful contacts' handout (E4) 'Further reading and sources' handout (E5) Flip chart and paper Post-it notes |
| | | G&T health issues case studies (if no representative available) (Objectives: 1, 3, 4) | Split participants into groups of up to 5. Distribute 'G&T Case studies' activity sheet (E3) Facilitate feedback Distribute handouts E4 and E5 at end of activity | In groups of up to 5 answer questions on activity sheet E3 and feedback | Trainer notes (E2) 'G&T Case studies' activity sheet (E3i, E3ii, E3iii) 'Gypsy and Traveller organisations and other useful contacts' handout (E4) 'Further reading and sources' handout (E5) Flip chart and paper |
| F | 11.15 | Introduction to the Personal Adult Health Record (Objective: 5) | Distribute and explain 'Copy of the PAHR' activity sheet (F2). Take 5 minutes to explain Distribute 'Patient's details' activity sheet (F3) and explain activity Facilitate feedback | Work individually to fill in activity sheet F3 Q&A | Trainer notes (F1) 'Copy of the PAHR' activity sheet (F2) 'Patient's details' activity sheet (F3) Flip chart and paper |
| G | 11.40 | Action planning checklist (what do you need to have in place to work with G&T communities?) | Distribute 'Action planning checklist' activity sheet (G2) Split group into pairs and ask participants to interview each other for 5 minutes each Ask each person to | Interview each other in pairs using activity sheet G2 Participate in feedback | Trainer notes (G1) 'Action planning checklist' activity sheet (G2) Flip chart and paper |

| Section | Example Time | Content and objectives | Teacher Activity | Learner Activity | Resources |
|----------|--------------|-------------------------------------|---|--|--|
| | | (Objective: 4) | feedback 1 action to group and record on flipchart | | |
| H | 11.50 | Monitoring and evaluation | Distribute 'Learner Equalities monitoring form' activity sheet (H2) Ensure participants complete 'Learner evaluation form' activity sheet (H4) Collect in completed forms from participants. Thank participants for their time and tell them how (if) this session will be followed up | Complete activity sheets A8 and H2 | Trainer notes (H1) 'Learner Equalities monitoring form' activity sheet (H2) Trainer notes (H3) 'Learner evaluation form activity sheet (H4) – participants to complete |
| | 11.55 | Closing question to learners | How will we ensure the learning from today can best be used to challenge negative attitudes and practices within our respective department? | All learners to verbally respond in the plenary. | |

Appendix 3 Voscur evaluation form- post PAHR training :

Learner Evaluation form

Name of Session: Gypsy and Traveller Awareness and Health Needs

Date: _____

Your job title: _____

We would like to take this opportunity to find out what you thought of the session.
Your feedback will help us develop and improve future events.

The event is designed to achieve the following learning outcomes:

1. To improve awareness of the specific health inequalities and health needs of Gypsies and Travellers
2. To gain an improved awareness and understanding of the ethnic identities of Gypsies and Travellers
3. To understand the specific barriers for Gypsies and Travellers in accessing and using health services appropriately
4. To learn from examples of good practice and identify specific actions you propose to take following this training to improve the access to health care for Gypsy and Travellers.
5. To demonstrate use of the Personal Adult Health Record

Using a scale one (low) to five (high), to what extent did the training achieve the intended outcomes? (Please write number here)

2. What did you hope to achieve from the training?

- | | |
|-------------------------------------|--------------------------|
| Raised awareness | <input type="checkbox"/> |
| Better understanding | <input type="checkbox"/> |
| Networking | <input type="checkbox"/> |
| Improved skills | <input type="checkbox"/> |
| Ideas share/practice | <input type="checkbox"/> |
| Signposting for further information | <input type="checkbox"/> |
| More confidence | <input type="checkbox"/> |
| Other (please state) | <input type="checkbox"/> |

3. Please list 3 most important things you learnt in the training

4. Have your views changed as a result of the training? No Yes

If yes how?

5. What are you thinking of doing differently as a result of attending the training?

6. Which part of the training did you find most useful? For example a particular activity, discussions, networking etc.

7. Is there anything we could do better? No Yes if yes, what?

8. We are committed to working in a way which is anti-oppressive, accessible and promotes the equality of women, black & minority ethnic communities, transgender people, faith groups, disabled people, older people, young people and lesbians, bisexuals & gay men. Do you feel that this aim was met on the day? Yes
No if no, why not?

9. Do you have any other comments?

We occasionally use feedback comments in our publicity – please put your name and department / organisation below if you are happy to be quoted! Thank you!

Name _____

Contact Details _____

Thank you for taking your time to fill in this form.
Please hand it into the trainer

If you would like to feedback directly, please contact: (training provider's details / organisation)

