

# A dialogue of equals

The Pacesetters programme Community Engagement Guide



Look beneath the surface, change the way we think

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# **A dialogue of equals**

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## Introduction

I have been contracted by the Pacesetters programme to provide advice on community engagement to the various Pacesetters sites. This was a particularly bold and brave move by the Pacesetters leadership, as I have no direct experience of working in the NHS. I was recruited because I am an advocate of the benefits that service providers can achieve through empowering communities to become involved in helping to shape the services that they receive from public sector bodies.

I come from a marginalised community myself; I am often described as a community representative, and I have been an outspoken critic of the quality of some of the public services that are being delivered to the black community, of which I am a member.

I admit that I came to Pacesetters with some preconceived ideas about the quality and amount of real community engagement that is taking place. I have been pleasantly surprised, however, to find that in many areas the NHS is engaging with its users and local communities in innovative and imaginative ways.

However, the groups that are targeted by the Pacesetters programme are recognised as being seldom heard and seldom involved. In recognition of this lack of previous involvement, I have been asked to write a guide that will support NHS staff with responsibilities for patient and public involvement to understand better how to identify and create opportunities for engaging with seldom-heard communities or marginalised groups.

This guide should, therefore, supplement the guidance manuals and engagement processes already in place, not replace them.

It is as appropriate for foundation trusts as for other trusts. Indeed, foundation trusts will find it particularly useful in recruiting and developing their membership.

Following this guidance will help you and your organisation in delivering the NHS Operating Framework. One of the 'ambitions' of the Framework is described as: 'Ensuring we improve the patient experience, staff satisfaction and engagement.'

This document will also help you achieve Lord Darzi's vision for an NHS that is: 'Personalised – tailored to the needs and wants of each individual, especially the most vulnerable and those in greatest need.' (*Our NHS, our future*, October 2007.)

**Stafford Scott**  
Community Engagement Adviser  
to the Pacesetters team

**This document provides guidance to Pacesetters sites on community engagement, with particular emphasis on engaging seldom-involved communities. It is not intended to be a detailed guide to working with people covered by all the equality strands, but includes a template for a Community Engagement Strategy, which Pacesetters sites are asked to put in place.**

# 1. The Pacesetters programme

The Pacesetters programme is a partnership between local communities who experience health inequalities arising from discrimination, the NHS and the Department of Health. Working with strategic health authorities (SHAs) and trusts, the programme's overall aim is to deliver 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 from communities who experience discrimination and disadvantage; and
- working environments that are fair and free of discrimination.

We are currently working with six SHAs:

- NHS East Midlands
- NHS London
- NHS South East Coast
- NHS South West
- NHS West Midlands
- NHS Yorkshire and the Humber.

Each Pacesetters trust will work on a range of locally important issues based on the following equality strands:

- age
- disability
- ethnic group
- gender
- religion and belief
- sexual orientation and gender identity.

For more information about the Pacesetters programme, visit [www.dh.gov.uk/pacesetters](http://www.dh.gov.uk/pacesetters).

## The objective of this document

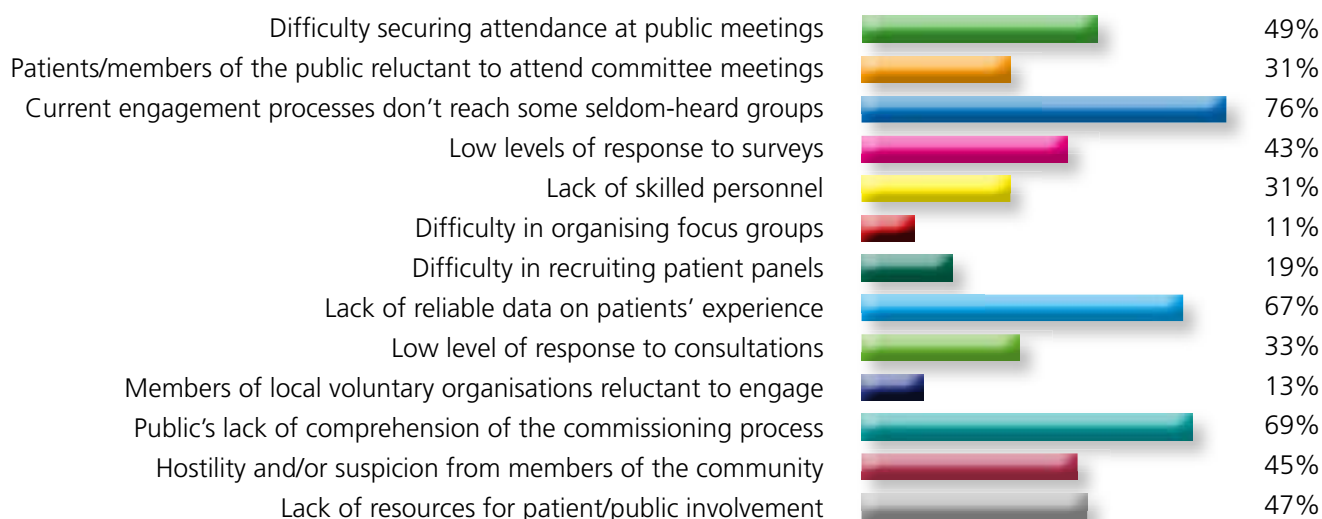
This guidance offers a framework for effective community engagement, particularly with communities and groups who are seldom heard or who are described by some as being 'hard to reach'.

It has been written for Pacesetters sites, in the first instance, as they develop, work on, monitor and evaluate the ideas that will lead to a sea-change in the way in which the NHS deals with equality and diversity. Although written for Pacesetters sites, the guidance may be readily used by any NHS organisation. The guidance has been written to create a common understanding – across all Pacesetters sites – of the intrinsic role that engagement with the groups targeted to benefit from Pacesetters interventions can play within the Pacesetters process.

Our target groups are based on our target strands of age, disability, ethnicity, gender, religion, sexual orientation and gender identity. This guide will focus on these groups, as we believe that some of their members have at some time or other faced discrimination in services delivered by public sector service providers. It is our understanding that, as a consequence of this, some members of our target groups may appear to some service providers to be more difficult to engage with than is generally the case. We also believe that a further consequence of this is that service providers are not as confident in carrying out engagement with so-called 'hard-to-reach communities' as they are in engaging with the general population.

Supporting this assertion are the findings of a recent survey of primary care trusts (PCTs) conducted by the Picker Institute (see Figure 1), in which 76% of the trusts' respondents cited that their biggest barrier to successful patient and public involvement was their inability to involve seldom-heard groups.

**Figure 1: Challenges faced by PCT staff**



Source: Picker Institute, July 2007

With this in mind, this guide has been written to support colleagues wishing to engage with seldom-heard groups and members of seldom-heard communities and, in particular, to support Pacesetters colleagues with a responsibility for patient and public involvement to:

**Be more strategic and effective when carrying out community engagement activities with seldom-heard groups.**

To enable this to happen, we believe that healthcare professionals will need to have a better understanding of what communities are, how they function at a neighbourhood level **and** the differences that exist between community aspirations and patient needs if they are to:

- create a meaningful 'dialogue of equals' between health professionals and members of seldom-heard communities/groups;
- empower seldom-heard communities to become involved as **partners** in the development of new policies and service changes;
- improve the overall experience of members of the target groups when receiving services from Pacesetters organisations;

- empower local communities to monitor and evaluate the services delivered to them, with a view to joint learning from the experience which then informs future policy and service development; and
- identify and map local unmet needs, i.e. to support marginalised communities to set their healthcare priorities.

**The Pacesetters principles on engaging with seldom-heard groups**

The guidance is based on three fundamental principles:

- First, without community engagement the NHS will not respond as well as it can to the health needs and circumstances of the various communities it serves.
- Second, community engagement is much more than community consultation. The former is about a continuous dialogue and the development of a good working relationship. The latter is about one party seeking the views of another at occasional intervals.



- Third, if it is to be successful, community engagement must involve a ‘dialogue of equals’. In the context of the NHS, this dialogue is about individuals and local communities who are properly informed about their health needs and what the NHS can offer. They are also empowered to talk as equals to NHS planners and professionals, while recognising the expertise of health planners and professionals. Equally, it is about health professionals who **genuinely** understand the needs and circumstances of different communities, and are prepared to recognise the experience and expertise that community members can bring to any debate.

This document also seeks to acknowledge the contribution people can make as patients, staff and members of the wider community in promoting healthier lifestyles, setting priorities, planning and developing services and evaluating outcomes. To enable this to happen, the Pacesetters programme is trialling a method of community engagement that encourages communities to have a greater input into the design, delivery and evaluation of all Pacesetters programme interventions. This will mean that local communities will need to be properly supported – and, in some instances, they may need to have their capacity built – to help them understand the issues and constraints facing a modern health service.

At the same time, NHS professionals will also need to be engaged, emotionally as well as intellectually, to understand and appreciate better the needs of all the communities they serve. An improved understanding of community needs will lead to improvements in service take-up and delivery. Community engagement should also be a significant driver affecting the way in which services are commissioned locally.

This guide will not focus on internal NHS processes; Pacesetters recognises that the majority of the guidance documents produced have focused on processes. Though well meaning and well written, they tend to be set aside once the particular consultation process on which the guidance is focused moves on from being the current flavour of the month.

Because of the continual cycle of changes that colleagues in the NHS have faced, we believe that, through no fault of their own, some colleagues who have a responsibility for patient and public involvement may now be more knowledgeable about the various internal processes relating to consultation than they are about the communities whom their trust seeks to serve. One of the consequences of this is that the communities who are already isolated and seldom heard become communities who are even less likely to be involved in engagement activity.



## 2. Community engagement – what is it and why is it important?

While community engagement as a concept has been around for many years, there is no common or widely agreed definition of it. At Pacesetters, we have adopted the Centre for Ethnicity and Health's<sup>1</sup> meaning of 'community engagement':

- Community engagement is built on the principles of equality and social justice.
- It acknowledges that barriers to healthcare services exist for many people and that those barriers are often rooted in the failure of agencies to recognise adequately the complex social, cultural, religious, economic and generational experiences of some distinct communities.
- It further recognises that within some communities there is a lack of awareness and knowledge around a range of health and social care issues and services.
- Stigma and denial exist around some of these issues (e.g. substance abuse and mental health) and within some communities.

Community engagement takes as its starting point the premise that the community itself has the greatest ability to access its own members in order to raise awareness and assess need, and that agencies have the responsibility to develop services to meet that need. However, the complete body of knowledge required to identify the needs of all people, raise awareness on a range of health and social care issues, educate and disseminate information does not lay wholly with the community or with the agencies. Hence, creating an environment where communities and agencies can share that knowledge will fill the gaps."

In a nutshell, community engagement provides benefits to the public, to patients and service users, to staff, to the NHS and UK plc as a whole.

### What is engagement?

Engagement is the involvement of the public, either as individuals or as a community, in policy and service decisions which affect them. In practice this involvement can take a number of different forms.

The three main stages of engagement are:

#### Information gathering

The collection of information and data about public attitudes and requirements through surveys, etc. There is no ongoing dialogue between the public and the organisation seeking the information. The public usually participate in this as individuals.

#### Consultation

Members of the public and the organisation work together for a defined period to discuss a particular policy or service issue. The methods used can range from focus groups to citizens' juries. People are brought together as representatives of the demographic profile of a particular community.

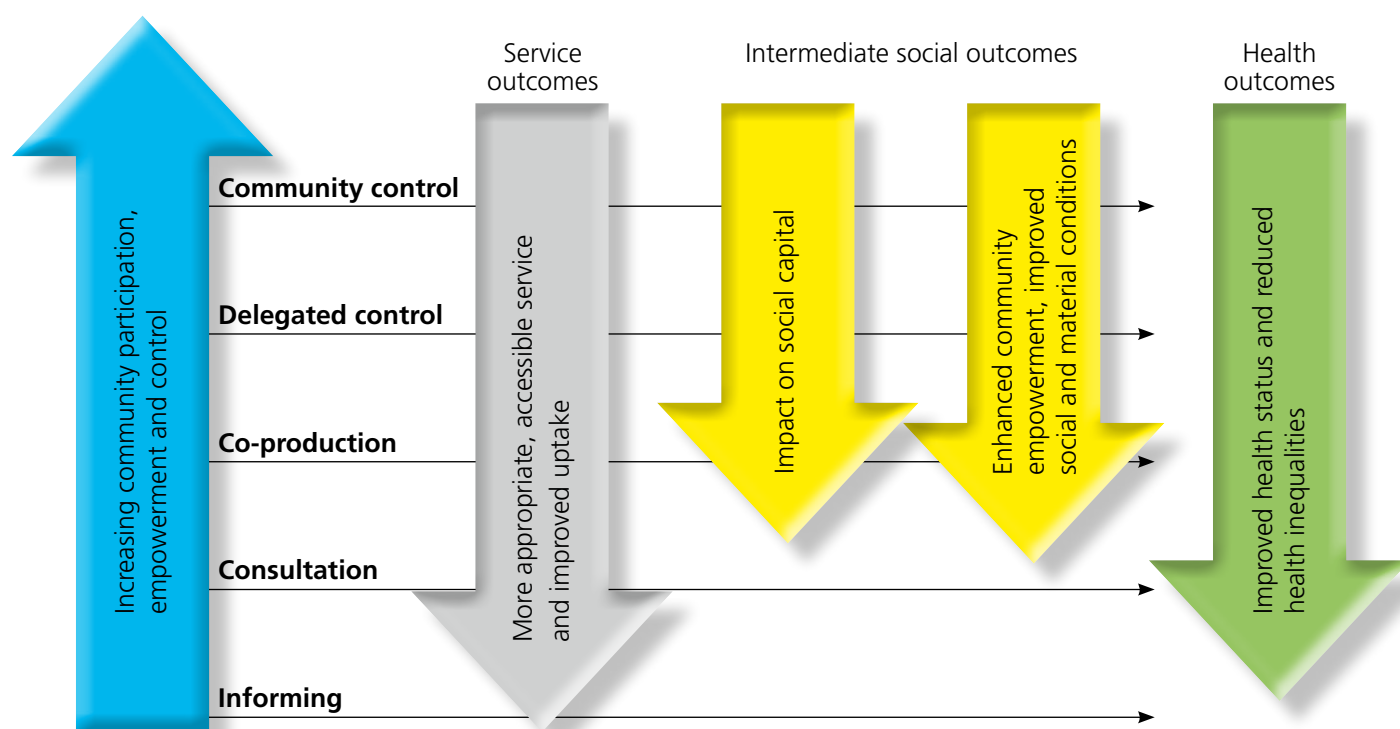
#### Participation

Members of the public and the organisation work together, on an ongoing basis, on a range of policy or service issues. These tend to focus on the community rather than on individuals. Community forums are an example.

A key difference between the different approaches to engagement outlined above is the extent of the dialogue that takes place. The word 'dialogue' refers to the exchange of views, ideas and concerns between different groups, for example between a local community organisation and a service-commissioning agency such as a local PCT.

<sup>1</sup> Winters M, Patel K (2003) The Department of Health's Black and Minority Ethnic Drug Misuse Needs Assessment Project Report 1: The Process. Preston, Centre for Ethnicity and Health, University of Central Lancashire.

**Figure 2: Pathways from community participation, empowerment and control to health improvement**



Source: J. Popay (2006) *Community engagement and community development and health improvement: a background paper for NICE*

The information-gathering approach does not involve much dialogue, whereas the participation approach is about a continuing dialogue as part of joint working.

Figure 2 provides a new way of looking at Arnstein's ladder of citizen participation as it looks not only at the different types of community engagement, but also at the different levels of community empowerment that can be gained when communities are more fully involved.

Figure 2 attempts to show that in empowering communities and groups by giving them delegated powers or handing control to the community there can be added benefits in terms of service improvements and improved social outcomes. With time, this will lead to a greater sense of community wellbeing, as people will begin to address the issues of greatest concern to them. This will in turn impact positively on their health status and, in the longer term, will help to lead to a reduction in long-standing health inequalities.

## Why it is important

The benefits of involving the community in partnerships have been well rehearsed in many sets of guidelines over the last ten years, and are now generally accepted as being as follows:

### Better decision making

By consulting the community and deepening their understanding of the issues, partnerships are more likely to select the right kinds of programmes of activity delivered in the right kind of way, and thus achieve better results.

### More effective service delivery

By involving the beneficiaries in the design – and possibly also in the delivery – of services, programmes of activity are more likely to be successful in terms of their relevance, usage levels, outputs and hence their impact.

### Greater community support

By obtaining the co-operation and active support of the community, programmes, projects and partnerships will get wider endorsement, again increasing their chances of success. In turn, this will increase the lifespan of the activities (their sustainability) as the community steps in to play a greater role in delivering the activities in the longer term.

### Community development

Engagement activities can be the spur to more community involvement in local neighbourhood affairs, and can give residents the chance to gain the knowledge, skills and confidence to play a more active role in their communities in the future.

From an NHS perspective the benefits can be viewed as:

- **helping to improve communication** between patients and staff;
- giving patients, carers and their families **a better understanding** of their conditions and treatment plans to achieve better outcomes;
- **increasing understanding** of patients and the public about the health service;
- **empowering the community** to have a voice and a say in the delivery of local services;
- **encouraging better decision making** by consulting the community and deepening their understanding of the issues – service providers are more likely to select the right kinds of programmes of activity delivered in the right kind of way, and thus achieve better overall results;

- **establishing more effective service delivery** by involving the beneficiaries in the design and possibly also the delivery of services – programmes of activity are more likely to be successful in terms of their relevance, usage levels, outputs/outcomes and, as a result, their impact;
- **gaining greater community support** by obtaining the co-operation and active support of community – programmes and projects will get wider endorsement, again increasing their chances of success. In turn, this will increase the lifespan of projects (sustainability), as the community might well step in to run the activities in the longer term; and
- **encouraging community development** by involvement in engagement activities can inspire community members towards more community involvement in neighbourhood affairs and can give local residents the opportunity to gain knowledge, skills and confidence to play a more active role in their communities in the future.

### Empowering others does not mean giving up your powers

Community engagement should not be seen as an abdication of leadership and responsibility on the part of service providers. It is a requirement of the Pacesetters programme that the targeted communities – i.e. the intended beneficiaries – be involved in shaping the provision of local services. However, we also understand that the views of patients and the wider community will only ever be one of a number of considerations to be taken on board when making funding and operational decisions at a local level. For example, nationally defined targets that are tied to resource availability may create a tension with locally perceived priorities. Ensuring that service users, patients and the wider community are aware of this and have an understanding of

how the decision-making process works is an important responsibility of those engaging on behalf of the service provider.

Another reason why transparency around decision-making processes is a vital element of effective community engagement is that a common weakness of previous mechanisms is the often reactive nature of the engagement process. In the past, communities have tended to mobilise in response to the threat of service reduction, such as the closure of a hospital department or the ending of a particular service.

Having effective community engagement mechanisms in place should make this less likely to happen. Therefore, improving the intelligence around planning and decision making is an important part of this. Involving the local community at appropriate points in the process, rather than once decisions have been made, is another key element of effective engagement.

Following these steps will not only alter the often adversarial nature of the provider–user relationship, but it will ultimately help to promote higher levels of awareness around the decision-making process that underpins the allocation of finite resources.



## The need to be more strategic

All too often patient and public involvement is left to a few members of staff who do not always have the resources or authority to do all that they would wish. As a result, community engagement initiatives are often delivered in an ad hoc and unplanned fashion. One of the consequences of this is that there is not enough evaluated evidence to show clearly the benefits derived from the engagement that has taken place. This failure to evaluate also means that the lessons of what works and what does not work are not properly captured.

There is enough anecdotal evidence to suggest that the lack of evaluation is directly linked to professionals undertaking engagement without a strategy. If there is a lack of clarity around the aim and objectives of the engagement, then it is virtually impossible to measure how successful or otherwise the engagement has been.

It needs to be understood that undertaking engagement without a strategy is akin to a boxer entering the ring with one hand tied behind his back. It is unprofessional and unacceptable, and it is far less likely to be successful, as it undermines community participation and disempowers those who contributed to the process.

The lack of clear objectives also means that far too often the service provider fails to feed back the benefits derived from the engagement to those who participated in it. This can lead to resentment and reluctance to be engaged in future and is clearly counterproductive as it leaves little, if anything, to build on in terms of evaluated outcomes and further community involvement. The upshot of this is that each time a service provider is required to engage, the process starts, from the beginning, all over again.

## 3. Developing a Community Engagement Strategy

We believe that each Pacesetters site should develop its own stand-alone Pacesetters Community Engagement Strategy with an action plan for involving our target groups. A Community Engagement Strategy will allow each trust to identify its baseline and to build on it. Having a strategy will also enable trusts to measure the amount and quality of the engagement that is undertaken and will identify where gaps in engagement may exist.

### Before drafting a strategy

Before drafting the strategy, it is strongly recommended that you give full consideration to the following:

- Which communities are to be targeted as part of the engagement? (We strongly suggest that you choose to start with groups who are seldom involved.)
- What are the most appropriate methods of engagement to be used?
- What decision(s) will be informed as a result of the engagement activities?
- What mechanisms will be in place to enable ongoing community input into the decision-making process?
- What other factors, information, opinions and research will also be considered in making decisions?
- What forum/mechanism will make the decision(s)?
- Who will be involved in this?
- What will the timescales be?
- How will the decision(s)/outcomes be communicated?

Properly applied, this approach will provide improved clarity on how decisions are made and the importance of community engagement mechanisms within this. It will also assist the commitment to provide feedback from all engagement activities.

This list is not intended to be exhaustive. In the spirit of consultation reflected throughout this document, we recognise that it is essential that finalising this approach must in itself be based on a meaningful dialogue with the various communities on whom the trust seeks to focus its engagement.

Each strategy will need to have at its heart a clear statement of intent, outlining the overall aims and objectives for the engagement.



## Towards a strategy

The aim of the Community Engagement Strategy should be kept relatively simple, for example:

**To support and enable *all* communities in Pacesetters regions to participate meaningfully in shaping the services they use and thereby contribute to better service provision and improved health access, outcomes and experience.**

To deliver on these aims trusts will have to ensure that they do the following:

### 1. Develop systems and processes that allow communities to engage in accessible ways

The methods of engagement should be clearly thought through as fit for the purpose. A range of engagement methods should be used depending on the needs and preferences of intended participants.

All groups interested in or affected by a particular issue should be identified and proactively engaged in the process.

### 2. Clearly communicate opportunities to engage and explain how systems work

The purpose of engagement should be made clear and be agreed from the outset.

### 3. Provide accessible, 'fit-for-purpose' information on partner services and the mechanisms that exist to comment on these on an ongoing basis

For example, a trust may select a partner organisation to deliver a project or part of a project on its behalf, or in conjunction with it. Consideration needs to be given as to how 'service users' of this project might feed back on the experience directly to the

partner organisation. The outcome of these considerations should be that organisations with which Pacesetters trusts enter into partnership will be required to ensure that they have a robust process for engaging with service users and the wider community.

### 4. Establish and maintain structures to support engagement

The style of working together should include openness, information sharing and equality in terms of input, mutual respect and the use of plain language.

### 5. Provide appropriate developmental and administrative support to local people involved in the process

Appropriate support to empower community members to participate fully as partners in a dialogue of equals requires that support is provided in identifying their training and development needs, and when undertaking any required training. This should be done within the spirit of continually improving the process and impact of community engagement.



## **6. Place particular emphasis on engaging excluded and minority groups**

Particular developmental effort should be made to support and develop the engagement of groups and individuals facing barriers.

The support needs of participants engaged in the processes should be identified and, where possible, met. The support may include practical and financial assistance to help overcome the barriers to involvement, including: transport, reimbursement of expenses, care of dependants and appropriate communication aids.

Meetings should be held at times most suitable to participants, and suitable premises should be provided.

Trusts should also look at the implications of community representatives having access to the equipment they require (phones, photocopiers, computers, etc.) and to independent community development advice.

## **7. Establish robust systems of review and quality control of all engagement activities**

Enabling and encouraging local communities to monitor and evaluate the services delivered to them with a view to joint learning from the experience – good and bad – will then inform future policy and service development.

All staff involved in community engagement activities will have to make a commitment to provide feedback to all those involved and affected by subsequent decisions. This should be done through clearly communicated mechanisms and simply outline what, how and why the decisions were made.

The strategy should be available at consultation meetings for members of the public to examine if they so wish.

## **Creating and maintaining a local database**

Once you have drafted your strategy you may also need to consider the following:

- Can you identify the real influencers within your local community?
- Can you specify what motivates them?
- Why is it in their interest to tackle health inequalities?
- How can you involve them in the process?

To assist in answering the above questions it is strongly recommended that each trust ensures that it has a robust contact database that includes, as a minimum, the following:

- local voluntary and community sector groups and organisations covering the Pacesetters equality strands;
- regional voluntary and community sector groups and organisations;
- local and regional media contacts (including specialist media and websites, community newsletters, etc.);
- religious organisations and multi-faith councils, etc.;
- community development workers;
- specialist agencies and bodies (race equality council, disability groups, etc.);
- other equalities specialists/networks;
- members of local strategic partnerships; and
- members of Local Involvement Networks (LINKs) (please see the section on LINKs on the next page).



The database will support trusts to better identify who their local stakeholders are. It will also allow for and encourage efficient communication with local communities when a meeting or consultation event needs to be arranged.

The database works best if it is part of a community profile (see the Gypsy and Traveller community profile as an example of this on page 28). There are a number of organisations, such as local councils for voluntary services, which undertake scoping and mapping exercises relating to local needs. In addition, the database of contacts can also inform distribution of information and job opportunities, etc.

## LINKs

In recent years, there has been clear recognition within government that health and social care services will get better if they can listen and respond to the needs of the people who use them. To date, one of the main tools the NHS has used to help listen to patients has been the local patient and public involvement forums. However, too often the forums have failed to be representative of the diversity of the local community, and have suffered from limitations that have stopped them being as effective as they could be.

The Government has announced its intention to replace these forums with Local Involvement Networks (LINKs) made up of individuals and groups from across the community. LINKs will be funded and supported to hold local health and social care services to account. This is part of the wider agenda to strengthen the ability of local communities to influence what health and social care services are provided and how they are run. In order to achieve this goal and ensure genuine representation, NHS organisations should look to be proactive in embarking on wide-ranging community engagement as part of the process of establishing a local LINK that is diverse and works from the principle of a dialogue of equals.

## Engaging the emotions as well as the community

At Pacesetters, we believe that a far greater emphasis needs to be placed on understanding 'the community'. We are convinced that without a proper understanding of the make-up and machinations of the communities that we serve, service providers will be unable to engage at a level that will ensure the sustained involvement of seldom-heard or involved groups. Therefore, the rest of this document has been written to support colleagues to increase their understanding of communities and how to reach the most marginalised groups within them.



**We believe that, to create a dialogue of equals, professionals will need to understand how to engage emotionally as well as intellectually.**

Emotional engagement does not mean that professionals are now required to wear their hearts on their sleeves – 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.

Through our community engagement learning workshops and discussions with members of seldom-heard communities we have identified three common characteristics/traits of engagement professionals.

They are:

**1. Those professionals with a superficial understanding of the target community and their circumstances**

They may have little or no knowledge of the community with whom they have been sent to engage. This soon becomes apparent, as they are unable to engage the community properly on any subject other than the one that they are there to discuss. The likelihood of the engagement being successful is considerably limited by the professional's lack of knowledge of the social, cultural and economic drivers that are equally, and sometimes more, important to the community.

**2. Those professionals with a rounded knowledge of the wider underlying issues**

They will have an understanding that exceeds the issues on which they are engaging. They will also understand how these issues may impact on other parts of the community's lives and vice versa.

Their knowledge and understanding of the community's needs and aspirations will be recognised and rewarded by the increased involvement of the target community. The likelihood of the engagement being successful is increased considerably. The likelihood of it being sustainable is also increased as the professional will be able to make links to other agencies that can support the target community to address other areas of concern.

**3. Those professionals with a rounded knowledge of the wider underlying issues who are not only able to understand their needs, but who can also empathise with the target community**

The most successful engagement processes are co-ordinated by people who not only understand the need to engage with particular groups, but are also determined to make a difference. The ability to be empathetic will immediately be recognised by community members and their advocates. They will, in recognition of the quality of the engagement taking place, encourage and persuade other community members and, where appropriate, other communities to join the engagement process. The empathetic professional is far more likely to seek to create meaningful partnerships and will often go further by enabling and empowering communities to set their own agendas. And, where practical, they will help communities to deliver services themselves.

Professionals need to look at themselves **before** they attempt to engage with seldom-involved communities. The term 'hard to reach' was coined by professionals with a superficial understanding of the needs of marginalised communities. It is an anathema that is unhelpful and untrue. Some service provider organisations, such as the police service, have an outstanding track record in reaching members of these very communities, so why can't all service provider organisations?

To avoid falling into the trap of blaming communities and groups for being hard to reach, professionals will need to develop a full understanding of the make-up of the communities with whom their trusts are seeking to work. Equally important is having an understanding of what a community is and how it functions at grassroots and organisational levels.

## 4. What is a community?

One of the factors which makes community engagement so complex is that there really is no such thing as **'the community'**. The term is used to describe the thousands, if not millions, of individuals who live in a given area and may also work there to help local people.

When we talk of communities, we can have different things in mind. At Pacesetters, our understanding of a 'community' includes those people who are linked to a particular locality, through residence, work or regular visits. It includes 'communities of interest', by which we mean people who have a shared experience that transcends their geographic location.

The key thing to keep in mind is that a community **always** consists of a number of **other** communities, be they based on ethnicity, gender, age, disability, location, etc. In essence, all communities are linked and intertwined in a myriad of different ways. No individual community is so different from the rest of society that its particular needs should not be understood.

For those who carry responsibility for delivering public services, engaging with the community means ensuring that **everyone** in their local area is given the opportunity to comment on the services provided for them and on the trust's priorities. It also means involving them in major decisions that will improve their quality of life. This is meant to be a two-way process – a true dialogue of equals – with NHS organisations benefiting from the imagination and energy of local people.

### Potential roles for individual community members involved in community engagement activities:

**As users and the beneficiaries** of the services provided by the service provider. This is the most basic level of engagement.

**As advisers** to the project or programme through their involvement in consultations, working parties and evaluations that seek their guidance and feedback.

**As contributors to management** through membership of forums and steering groups, who work alongside project staff supervising progress on partnership activities.

**As decision makers**, primarily through membership of the programme board and when periodic consultations are taking place about strategic choices and other major decisions.

### The community's infrastructure

The infrastructure of a local community can be said to be made up of a number of different groupings. These groups are listed in order of their importance when it comes to undertaking engagement.

They are as follows:

**Local residents** are the individuals and families who live in the area under consideration – they might be described as being 'communities of place' or 'geographical communities'. This group may also include homeless people who live within the locality.

**Grassroots community groups** are made up of local bands of volunteers who have come together to take action on a common cause. They tend not to have formal organisational structures, as they generally do not have funds

and paid staff. They are fluid groupings of activists with perhaps a single-issue focus on which they are campaigning or protesting. These groups represent the voice and heartbeat of a community. They not only campaign on issues of concern to a community, but often set the agenda for marginalised groups. If grassroots organisations are engaged in the process, then those involved in engagement can truly claim to have the community on board.

**Locally run voluntary groups** range from tenants' associations to local trusts, but all have in common the fact that local people manage them. They can range from small self-help groups run entirely by volunteers to well-funded community centres with paid staff and grant-funded programmes, but their management committees have local people in the majority.

**Communities of interest** are sections of the community who share common life factors, which means that they can be seen as discrete groups within society. Teenagers, people over the age of 60, individual minority ethnic groups and members of lesbian, gay, bisexual and transgender communities are some examples of communities of interest.

**Other community and voluntary sector organisations** may also have a considerable presence in the local community but they are not generally seen as part of the community because they are not run by local people. However, they can and do have an important role both in the community and in partnership working because of their skills, contacts, client groups or the resources they can bring into the locality. This part of the voluntary sector includes local or regional branches of national charities such as Age Concern or the Disabled Living Foundation. This will also include local councils for voluntary services, rural community councils and a wide range of agencies with specialist services.

## Understanding the differences

These differences matter because they matter to local people. Residents can feel excluded if statutory organisations assume that the director of a voluntary agency can speak on their behalf.

The majority of voluntary sector agencies, even well-established locally run groups, will feel very uncomfortable if they are asked to 'represent' the broad spectrum of local views, although they will feel more assured if asked to act as go-betweens with their own client groups. As a result, service providers need to develop a sophisticated understanding of the make-up of the community in their area and create a range of mechanisms to reach out to the relevant groups within it.



Above: Mary O'Reilly (service user) and Lindsay Dyer (clinician) of Mersey Care NHS Trust demonstrated excellence in practice by working together to develop services. Photo by Peter Searle courtesy of HSJ

Securing participation from all sections of the community will depend on whether those undertaking the engagement are emotionally engaged and understand the broad range of perceptions, needs, aspirations and priorities that exist among local people and groups. For example, certain communities of interest are less likely to become involved if they are not specifically targeted. These include black and minority ethnic groups, young people and those who are socially excluded for economic, social, cultural or political reasons – precisely the groups who most need service providers' interventions. The barriers to their inclusion are higher than those for other groups and, as a consequence, they sometimes appear to be harder to reach. However, by being more aware of their circumstances, service providers can tailor their communications and their programmes, undertake outreach work, provide extra resources and offer outcomes that are far more likely to meet their particular needs.

### **Potential roles for groups involved in engagement activities**

Bearing all this in mind, it is up to each trust to determine whether it is more appropriate to work with patients and service users, work more directly with local residents and/or intermediary groups, or do both. The type or purpose of the engagement will be a major determinant of this. For example, city- or county-wide programmes will, for practical reasons, need to work on the whole with a range of broadly representative groups because of the sheer number of residents or clients covered by their geographical area.

While the advantages of working with patients and service users have become abundantly clear over the last decade, the potential advantages of involving groups in project activities are not always as explicit. At Pacesetters, we believe that the potential advantages of engaging local

groups in project and programme activities might include the following:

- tapping into reservoirs of local knowledge about the area, particular client groups, local networks or specialist subjects;
- gaining access to communities of interest who are seldom involved, and perceived as hard to reach, through other means;
- meeting the Pacesetters organisations' objectives through supporting existing community-based initiatives rather than duplicating them;
- accessing outreach or capacity-building services that already have a good track record with local people or smaller groups;
- building up skills and experience within agencies which can add value to the project's activities now and after the project's funding expires; and
- encouraging local groups to deliver projects and programmes on behalf of the partnership and develop local successor bodies to take over projects and programmes from the partnership.

### **Deciding when to engage with individuals or groups**

The processes above recognise that most meaningful community engagement will come through existing groups and forums or new groups created specifically to support the engagement. However, not everyone has an interest in participating in this way. It is important that the strategy also provides space for input from individuals, service users and patients who may wish to be involved from time to time in specific issues of concern. The mechanisms employed in any specific engagement activity will require that there is appropriate scope to encourage this type of contribution.

## 5. Understanding the difference between patient needs and community aspirations

Although the NHS has developed an enviable record of accomplishment in consulting its users, it still has some way to go when it comes to engaging with the wider community. The views of patients are often given precedence over the aspirations of the community. While this may be understandable, it is also an anomaly that needs to be addressed. Healthcare professionals need to understand better the differences that exist between patient needs and the aspirations of the wider community so that they are better able to identify when there is a need for extending the engagement process.

**Service users and patients** care more about the quality of their everyday interactions with health professionals than about how the service is organised.

**Local community members** often care passionately about perceived threats to services, how the service is organised and about health risks.

**Therefore, engaging patients equates to tackling the clinical agenda and, where necessary, changing the culture of care. However, engaging the community equates to opening up a debate about the pattern and nature of service provision and health protection.**



### **What service users and patients want:**

- Fast access to reliable health advice.
- Effective treatment delivered by trusted professionals.
- Participation in decisions and respect for preferences.
- Clear, comprehensible information and support for self-care.
- Attention to physical and environmental needs.
- Emotional support, empathy and respect.
- Involvement of, and support for, family and carers.
- Continuity of care and smooth transitions.

### **The goals for engaging with service users and patients should therefore be:**

- to ensure appropriate treatment and care;
- to improve health outcomes;
- to reduce risk factors and prevent ill-health;
- to improve safety; and
- to reduce complaints and litigation.

### **Tips for engaging with service users and patients:**

- Focus groups with patients from seldom-heard groups.
- Constant monitoring 'ward to board'.
- Fast turnaround surveys using new technologies.
- Disease-specific 'pathway' surveys.
- Patient-reported outcomes.
- Patient feedback in appraisal/revalidation.

### **What local communities want:**

- Affordable treatment and care, free at the point of use.
- Safety and quality.
- Health protection and disease prevention.
- Accessible local services and national centres of excellence.
- Universal coverage: geographical and social equity.
- Responsiveness, flexibility and choice.
- Participation in service developments.
- Transparency, accountability and influence.

### **The goals for engaging with local communities should be:**

- to determine priorities;
- to improve service design;
- to manage demand;
- to meet expectations/reduce inequalities; and
- to strengthen accountability.

### **Effective strategies for engaging with communities:**

- Patient feedback/surveys.
- Public reporting of performance.
- Advocacy for disadvantaged groups.
- Lay representation on policy bodies.
- Consultation on priorities.
- Consensus conferences.
- Citizens' juries.

### **Ways to get information from individuals and groups:**

- Identifying the issues: through rapid appraisal.
- Determining priorities: through population surveys.
- Ongoing engagement: through online panels.
- Monitoring performance: through patient surveys.
- In-depth investigation: through focus groups.
- Testing services: through mystery shopping.
- Face-to-face consultation: through deliberative events.
- Clear communications: through a media strategy.



## When to engage

At Pacesetters, we believe that community engagement is as much about developing trust and relationships as it is about giving out information. Therefore, engagement should be viewed as being part of an ongoing process. However, for the purposes of the Pacesetters programme, there is an expectation that all trusts which have previously engaged with the target group will use the Pacesetters baseline audit information or locally available audit data to help them to decide the interventions to focus on. Once this has been achieved, it is expected that the communities who will benefit from the service improvement will be engaged, with a view to their being fully involved in the designing or re-designing of the new service and in considering how the service will be delivered and measured for impact.



As a rule, consultation and engagement **must** take place at the point at which changes to an existing service or policy are being considered, or when a new policy or service is being designed or reviewed. However, there may be occasions when the views of the community are already well established and understood. Trusts can use this information along with local data to decide how best to proceed.

## What about excluded groups?

To ensure the diversity of views and to enhance community cohesion locally it is essential to identify if any groups or communities of interest are not being properly engaged and to ascertain if any specific reasons or barriers exist that might explain the lack of involvement. Some of the reasons might include:

- the community or group's negative image of the organisation or the NHS as a whole;
- language or cultural barriers;
- disability;
- lack of childcare facilities;
- a lack of awareness of processes;
- the identified issues have little relevance; and
- perceived discriminatory practices.

There are a number of approaches that can be adopted to facilitate the engagement of excluded groups. These include:

- making the engagement process open and accessible and designing it around the profile, needs and lifestyles of excluded groups;
- making sure there are clear messages about why and how we are engaging, and giving people options about how they can be involved; and
- involving local or regional partners who may have more in-depth knowledge of and contact with excluded groups.



## 6. Community outreach work

Outreach – taking the message to the community at a grassroots level – is particularly important for seldom-involved groups, particularly those communities who are served by neither mainstream nor specialist media (e.g. the Somali community), and new arrivals from Eastern Europe (migrant workers, etc.).

Many voluntary sector organisations that service seldom-heard communities also deal with the needs of non-English speakers. They often give advice on issues such as housing, health and benefits and can provide a social focus for communities and a venue for cultural events. Community organisations form an important part of any Community Engagement Strategy, as they offer a valuable distribution network and a source of advice and expertise on the best ways to inform people about particular issues.



When considering outreach work, **do**:

- look for any community organisations that can help you reach a particular population;
- consult community organisations at the outset, as they can give you invaluable advice. Research shows that they are keen to work in partnership provided that their involvement is not tokenistic;
- think of community organisations as an audience in their own right, not just a distribution channel;
- find out how they work with their members and how to support that work. For example, producing summaries of key information points for staff to use with members may be more useful than producing a leaflet;
- ask how they think you should go about achieving relevance and impact and what the best ways are to present information to a diverse client base;
- find people who have influence and respect in local communities. Local councillors, chairs of community organisations, professionals and religious leaders may be powerful ambassadors for your message. However, be aware that such people are not always perceived as leaders by all members of that community – some may be viewed as privileged or out of touch; and
- look for opportunities around religious festivals such as Diwali, Eid or the Chinese New Year. Check [www.multicultural-matters.com](http://www.multicultural-matters.com) for details of the dates – note that they may change each year.

## Involvement – making contact

One of the main challenges of engaging with groups or communities that are seldom heard is working out how to make contact with individuals and groups. It is important to:

- **work with trusted organisations** – communities may have already built up links and trust through community groups, or may already work with voluntary organisations. Try to find out if there are established groups in your area who may be able to work with you to encourage involvement;
- **work with group leaders** – if there are existing community groups, you will need to build up trust to ensure that people want to become involved in community engagement activity. This will often involve taking time to meet with group leaders to explain what you are doing, and allowing time for the group leader to gain approval from the other group members. This stage is very important, as it can occasionally be challenging to get past the ‘gatekeepers’ of an organisation. It can take time and patience to develop a good working relationship;
- **take time to develop relationships** – in areas where there are no formalised networks or groups, you will normally need to spend time developing relationships with communities. This can involve community development activity, such as helping to set up a community group. This can help to build trust and encourage people to become involved;
- **support: helping people to get involved** – within all of our target communities, people may need support to be able to take part in community engagement activity. Overall, you should remember that people are giving up their own time to get involved. This should be recognised by making it as easy as possible for people to participate;
- **strengthening community groups** – providing grants, training and staff time for community groups can be an extremely valuable way of supporting people to engage effectively. Simple activities such as providing administrative support or training can have a big impact on the capacity of community groups;
- **interpretation and translation** – this should always be offered if language is identified as being a barrier to engagement and to make sure that everyone can participate effectively. If interpreters are to be used, then it is worthwhile taking time to discuss the format and content of the consultation with them, so that it is clear what is going on;
- **build up networks** – often, the best source of support can be having family and friends involved. This can make people feel much more confident about getting involved. Try to build on existing networks that are already in operation, such as social groups; and
- **meet any expenses** – it is important that people are not out of pocket because of engagement activity. Travel costs and other expenses should be paid. In some situations, such as in focus groups, it might be appropriate to give a small incentive for attendance.

## Providing support

In organising support, it is important to remember that culture and religion can have a big impact on whether people are able to attend. For example, providing childcare is often a very effective way of making it easier for people to get involved. But, for some, childcare provided outside the family may be a new concept. This means that it might also be appropriate to look at other options, like reimbursing participants for any childcare arrangements made.

When planning engagement activity, it is first vital to be clear about:

- the purpose of the consultation; and
- what it will involve.

You should also think about who should be involved. Some cultures have traditions about social interaction between men and women. This means you might need to hold separate events for men and women. It might also be useful to hold separate events for younger and older participants. In some cases, young people in a group of older people may not participate out of respect.

#### **When facilitating discussions, you need to think about:**

- the gender of the facilitator – in male- or female-only events;
- the clothing you wear – particularly to places of worship;
- whether you need translation and interpretation services;
- what support you should offer – e.g. childcare, incentives;
- the location of the event – what makes it easiest for and most familiar to participants; and
- the timing of the event – including time of day and year, paying particular attention to religious festivals.

You might also want to think about using incentives or innovative methods to encourage people to participate. For example, organising an event around (appropriate) food can be very successful in encouraging people to take part. But it is very important to find out about people's dietary requirements in advance.



#### **Methods**

A wide range of methods can be used to engage with marginalised communities. The key issue is that the method you use should be flexible. You should speak with local groups who work with or involve people from minority ethnic communities, and discuss how people would like to be involved.

Often, **informal** methods of consultation work best. For example, small discussion groups can work well. Large meetings, especially where there are a variety of languages being used, can lead to frustration. But smaller (even one-to-one) events which are relaxed and more sociable have proven popular and effective.

Where informal consultation is appropriate, try organising a relaxed, culturally appropriate **social event**. For example, one very successful consultation event for women involved informal chats against the backdrop of a meal and a Hindi movie.

Methods of consultation that involve travelling away from the local area or the need for writing are less likely to be successful across some communities such as Gypsy and Traveller communities and those for whom English is not their first language.

Surveys are another way of identifying the views of some marginalised groups and communities. However, the size some of our target groups outside the major cities is often very small and it is important to recognise that standard sample sizes do not apply to small groups.

## Working together

To engage effectively, at a basic level you need to be respectful and non-discriminatory. It is vital that you are sensitive to the differences that culture, religion and language bring. It is also essential that all members of the communities you are working with are respectful of any cultural, religious and language differences.

Some of the issues you should consider are:

- **multiple identities** – everyone is an individual. You should always take into account the impact that factors like gender, disability, age, religion and sexual orientation have on people from minority ethnic communities; and
- **different viewpoints** – people have different opinions on issues. Be careful not to assume that everyone has the same viewpoint. Remember that there are different voices – for example between generations within the community.



## Sharing information

Information sharing and communication between participants are key elements of effective community engagement. Information should be:

- accessible, clear, understandable and relevant;
- available in appropriate formats;
- available in time to enable full participation; and
- available to all participants equally.

Use of **language** is important. Material should be prepared in appropriate languages. Keep in mind that, as with all communities, there will be a wide variety of reading skills.

Try to write in plain language, making it clear what you are trying to convey to people.

It is worth noting that where **translation** is required, this can make events run on for longer than usual. Using plain language is important and taking the time to explain the purpose of your engagement activity is essential.

## Improvement

Part of community engagement is about giving people opportunities to learn and to build the capacity of community groups and organisations.

This means that you should take the time to **support** community groups – for example through training or providing resources.

Community groups often become involved in consultation activity. These groups tend to be small, with limited resources, and members take part on a voluntary basis. Providing some financial recognition or in-kind support will help to ensure that these groups are sustainable and are able to develop their community engagement activities further. In turn, this will result in more effective and wider-ranging engagement.

## Feedback

Providing feedback is essential to all community engagement activity. At a basic level, it is simply polite to provide feedback to people who have been involved. At present, many of those who participate in consultations do not receive any form of feedback. This generates resentment and frustration. If people do not know whether their contribution has made a difference, they will be much less likely to take part in consultation activity in the future.

As with all stages of consultation, feedback should be provided in an appropriate format. For example, if you have consulted with community groups, often the most effective way of providing feedback would be to go in person to meet with this group.

If providing written feedback, you need to make sure that this is in appropriate languages and distributed to places where minority ethnic communities will be able to access it easily.

## Monitoring and evaluation

Engagement with local communities or groups should not be viewed as a one-off activity. You should make sure that the results of engagement are fed into your plans for the future. Where possible, you should try to record this in a clear action plan.

Throughout the process of engagement you will have built up relationships with these communities. It can be extremely valuable to involve the communities in monitoring and evaluation frameworks. Some ideas could include the following:

- **Training community members to evaluate activities** – this can be a great way of building capacity at the same time as undertaking consultation activity. It can mean that people from this community are more likely to take part as members, and they are able to tap into their own networks.
- **Setting up a group to monitor progress** – it can be useful to involve people from seldom-heard communities in measuring how well you progress with an agreed action plan. A group could be set up to monitor and scrutinise progress, and make suggestions for future activities.



## 7. Hints and tips for addressing minority ethnic audiences

**Do** think about what you are trying to achieve when addressing seldom-heard groups. For example, when addressing minority ethnic groups consider the following.

### The audience

- What issue are you addressing?
- Who does it affect – everybody in the community or a particular group within it?
- Which communities are you trying to reach – and why?
- Do you know the relevant facts and figures about the target audience?
- Where does your audience live? Are they found primarily in one particular part of town or everywhere?

**Do** think about whether you actually need a tailored approach. Many younger members of minority ethnic communities see themselves as being part of mainstream culture, so they can be reached effectively through mainstream media. Communities that are already well established, such as the African Caribbean community, may also be effectively reached using mainstream media. However, older people, some women and non-English speakers may need a more tailored approach.

### The message

- What is your message?
- What is your message in relation to this specific audience?
- Do any generic messages need adapting?
- How can you make your message as relevant as possible? Could case studies help?

- Is your message stronger or weaker if it comes from an official source?
- Does your message need endorsement from community groups in order to be effective? Some groups ignore information if they see that it comes from the Government.
- What actions do you wish people to take as a result of your campaign?
- Within your target community, who needs to know what? Are there different messages for young people, women, older people, etc.?

### Maximising the value of translated leaflets

These guidelines will apply primarily to people whose first language is not English. Non-English speakers have much in common with the rest of the population in what they want from written communications:

- **Do** use clear, short, simple documents that are well laid out and expressed in straightforward language.
- **Do** use **bullet points, summaries, and step-by-step action plans.**
- Where possible, **do** use a series of targeted factsheets, rather than a single, large booklet.
- **Do** use clear typography and large font sizes.
- **Avoid** large blocks of text by using:
  - bullet-point summaries of longer documents;
  - illustrations and colour to create a visually inviting appearance;
  - a clear visual indication of the contents on the cover, to indicate the subject matter for those who cannot read any language; and

- bilingual materials produced in English and mother tongue for topics targeting different generations (i.e. for those who may only be able to read English and those who may only be able to read their mother tongue). This can be very effective, as children can act as translators for their parents or for older generations.

### Alternative formats – audio and DVD

**Do** be aware that many ethnic minority groups have a much stronger tradition of oral communication than written. And in many cases, people who are illiterate in written English tend also to be illiterate in their own languages (e.g. the older Bangladeshi community).

Although translated leaflets are the most common material produced in minority ethnic languages, **do** consider audiocassettes, DVDs and video tapes, as these are also popular:

- Audiocassettes are probably less common than video tapes, but appear to have considerable potential. They overcome the barriers of illiteracy, and they fit into existing patterns of behaviour and use easily available technology. The use of cassettes is common in the South Asian communities and also among Somali people for listening to music, religious recitals or even news from relatives in their country of origin. The format also lends itself to imitating radio talk shows, which are very popular with South Asian people.
- Video tapes/DVDs are also popular and can be used as part of a discussion or meeting to address particular topics.

### Use of specialist ethnic media

The choice of whether to consider mainstream or specialist (minority ethnic) media is not an either/or solution. The choice very much depends upon the target audience, as quite often a media schedule requires the combination of both mainstream and specialist media.

**Do** remember that there are many shared media consumption patterns between minority and majority populations. Mainstream media is important for younger audiences and those who are well integrated into the wider community (the Black Caribbean and Indian communities in particular).

**Do** consider local/regional press, as this is also popular and promotes a strong sense of local community. It tends to cover issues that are more relevant to minority ethnic communities.

If you have a specific message aimed at specific communities, then **do** consider using minority ethnic or specialist media. These allow you to tailor your message to specific communities or faith groups and can reinforce messages promoted in mainstream media. Bear in mind that:

- the older generations from Asian and Chinese communities are heavy consumers of specialist media in mother tongue; and
- the younger generation dip in and out of minority ethnic media for specific purposes – TV and radio are good for overcoming language and literacy barriers.

## 8. Sample community profile: the Gypsy and Traveller community

No official figures exist on the size of the Traveller population. However, community estimates indicate that there are more than 300,000 Gypsies and Travellers in Britain.

Ethnic Gypsies were first recorded in Britain around the year 1500. In 1989, Romany Gypsies were recognised as an ethnic group under the Race Relations Act 1976. Irish Travellers were acknowledged as an ethnic group under the same Act in August 2000.

As many as 100,000 Travellers have no safe, legal or secure stopping place, potentially lacking access to water, refuse disposal or other essential amenities. As a consequence, they often live on temporary sites near to industrial estates or busy roads.

**Compared with mainstream communities, Traveller communities face: lower life expectancy; higher birth rates and infant mortality; and a high incidence of chronic illnesses, such as respiratory disease, rheumatism and digestive illness.**

Research has shown that Gypsies are one of the most socially excluded and disengaged groups in the UK, mainly due to:

- basic demographic factors;
- poor health;
- prejudice and discrimination on the part of the settled community; and
- very poor living conditions experienced by Gypsies and other Travellers on both authorised and unauthorised sites.

Gypsies often prefer to be known as Romany. Romanies are descendants of the ancient warrior classes of the Punjab: their language, religion and customs have roots in Northern India.

Many Gypsies and Travellers are afraid of being corrupted by outside influences, and so do not seek integration. This deliberate separation and distance from mainstream society places the Traveller community at a greater disadvantage to other, less separatist, ethnic minority communities.

The Traveller community is organised along traditional lines. The family and home is the domain of women, while men are responsible for earning money. Travelling people have very strict conventions about what can be discussed and with whom. For example, it would not be appropriate for a man who is not a member of her immediate family to be alone with a young girl from this community.

English Romany Gypsies and Irish Travellers use English as their mother tongue. However, despite the fact that English is the mother tongue of the Traveller community, there are high levels of illiteracy due to poor access to education and traditional values that prioritise practical skills.

Travellers can have difficulty accessing education for their children due to being on the road, for example, and often suffer a lack of support on issues such as bullying or exclusion.



## Engaging with the Gypsy and Traveller community

Communication methods include:

- mainstream media;
- specialist media – *Travellers' Times*, Rokker Radio;
- outreach; and
- church networks (Catholic for Irish Travellers, Evangelical Christian for Romany Gypsies).

Key points include:

- Low literacy levels reinforce the need for audio/audiovisual communication materials distributed via outreach activity.
- This is a close-knit community. As such, the use of intermediaries (via outreach) is key to engaging the community and engendering trust.
- There has been a rise in Evangelical Christianity among the Gypsy community in recent years. The religious rallies that they hold are a useful opportunity to meet people from the community.
- Issues concerning children are generally the province of mothers, so messages should be targeted at them in the first instance.



## Section 9 – Additional support

The Pacesetters central team has a Community Engagement Adviser in post to support the development of a community engagement 'ethic' that is embedded throughout the programme. The Community Engagement Adviser is available to support the Pacesetters sites to maximise opportunities to engage with the targeted communities. The Community Engagement Adviser will also host a number of learning workshops to help bring new and innovative Community Engagement Strategies and techniques to the attention of local LINKs and other interested colleagues working at Pacesetters sites.

Pacesetters has also allocated funds to each of the participating organisations to ensure that the proposed service improvements happen. We fully expect that some of this funding will be made available to support the engagement process.

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