



East Midlands
Centre for BME Health

How to guide

How to engage seldom heard groups

Updated 08/09/2015

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Introduction

This paper pools what we know about how to engage with groups in society that are sometimes called 'seldom heard' in order to improve health and add value to health services or research organisations. It was drafted by Peter Bates on behalf of the [East Midlands Academic Health Science Network](#) and the [East Midlands Centre for Black and Minority Ethnic Health](#) as part of their work on Public Leadership. Several people have contributed ideas¹, but further opinion, references and suggestions for improvement are very welcome.

Please contact shahnaz.aziz@nottingham.ac.uk to suggest improvements or tell us how you have made use of this paper.

¹ We acknowledge our gratitude to the following people who commented on an earlier draft: Trish Gamble, Fiona Loft, Naina Patel, Gillian Sills and Paula Wray. Any errors in this document are the responsibility of the author.

Who do we mean by 'seldom heard groups'?

The language we use always carries both intended and unintended meanings, and this is particularly the case in this *How To* guide.

- We are considering both those groups in society who are rarely invited to give their opinion, and those whose voice is heard but it carries less weight than others².
- Some individuals actively choose to engage with others who share a particular characteristic and together they form a social group where people know one another. Others share a similar characteristic with others, but do not know them or interact socially. In this guide, we are considering seldom heard *groups* and also *individuals* who fall into a category that is seldom heard.

A note on language and the scope of this paper

In this paper, the term:

- *Public contributor* means a patient, service user, carer or member of the public who brings their lived experience of managing a health condition or using health services to the task of improving services and research.
- *Health services*. In order to produce a document with clear messages, we have focused on health services, but acknowledge that much of what is found here is applicable to social care and other publicly funded services.
- *Seldom heard groups*. This is a broad term which includes, but is not limited to, people who fall into two specific lists. The first list includes people who are at risk of unfair treatment because of one of the protected characteristics defined within the Equality Act 2010 – age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. The second list comes from Inclusion Health³ and includes people who are at risk of unfair treatment because they are carers, people experiencing economic

² It has been said that such groups are often researched, and so may be 'easily ignored' rather than 'seldom heard'.

³ <http://webarchive.nationalarchives.gov.uk/+/http://www.cabinetoffice.gov.uk/media/346574/inclusion-health-evidencepack.pdf>

and social deprivation, vulnerable migrants, homeless people, people who misuse drugs, people who are long-term unemployed, sex workers, gypsies and travellers, people who have limited family or social networks and people who are geographically isolated.

- *Black and minority ethnic groups* refers to ethnic groups who are fewer in number or are perceived as having less status than others in society. It is often used in relation to groups whose origins lie mainly in South Asia (eg. Indian, Pakistan and Bangladesh), Africa, the Caribbean and China. It also includes people from Scottish, Irish, Polish and Italian communities as well as refugees, asylum seekers and Gypsy Travellers, amongst others. Exact definitions vary.

In drafting this document, we have used a number of examples and illustrations. Rather than attempt to achieve an exact balance of stories to illustrate all twenty of these characteristics, we have drawn on our own experience. As a result, many, but not all, of the examples relate to issues of race, ethnicity and religion. While this might lead to the suggestion of a hierarchy of exclusion⁴, we press for equality for all, and urge readers to combat exclusion wherever it may be found.

Policy and historical context

Publicly funded services have a threefold duty towards the community, as follows:

- To ensure that services are effective for everyone who needs them, by making a particular effort to reach out to underserved and diverse communities, to co-design interventions with them and check that they are acceptable to and effective for them.
- To share decision-making with the whole community, so that local public opinion contributes to the design, evaluation and improvement of services. This should work both at the level of large-scale service design⁵ and also

⁴ <http://www.tandfonline.com/doi/abs/10.1080/0968759032000127317#.Vdw5fvViko>

⁵ “Local authorities and Clinical Commissioning Groups have a duty to involve the local community in...Joint Strategic Needs Assessments and joint health and wellbeing strategies... The local community will include people from all walks of life, such as... excluded groups.” Department of Health (19 Jan 2012) [JSNAs and joint health and wellbeing strategies – draft guidance](#) Page 18.

by coproducing health and social care in a personalised manner with each individual in receipt of a service⁶.

- To promote the development of active, inclusive and cohesive communities where unwarranted inequalities are minimised⁷.

This three-fold duty applies to assessment and commissioning, research⁸ and service delivery. More details on the legal framework for consultation can be found in a companion *How To* guide⁹.

While opportunities for participation have increased over recent decades, there is evidence that participation by black and minority ethnic groups has reduced¹⁰. Research is currently underway on involving people from BME communities in health research¹¹. This trend may have been followed for other excluded groups also and highlights the need to give proper attention to engaging with seldom heard groups.

“The views of those people and areas most affected should be sought. Attempts should be made to listen to the views of non-users, especially when service changes are being consulted on. Attempts should be made to include the views of groups frequently excluded or overlooked. Consultations should consider the needs of people with impaired sight or hearing or people whose first language is not English.”¹²

⁶ As an example, see the following advice to commissioners about consulting with people using care homes. “Commissioners should engage local groups of people who use services and carers and the voluntary organisations that represent them. They should also endeavour to involve people who are hard to reach by providing advocacy and support.” SCIE (2012) [Safeguarding and quality in commissioning care homes](#).

⁷ Public Health England (2015), [A guide to community-centred approaches for health and wellbeing](#), Public Health England, London. Also National Institute of Health and Care Excellence (2008) [Community Engagement](#).

⁸ “Consideration should be given to issues likely to act as a barrier to participation, and reasonable steps taken to address these. Possible measures include... consulting hard-to-reach groups...to ensure that possible barriers to participation are identified and minimised.” GSRU, HM Treasury (2006) [Ethical assurance for social research in government](#) para 2.12. Also “Research [should be] pursued with the active involvement of service users and carers including where appropriate, those from hard to reach groups....” DH (2005) [Research Governance Framework for Health and Social Care](#) Second Edition, page 15.

⁹ See *How to meet legal obligations in your consultation process* – available from <http://www.emahsn.org.uk/public-involvement/>.

¹⁰ SCIE Report 14: [Doing it for themselves: participation and black and minority ethnic service users](#).

¹¹ A PhD student at the University of Manchester is seeking researchers willing to be interviewed about their experience of involving people from minority ethnic groups in health research, and their recommendations for improving involvement. This involves one 60-90 minute telephone interview between in autumn 2015. Contact shoba.dawson@postgrad.manchester.ac.uk.

¹² <http://goo.gl/oCGPcv>

Values and Approaches

Your choice of theoretical approach can influence the approach you take to engaging with seldom heard groups. In addition, your values will affect how your efforts are perceived. Are you engaging with people simply because it is a formal obligation, or because you are genuinely curious about their experiences and views? Are you simply going through the motions or will you take seriously any suggestions that are made? Some theoretical options that inform practice are set out below.

- **Competence and skills-based approaches** locate the explanation for exclusion with the person – perhaps their lack of language or committee skills, low self esteem or inability to travel to a meeting. This approach uses terms like ‘hard to reach’ and identifies weaknesses such as poor literacy, or misunderstandings about how public services function in the person or group rather than the community. In contrast, a search for individual and community assets will identify sources of strength and resilience¹³.
- **Discrimination or the ‘social model’** identifies barriers in the community that shut people out – such as when consultation is advertised in obscure places, questions are presented in jargon and consultation periods are impractically short. This approach sees people as oppressed or marginalised rather than as incompetent.
- **Intersectionality**¹⁴ focuses on the way in which multiple forms of exclusion (ethnicity, gender, disability and so on) intersect in complex ways to reinforce and amplify one another.
- **Democratic and Human Rights** approaches attend to the legal foundation of equality and use population monitoring and individual advocacy to educate people about their rights to use their voice; to press for ‘reasonable adjustments’ to be made in anticipation of the need for them; and to challenge abuse, particularly in relation to specific ‘protected characteristics’¹⁵. Some advocates move beyond the

¹³ https://www.nice.org.uk/guidance/gid-phg79/resources/community-engagement-update-draft-full-guideline2?utm_source=The+King%27s+Fund+newsletters&utm_medium=email&utm_campaign=6030338_HWBB+2015-08-24&dm_i=21A8,3L91E,FLWSAT,CXECM,1

¹⁴ See, for example, <http://www.vanmens.info/verhulst/en/wp-content/Intersectionality%20and%20Health%20Care-%20january%202006.pdf>

¹⁵ The nine protected characteristics are set out in the [Equality Act 2010](#).

letter to the spirit of the law and seek to extend these approaches to all unwarranted inequalities.

Committee or community?

In order to reach everyone who lives with a particular health condition or life experience you need to go beyond the people who attend groups. This will require you to place notices in the media, provide information in places people wait, and to engage with 'cold contacts' in the shopping centre and elsewhere¹⁶.

If you do decide to approach a group, then it is important to remember that, while some community groups have adopted a traditional, Western 'committee meeting' format, many operate in a very different way. The focus may be more on enjoying one another's company rather than just achieving specific tasks or making decisions.

People arrive and leave at varying times, discuss their personal lives and tell stories, have multiple, simultaneous, heated conversations, and appear to take a very long time to make very few decisions. The result is often a high level of commitment to a small number of actions, while in traditional committees, the action plan may be very long, but the commitment is sometimes low.

When a visitor arrives, they may be expected to join in with what is already happening, rather than be allowed to present their topic straight away, and may then be asked for advice on other matters before being invited to give their presentation. This slow approach to community development¹⁷ sits uneasily with the outcome-driven pressures of many public services, but is a vital part of engaging with many seldom heard groups.

¹⁶ http://www.helptheaged.org.uk/documents/en-gb/for-professionals/participation-and-involvement/id6980_consulting_and_engaging_with_older_people_dos_and_don%E2%80%99ts_2007_pro.pdf?dtrk=true

¹⁷ Bates P (2005) *In praise of slow inclusion* Ipswich: National Development Team.

Some resources

Specific guidance is available for:

- Particular care groups, including seldom heard young people¹⁸, older people¹⁹, older people with high support needs²⁰, Black and minority ethnic communities²¹, BME elders²², people with dementia²³ and older lesbians and gay men²⁴
- Particular circumstances, such as in relation to adult safeguarding obligations²⁵
- Particular environments, such as increasing the number of BME responses to a survey of inpatient hospital care²⁶.

¹⁸ <http://goo.gl/Nz5wi4>

¹⁹ http://www.helptheaged.org.uk/documents/en-gb/for-professionals/participation-and-involvement/id6980_consulting_and_engaging_with_older_people_dos_and_don%E2%80%99ts_2007_pro.pdf?dtrk=rue

²⁰ <http://www.scie.org.uk/publications/reports/report61/>

²¹ <http://www.scie.org.uk/publications/reports/report14.asp>

²² Age Concern East Midlands (2009) *Involving and consulting black and minority ethnic elders: Proud to speak up* Nottingham: Age Concern East Midlands.

²³ Murphy, C., Killick, J. and Allan, K. (2001) *Hearing the user's voice: Encouraging people with dementia to reflect on their experiences of services*, Stirling: University of Stirling, Dementia Services Development Centre.

²⁴ Ward, R., River, L. and Fenge, L. (2008) 'Neither silent nor invisible: a comparison of two participative projects involving older lesbians and gay men in the United Kingdom', *Journal of Gay and Lesbian Social Services*, vol 20, no 1/2, pp 147–65.

²⁵ <http://www.scie.org.uk/publications/reports/report47/>

²⁶ http://www.nhssurveys.org/Filestore/documents/Increasing_response_rates_stakeholder_consultation_v6.pdf

Shaping your activities

- Make your plan *with* the community, rather than imposing it on them. Some involvement projects are entirely managed and delivered by the people themselves, rather than by professionals²⁷. If local advocacy and patient-led organisations are not diverse, aim to help them change rather than simply ignoring them.
- Go out rather than expect people to come to you²⁸. Use the community's existing meetings and networks (via faith organisations or community groups) rather than try and create new ones. Some seldom heard communities are very democratic and their leaders listen carefully to ordinary members, but other community leaders do not, so try and engage with 'rank and file' members of the community. Do not rely too heavily on community leaders, staff who have personal experience of the issues you are concerned with, or other surrogates²⁹.
- Find out what the people you are meeting are already involved in. Whilst some groups are seldom heard, it might not be for want of trying, and other groups may be suffering from consultation fatigue, which more often results from their input and comments being disregarded rather than being listened to and taken seriously.
- Frame your issues in the language and values system of the community, so people can see what is in it for them, on their own terms. This often means recognising people's concern for others rather than self-interest. For example, some researchers are interested in finding things out, while community groups want to make things better.
- Check out your assumptions about the specific cultural norms that operate within the community, discard those that are untrue and adapt your approach in the light of this cultural understanding. Be attentive to local variations. For example, while South Asians have a higher incidence of diabetes and some need help with adopting a healthy diet, local initiatives in Leicester have already provided significant education to address this,

²⁷ For example, the research published in Beresford P (2013) [Beyond the usual suspects](#) was user controlled, carried out by service users and overseen by a service user advisory group.

²⁸ While the advice to 'go out to them' is helpful, it also carries unwarranted freight. It implies that seldom heard people are a separate group, 'over there' rather than our neighbours, friends and colleagues.

²⁹ Begum N (2006) *Doing it for themselves: participation and black and minority ethnic service users* London: Social Care Institute of Excellence and Racial Equality Unit.

so a new consultation will be reaching an unusually well-educated audience.

- Use role models and stories to raise ambitions and expectations about the benefits of engagement.
- Offer a variety of ways³⁰ for people to use, so each person can choose the method that suits them best.
- Embed ongoing curiosity and listening into everyday practice rather than 'bolting on' a special consultation event³¹. This is important for many reasons, not least that people in your target community may be too busy with their other commitments and interests to attend your event.
- Be honest about which things can be changed as a result of feedback and those areas that are non-negotiable. For example, the people running an established national survey refused a request to change the questionnaire, as they wanted to compare results year on year³². So consider why you are planning a consultation, and abandon your plans if you are unable or unwilling to change anything in response to what people say.
- Reflect on your own practice and strive to recognise and eliminate conscious and unconscious bias in your attitudes and behaviour. This may consist of fear of the unknown, personal feelings about particular communities or circumstances, or a more global issue, such as a determination to be positive or a fear of conflict, which makes you defensive when people are challenging, nonconformist or ungrateful. Some people labelled as seldom heard are going to be angry and dismissive of your efforts, and yet may have some crucial messages to impart. Sometimes you will need to set aside your personal preferences in order to join in with a community group, as shown in the following example.

³⁰ Rotherham's catalogue of consultation techniques is at <http://www.thinklocalactpersonal.org.uk/asset.cfm?aid=7617>

³¹ See IRISS (2015) *Effectively engaging and involving seldom-heard groups*. Also SCIE position paper 10 (2008) *Seldom heard: developing inclusive participation in social care*.

³² Sheldon H (2007) *Increasing response rates amongst Black and Minority Ethnic and seldom heard groups*. Oxford: The Picker Institute. This was a consultation on the national inpatient survey.

“I wanted to link with an unfamiliar faith-based group, and so had to make arrangements to work at the weekend, remove my shoes, attend prayers, meet only with women and work with an interpreter. Each of these steps took me out of my comfort zone.”

- When you are successful in communicating genuine interest to the person or community group, members may want to talk about other concerns. This is *not* the time to explain that their problem is not your problem or to advise them to take their concerns to another department. Community members rarely hold the administrative structures of all publicly funded services in their head, and one official (i.e. you!) can be seen as representing all. Furthermore, people who have been subject to abuse or who lack basic amenities will find it difficult to focus on strategic development or service change, as their basic needs will dominate³³. Think this matter through before you go out and discuss how you will respond to these wider issues with your line manager³⁴.
- Keep on widening your net, so that you hear fresh voices and recent experiences, and so those who engage with you are not exhausted or exploited.
- Always close the feedback loop by telling people what happened as a result of their contribution. This is true for all consultations and involvement activities, but seldom heard groups are sometimes missed out, reinforcing the belief that they are not being listened to.
- Work in partnership with community organisations to distil your learning into a code of practice³⁵ that will shape your future ‘terms of engagement’.

³³ Maslow’s hierarchy of need is sometimes quoted here, where the basic needs for food and shelter come before self-actualisation and expression. See Maslow, A. H. (1970). *Religions, values, and peak experiences*. New York: Penguin. (Original work published 1964).

³⁴ People may need signposting to other services or introducing to advocacy organisations or complaints procedures. This may work best when you take the matter away and arrange a personal introduction.

³⁵ See this example from Bristol - <http://www.bristol.gov.uk/page/council-and-democracy/code-good-practice-public-consultation>, and this one from Edinburgh - http://www.edinburgh.gov.uk/download/meetings/id/42984/item_75_consultation_framework.

Step by Step

The following bullet points illustrate a range of ways to connect with seldom heard groups. Most of these suggestions are illustrated by reference to a particular kind of disability or other protected characteristic. We hasten to emphasise that this association is a broad generalisation designed to sharpen our understanding, and should not be taken as meaning that all individuals with that health condition or circumstance will be affected in the same way.

1. **Adequate resourcing.** Engaging with seldom heard groups takes time and money, so does not happen for free. Building effective relationships will not be accomplished by a single meeting. Failing to pay expenses or participation fees, making people beg or wait too long for their payment can be an extra barrier to seldom heard groups. In addition, negative and dismissive attitudes can kill fledgling efforts to engage with seldom heard communities. Provision of culturally appropriate food and other signs of hospitality help to make people feel welcome.
2. **The right team member.** Some staff speak the language or have a good knowledge of the relevant community group or organisation and so will feel at home amongst its people, be comfortable with the jargon employed in that setting and be able to adopt culturally appropriate behaviour. Other staff will need training in cultural competence to even understand seasonal celebrations and other landmarks on the community's calendar. Your agency may need to carry out some targeted recruitment³⁶ to improve the diversity of your workforce.
3. **Select and locate your community.** The statistics on your local community, on service uptake and on public engagement will indicate if particular groups are under-represented³⁷. You may have already acquired contact details and allies for mainstream community organisations, so it will take extra time and effort to build relationships with communities that you have previously neglected. Your local library will be able to direct you to a database of community groups and organisations and you can then use positive targeting to reach out³⁸.

³⁶ This may include reviewing the job description and person specification, advertising vacancies in community newspapers and on community radio or informing community leaders of the opportunity.

³⁷ Much of this information will be captured in the local Joint Strategic Needs Assessment.

³⁸ For an example, see pp19, 26 of Department of Health (2006) [Evaluation of your health, your care, your say](#).

4. **Look out for subgroups.** Groups that appear from the outside as holding a single shared identity often turn out to contain a variety of subgroups with different experiences. For example, second-generation migrants from Eastern Europe may have quite different experiences and allegiances to recent arrivals. Then there are wider variables, such as the impact of mobility. If people are vulnerably housed or have no fixed abode, and if they frequently move their home, email address and mobile number, (as students do, for example), then attempts to stay in touch will quickly fail.
5. **Keep everyone safe.** Consider the issue of safeguarding when engaging with children and other vulnerable persons. Guidance is available in relation to children and research³⁹, and to the relationship between safeguarding and involvement⁴⁰.
6. **Dates and times.** You may need to work outside office hours, so review your organisation's lone worker policy. Consider the significance of particular days and dates to faith or nationality groups and check a [festivals calendar](#).
7. **Transport.** Choose an environment that is accessible, familiar to the person, neutral ground, hospitable and uninterrupted. People in rural communities, with extra living costs or with limited time or income will find it difficult to travel a large distance to attend a meeting. Good public transport links and disabled parking spaces help some people, but only if there is enough of it. Some people with learning disabilities commonly report abusive behaviour from school children on public transport and so prefer to travel at a different time.
8. **Facilities.** Wheelchair users and people with buggies will prefer step-free access while people with sensory sensitivity (a common feature of autism) or hearing impairment may need a quiet space without bright sunlight or fluorescent lighting. A break in the middle of the meeting will need to be longer than normal if people need help getting a drink, going to the toilet or calming down after a heated discussion. Does the building have a [Changing Places](#) toilet, or just an ordinary disabled toilet?

³⁹ Nuffield Council on Bioethics (2015) [Children and clinical research: ethical issues](#).

⁴⁰ Social Care Institute of Excellence (2011) [User involvement and adult safeguarding](#). However, this document looks at how to involve people in the adult safeguarding process, rather than how to safeguard consultation and engagement processes.

9. **Communication** – people who do not speak English, who have a hearing impairment or use [Makaton](#) may need an interpreter⁴¹. You may need to obtain a portable hearing loop system, and check with a person who uses it whether the hearing loop is working. Not everyone speaks ‘NHS’ so jargon-free explanations help. Some people with limited or idiosyncratic speech will prefer to participate alongside people who know them well and can help to interpret their contributions. People who get nervous when official letters land on their doormat are unlikely to respond to a postal survey.
10. **Documents.** Some people with learning disabilities, dyslexia or visual impairments will need audio description, a summary of powerpoint slides and documents in Plain English⁴². Powerpoint slides should be uncluttered and use colours that can be easily seen by people with visual impairments. Other seldom heard groups may have poor literacy too. The standard print size for anyone with a visual impairment is 16 point font, but it is best to check with individuals.
11. **Activities.** Include a diverse range of activities to enable people to contribute in different ways. People with dementia have benefited from Talking Mats⁴³, while a traveller community responded well to a Walkabout approach⁴⁴. As one person⁴⁵ put it:

‘We were quite clear we did not want the traditional user involvement model of meetings, committees and paperwork. We knew we had to use other ways of getting our message across... We decided we would use art, music, poetry and writing to raise our issues and campaign for change, enabling as many people as wanted to become involved.’

⁴¹ Access to interpreters may have become more difficult since the following guidance was given by the UK government; “Stop translating documents into foreign languages: only publish documents in English. Translation undermines community cohesion by encouraging segregation.” Department for Communities and Local Government (19 Dec 2012) [50 ways to save: examples of sensible savings in local government](#) page11.

⁴² See guidance published in June 2015 on accessible information at <http://bit.ly/1dqllB2>.

⁴³ Joseph Rowntree Foundation (2010) [Talking Mats help involve people with dementia and their carers in decision-making](#), York: Joseph Rowntree Foundation

⁴⁴ North Bristol NHS Trust (2010) [Seldom heard report – involving and consulting hard to reach equalities patient groups](#) paragraph 8.4.

⁴⁵ Trivedi, P. (2002) ‘Let the tiger roar...’, *Mental Health Today*, August, pp 30-33.

12. **People may fear discrimination** or harassment on public transport or in services. They may have found that staff hold low expectations of them. They might be worried that anyone who makes a negative comment will suffer reprisals or even lose their access to vital services. Indeed, some people have not found professionals trustworthy in the past, especially where so-called consultations have been hurried and single-event contacts rather than sustained relationships, and so at first, they may be suspicious of your motives and conduct.
13. **Speaking.** Some people with aphasia may need extra time to form their ideas while stroke survivors may speak slowly. Anxious people may find it difficult to speak up, while some people with obsessive traits need to speak for a long time. Find out if the person wants you to speak out your guess about the end of their sentence or prompt them to stop speaking.
14. **Support.** As well as interpreters, some people will need access to a personal assistant or carer, an advocate or a friend. Negotiate the role of these individuals beforehand, so you can engage with them appropriately.
15. **Plan the meeting** – but only if it is yours to plan! Some people with autism need plenty of notice about arrangements and preferably no changes or cancellations, along with a clear explanation of the purpose of the meeting and their role in it. People with fatigue or reduced stamina need short meetings and may need a late start, while parents of young children may need to fit the meeting in between their duties at the school gate.
16. **Think about facilitation.** If you have any responsibility for facilitating a meeting, ensure that you engage the right skills to do so. Committees are much easier to lead than facilitating community sessions that blend informality, friendship and productivity. Those skills might exist in the community group already or you may need to bring them in or learn them.
17. **Participation in meetings.** People with learning disabilities may find it difficult to move from one agenda item to the next. Some people with personality disorders misread the contributions made by others in the meeting or distrust their motives. If the meeting is not chaired well, then some members may dominate and others may dislike the whole experience and be reluctant to attend future events. Indeed, some people are not joiners and just don't like meetings, so need an alternative way of contributing.