



## TOOLKIT FOR:

# Increasing Participation of **Black Asian and Minority Ethnic Groups** in Health and Social Care Research

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# ABBREVIATIONS

<b>BAME</b>	Black, Asian and Minority Ethnic
<b>BME</b>	Black and Minority Ethnic
<b>BYCS</b>	Bangladeshi Youth and Cultural Shomiti
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CASSP</b>	Child and Adolescent Service System Program
<b>CLAHRC</b>	Collaborative Leaderships in Applied Health Research and Care
<b>CRN</b>	Clinical Research Network
<b>LSE</b>	London School of Economics
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NIHR</b>	National Institution for Health and Care Research
<b>NRES</b>	National Research Ethics Service
<b>ONS</b>	Office of National Statistics
<b>PPI</b>	Patient and Public Involvement



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# INTRODUCTION

Black and Asian Minority Ethnic Groups make up about 13% of the population of the United Kingdom (Office of National Statistics, 2011) and are forecast to increase significantly in the coming decades (Box 1).

Black and Asian Minority Ethnic Groups are more likely to suffer from poorer health outcomes and health and social care inequalities in general. However, they are much less likely to be represented in health and social care research studies. This makes obtaining good quality research information from, and with, these groups even more important. The need for more relevant research data to inform health care planning and practice has been highlighted in a number of reports and recommendations (Department of Health, 2008; Mir et al, 2012).

The reasons for under-representation of Black and Asian Minority Ethnic Groups in research are complex, and include barriers such as language, cultural values, and beliefs between those who conduct research and potential participants, and issues related to general accessibility to research in deprived areas, including funding issues.

Poorer engagement of Black and Asian Minority Ethnic Groups can be a relevant factor along any part of the research pathway from developing the research idea through to dissemination and translation of changes into practice.

However, despite the difficulties, there are many examples of excellent practice in this area (including high quality research) which have resulted in real changes in health care delivery, and from which we can learn.

This Toolkit aims to capture such best practice and provide researchers with a framework on how to improve the participation of Black and Asian Minority Ethnic Groups in research. The Toolkit was developed by researchers with experience in this area, and involved a review of the existing literature as well as engagement and collaboration with members from both the research and Black and Asian Minority Ethnic Groups.

The suggestions, strategies, and tips in this document will help researchers avoid some of the pitfalls in this difficult area. These include avoiding oversimplification of the issue of ethnicity, e.g. by recognising heterogeneity in Black and Asian Minority Ethnic Groups, and the impact of other factors such as gender, educational status, and religion. The Toolkit should help researchers develop more relevant research questions, consider engagement of Black and Asian Minority Ethnic Groups in a more structured way, and provide tips on better participation and dissemination of research findings.

The Toolkit should also be useful in the preparation of grant applications, and help researchers demonstrate that they have taken account of the relevance of Black and Asian Minority Ethnic Groups to the success of their proposed study.

**Professor Azhar Farooqi, OBE**



# HOW THIS TOOLKIT WAS DEVELOPED

The Toolkit has been developed under the leadership of a steering group consisting of a multidisciplinary group of researchers and Lay members from a variety of institutions. The process for developing the Toolkit included a detailed literature review, workshops involving the research community and a range of community representatives and extensive discussions in the steering group. Interim findings were taken back and tested with community groups on a number of occasions.

The final Toolkit was guided by the themes and issues identified by researchers and lay communities as being of the greatest relevance and importance. Box 1 and box 2 describe the process in more details.

## BOX 1: Literature Review

An extensive literature review was carried out and key findings with respect to the barriers for Black and Asian Minority Ethnic Groups communities identified:

- The use of language, ability to speak English, translation and interpretation. (Mir and Tovey, 2003; Papadopoulous, 2006; Lloyd, et al., 2008; Atkin, Ali and Chu, 2009; Hoopman, et al., 2009; Rooney, et al., 2011; De La Nueces, et al., 2012; Gill, et al., 2012; Vickers, Craig and Atkin, 2012)
- The socio-cultural barriers for people from BAME communities as they experience: unfair access and health inequalities; cultural and linguistic barriers; issues concerning modesty associated with religion and culture (Hussain-Gambles, Atkin and Leese, 2004)
- A lack of understanding of the concept of research in some BAME communities so that what it involves can result in potential participants refusing to take part (Cronin and Ward, 2004; Sheik, et al., 2009; Rooney, et al., 2011; Gill, et al., 2012)
- BAME communities reporting practical issues such as, research causing additional costs to participants and researchers (Cronin and Ward, 2004; Hussain-Gambles, Atkin and Leese, 2004; Vickers, Craig and Atkin, 2012; Brown, et al., 2014); inaccurate / unregistered housing (Hoopman, et al., 2009). Some groups may have particular challenges to participation because of other priorities such as, family. Accessibility, location and timing of activities such as interviews and focus groups are therefore important considerations (Cronin and Ward, 2004; Waheed, et al., 2015)

## BOX 2: Black and Asian Minority Ethnic Groups Workshop

On Monday 18th July 2016 a workshop was held at the Peepul Centre in Leicester where researchers, service representatives, and lay members of the public from Black and Asian Minority Ethnic Groups, were invited to give their feedback and experiences of conducting and participating in research. Participants were invited to attend the focus groups via emails and letters, through community leaders, charities, and word of mouth.

The criteria for participation were that researchers had to be involved in research which included the Black and Asian Minority Ethnic Groups communities, and members of the public had to belong to a Black and Asian Minority Ethnic community.

All participants were over the age of 18.

A total of 21 researchers and 14 members of the public attended, although prior to the event an equal number of each group (approx. 40 of each group) were invited.



Workshops took place which focused on:

1. The enablers and barriers for conducting research from the perspective of Black and Asian Minority Ethnic community members.
2. The enablers and barriers for conducting research from the researchers' perspective.
3. Key themes needing to be addressed in good practice guidelines - mixed group 1 (researchers and Black and Asian Minority Ethnic community members).
4. Key themes needing to be addressed in good practice guidelines - mixed group 2 (researchers and Black and Asian Minority Ethnic community members).

All workshops were audio recorded with consent, and transcribed for analysis using a thematic approach.

### Analysis

A full transcript was provided of the workshops, and independently analysed by 4 members of the project steering group using framework analysis. Common themes and statements from participants were highlighted and then discussed and agreed between the researchers. The researchers then agreed on what themes and content should be added to form the Toolkit.

### Results

The following themes were identified which aided the development of the Toolkit:

- Theme 1: Over-researched, under-serviced
- Theme 2: Working with language barriers – specific issues of non-English speakers
- Theme 3: Communication barriers surrounding research – how to inform Black and Asian Minority Ethnic communities
- Theme 4: Engaging with communities to improve communication – engagement not just to inform but to encourage participation
- Theme 5: Lack of trust – how do we overcome this, cultural competence, trusted individuals etc
- Theme 6: Stigma - of disease, of engagement, of admitting problems or needs

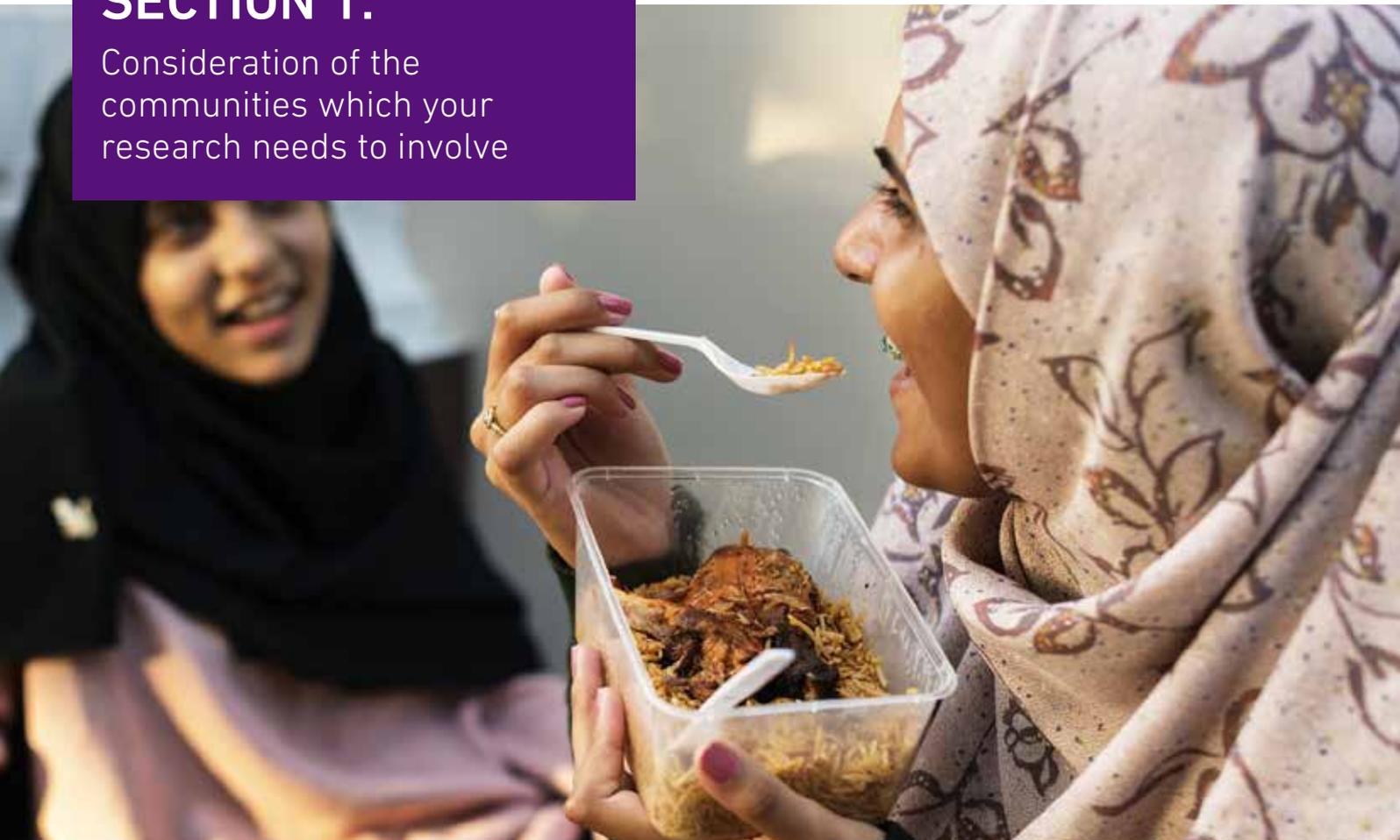
Following the development of the Toolkit all those who attended the first session were invited to a half-day follow-up event in Leicester on the 10th May 2017. Participants were asked to have a round table discussion around each theme during a set time period; these thoughts were collated and added to the final draft of the Toolkit.



# THE TOOLKIT

## SECTION 1:

Consideration of the communities which your research needs to involve



### **Have you considered the characteristics/demographics of the population your research will include?**

A starting point for the study team may be detailed consideration of whom you want to include in your study and consideration of why it is important for Black and Asian Minority Ethnic Groups communities to be represented within your study. It may be important to ensure Black and Asian Minority Ethnic Groups participation as they are an integral part of the general community (relevant in studies aimed at the general population), or perhaps your study is aimed at specific groups?



**Why?**



**How?**



**Case Study**



**Top Tips**

## BOX 3: The Changing UK Population

According to Office of National Statistics data (ONS, 2017), the UK population is growing at the fastest rate for almost a century. Unlike previous episodes of growth, the major reason for this increase has been the high level of net migration.

Net migration adds to the population both directly, from the migrants themselves and indirectly, by increasing the number of births in the country. In 2016, well over a quarter (28.2%) of live births in England and Wales were to mothers born outside the UK; the highest level on record. This percentage has increased every year since 1990, when it was 11.6%. In 2001 the population of the UK was estimated at 59.1 million, with 4.9 million (8.3%) foreign-born. By 2011 the population of the UK had increased by 4.1 million to 63.2 million, with the foreign-born population at 8 million (12.6%). The population now stands at 65.6 million (mid-2017). It is estimated that net migration plus births to foreign-born parents has accounted for 85% of population growth between 2000 and 2014.

It is suggested that minority ethnic communities will make up a fifth of Britain's population by 2051 compared with 8% in 2001. According to the Office of National Statistics there were approximately 64.6 million people living in the UK in mid-2014. Of these 56.2 million (87.2 per cent) were White British. The most recent Census in 2011 highlights that in England and Wales 80% of the population were White British. Asian (Pakistani, Indian, Bangladeshi, other) groups made up 6.8% of the population; Black groups 3.4%; Chinese groups 0.7%; Arab groups 0.4%; and other groups 0.6%. In London in 2011, 45% (3.7 million) of 8.2 million usual residents were White British. A total of 87% of those in England and Wales were born in the UK. Of those not born in the UK, 9% were born in India, 8% in Poland, and 6% in Pakistan.



- If you are looking to include specific groups, have you considered issues of heterogeneity (few ethnic groups are homogeneous)?

As an example, South Asian groups have religious, regional, and national differences related to diet and cultural practices which can impact on health and lifestyle. Some groups, for example, are vegetarian or vegan, some may not consume alcohol, and different religions have very different festivals and fasting practices which affect dietary practice.

It is worth speaking to your local authority which will have detailed local population statistics. NHS communications teams, for example, at hospital trusts or clinical commissioning groups (CCGs) may have more details of the populations for which they provide services. Community organisations can also help identify and provide information on some of these issues. These include voluntary sector organisations which provide/ support health care activities, or community religious institutions. It is important to try and obtain information from a broad range of sources, but local authority data is often a good place to start.

If you are investigating a particular issue or problem, have you considered the data regarding differences in prevalence or impact on particular groups, and taken these into account in your protocol?

Human beings are complex; our health is impacted by a mix of factors including those which are genetic, social, and environmental. Ethnicity is just one of these factors and we need to be conscious of this when we conduct research. There are many sources of data which can help us identify issues in this regard including:



Prevalence data, e.g. public health observatories, local Healthwatch, health and well-being boards, health and well-being strategies



GP practice data



Research literature, e.g. peer reviewed and 'grey' literature

As an example, there is an established variation in the prevalence of conditions such as diabetes, hypertension, and mental health issues in different ethnic groups. For example, the definition and impact of normal BMI and obesity are different in different ethnicities (NICE, 2013).

Consideration of whom you need to include in your study and why, are just the first questions for you, but answering these is a good starting point and will prompt you to then ask questions regarding how you will actually recruit participants and conduct your study.

Have you considered your research methodology?  
Is it appropriate for your study?

Box 4 highlights some of the issues that may be relevant to research with Black and Asian Minority Ethnic Groups communities.

## BOX 4: Research Methodology for Black and Asian Minority Ethnic Groups Citizens/Communities

The diverse ethnic population of the UK calls for a more appropriate and inclusive research methodology for active engagement with Black and Asian Minority Ethnic Groups citizens and communities. Researchers need to consider if their proposed research addresses this.

The purpose of research is to answer questions through the application of scientific procedures. The main aim of research is to find out the truth which is hidden and which has not yet been discovered. Though each research study has its own specific purpose, we can think of research objectives as falling into several broad themes:

1. To gain familiarity with a phenomenon, or to achieve new insights into it (e.g. exploratory or formative research).
2. To accurately portray the characteristics of a particular individual, situation or group (descriptive research).
3. To determine the frequency with which something occurs, or with which it is associated with something else (diagnostic research studies). To test an hypothesis of a causal relationship between variables (hypothesis testing studies).(Kothari 2005)
4. The research method(s) you choose must be appropriate both for the research questions/ issues that you want to explore, and your target group(s).

### Quantitative research issues

#### ➤ Sampling:

Remember that target groups may be 'low penetration' (they represent a tiny proportion of the general population). They may also be 'clustered' (tend to live in particular post code areas, wards etc.) Black and Asian Minority Ethnic Groups target groups may also be 'low penetration' and 'unclustered' (for example, the Chinese community).

Sampling strategies that might be helpful for Black and Asian Minority Ethnic Groups communities are:

1. 'High penetration sampling' – sampling from areas where the target Black and Asian Minority Ethnic Groups represent a large proportion of the general population.
2. Snowball sampling - asking respondents to nominate others they know who fit the recruitment criteria.
3. Focussed enumeration – the respondent acts as 'proxy screener', i.e. they are asked to suggest participants who may fit the recruitment criteria.

#### ➤ Questionnaires:

Self-completion questionnaires sent to certain ethnic groups (e.g. postal surveys) often have poor response rates. Even with tailored covering letters response rates are often low because of misunderstanding/ suspicion of the purpose of the research and language/ literacy issues. If the postal method is to be used, a translated sheet should be enclosed that allows respondents to request information in another language.

Respondents who have language or literacy barriers sometimes ask family members and friends to help them to complete questionnaires. Responses may therefore not reflect the views of the target groups.

Translated questionnaires are often not cost-effective. Translations must be checked properly (and piloted if possible) to make sure they are accurate, make sense, and that the language is not too formal or traditional. It should also be noted that second and third generation Black and Asian Minority Ethnic Groups respondents may speak the language fluently but not read it.

### ➤ Questionnaires - using interviews:

'Real time' translation (i.e. an interviewer translates the questionnaire face-to-face with the respondent) is likely to produce much better response rates than pre-translated questionnaires. You should first consider using interviewers who are able to speak the same language as the respondents. Translators accompanying interviewers are possible alternatives but will require a field work phase that is much longer, expensive, and less satisfactory. The use of bi-lingual interviewers in Black and Asian Minority Ethnic Groups research needs to be carefully planned. Some key points to remember are:

- An initial small-scale qualitative phase may help to improve the questionnaire design and content. This may require liaison with community leaders, organisations or community advocates
- Same sex interviewing may be necessary for some Black and Asian Minority Ethnic Groups
- Allow a minimum of 20% more time for undertaking translated interviews
- Allow more time for recruiting skilled interviewers
- If show cards (i.e. cards which list options that can be selected when answering questions) are to be used in questionnaire interviews, they should be bi-lingual
- Interviewers must have a strong ability in both languages and be well briefed, rehearsed, supported, and quality controlled
- Higher costs will result from all the above

### Qualitative research issues

#### ➤ Recruitment:

Standard recruitment methods 'in the street' or door-to-door tend to lead to under-representation of Black and Asian Minority Ethnic Groups. Using Black and Asian Minority Ethnic Groups research assistants/ fellows (who are familiar with the culture and language) can have advantages, such as, their greater cultural understanding, language skills, and contacts in the community.

Resistance to research participation from Black and Asian Minority Ethnic Groups communities can sometimes be overcome with good publicity to raise the profile of the research, and seeking guidance on language and cultural issues using community organisations/ individuals to help overcome concerns and provide 'insider' information. Using community organisations in the recruitment process does have disadvantages. For example, they are potentially inexperienced in recruitment and research, may introduce bias, and may assume they know better. However, thorough briefings on the research objectives and who/ how to recruit can help with this.

Using community 'leaders' in the recruitment process can help to promote the research, and benefit may be gained from their cultural know-how. However, as with community organisations, there can be disadvantages to their involvement. For example, what standing do they have in the community? They are also potentially difficult to get hold of and could be obstructive gate-keepers. An alternative may be to use community workers who will provide 'cultural know-how', may be closer to the 'real people', and possibly more accessible.

#### ➤ Matched or mixed Black and Asian Minority Ethnic Groups respondents:

Mixing Black and Asian Minority Ethnic Groups and White British participants in group discussions can be acceptable if the budget and time scales are tight, if ethnicity is not the core focus of the research, and if the topic is one of general or 'neutral' debate. However, including one or two Black and Asian Minority Ethnic Groups participants in a mixed group can be seen as 'tokenism' and may overlook essential issues, details, and contexts of Black and Asian Minority Ethnic Groups communities. Mixing Black and Asian Minority Ethnic Groups groups may also result in tension and disruptions because of cultural/ religious conflicts.

Researchers must also consider the makeup of qualitative groups in terms of gender, age, religion, and cultural background. Separation should be considered in some instances. For example, separate male and female groups are preferable for some communities when respondents are older, or when researching sensitive issues.

## Case Study 1.1

Members of a research study wanted to investigate the high incidence of congenital abnormalities in South Asians, which was thought to be related to consanguinity. The group wanted to undertake qualitative interviews to understand the perception and understanding of this issue in a city with a large South Asian population.

They were about to look at a sample of participants to interview when it was pointed out that consanguinity is, in fact, only an issue in a small subset of the South Asian population of that particular city. Further, the group had not taken full advice on the religious and social ramifications of the proposed study

which could have led to issues of great sensitivity being misinterpreted by potential participants. The issue of explaining risk as a concept to lay people had also not been properly considered.

The group subsequently set up a patient advisory group to look at these issues in more detail before proceeding with the study. This led to the study focusing on one religious group, and the extension of the study to another town with a high rate of consanguinity.

## Case Study 1.2

A study on Type 2 diabetes was looking for participants to join a patient education study. The patients were to be recruited in general practice.

After one year it became clear that over 90% of recruits were of White British origin, although local data indicated that 50% of all patients with Type 2 diabetes were of Black and Asian Minority Ethnic Groups origin.

On further investigation it was discovered that although a range of practices were recruiting, the majority were in suburban areas and fewer inner city practices were part of the study.

Furthermore, most of the recruitment literature was in English, and no extra resources had been allocated to the inner-city practices, which were struggling to find time for the study.

The study team reviewed the recruitment strategy, engaged a researcher of Black and Asian Minority

Ethnic Groups background, and put in extra support for the inner city practices. The study team also arranged to advertise the study on the radio and went into community venues to promote it.

Recruitment from Black and Asian Minority Ethnic Groups communities subsequently improved, but a year had been lost, and the study lead needed to go back to the funder for an increase in funding.

Key lessons learnt included:

- Make sure that the recruitment strategy targets the correct demographics and does not miss out key groups (e.g. those of Black background, where the main Black and Asian Minority Ethnic Groups community is of South Asian origin)
- Ensure your recruitment materials are appropriate to the community from which you wish to recruit

## Case Study 1.3

The Radiate Study aimed to explore Black and Asian Minority Ethnic Groups communities knowledge and understanding about how to prevent Type 2 diabetes.

The study also involved an evaluation of a national social marketing campaign to raise awareness of Type 2 diabetes in Black and Asian Minority Ethnic Groups communities. The research team used a qualitative approach to undertake the study. This involved conducting focus groups using the principles of Open Space, with eight ethnic groups in Leicester City.

One significant finding was that both the African and Caribbean focus groups' participants were particularly keen to ensure health information leaflets/posters are designed to be inclusive and representative of the diversity of Black and Asian Minority Ethnic Groups communities. So, for example, visual images depicting complications associated with diabetes should use images and languages that reflect the ethnic diversity in the local community.

The participants perceived such an approach is more likely to generate an interest because they are perceived as relevant and reflective of their ethnicity, and may result in achieving a greater impact of health messages within Black and Asian Minority Ethnic Groups communities. It is suggested for the purposes of this toolkit that these findings are also relevant and pertinent for the design of research study documentation:

**“Would like to see a poster of all races showing critical conditions... amputated leg or harm from diabetes”**

**(Feedback from Caribbean group)**

**“ In the posters we need to show all races Black, White, Asian, the people need to be aware they can be next”**

**(Feedback from African group)”**

## Top Tips

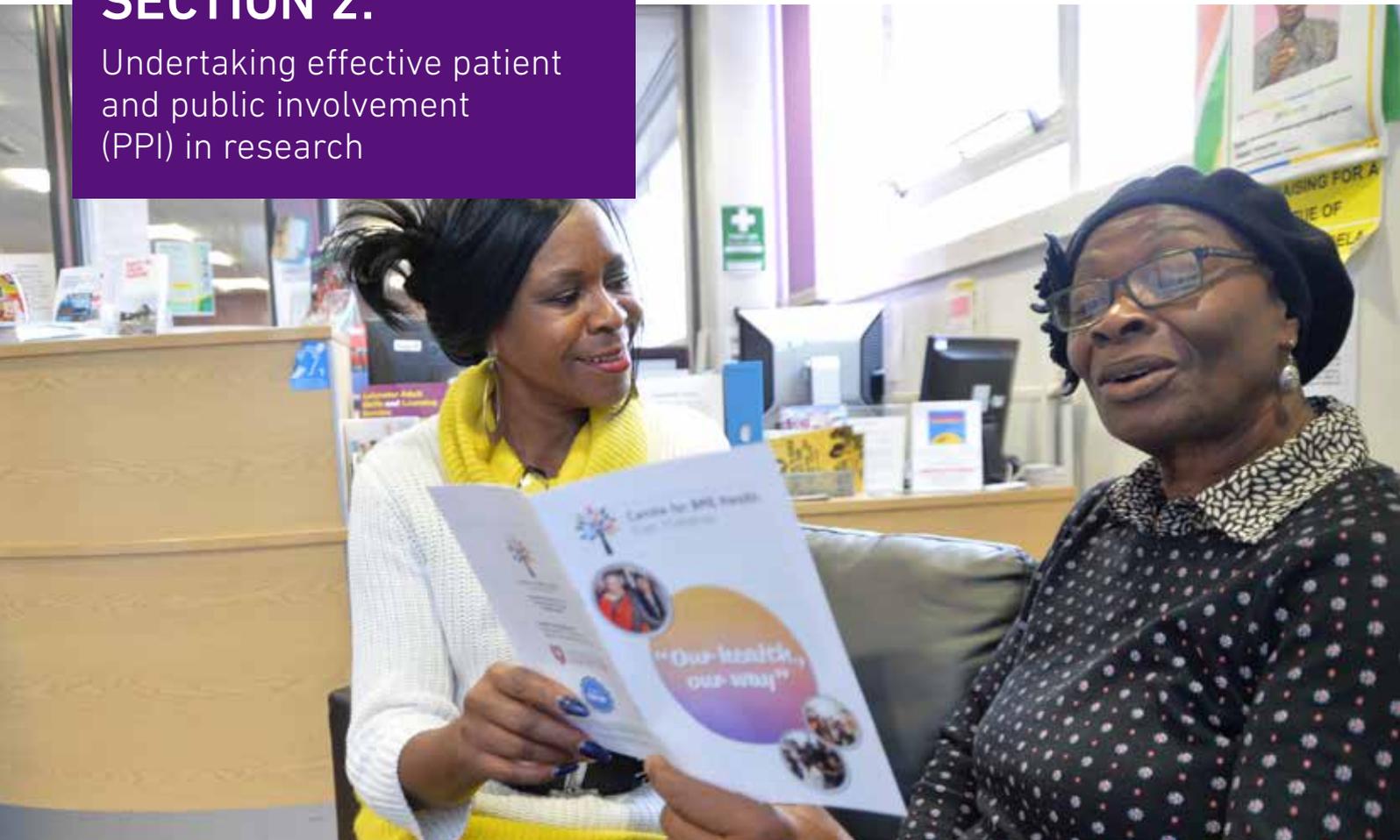


1. Understand your local demographics and how these will impact on your research.
2. Is your study explicit in its aims of ensuring adequate representation?
3. Does your sampling limit the ability to recruit from certain populations? For example, are any participating GP practices only located in certain geographical areas? Is there lack of promotion to particular populations? Are there language or cultural barriers to participation?
4. Consider sampling methods depending on the type of study you are undertaking (e.g. purposeful sampling in qualitative research and power calculations in quantitative research to ensure the numbers of specific groups are adequate).
5. Seek specialist advice if you need to. This may be colleagues with experience in this area, your local NIHR Research Design Service, or a specialist service such as the Centre for Ethnic Health Research, ethnicity and health research centres (e.g. Mary Seacole Research Centre at De Montfort University, Leicester).
6. Consider whether your Patient and Public Involvement (PPI) or project group is able to help you address issues regarding the participation of specific groups.

# THE TOOLKIT

## SECTION 2:

Undertaking effective patient and public involvement (PPI) in research



### What is Patient and Public Involvement (PPI) in research?

Public involvement includes patients, potential patients, carers, and people who use health and social care services, as well as people from organisations which represent people who use services. It does not include involvement from staff who have a professional role in health services. The principle underpinning public involvement is to promote research which is conducted with, or by, members of the public rather than 'to' or 'about' or 'for them' (INVOLVE, 2012).



Why?



How?



Case Study



Top Tips

## Why should we undertake PPI?

Encouraging PPI from Black and Asian Minority Ethnic Groups helps to facilitate research which is of relevance to Black and Asian Minority Ethnic Groups communities, as well as identifying topics of potential new research. It can also help with supporting research which reflects the public interest and priorities, as well as being an efficient use of resources.

## What do research grant giving bodies say about PPI?

Funding bodies such as the National Institution for Health and Care Research and the National Research Ethics Service (NRES) in their assessment of proposed applications will seek to identify how PPI has shaped the plans for the research, including consideration of whether it is 'ethical, relevant and acceptable from a public perspective' (INVOLVE, 2012).

INVOLVE was established in 1996 and is part of the NIHR. INVOLVE supports active public involvement in NHS, public health, and social care research, and is one of the few government funded programmes of its kind in the world. INVOLVE has produced a number of guidance documents for researchers to help support them with PPI, such as, ensuring PPI plans are inclusive and take account of diversity (INVOLVE, 2012).

## How can PPI contribute to the quality of research?

PPI can contribute to the quality of research in many ways. A key aspect of PPI is how it can help to clarify whether the proposed research is feasible, acceptable, and accessible to potential participants from Black and Asian Minority Ethnic Groups. This may lead to researchers, for example, to:

- Make changes or adapt recruitment strategies to ensure appropriate groups/individuals are targeted
- Produce participant information sheets and consent forms in different formats, such as, audio-visual and translated versions
- Be sensitive about the acceptability and suitability of proposed research methods, for example, there may be a reluctance to discuss certain health topics in focus groups due to stigma or concerns about privacy



## How can researchers recruit potential PPI members from Black and Asian Minority Ethnic Groups?

INVOLVE guidance provides a useful starting point for your PPI journey, and one essential tip within this guidance is to start early and take time for preparatory work. Recruitment of potential PPI members from Black and Asian Minority Ethnic Groups should be undertaken using a variety of methods to ensure barriers arising out of literacy and language are addressed, and to maximise your reach of interested participants. To enable you to undertake this effectively, consider the following ways to identify potential participants from a range of people with whom researchers can build relationships and trust:



Attending local health fairs and community events, workplaces, and health and well-being sessions



Arranging to give talks on the radio



Engaging with community, voluntary, and faith-based organisations



Using Facebook and Twitter



Creating links with patient support groups



Talking to people attending public and festival events



Linking with patient participant groups within general practice surgeries



Engaging with community workers and volunteers

Once you have identified a group of people interested in being involved, use the INVOLVE guidance for practical tips and suggestions about supporting PPI, including payment and reimbursement for expenses. You can also consider reciprocal arrangements with community and voluntary sector groups for their time, such as, undertaking education sessions for their groups on health topics or presenting information about research that your group or department undertakes.

### Case Study 2.1

Members of a research team sought to bring together a diverse group of South Asian communities to contribute their patient and public perspective on a NIHR research development grant related to diabetes education. The work for recruitment of potential PPI members commenced with contacting community and voluntary organisations with a view to engaging a diverse group of South Asian ethnic subgroups to contribute a PPI perspective to the proposed research.

Meetings with two PPI groups were organised on a monthly basis over a six month period, and these meetings generated a great deal of enthusiasm and interest. It was apparent fairly early that participants required some support and time, to understand the difference between PPI and participation in research. The research team addressed this issue by visually depicting the difference in the form of images, including representations of

the different aspects of the proposed research work programme. This approach worked really well and resulted in an informed PPI engagement and provided clarity to group members about their role and contribution.

Researchers were also asked a lot of questions about diabetes, and therefore one meeting focused exclusively on delivering some education about diabetes so that PPI members could meaningfully engage with subsequent discussions about the proposed research.

The PPI meetings involved costs that were budgeted for in advance of submitting the grant and included voucher payments for the core group of PPI participants, hiring rooms in community venues, and basic refreshment costs. The community group that hosted these meetings and helped to recruit group members was also recompensed for venue hire and administrative charges.

## Top Tips



1. PPI takes time; make sure you build in the time it takes to recruit to, and support, meaningful engagement in PPI.
2. Consider using different ways in which to explain PPI, your research project, and the health condition, such as, using visual and interactive resources.
3. Put yourselves in their shoes; what would you like to know before committing to be a member in a PPI group, or individually.
4. Ask how people would like to be supported, for example, with an education session on the health condition and/ or background information to the research proposal.
5. Budget for potential costs in advance so that funding for participation is facilitated in relation to costs, such as, store vouchers. In the absence of any funds, think creatively of how non-monetary contributions can be provided by the research teams, including giving health talks or assistance with their grant proposals to the community and voluntary sector organisations that assist you.

# THE TOOLKIT

## SECTION 3:

Conducting effective recruitment in Black and Asian Minority Ethnic Communities



### What is patient and public involvement in research?

Researchers need to address a number of questions when considering how to conduct effective recruitment that is appropriate to their particular study.



Why?



How?



Case Study



Top Tips

## How will you effectively access, recruit and communicate with Black and Asian Minority Ethnic Groups communities?

One important consideration is how to ensure study materials can be communicated in an easy-to-read format, or to consider alternatives to written materials, such as, DVDs or audio-consent. This may help to overcome language barriers, including lower levels of literacy. Using a researcher from within the community as part of the research team can be effective in making it easier to reach out to the community, help instil greater confidence in the study, and remove barriers in some groups or individuals to participating. However, issues of skills and training to undertake research may need to be addressed.

Another method to recruit participants might be to contact local community groups (such as women's groups, drop-in centres) and going personally into the community centres to explain what you are trying to achieve, and why their help and participation is crucial.

It may be important to attend on specific dates and times to gain access to different age groups and genders.

Various communication media can also be effective, for example, recruiting via local newspapers, radio stations, and posters displayed in key places (such as community centres, religious places, on the streets, local shops, and other venues) may be effective for specific groups (Patel, Doku and Tennakoon, 2003). It is important to find out where different groups tend to access information in order to tailor any strategy. The 'snowball method' where the researcher establishes links and contacts with local communities/ citizens, especially those communities or members of the community that are considered to be 'hard-to-reach', has been shown to be effective (Denscombe, 1998).

Other aspects to consider include the location of your study, how people will get to you, issues of transport, disability/ access issues, light refreshments, their comfort, whether you will travel to them, your safety, and reimbursing participants with a 'thank you' for taking part in your study.

### Case Study 3.1

In a study to increase participation of Black and Asian Minority Ethnic Groups in health and social care research (Black and Asian Minority Ethnic Groups Workshop, 2016) a lay member representing the local Bangladeshi community in Leicester initially contacted the Bangladesh Youth and Cultural Shomiti (BYCS), a community and cultural centre, and explained the purpose of the focus group, and also invited key figures from the community.

This was initially accepted by the committee. Then written invitations were hand-delivered to BYCS inviting key persons from the Bangladeshi community to attend and contribute to the focus groups on how they felt better representation of their community in research could be achieved.

### Case Study 3.2

Jutla (2011) researched experiences of dementia care in the Sikh community in Wolverhampton. This research revealed that dementia has associated stigma in this community due to misunderstandings of it being a mental health problem. Consequently, materials used to advertise for participants made no reference to mental health and approached dementia as a neurological disorder. Despite several attempts to recruit participants from religious organisations, the majority of Sikh carers came forward via 'snowballing' (a recommendation via word of mouth) and radio interviews.

### Case Study 3.3

Raghavan, Pawson and Small (2012) and Small, Raghavan and Pawson (2013) researched transition experiences of young people with learning disabilities and their families from Black and Asian Minority Ethnic Groups in Bradford. They developed a short DVD with young people with learning disabilities and their families about the research process, and to provide information about the research project.

This DVD was made in English, translated into four South Asian languages and circulated in schools and colleges, making the research information more accessible for young people with disabilities from Black and Asian Minority Ethnic Groups communities and their families, so that they could understand about the research project and to how to participate.

### Have you considered the possible use of advocacy and link workers?

Consider how the participants will be recruited, and how you will ensure variety /a good mix of individuals representing the local communities in the sample. It may not be enough to just go into the local community centre or religious institutions and talk to the community leaders. Not all members of Black and Asian Minority Ethnic Groups communities will visit the local community centre or have the ability to, and despite belonging to a religious group, whether it is by choice or expectation, not everyone will visit religious places. For those that do visit religious institutions, some people may like to keep a low profile and may not even be known to the religious leader (Chauhan, 2001).

Community leaders can have influence over people; this can be positive, where people trust the leader and have faith in what they are saying and are therefore willing to come forward and help, and negative, where people are discouraged from participating directly or indirectly, or through the giving of inaccurate information (James, Kim and Amijol, 2000). Arora and Khatun (1998) in their study exploring drug use among Asian communities in Bradford, found that families kept drug related problems hidden, and Asian community and religious leaders colluded with the idea that drug problems did not exist in their communities, mainly to prevent people in the community finding out and shame ('sharam') and dishonour ('loss of izzat') occurring. We have evidence to show that researchers who act as liaison workers or link workers with Black and Asian Minority Ethnic Groups communities enable better participation and engagement with a study and its dissemination (Raghavan, et al,2009).

### Case Study 3.4

In a study by Uddin, Bhugra and Johnson (2008) exploring perceptions of drug use in the local Bangladeshi community in Leicester, utilising religious institutions as a way of approaching hard-to-reach or vulnerable sections of the community (Mufti, 1986; How, 1997; Simpson and King, 1999) did not produce a high response rate. Upon reflection, it was acknowledged that given the guilt, shame and stigma (with an element of illegal activity) associated with drug use, perhaps utilising religious institutions to recruit participants was, in many

respects, flawed. Jutlla (2011) similarly found difficulties seeking permission to advertise for Sikh participants from within religious organisations. This highlights the importance of identifying appropriate places from which to recruit participants in line with the topic being researched.

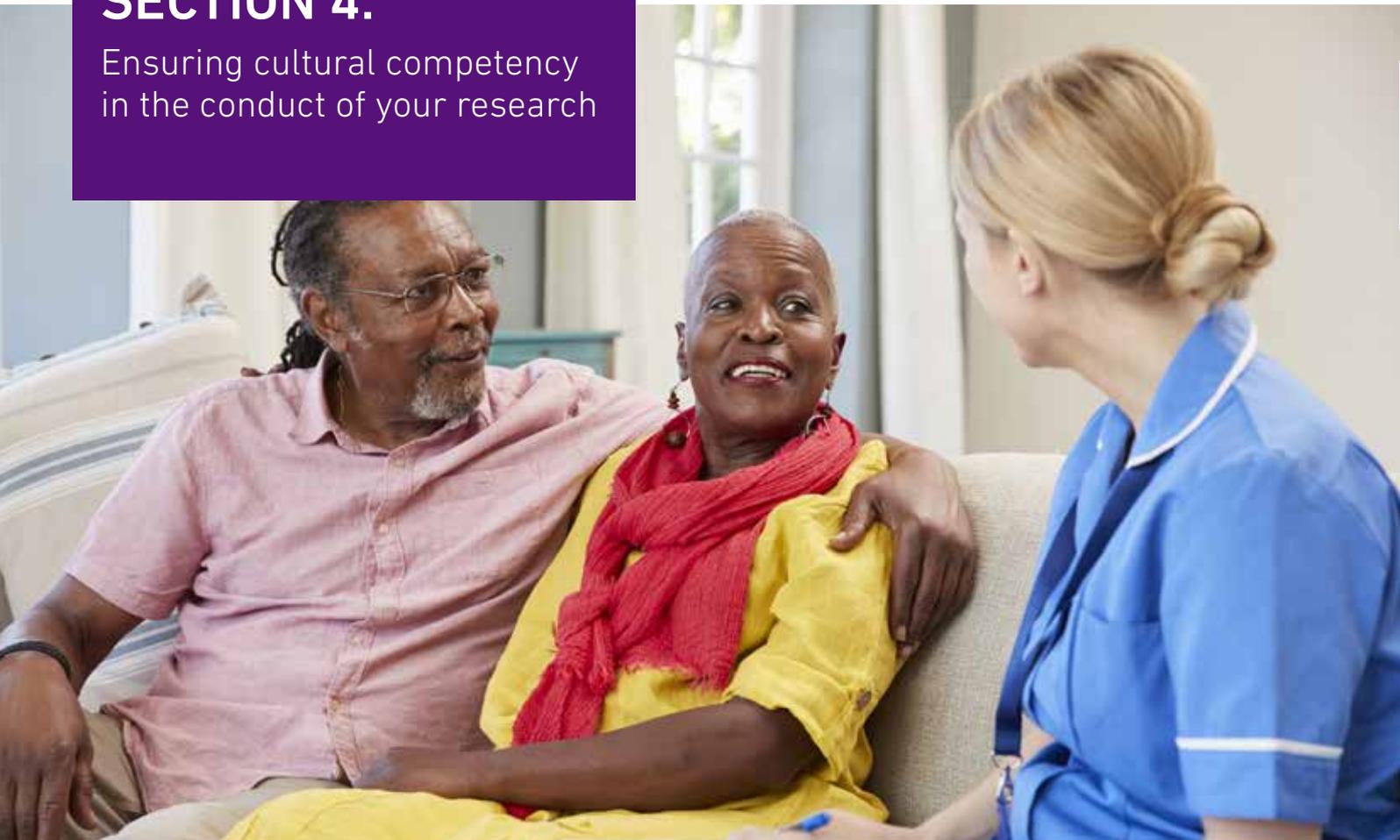


1. Whilst it is important to talk to community leaders, acknowledge that they can also influence, directly or indirectly, people's participation.
2. The 'snowball method' where the researcher establishes links and contacts to reach the 'hard-to-reach' sections of the community has been shown to be effective.
3. People may not respond to the research request in the conventional way. Consider seeking potential participants through local supermarkets and shops, through effective use of posters and leaflets, even by going out onto the streets to find people.
4. Trust and confidentiality are very important; people will come forward if they trust you, and you make them feel at ease. A genuine non-judgemental approach and communication with people is most important. Be conscious of your potential cultural bias, stereotypes, and prejudices.
5. Explain why your research is important and how it will benefit the individual and the community, and the potential difference it could make in the local and wider context.
6. Consider using alternatives to written material for providing research information, and during the research process.
7. Acknowledge any potential lack of confidence of the researcher to be able to engage effectively with the participants. Consider approaching someone who is already working with the community to seek advice and useful contacts to follow up.
8. Consider the location of your study, how people will get to you. Consider transport, disability/ access issues, light refreshments, their comfort, whether you will travel to them, your safety.

# THE TOOLKIT

## SECTION 4:

Ensuring cultural competency in the conduct of your research



### What is cultural competency?

'Culture' refers to integrated patterns of human behaviour that include the language, thoughts, actions, customs, beliefs and institutions of racial, ethnic, social or religious groups. 'Competence' implies having the capacity to function effectively as an individual or an organisation within the context of the cultural beliefs, practices and needs presented by people and their communities (Lee and Farrell, 2006; Cross, et al., 1989).



Why?



How?



Case Study



Top Tips

For Gallegos, Tindell and Gallegos (2008), cultural competence refers to:

**The process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognises, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each.**

Cultural competence, therefore, involves more than having an awareness of cultural norms. It is an approach that values diversity and promotes inclusivity. It represents a value-based perspective that recognises individuality (Gallegos, Tindell and Gallegos, 2008). Cronin and Ward (2004) define cultural competence as having the necessary self-awareness, cultural knowledge, and skills to foster culturally effective and ethical communications, interactions, and relationships with people of various cultural backgrounds. It therefore requires 'cultural humility', which is a lifelong commitment to self-evaluation and the awareness that one's own culture is not the only or best one (Schuessler, et al., 2012).

## How is this relevant in research?

As has been previously suggested, for some studies recruiting a researcher from the same background as the participants may improve recruitment and the overall research experience. However, as evidenced by the literature review and our workshops with members of Black and Asian Minority Ethnic Groups communities, it is not one's ethnic identity that matters most, but rather the ability to be culturally competent as defined above.

- This involves a process of self-reflection and self-evaluation:
  - McDonald (2009) highlights the need for cultural self-awareness for researchers, as stereotypes and beliefs/ pre-dispositions about certain communities, create barriers in research. For example, assumptions that particular groups will be 'difficult' or 'hard-to-reach' create obstacles for recruitment and research participation
  - Hussain-Gambles, Atkin and Leese (2004) emphasise the importance of researcher attitudes by highlighting how prejudicial biases and stereotypes towards Black and Asian Minority Ethnic Groups groups create obstacles not only in relation to recruitment, but also for building trust and rapport. McDonald (2009) based on his experience of cancer research, highlighted that greater awareness of one's own culture's pre-judgements would have helped the researchers understand the differences of the Black and Asian Minority Ethnic Groups groups and deal with them in a more culturally sensitive manner. McDonald also points out that researchers should be aware of their own occupational culture and how members of the public may not share this
  - As highlighted in the literature review and the workshops, there is often mistrust towards health professionals from members of Black and Asian Minority Ethnic Groups communities. It could be argued that this is the result of differing beliefs and perspectives towards health based on an individual's professional background (e.g. Eastern vs. Western ideologies). It is therefore important not to see all differences through the lens of culture (such as wealth, social status, or education). As pointed out by Torres (2015) an ethnic minority background should not be assumed to entail disadvantage. Equally, data analyses must be developed to recognise the interaction between ethnicity and other key social status – notably age, class, gender, and sexuality (Phillipson, 2015).
  - A culturally competent researcher will thus actively develop and practice appropriate, relevant, and sensitive strategies/ skills in working with individuals from different cultures (Cronin and Ward, 2004). Using modalities that are consistent with the life experiences and cultural values of the participants will build trust and rapport, which is an important component for research with Black and Asian Minority Ethnic Groups.

- It is important to note, however, that for some research studies it may be more appropriate to have the researcher be of a specific gender or age. For example, Gill, et al. (2012) in their primary research with members of the Black and Asian Minority Ethnic Groups argue that the profession, age and ethnicity of the researcher was unimportant to the research participants, though same sex was appreciated. Similarly, Hoopman, et al. (2009) found that the gender of the researcher is important and argues that women are generally more acceptable because in many cultures (as is the case for Moroccan people) it is more acceptable for a woman to interview a man rather than the other way around. The authors also suggest employing older and mature researchers due to the sensitivities and complexities of health research. Overall, as highlighted by their research, the personal qualities of the researcher outweigh other attributes (Gill, et al., 2012).

## What are the issues around cultural competence training and how can training help?

As we become more knowledgeable and appreciative of the importance of being culturally responsive and competent, the need for education and training in this area increases. Although cultural competency as a concept and model for practice has been around for a while, training in this area is yet to be validated. Quite often training is delivered discussing the cultural norms and sensitivities within different communities, which is then often construed as cultural competency. As stated above, cultural competency is more than having an awareness of cultural norms and practices. Though these are certainly helpful, training for cultural competency in research should focus on a process of self-evaluation and reflection to ensure that the sub-conscious prejudices and stereotypes we may hold towards communities do not impact on the research process. For example, Jutlla (2011) researched how migration experiences impact upon experiences of caring for a person with dementia in the Sikh community in Wolverhampton.

As a Sikh woman, born and bred in Wolverhampton, insider knowledge of the community meant that access was relatively easy. However, the researcher had not considered how elements of her own cultural biases towards her community could potentially impact upon her analysis and interpretation of the qualitative data collected. Consequently, a peer group was utilised to analyse segments of the data where possible bias might exist. A reflective journal was also kept throughout the entire research process. In order to unpick the social realities of the participants, the researcher had to firstly unpick her own, and develop self-awareness. Research with Black and Asian Minority Ethnic Groups should therefore consider the following:

- A peer review group to help analyse and interpret data
- The utilisation of reflective diaries as a process of self-awareness and self-evaluation
- Culture bias: this occurs when there is a tendency to judge another culture or a group of people solely by the values and standards of one's own culture or background
- That the emphasis should be on understanding and appreciating an individual's beliefs and activities in terms of that individual's own culture
- Stigma and discrimination have a direct impact on how an individual participates in the wider community and society. Internalised stigma is an individual's own sense of devaluation and discrimination (Owuor and Nake, 2015)
- To avoid the effects of stigma, consider whether the topic being researched is considered taboo or stigmatised by certain communities, and if so, careful consideration must be given to such sensitive issues

## Box 5 - Reflection of Lay members on Cultural Competency in Research

Explain why your research is important and what value participation by the community will add to your endeavour. Also, be honest and realistic; explain that it can take a number of years for the initial research to have actual impact on people or services

Most relevant to conducting effective recruitment is 'cultural knowledge' and having the confidence and interpersonal ability to engage with different groups of people using a non-judgemental and an 'accepting approach' to overcome barriers and instil confidence

You need to remain neutral and not show any direct affiliation to any sections or sub-sections of a community or culture. Particularly in relation to South Asian communities (for example, Indian, Bangladeshi, and Pakistani) social class and status in society (determined and perceived by profession, area of habitation, finances, education, and children's occupation) and caste/ family origins can either enhance status or significantly marginalise people (Winters and Patel, 2003)

Do not judge another culture or a group of people solely by the values and standards they live by, nor by one's own culture or background

The emphasis should be to understand and appreciate an individual's beliefs and activities in terms of that individual's own culture. Often value judgements can be placed on others subconsciously. In research, this can have an impact on the results. Supervision to explore one's own thoughts and feelings is an effective medium through which the researcher can enhance their self-awareness and remain impartial (Collier and Mahoney, 1996). The researcher also needs to be always willing to learn and prepared to ask for help

Trust and confidentiality are very important; people will come forward if they trust you, and you make them feel at ease. A genuine non-judgemental approach and communication with people is most important and that they are reassured that whatever they disclose to you will remain confidential. One of the biggest reasons members of Black and Asian Minority Ethnic Groups communities do not come forward to take part in research is due to the fear of others finding out (through researcher associations) in the community (Arora and Khatun, 1998)

Some health conditions can invoke stigma and can have a direct impact on the willingness of an individual to take part in research. Stigma and discrimination can have a direct impact on how an individual participates in the wider community and society (Boyd, et al., 2014). Internalised stigma is an individual's own sense of devaluation and discrimination (Owuor and Nake, 2015). Consider whether the topic being researched is considered taboo or stigmatised by certain communities and if so, careful consideration must be given to such sensitive issues by considering the use of different methods of recruitment and of investigation. Seeking training and advice from mentors as well as having a willingness to learn about other cultures can enhance your cultural competency

## Case Study 4.1

Raghavan, et al. (2009) in their study of improving access to mental health services for young people from Pakistani and Bangladeshi communities, used a South Asian researcher who also acted as a liaison worker to broker appropriate help and support for families to access child and adolescent mental

health services (CAMHS). This randomised controlled trial showed that the liaison worker model encouraged better participation in research, and also showed increased access and use of the CAMHS services, thereby improving health outcomes for the families involved.

### Top Tips

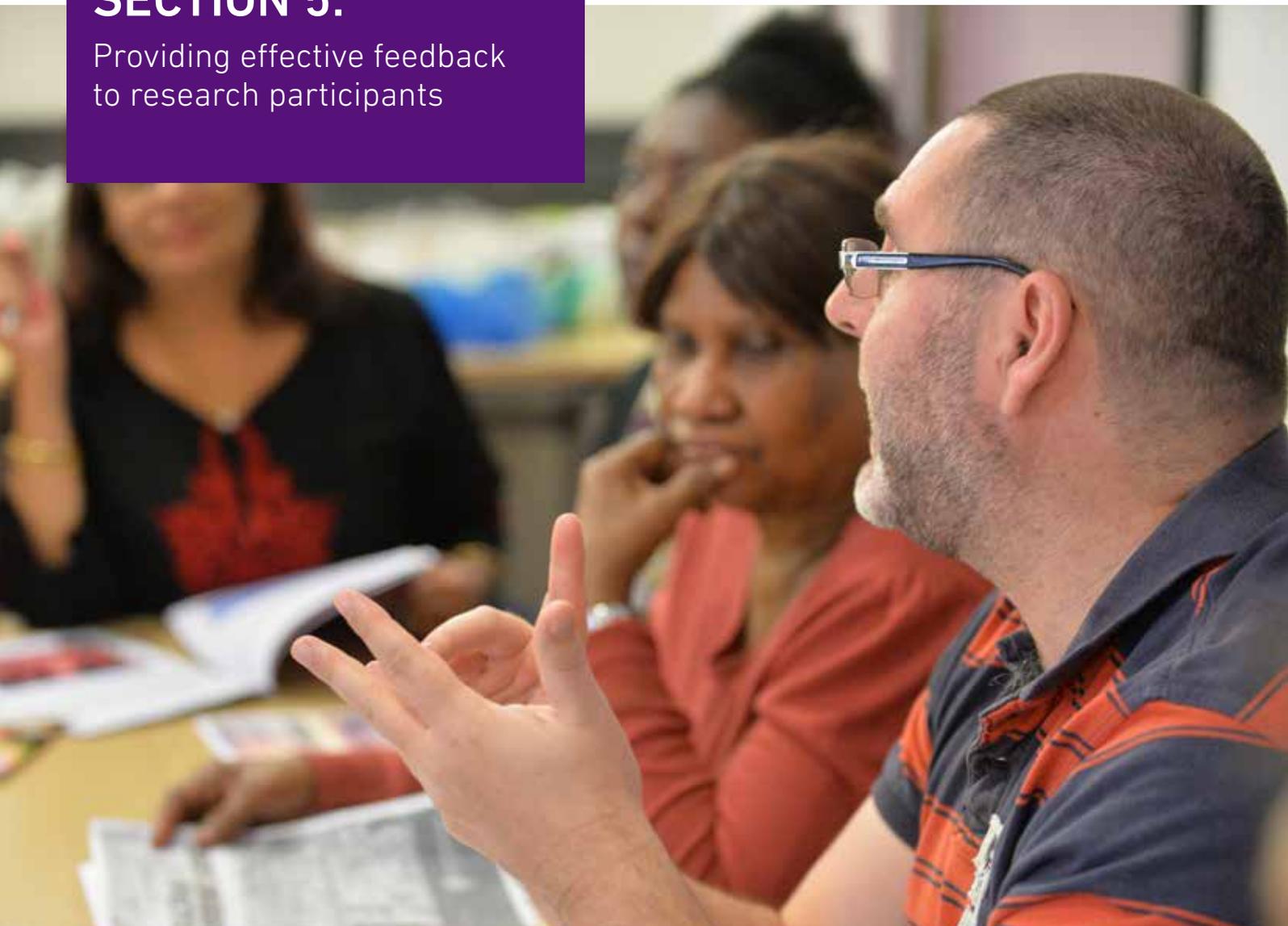


1. Cultural competency is a continuous process. This is not something that can be achieved with a half day or a full day course, however attending courses will always help to broaden knowledge and attitudes.
2. Cultural competency is not guaranteed just by being a member of a particular community . It is as much about attitudes and empathy as it is about knowledge and experience
3. Researchers need to actively ensure their teams include cultural competency attributes including:
  - Having the self-awareness of one's own culture and values, and the ability to fully function within diverse ethnic communities.
  - Having the confidence and ability to communicate, explore and discuss the cultural practices of different ethnic populations.
  - Empathy and willingness to learn about cultural practices and the unknowns, in different ethnic communities and cultures.
  - A non-judgemental attitude towards diverse cultural norms, values, and practices.
  - A willingness to seek help to understand cultural practices.
  - Demonstrate the ability to challenge health inequalities and to work with researchers, commissioners, and service providers to address prejudice and discrimination in our health and social care services

# THE TOOLKIT

## SECTION 5:

Providing effective feedback to research participants



Why?



How?



Case Study



Top Tips

The issue of feedback should be part of your dissemination strategy. Often researchers focus on publications in journals and posters or presentations at conferences. However, feedback to participants, communities, and to those who may have a role in implementing findings is equally important. So, include all these issues at the project planning stage. The dissemination plan should ideally have input from your PPI group and should have dedicated funding/ resource within the project.

There are differing ways to provide feedback on your research to the participants and communities involved. For example, what type of feedback should it be? Verbal or non-verbal?

## Non-verbal or written feedback

When providing non-verbal or written feedback, it needs to be tailored to the population you are researching. The content of feedback needs to be engaging and relevant to the intended audience and provide information on the impact of contributions. The language used needs to avoid academic terminology and should be free from jargon in order to be understood by the general/lay public. It is also important to highlight, when researching Black and Asian Minority Ethnic Groups, that while it is often assumed that English is not their first language, research now needs to accommodate second generation Black and Asian Minority Ethnic Groups where English may be the preferred language, even though it is not the first language traditionally associated with those communities (BAME Workshop, 2017). Non-verbal feedback can be in the form of newsletters, emails, websites etc.

## Verbal feedback

Verbal feedback can be used effectively, and it is often a good idea to deliver this by going back to the communities and to venues where the research took place or previous engagement occurred. Ideally this should have been announced early in the study, so participants or communities can be made aware and reassured that feedback has been planned on their input into the research, and to provide information on the work which the research team have conducted.

Verbal feedback can also be communicated through the research PPI or community leaders, although a disadvantage of this method is that there is less control on the message content and, if given via lay members, there may be problems in responding to detailed queries.

Researchers could also organise focus groups with those from the Black and Asian Minority Ethnic Groups using a similar structure to the data collection, to highlight to the communities that feedback is just as important as data collection.

Verbal feedback has been found to have a positive influence on the intrinsic motivation (Vallerand and Reid, 1988) of research participants. The higher the intrinsic motivation the higher the level of engagement, and the more likely individuals are to engage in research in the future (Vallerand and Reid, 1988).

## Feedback can be positive or negative in terms of results - the first rule is to be honest with what has been achieved

Honest feedback is important; for example, there may be negative findings which are not expected by the community, and there may have been barriers leading to the research not being completed satisfactorily (e.g. funding or recruitment issues).

Research findings can sometimes take many years to influence health services, and this needs to be explained to the participants who may be expecting immediate changes as a result of the research.

Any changes to the study protocol or changes to the time scale (or even if the study is to be terminated) needs to be fed back to the participants with appropriate and honest explanations.

## At what stage would you provide feedback?

The time scale when feedback is best provided may vary depending on the type of study and is something to consider when applying for a grant, and in the study protocol.

Feedback can potentially be provided at various stages of the research but will often take place following analysis of the data, or once the findings are ready for dissemination. Faulkner (2004) has suggested it would be beneficial to involve participants in feedback during the analysis stage as this could allow the capture of any perspectives or comments on the interpretation of results.

## Dissemination of research findings

Dissemination of research is often considered only within the academic context, such as, peer reviewed journals, publications, and conferences. It often does not consider the community who have participated in the research findings. Researchers do have an ethical and moral responsibility to disseminate research findings to the community in a suitable and understandable format for that community (Berwick, 2003). Dissemination is important to update those involved as participants, as there is often a long time interval between clinical research being completed and formal publication, and even longer before research findings have an impact on health outcomes and services (Health Economics Research Group, 2008). Chen, et al. (2010) found when working with the community that dissemination is successful when using relevant media, such as, local cinema, and making the findings more relevant to the community, such as, using symbols rather than bar charts. It is important to find a good balance between community and academic dissemination.

## Role of social media

Social media is a positive way to bring both academic and community together as social media is now used on a regular basis by many. Using social media, such as, Facebook, Twitter, and blogs can improve knowledge for both the local public and experts. It is a channel where good practice can be shared between experts and immediate feedback provided on findings. For researchers, it can be a cheaper method for reaching a wider audience.

One potential disadvantage is less ability for researchers to control the discussion and comments made by others. Negative comments may impact on future participation (Tinkler, 2004) but an alternative view is that wider debate may allow important lessons to be learnt and considered for future research.

## Case Study 5.1

During September 2014 Leicester City CCG commissioned seven focus groups with ethnically diverse Black and Asian Minority Ethnic Groups participants to discuss the impact of a recent national diabetes prevention poster campaign (RADIATE- Raising awareness and prevention of Type 2 diabetes). The focus of the research also included how to raise awareness, and knowledge of how to prevent Type 2 diabetes, within Black and Asian Minority Ethnic Groups communities. The project team not only provided feedback on the findings of this project to many of the project's participants, but also developed a number of initiatives in response to the findings.

These initiatives involved physical activity, dietary interventions, and education, as well as Type 2 risk assessments in community settings. These were undertaken in collaboration with Black and Asian Minority Ethnic Groups communities, voluntary organisations, Leicester CCG, Centre for Ethnic Health Research, and Loughborough University's National Centre for Sports and Exercise Medicine.

## Case Study 5.2

Following a £2m, five-year research programme, a booklet was written to help people living with bipolar disorder advance plan for times when they might lose capacity to make their own decisions. The guide went through the advance planning options that are currently available.

The self-management guide was one part of a £2m NIHR programme called PARADES and was led by the University of Lancaster in collaboration with Manchester and Nottingham.

The Centre for Ethnic Health Research ran a number of community-based discussion groups about the acceptability of the self-management guide. The findings included that it had too much written information, that the booklet itself was overwhelming, and that it should be applicable to all communities and mental health conditions. In response the Centre has led the redevelopment of the booklet to make it accessible to a wider audience and inclusive of all communities.

## Top Tips



1. Include opportunities for giving feedback in your research proposal (e.g. in research dissemination or PPI section).
2. Provide feedback as soon as you are able to/avoid too much delay.
3. Use local community radio stations, social media (Facebook, Twitter and WhatsApp groups) or theatre productions for dissemination, as this will provide an opportunity for interaction and collective engagement of communities, commissioners, researchers, and service providers leading to service planning/ better health outcomes.
4. Feedback needs to be appropriate to the generation of the Black and Asian Minority Ethnic Groups community (BAME Workshop, 2017).
5. Make sure feedback is relevant to the individual/ focus groups, i.e. tell them their contribution (Hattie and Timperley, 2007).
6. Deliver feedback which is appropriate to your participation group, i.e. make sure feedback is not too complex and is free from jargon (Hattie and Timperley, 2007).
7. Provide information about the progress made and the next steps.

# THE TOOLKIT

## SECTION 6:

Recognising the importance of recruiting Black and Asian Minority Ethnic Communities in research: preparing a grant application



### Preparing Grant applications

It is important to highlight the relevance of ensuring representative recruitment in your research grant application. Most funding bodies now recognise the importance of ensuring research studies are fit for purpose, and will give due recognition to studies which have carefully considered a recruitment strategy which includes addressing barriers or obstacles.



Why?



How?



Case Study



Top Tips

The 2017 NHS England research plan is subject to the Equality Act 2010 and emphasises the importance and duty the NHS has in promoting research to reduce health inequalities (NHS England, 2017). We suggest that it is a good idea, where possible, to discuss with the funder some of the issues with respect to appropriate recruitment of Black and Asian Minority Ethnic Groups. This is particularly so if the clinical area is one which will impact on these populations or help address health inequalities.

Gaps in current knowledge or previous studies which have not addressed this population should be identified and brought to the attention of the funding body (usually by a literature review).

A good way to make a powerful case for a Black and Asian Minority Ethnic Groups specific strategy as part of your study is to include feedback/ engagement data from patients and communities. Pilot study data (e.g. illustrating recruitment difficulties or highlighting good ways to recruit) is also a powerful way to influence research funding bodies.

A strong proposal for PPI within the project structure is also important.

Having good communication with the community being researched is important; the researcher needs to network well within the community and gain their trust. Input may be better coming from a community member themselves, such as a 'champion'. Professional researchers need to have a positive attitude towards the communities amongst which they are undertaking research.

Allowing more time in the planning stage creates a sense of ownership within the community as well as allowing relationships to build. There is likely to be greater success where there is ownership and where the community has a significant level of decision making opportunity.



## Funding proposals

Funding appropriately is a balancing act; on the one hand, available funds within a call for bids may be restricted, but on the other hand, research in Black and Asian Minority Ethnic Groups can result in extra costs. To balance this potential dilemma, you will need to consider how to make your bid as cost effective as possible.

Whilst it is important to consider ethnicity within all design stages, whatever flexibility the funding body is prepared to allow needs to be understood at the outset, so you can 'pitch' your bid at the correct level.

Where possible extra costs should be identified, and consideration given to the following additional costs that might be required.

### 1. Research team costs:

- Cultural awareness training
- Extra travel costs to community venues
- Costs of PPI
- Extra costs of bilingual staff

### 2. Conducting research costs:

- Hire of venues
- Promotion of study costs (e.g. radio/ TV, literature, posters)
- Translation/ interpretation
- Workshops/ focus groups with communities
- Extra transcription costs
- Refreshments
- Extra time required for study

### 3. Dissemination costs:

- Social media
- Conventional media
- Public meetings
- Translated reports

## Making your bid cost effective

These are issues you may wish to consider:

1. Do you really need translation/ interpretation? Increasingly, members of Black and Asian Minority Ethnic Groups do speak English or relatives are able to interpret. Consider what is really needed in your study.
2. Can you undertake recruitment in a single venue (e.g. a community centre) at specific times in order to minimise travel and researcher time?
3. Make use of free community resources, e.g. community radio stations. There is a lot of good will in the community and often this can be used to support research which Black and Asian Minority Ethnic Groups value.
4. 'Piggy back' onto existing work in communities, e.g. undertaken by public health or the NHS.
5. Recruit a multilingual researcher as part of your core team.
6. Be clear on study size and stick to the number of recruits you actually need in the study.
7. Make use of other resources to support your research, such as, any local expertise in Black and Asian Minority Ethnic Groups research, support from organisations whose remit is to promote research or reduce health inequalities, such as, the CRNs (Clinical Research Networks), CLAHRCs (Collaborative Leadership in Applied Health Research and Care), CCGs (Clinical Commissioning Groups), and organisations which support research training.

### Case Study 6.1

A research team looking at undertaking an awareness study in Black mental health found that once the local community became aware of the proposed study, they became instrumental in helping to identify affected families, put on a free engagement event at the local African-Caribbean centre, and volunteered individuals to help collect data.

They provided free transport for participants to attend the venue.

This greatly reduced the time and resources required by the research project.

### Case Study 6.2

A study looking at heart health in South Asians recruited 2 multilingual researchers as part of the research team. The local research support service provided free training to the researchers, so they were fully competent in the work required.

The study was a face-to-face questionnaire study. The multilingual researchers reduced the need for any translated materials or interpretation costs, which would otherwise have made the study impossible to conduct within the resources available.

## Top Tips



1. Be explicit about the need to include specific communities in your research and why it is important. Include as much data as possible to support this.
2. Ensure you include the extra costs of research associated with including Black and Asian Minority Ethnic Groups, e.g. production of participant materials, training costs, PPI costs, recruitment costs, travel costs, extra time for engagement.
3. Have a clear PPI strategy for your project.
4. A pilot study, including the Black and Asian Minority Ethnic Groups perspective and potential challenges of recruitment, will be valuable.
5. Include the key sections of this Toolkit as part of your application, as appropriate.
6. Where possible, include the community as part of your application (e.g. via quotes, testimonials to support, or co-application)
7. Make sure you have had initial consultations with community members or groups in formulating your research idea and outline proposal.
8. Use all the available support to minimise your extra research costs.

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