



# **Patient and Public Participation**

Equality and health inequalities – full analysis and associated resources

## NHS England INFORMATION READER BOX

Directorate		
Medical	Operations and Information	Specialised Commissioning
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance	<del></del>	

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## **Document Status**

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# Equalities and health inequalities full analysis form

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Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

#### Part A: General information

## 1 Title of project, programme or work

Patient and public participation in commissioning health and care: statutory guidance for clinical commissioning groups (CCGs) and NHS England

#### 2 What are the intended outcomes?

Through this refreshed guidance NHS England is seeking to strengthen participation across the NHS, including policy making and commissioning (the process of planning, buying and monitoring health services) both for CCGs and for NHS England.

Under the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012), CCGs and NHS England have duties to involve the public in commissioning, under sections 14Z2 and 13Q respectively. The wording of these duties is set out in Appendix A of the statutory guidance document. The guidance is statutory and CCGs must have regard to it, as must NHS England staff.

NHS England's ambition, in line with the <u>NHS Constitution</u> and the NHS <u>Five Year Forward View is</u> for patients and the public to be at the heart of everything the NHS does.

Patient and public participation is important because it helps the NHS to improve all aspects of health care quality, including:

- patient safety
- patient experience and
- health outcomes giving people the power to live healthier lives.

Participation, by the people who use and care about services, enables the NHS to understand and respond to their needs, including those people who have the poorest health. This helps us to improve access to services and reduce differences in health in different communities. It helps us to see things through other people's eyes and to be innovative, leading to better use of taxpayers' money.

For NHS England, this work is underpinned by its <u>Patient and Public Participation Policy</u>. NHS England also has a suite of documents to strengthen patient and public participation in the services it is responsible for commissioning (the process of planning, buying and monitoring). There is one <u>framework for patient and public participation for each area of NHS England direct commissioning</u>.

This analysis applies to all the documents referred to above.

This guidance will support business plan priorities nine and 10, around transforming commissioning for patients and involving patients and the public and addressing health inequalities.

### 3 Who will be affected by this project, programme or work?

This work may affect patients, carers, service users, members of the public, NHS England's public sector partners, stakeholder bodies, the voluntary and community and social enterprise (VCSE) sector and others with an interest in and/or who are, or may be, affected by the work of the NHS.

The primary audiences for the refreshed guidance are CCGs and NHS England staff locally, regionally and nationally. It will also be of interest to patients and the public, local authorities and providers of health and social care. A range of partner organisations have an interest in the development and ongoing implementation and review of the guidance, including VCSE organisations and networks, patient groups and local Healthwatch.

# 4 Which groups protected by the Equality Act 2010 and/ or groups that face health inequalities are very likely to be affected by this work?

The programme of work aims to increase levels of participation across the NHS for all, with a particular emphasis on enabling approaches which increase engagement from those who are less frequently heard and who experience the greatest inequalities in health outcomes, including 'protected characteristic' and 'inclusion health' groups.

Whilst this document considers specific barriers and enablers for these groups, it is important to take a holistic approach to planning and delivering approaches to participation, recognising that people can experience multiple disadvantages and barriers which cannot be addressed by taking a 'tick box' approach.

We anticipate that the statutory guidance will have a positive impact, including on 'protected characteristic' and 'inclusion health' groups as detailed in the following sections. Following a review of evidence, detailed below, we have identified the following barriers and enablers for different groups, which will inform further development and implementation of the support for participation in commissioning.

# PART B: Equalities groups and health inequalities groups

## 5 Impact of this work for the equality groups listed below

People with protected characteristics may experience discrimination when seeking to engage in public participation activities. It is anticipated that this guidance will contribute to advancing equality and good relations, and support compliance with the public sector equality duty.

Following a review of the evidence (references provided) some potential barriers to participation, and actions that may be taken by commissioners to address any potential adverse impact in relation to protected characteristics, have been considered below.

#### 5.1. Age

Potential barriers and actions to address potential adverse impact:

- Virtual meetings (such as internet and email technology) may have a negative impact on older people, who are less likely to engage digitally. Conversely, they may have a positive impact for older people who are more likely to have mobility issues and may be less able to travel and participate in person.
- Virtual meetings can encourage participation by more young people, who have been traditionally under-represented in engagement and participation activity.
- Commissioners should therefore use a range of appropriate participation approaches based on the specific needs of the group concerned, offering alternative approaches where necessary.
- Commissioners should consider working with networks and organisations that already engage with older people and young people.
- Where possible commissioners should use virtual approaches alongside more traditional participation approaches, for example offering paper copies of online surveys.
- Commissioners should consider the timings of any meetings or events to ensure that this is suitable for the people of different ages and enables wider access (for example considering school or college times, work time, evenings etc).
- All commissioners should have systems in place to ensure that expenses are
  reimbursed promptly and in full. Both young and older people may experience
  financial barriers to engagement and the cost of attending participation events
  may exclude people. NHS England commissioners should refer to the <a href="NHS England Patient and Public Voice Partners Expenses Policy">NHS England Patient and Public Voice Partners Expenses Policy</a> for further
  guidance about expenses and participation payments.

#### **Supporting evidence and resources**

#### Older people:

- Age UK: Engaging with Older People Evidence Review
- Social Care Institute for Excellence <u>At a glance 61: Coproduction and</u> Participation Older People with High Support Needs

#### Children and young people:

- Not Just a Phase (Royal College of Paediatrics and Child Health)
- Involving Children and Young People in producing health information, Patient Information Forum
- 17 Best Practice Case Studies of Children and Young People Engagement
- Tools and resources from 'Me First' to improve communication between children and Young People and Health Care Professionals
- Children's key worker service evaluation project from CLIC Sargent

#### 5.2 Disability

Potential barriers and actions to address potential adverse impact:

- People with disabilities ('disabled people') experience a range of barriers to participation, including those associated with physical, financial and societal factors. These barriers include, but are not limited to, the following:
  - Disabled people may experience difficulties and barriers to participating in face to face meetings, workshops and events due to the inaccessibility of venues, including a lack of 'level floor' or 'step free' access, an absence of lifts or accessible toilets, inaccessible transport or travel facilities, a lack of communication or other support.
  - Disabled people may experience barriers to virtual engagement due to being digitally excluded. Inaccessible websites and electronically published information can result in users being unable to access websites and documents which are not compatible with assistive technologies such as screen readers (these convert text to speech for people who are blind, deafblind or have visual loss).
  - Disabled people may experience barriers to engagement due to inaccessible information (in both printed and online formats). This includes barriers to accessing 'standard' printed English documents and/or a need for information in alternative formats such as braille, audio or 'easy read'.
  - Disabled people continue to experience stigma, disadvantage and poorer health outcomes as well as, often, poorer care. Such negative experiences may also pose barriers to their active engagement.
- Commissioners should consider the barriers experienced by disabled people, including access needs, when developing approaches to participation to ensure that activities are designed appropriately. This includes considering the barriers highlighted above, and how they can be addressed. It also includes considering the barriers known to be commonly experienced by people with different disabilities and taking steps to overcome them. Such groups include people with sensory loss (people who are blind, d/Deaf or deafblind, and people with hearing and/or visual loss), people with limited mobility (including people who use a wheelchair and people with other physical access needs), people with a learning disability, people with mental health conditions, and people with long term conditions (such as chronic obstructive pulmonary disease or cardiovascular disease) who may, for example, need clinical or personal care support when attending meetings.

- Effective planning for participation is necessary to ensure that engagement is accessible, including identifying individuals' needs in advance and considering resource and budget implications. Registration processes for events and meetings, and application processes for recruiting lay voices, should include questions about access and communication needs, to enable actions to be taken to ensure that such needs can be met. This includes ensuring funding is available for specific access needs, for example provision of British Sign Language (BSL) interpreters and/or speech-to-text-reporters (STTR) where appropriate/required. Sufficient time should be built into planning processes to ensure that access requirements can be addressed appropriately. It is also useful to consider how energy levels may impact on timetable planning.
- Consideration should be given to identifying, recording and making provision for the accommodation of carers, support workers or personal assistants who may support some disabled people at events or meetings. This includes enabling sufficient time for participants to arrange support.
- Commissioners should also seek to create an inclusive environment which
  enables people to participate in the way which works best for them. This should
  include considering the environment itself, the provision of alternative means of
  engaging, and consideration of the time of events (for example the length of
  meetings and start and finish times). Meeting agendas should give consideration
  to access requirements.
- Commissioners should consider following the 'five step' process set out by the
   <u>Accessible Information Standard</u> to meet disabled people's participation needs.
   That is, they should ensure such needs are consistently and proactively identified,
   recorded, 'flagged' (made highly visible), shared (with colleagues as appropriate)
   and met.
- Virtual meetings should be considered where this will help improve access for people who may not be able to attend in person. However, virtual approaches may not be suitable for everyone.
- Commissioners should consider working with existing organisations and networks of people with disabilities.
- People with disabilities experience multiple barriers to employment and the cost
  of attending participation events may exclude people. NHS England
  commissioners should refer to the <a href="NHS England Patient and Public Voice">NHS England Patient and Public Voice</a>
  <a href="Partners Expenses Policy">Partners Expenses Policy</a> for further guidance about expenses and participation
  payments.
- NHS England commissioners should use the <u>NHS England Accessible</u> <u>Information and Communication Policy</u> to ensure that disabled people (and people with limited or no English) receive accessible information and communication support.
- Consideration should be given to how best to build trusting relationships with those who may wish to participate, taking into account how poor experiences may have contributed to a lack of trust. Coproduction approaches and jointly establishing terms of engagement can help with this.
- People with disabilities, including people with learning disabilities, may be considered 'vulnerable adults' and commissioners should refer to the <u>NHS</u> <u>England Safeguarding Policy</u> to ensure that appropriate actions are taken in this regard.

#### Supporting evidence and resources

#### General:

- Making health and social care information accessible report of consultation 13
   August 09 November 2014 and the Analytical Report on the consultation
- Making health and social care information accessible: Report of engagement activity November 2013 – February 2014 and the <u>Analytical Report on the</u> engagement activity
- Involving Disabled People in Policy Development
- Involving disabled people: an introduction
- Involving Black Disabled People in Shaping Services

#### Learning disability:

- Barriers to participation for people with a learning disability: <u>Valuing People: A</u>
   <u>New Strategy for Learning Disability for the 21st Century (Department of Health, 2001)</u>
- <u>Mencap Involve Me:</u> How to creatively involve people with profound and multiple learning disabilities in decision making.

#### Sensory loss:

- Access all Areas? (Action on Hearing Loss, 2013): A report into the experiences
  of people with hearing loss when accessing healthcare.
- Action Plan on Hearing Loss (NHS England, 2015)
- <u>Report</u> from the initial consultation event on SCCI (Standardisation Committee for Care Information) 1605
- Improving deafblind patient and carer public voice in the NHS
- A film of the panel session on participation discussing good and bad experiences.

#### Mental health:

<u>Involvement to Influence: 4Pi National Involvement Standards, National Survivor User Network (NSUN), March 2015</u>

Evidence relating specifically to participation in primary care:

- Mencap: GP Toolkit
- Sense guide for primary care professionals on identifying and supporting patients with dual sensory loss.

#### 5.3. Gender reassignment

Please note: gender reassignment is a personal process (rather than a medical process) which involves a person expressing their gender in a way that differs from or is inconsistent with the physical sex they were born with. This section includes information about transgender (trans) and non-binary people (people who do not define their gender as exclusively male or female).

Potential barriers and actions to address potential adverse impact:

- Trans and non-binary people especially experience multiple barriers to
  employment including discrimination and the cost of attending participation
  events may exclude people. NHS England staff should refer to the <a href="NHS">NHS</a>
  England Patient and Public Voice Partners Expenses Policy when planning
  activity and ensure that transactions are processed efficiently.
- Many trans and non-binary people are anxious about disclosing their status and may have distrust in authority figures.
- Commissioners should ensure that confidentiality is respected and seek to create inclusive and supportive environments. This will also help to build trust.
- Trans and non-binary people may suffer from mental health problems and find it difficult to participate. Consideration should be given to this when planning engagement activities.
- Name and pronoun badges. Many trans and non-binary people feel unable to participate in events where they fear they will be misrepresented referred to by he instead of she, or by she instead of they, for example. This is particularly true for non-binary people. Introducing name and pronoun badges and normalising the idea of asking someone what their pronouns are, rather than guessing their gender based on appearance, will make trans and non-binary people feel more included and catered for.
- Consideration should be given to how best to build trusting relationships with those who may wish to participate, taking into account how poor experiences may have contributed to a lack of trust. Coproduction approaches and jointly establishing terms of engagement can help with this.

#### Supporting evidence and resources

- Men's Health Forum guide for Trans Men
- Action for Trans Health Non-binary Research
- Falling Through the Cracks: Non-binary people's experiences of transition related healthcare
- Trans Mental Health and Emotional Wellbeing Study 2012
- Brighton and Hove Trans Needs Assessment 2015 full report
- Shining the Light: 10 keys to becoming a Trans positive organisation
- Lesbian, Gay, Bisexual and Trans (LGBT) Health and Inclusion Project
- GP Guide: Supporting Patients Accessing Gender Identity Services
- Transgender equality enquiry
- Emotional Wellbeing Study: Scottish Transgender Alliance
- What's it got to do with you? Stonewall

#### Elearning resources

- Guidance for GPs: Gender Identity Research and Education Society (GIRES)
- Guidance for professionals and families on caring for gender variant young people
- GIRES trans health factsheets

#### 5.4. Marriage and civil partnership

This equality group does not face discrimination in this work area. The guidance is not expected to have a specific impact on this protected characteristic.

#### 5.5. Pregnancy and maternity

Potential barriers and actions to address potential adverse impact:

- Travelling to face to face meetings could be more difficult for pregnant women in the late stages of pregnant or while caring for young children.
- Where appropriate, commissioners should work with networks, groups and providers to develop accessible approaches to engagement.
- Virtual meeting approaches should be considered alongside more traditional approaches to ensure opportunities for engagement are accessible to those who do not wish to travel due to pregnancy or caring commitments. Telephone and online survey approaches can also be used.
- Consideration should be given to how to enable participation for people with caring responsibilities.
- Commissioners should refer to the <u>NHS England Patient and Public Voice</u>
   <u>Partners Expenses Policy</u> for further guidance about expenses and participation payments for NHS England staff, including the potential to provide childcare expenses.
- Events should be organised in a way that is accessible to those who are caring for children, for example by providing facilities for children and for women who are breastfeeding.

#### 5.6. Race

Potential barriers and actions to address potential adverse impact:

- Some ethnic groups have poor experiences of services resulting in lack of trust, for black, Asian and minority ethnic (BAME) groups with mental health services and Gypsy Traveller groups experiencing discrimination. This may make them reluctant to take part in mainstream engagement such as public meetings. Commissioners need to consider a range of engagement approaches, such as outreach and working through community organisations.
- BAME people are under represented in many decision making arenas, especially among senior NHS managers and in elected office. Demographic information, including on race, should be collected for people involved in health services. Commissioners should create supportive and inclusive environments, including considering how best to support BAME people to develop their confidence and capacity to engage effectively. There should be a focus on recruiting citizens for governance roles from diverse communities.
- For some minority ethnic communities, levels of literacy, and health literacy, may be lower and English will not be spoken or read by all. Communication support needs to be considered by commissioners to support participation, including access to translation services and availability of easy read documents.

- Commissioners should collaborate with local government, voluntary sector and NHS provider partners, building on their existing engagement with BAME communities and sharing data and intelligence on BAME groups. Voluntary, community and social enterprise (VCSE) sector and faith group partners can act effectively as intermediaries by providing commissioners with information that helps to engage the target group.
- Commissioners should consider support for existing community structures and networks that act as a voice for local communities and create links into BAME groups that are seldom heard. For example health link workers, networks and health champions have demonstrated success in building relationships with BAME service users and carers - increasing understanding of needs, developing trust, and increasing BAME people's involvement in service planning and provision.
- Consideration should be given to how best to build trusting relationships with those who may wish to participate, taking into account how poor experiences may have contributed to a lack of trust. Coproduction approaches and jointly establishing terms of engagement can help with this.
- Special efforts are needed to support participation by groups within BAME communities who may experience multiple discriminations, for example people with learning disabilities, lesbian, gay, bisexual, trans and non binary people.

#### Supporting evidence and resources

- How to engage with Gypsies and Travellers as part of your work: <u>Leeds Gate</u> Toolkit
- Dancing to our own tunes; Reassessing black and minority ethnic mental health service user involvement, NSUN/Afiya Trust, reprinted 2013
- The "snowy white peaks" of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England. Kline, Roger. 2014.
- Improving Access to Psychological Treatment (IAPT) Black and Minority Ethnic (BME) Positive Practice Guide
- NHS Confederation: Engaging with BME communities: insights for impact
- University of Birmingham: Learning Disabilities and BME Communities: Principles for Best Practice
- Mind: Mental health crisis care: commissioning excellence for Black and minority ethnic groups. A briefing for Clinical Commissioning Groups March 2013.

#### 5.7. Religion or belief

Potential barriers and actions to address potential adverse impact:

- Commissioners should consider religious diversity when planning for participation, including ensuring that events are accessible and inclusive. This should include consulting a multi faith calendar and considering other faith specific needs such as dietary requirements.
- Commissioners should take steps to ensure that choice of venues for meetings or events are not exclusive or off putting for people of different faiths, and ensure that registration processes ask questions about dietary requirements.
- Religious diversity can be overlooked when targeting engagement activity.
  This can have specific relevance in some healthcare settings. Commissioners should therefore consider the potential impact of their work on different religious groups when planning participation activity to ensure the right people are engaged, for example some faith groups have specific end of life requirements.
- Consideration should be given to how best to build trusting relationships with those who may wish to participate, taking into account how poor experiences may have contributed to a lack of trust. Coproduction approaches and jointly establishing terms of engagement can help with this.
- Faith communities often provide community based support and can be a useful conduit for engaging with excluded groups

#### Supporting evidence and resources

- Guidance on Equality of 'Religion or Belief' British Humanist Association
- Religion or belief: A practical guide for the NHS
- Making religious diversity work for your trust: Catholics in healthcare
- The Impact of Faith-Based Organisations on Public Health and Social Capital (FaithAction 2014)
- Working with faith groups to promote health and wellbeing (LGA 2017)

#### 5.8. Sex or gender

The development and implementation of the statutory guidance is not expected to have a differential impact on men and women. It is anticipated, however, that this guidance will contribute to advancing equality and good relations and supporting compliance with the public sector equality duty.

Potential barriers to participation and actions that may be taken by commissioners to address any potential adverse impact have been considered as follows:

#### Women

- Travelling to face to face meetings could have a negative impact for women, as evidence suggests they are more likely to have caring responsibilities. Virtual meeting approaches should be considered alongside more traditional approaches to ensure that opportunities for engagement are accessible to those who do not wish to travel due to caring commitments. Telephone and online survey approaches can also be used. Crèche facilities or support with childcare/carer costs can support participation, as can avoiding school holiday times.
- Women are under represented in many decision making arenas, especially among senior clinicians and in elected office. Public meetings can be dominated by those more familiar with participation, and by men. Demographic information, including on gender, should be collected for people involved in health services. Commissioners should seek to create supportive and inclusive environments, including considering how best to support women to develop their confidence and capacity to engage effectively. A range of options should be considered to engage women, including the option for women only sessions.
- Women are at greater risk of poverty than men and are more likely to suffer recurrent and longer spells of poverty (22 per cent of women have a persistent low income compared to 14 per cent of men, and the current gender pay gap for full time workers is 19.7%). Offering to reimburse travelling expenses will help to avoid excluding women living in poverty. Commissioners should refer to the <a href="NHS England Patient and Public Voice Partners Expenses Policy">NHS England Patient and Public Voice Partners Expenses Policy</a> for further guidance about expenses and participation payments.
- Commissioners should consider working with and supporting women's VCSE organisations that can enable women to participate and have a voice. In particular, specialist services for minority groups of women and women only services are often able to reach women who would not otherwise engage with services. Special efforts are needed to support participation by women who are most marginalised. This includes black, minority ethnic and refugee (BMER); women living with HIV; women with experience of prison; Gypsy, Traveller and Roma women; lesbians within the Muslim community; women involved in prostitution; and women who have experienced female genital mutilation (FGM).
- Some groups, such as women from some faith or ethnic minority communities, may find it easier to attend meetings that are women only. However, lesbians from these and other communities (including young women and girls) may find it impossible to speak out in open meetings at all, and may require separate, anonymised modes of engagement, such as focus groups held by representative organisations. Groups that speak for particular sections of the community may be led by men, excluding women's voices. Special care needs to be taken to reach women in those communities. Dedicated spaces for women offer opportunities for women to find their voice, develop collective understanding of the challenges women face, and develop confidence to participate and contribute on the basis of their experience and needs.

- Access should be considered, as women are less likely to have access to private transport than men, and therefore are disproportionately reliant on public transport. Venues should be convenient to public transport and meetings held at times when public transport is running. Research shows that many women do not leave their homes in the evening for safety reasons, and this should be taken into account.
- Differential access to and skills to use technology can limit participation for some women. For example, many consultations and other participation exercises depend on effective use of technologies that are not available across all social groups of women.
- Quotas and other positive action permitted by legislation can help create the structural conditions that encourage women to participate.

#### Men

- Men, especially during working age, are less likely to engage with health services, for example visit a GP or dentist.
- Some health issues are more stigmatised for men, such as mental health, eating disorders or sexual violation.
- Commissioners need to consider a varied range of participation approaches, such as engagement via social media, outreach into workplaces, surveys, focus groups, and working through organisations that support men.

#### Supporting evidence and resources

- WHEC: Better Health for Women
- Women's Health and Equality Consortium (WHEC): 'Women's voices on health: addressing barriers to accessing primary care
- <u>"Engaging the Women's Voluntary and Community Sector: A guide for public bodies"</u>, Women's Resource Centre, July 2011.
- Women's Resource Centre: Defending women only services
- "Why Women Only?" Women's Resource Centre, October 2007
- "Women only Services: Making the case" A Guide for Women's Organisations, Women's Resource Centre, July 2011
- <u>"Factsheet: Women and the Cuts 2012" Women's Resource Centre, October</u> 2012
- "Closing the Gender Pay Gap", Government Equalities Office, February 2016
- Men's health forum

#### 5.9. Sexual orientation

Potential barriers and actions to address potential adverse impact:

- For many lesbian, gay, bisexual and trans (LGBT) people, notably older LGBT people or LGBT people in rural areas, the main barrier is isolation. Isolation can also be caused by poor health, lack of finances or access to public transport. Commissioners should engage with local networks and groups to try and reach more isolated people, including with providers. Quality assurance services such as <a href="Pride">Pride in Practice</a> can help create environments that are conducive to LGBT people coming out to practitioners and sharing their experiences.
- LGBT people report feeling unsafe in certain areas or on certain transport routes because of discrimination and hate crime they have experienced, or feel in danger of experiencing. Holding participation events in locations that are not considered to be LGBT friendly may act as a significant barrier. However, some LGBT people who do not wish to be 'outed' may consider entering an LGBTspecific building a barrier to participation. For example this may apply to some trans people or LGBT people of faith. An enabler would be to use localised LGBT specific expertise and experience from VCSE organisations that can consult with the community on preferable locations and transport routes. Additionally, consider having a budget for alternative modes of transport for particularly vulnerable individuals. Flexible approaches to participation can help to ensure the greatest number of people can participate.
- LGBT people are less likely to access or engage with mainstream health services because they are more likely to rate their experiences as poor and fear that they will suffer unequal treatment as an LGBT person. Enablers include being visibly and explicitly LGBT inclusive and utilising local LGBT VCS organisations as a method of communicating with the community to advertise and facilitate participation.
- LGBT people experience higher rates of mental ill health and may not feel
  confident or comfortable to speak up about their experiences and views.
   Commissioners should seek to create supportive and inclusive environments,
  including considering how best to support people to develop their confidence
  and capacity to engage effectively.
- Consideration should be given to how best to build trusting relationships with those who may wish to participate, taking into account how poor experiences may have contributed to a lack of trust. Coproduction approaches and jointly establishing terms of engagement can help with this.
- Commissioners should consider offering alternatives to face-to-face participation approaches, which may encourage participation by LGBT people who do not wish to be 'outed', including online, telephone or paper surveys which enable people to participate anonymously.
- The Information Standard for Sexual Orientation Monitoring provides the mechanism for recording the sexual orientation of all patients/service users aged 16 years and over across the whole of health and social care in England in all areas where it may be relevant to collect this data.

#### **Supporting Evidence and resources**

- The LGBT <u>Adult Social Care Outcomes Framework (ASCOF)</u> is the
  Department of Health's key tool for measuring the progress of the adult social
  care system, supporting understanding of the outcomes and experiences of
  people who use care and support, and carers. The LGBT <u>Public Health</u>
  <u>Outcomes Framework Companion Document</u> brings together the existing
  evidence on the care and support needs of LGBT people, recognising that the
  picture it paints is necessarily incomplete.
- The LGBT Public Health Outcomes Framework Companion Document is a resource for all those commissioning and delivering healthcare services in order to support the delivery of an equitable public health system.
- <u>Sexual Orientation Monitoring Guidance</u> 'Everything you always wanted to know about sexual orientation monitoring but were afraid to ask' highlights that investing in equality makes good business sense, as understanding the needs of staff and service users leads to more targeted and successful work, saving money in the long run.
- <u>Pride in Practice</u>: Endorsed by The Royal College of GP's, pride in Practice is a support package that enables you to effectively meet the needs of your lesbian, gay and bisexual patients. It will also support in meeting the requirements of CCGs, the Care Quality Commission and other bodies.
- <u>Unhealthy Attitudes</u>: YouGov research conducted for Stonewall reveals that LGBT people are facing unhealthy attitudes from health and social care professionals.
- The RaRE study, Risk and Resilience Explored PACE was funded by the Big Lottery Fund to undertake a major research study on inequalities in mental health in LGBT people in England.

# 6 Implications of our work for the inclusion health groups listed below

This programme of work includes a commitment to facilitating effective engagement with people whose voices are less often heard by commissioners and policy makers.

Whilst barriers for specific groups vary, we expect commissioners to take a flexible and responsive approach to engagement activity which recognises the need to enable people from all sections of society to benefit. They should plan participation in advance and 'design in' accessibility and inclusivity by:

- offering a range of participation approaches
- working with trusted partners (including those from the VCSE sector)
- asking about access or support needs as part of registration and recruitment processes (and having an identified budget to meet such needs).

This will help ensure that participation is as accessible and inclusive as possible to the widest group of people. This includes the 'inclusion health' groups listed below. Further information about some key identified groups is also listed below.

#### 6.1. Alcohol and/or drug misusers

Please see note above and section 6.4

#### 6.2. Asylum seekers and /or refugees

Please see note above

#### 6.3. Carers

Potential barriers and actions to address potential adverse impact:

- Consideration should be given to creating flexible approaches to engagement which enable carers to participate in a way that works with their caring responsibilities. This may include virtual meeting approaches and organising activities at times which fit around other commitments.
- Consideration should be given to offering alternatives to face to face
  participation, including online or telephone surveys, which may encourage
  participation by people with caring responsibilities as it negates the need to
  travel or make alternative arrangements to support the cared for person.
  However, many older carers may be digitally excluded, so their participation in
  online activities should not be assumed.
- Commissioners should work with carer support organisations in the voluntary and community sector to support and facilitate participation from a diverse range of carers of all ages and backgrounds.
- When designing participation approaches, commissioners should consider
  how to ensure that the views of carers and of people who are 'cared for' are
  heard. In relation to NHS England, the <a href="NHS England Patient and Public Voice Expenses Policy">NHS England Patient and Public Voice Expenses Policy</a> makes provision for covering costs to enable carers to attend
  meetings or events (either with or without the cared for person).
  Commissioners should make this provision clear in pre event communications
  and in application packs for lay voice positions.

#### Supporting evidence and resources

- Carers Strategy, UK Government actions for 2014-16
- Good practice in working with young carers
- Engage Toolkit Supporting Black and Minority Ethnic Family Carers

#### 6.4. Veterans and armed forces families

Veterans and armed forces families experience a range of barriers to participation, including those associated with both physical and mental health, financial and societal factors.

Potential barriers and actions to address potential adverse impact:

- Lack of understanding and sensitivity about military culture among GPs and other key health care professionals.
- Poor understanding and inconsistency about commitments made under the Armed Forces Covenant regarding prioritisation of clinical needs.
- Access to services can be problematic for veterans as a result of presenting health needs. For example, veterans may present with a complex range of behavioural problems that do not fit service access criteria, such as anger and excessive or problematic alcohol use combined with social care problems. This can in turn impact on where and how veterans can engage in participation opportunities.
- One of the largest care gaps perceived by stakeholders is for families and carers, including recognising and addressing the needs of children of veterans. Particular concerns are expressed about access to child and adolescent mental health services (CAMHS).
- Commissioners should consider the wider access needs for both veterans and armed forces families when developing approaches to participation to ensure that activities are designed appropriately.
- Effective planning for participation is necessary to ensure engagement is meaningful and achieves the objectives.
- Commissioners should consider working with existing organisations and networks of veterans and armed forces families as part of a flexible range of methods.
- Recognition of the needs of family members, including children and parents of veterans, that takes account of the wider determinants of health such as access to employment and adequate housing.
- Commissioners should be aware of the Armed Forces Covenant a promise from the nation that those who serve or have served, and their families, are treated fairly.

#### **Supporting evidence and resources**

- Framework for patient and public participation in armed forces commissioning
- Call to mind: A framework for action
- A UK household survey of the ex-service community
- The Royal British Legion and Poppyscotland Policy statement The veterans' transition review
- The Armed Forces Covenant

#### 6.5. Those who have experienced female genital mutilation (FGM)

Please see introductory note in section 6 and section 5.8

#### 6.6. Gypsies, Roma and Travellers

Please see introductory note in section and sections 5.6 and 5.8

#### 6.7. Homeless people and rough sleepers

Please see introductory note in section 6

#### 6.8. Those who have experienced human trafficking or modern slavery

Please see introductory note in section 6

#### 6.9. Those living with mental health issues

Please see section 5.2 above

#### 6.10. Sex workers

Please see introductory note in section 6

#### 6.11. Trans people or other members of the non-binary community

Please see section 5.3 above

#### 6.12. The overlapping impact on different groups who face health inequalities

Please see introductory note in section 6

### 7 Other groups that face health inequalities that we have identified

#### **Health and justice services**

The NHS England Patient and Public Participation Policy and frameworks, and associated work programmes, seek to enhance the level and quality of participation across NHS England's business and commissioning responsibilities. Emphasis is given to enabling approaches which seek to increase participation from those whose voices are less frequently heard,

Over recent years, there have been efforts in the criminal justice system to promote and develop the involvement of offenders in the services they use. Playing an active role in their community and taking on a measure of responsibility can assist in the offender journey away from crime. Service user involvement can also have a tangible and positive impact on the individuals involved by boosting their confidence and skills; this can lead to other opportunities such as training or employment.

Health and justice settings include health service provision in the following areas:

- prison healthcare (including Youth Offending institutions)
- secure mother and baby units
- liaison and diversion services in community, courts and police custody
- sexual assault referral centres
- immigration referral centres, short term holding facilities, pre removal accommodation.

• Settings for children and young people, including secure children's homes, secure training centres.

Involving patients and the public in health and justice services comes with some inherent challenges that are unique to these settings and also to the groups of individuals, such as victims and people with complex needs. The issues outlined below can present significant challenges that make it hard for service users from justice settings to get involved:

- People in secure settings will experience barriers to digital participation and will not usually be able to attend public events without special permissions.
- Different settings will have different security arrangements; understanding the needs of the service users and the establishment regime will be important in order to develop appropriate and creative approaches to engagement.
- Lack of fixed address preventing access to services.
- There are groups who face specific barriers to participation in health and justice commissioning, and whose specific needs must be taken into account, such as:
  - o children and young people
  - o families and carers
  - o patients and service users with disabilities
  - o black, Asian and minority ethnic groups
  - o women.

There is evidence that those using health services in justice settings often have poorer health outcomes, are more likely to experience mental health difficulties, and experience greater health inequalities than other groups in society.

Commissioners of health services in health and justice settings should have arrangements for hearing the voices of these people and groups in line with our duties under equalities legislation.

- Commissioners should consider the wider access needs when developing approaches to participation to ensure that activities are designed appropriately.
- Effective planning for participation is necessary to ensure that engagement is meaningful and achieves the objectives.
- Recognition of the needs of family members including children.

Independent service user/patient feedback is critical, where service users have been able to speak freely without fear of repercussions from providers or staff within services.

Effective involvement and participation is essential for successful development of appropriate and sensitive evidence based services.

#### Supporting evidence and resources

- Guide to service user involvement and coproduction
- <u>Liaison and diversion manager and practitioner resources: Service user involvement</u>
- Framework for patient and public participation in health and justice commissioning

#### Those with lower levels of health literacy

Health literacy is defined as the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. In England, 43% of working age adults do not understand routinely published health information. Those with lower levels of health literacy are disproportionately from lower socioeconomic classes and BAME groups. Additionally, traditional methods of patient and public engagement exclude those with lower levels of health literacy.

#### Supporting evidence and resources

- Improving Health Literacy to Reduce Health Inequalities
- From tokenism to empowerment: progressing patient and public involvement in healthcare improvement

# PART C: Promoting integrated services and working with partners

# 8 How can this work increase integrated services and reduce health inequalities?

Through this refreshed statutory guidance we will promote the use of joint approaches to participation, particularly between NHS organisations and local authorities. Commissioners are encouraged to engage in a way that is logical and meaningful for citizens and that promotes integrated approaches to service development. We also emphasise the importance of working with the VCSE sector as means of enhancing participation.

# **PART D: Engagement and involvement**

#### 9 Engagement and involvement activities already undertaken

This updated analysis has drawn extensively from an earlier analysis developed in early 2016. Stakeholder engagement included:

- Working with the Voluntary Sector Strategic Partners that cover all protected groups and many 'inclusion health' groups to gather evidence and identify issues.
- Drawing on the NHS England Youth Forum, Transgender Network, Learning Disability Engagement team in the development of the Accessible Information Standard.
- Including specific questions related to the equalities and inequalities impacts of the policy in all engagement activity.
- Developing working groups for the relevant policy area has included members with a specific remit to consider impact on groups with protected characteristics.

To update this analysis and expand its remit to cover the statutory guidance for CCGs and NHS England we have undertaken further stakeholder engagement work. This has included:

- A dedicated workshop to gain insights and expertise from 'inclusion health' groups and those with protected characteristics.
- Seeking insight from key partners such as the Voluntary Sector Strategic Partners, CCGs, experts by experience and other key partners.
- Inclusion of specific questions related to the equalities and inequalities impacts of the new guidance in all engagement activity.

We have also undertaken extensive engagement on the statutory guidance itself. Further information is available in the engagement plan.

# 10 Which stakeholders and equalities and health inclusion groups were involved?

Please see section 11.

# 11 Key information from the engagement and involvement activities undertaken

Were key issues, concerns or questions expressed by stakeholders and if so what were these and how were they addressed? Were stakeholders broadly supportive of this work?

Stakeholders have been supportive of the guidance and made a number of constructive suggestions to contribute to this analysis which have been incorporated as appropriate. A general theme has been around placing equal value on the contribution of people with lived experience alongside that of health and other professionals. Further, in specific response to feedback we have:

- Strengthened the section on carers by advocating for the use of the VCSE sector as enablers in effective participation with carers.
- Strengthened the section of veterans by adding a link to the Armed Forces Covenant as an underpinning enabler.
- Strengthened the section on disability by emphasising the need to ensure that not only do meetings need to be accessible, but also designed in a way that enables maximum engagement and removes barriers for example when considering timings and style.
- Added additional links to resources around the role of faith groups in health.

#### 12 Further engagement and involvement activities planned

Are further engagement and involvement activities planned? If so what is planned, when and why?

The guidance will be reviewed to ensure it remains current and updated where necessary, either within the document itself or with supporting resources. The guidance is intended to facilitate ongoing and inclusive participation opportunities across the NHS.

# **PART E: Monitoring and evaluation**

# 13 In relation to equalities and reducing health inequalities, please summarise the most important monitoring and evaluation activities undertaken in relation to this work

The guidance includes a recommendation for all commissioners to collect, review and respond to monitoring data collected about who has been involved in their participation activities. This is intended to support a cycle of continuous improvement and the targeting of future engagement activities.

In relation to the actions identified specifically for NHS England these will be reviewed annually and updated as necessary.

# 14 Please identify the main data sets and sources that you have drawn on in relation to this work. Which key reports or data sets have you drawn on?

This analysis has drawn on a range of literature and research as listed in the relevant sections.

# 15 Planned action to address important equalities or health inequalities data gaps or gaps in relation to evaluation

Monitoring of participant data in relation to protected characteristics is an area that requires improvement. As outlined above the guidance includes a recommendation for all commissioners to collect, review and respond to monitoring data collected about who has been involved in their participation activities. This is intended to support a cycle of continuous improvement and the targeting of future engagement activities.

In relation to NHS England this will be facilitated by the development of an effective customer relations management system to record details of those who engage with the organisation. Where people choose to share equalities monitoring information this will be anonymised, recorded and analysed to measure progress and target future activity.

# PART F: Summary analysis and recommended action

# 16 Contributing to the first Public Sector Equality Duty (PSED) equality aim

This guidance aims to increase levels of participation across the NHS for all, with a particular emphasis on enabling approaches which increase engagement from those who are less frequently heard and who experience the greatest inequalities in health outcomes, including 'protected characteristic' and 'inclusion health' groups. This emphasis, and the practical advice provided both within the guidance, its supporting resources and this analysis, provides commissioners with tools and advice for widening understanding and participation.

## 17 Contributing to the second PSED equality aim

This programme of work will have a positive impact on all groups. Through raising awareness of the needs of 'protected characteristic' and 'inclusion health' groups, and of the importance of hearing from people that have traditionally experienced barriers to engagement, NHS England hopes to enhance understanding, advance equality and promote diversity.

#### 18 Contributing to the third PSED equality aim

This programme of work will have a positive impact on promoting good relations by promoting tolerance and diversity. Through raising awareness of the needs of 'protected characteristic' and 'inclusion health' groups, and of the importance of hearing from people that have traditionally experienced barriers to engagement, we hope to promote good relations between groups.

# 19 Contributing to reducing inequalities in access to health services

The programme of work aims to increase levels of participation across the NHS for all, with a particular emphasis on enabling approaches which increase engagement from those who are less frequently heard and who experience the greatest inequalities in health outcomes, including 'protected characteristic' and 'inclusion health' groups. Engaging those who experience the greatest health inequalities will help us to understand and better respond to their needs.

## 20 Contributing to reducing inequalities in health outcomes

The programme of work aims to increase levels of participation across the NHS for all, with a particular emphasis on enabling approaches which increase engagement from those who are less frequently heard and who experience the greatest inequalities in health outcomes, including 'protected characteristic' and 'inclusion health' groups. Engaging those who experience the greatest health inequalities will help us to understand and better respond to their needs.

## 21 Contributing to the PSED and reducing health inequalities

How will the policy or piece of work contribute to the achieving the PSED and reducing health inequalities in access and outcomes? Please describe below in a few short sentences.

The programme of work aims to increase levels of participation across the NHS for all, with a particular emphasis on enabling approaches which increase engagement from those who are less frequently heard and who experience the greatest inequalities in health outcomes, including 'protected characteristic' and 'inclusion health' groups. Engaging those who experience the greatest health inequalities will help us to understand and better respond to their needs.

## 22 Agreed or recommended actions

The following bullet points summarise principles identified in the course of developing this analysis. These are relevant to CCGs and NHS England:

 It is important that commissioners use a flexible range of methods to hear and engage with potentially excluded groups, or there is a risk that participation will reinforce inequalities in access to services and in health outcomes. For example, some methods such as digital engagement may exclude certain groups, and enable others.

- Planning involvement proactively (including identifying resources and support, and working with partners) helps commissioners to reach equalities protected groups and people that experience health inequalities. A planned approach will maximise involvement from different groups and reduce the risk that participation activities will engage the same groups and individuals. This should include budgets to support accessible engagement.
- Activities should be planned and adapted to ensure equitable access to public
  participation opportunities regardless of a person's cultural, linguistic or
  religious background, or communication and accessibility needs. A holistic
  approach should be taken which recognises people's lived experience and the
  range of barriers they experience, rather than 'tick box' approaches to
  addressing barriers.
- When planning participation activities commissioners should consider how
  they will identify and address the participation needs of those who share more
  than one protected characteristic or those that experience hidden
  discrimination or are part of an 'invisible minority' group such as LGBT people
  within BAME groups.
- Commissioners are required to support the <u>Accessible Information Standard</u>.
   This mandatory standard aims to make sure disabled people have access to information that they can understand, and to any communication support they might need. External stakeholders have highlighted the importance of ensuring that opportunities for people to participate in primary care commissioning are accessible to people with communication support needs.
- Commissioners should connect with existing patient, service users and voluntary sector organisations to reach in to and develop relationships with diverse communities, and especially with people whose voices can be harder to hear.
- Auditing and monitoring participation of equalities protected groups, for example in events and formal governance roles, supports commissioners to manage and improve performance in involving a more reflective range of people.
- Commissioners should review the available insight for evidence of experiences of different patient groups. The GP Patient Survey (GPPS), for example, provides rich and accurate national level data for differences in experience and satisfaction of patients by age, ethnicity, religion, gender, sexuality, long term condition, etc. The survey therefore can be used to clearly identify where there are inequalities at the national level, and any commissioner ought to be aware of these inequalities and looking to see whether these are indeed an issue locally. The GPPS data is also available at CCG level. This can be very useful for comparing patient groups and comparing local estimates with national averages. This can highlight where there may be potential issues that should be followed up with local insight gathering and that therefore may need to be a particular focus of the commissioning engagement activity.

In relation to its own responsibilities NHS England supports a number of targeted engagement approaches which seek to reduce the barriers to engagement for a number of groups. These include:

- National public involvement initiatives and partnerships to reach out to communities and service users from different backgrounds, such as the NHS England Youth Forum and Health and Wellbeing Alliance.
- Working with CCGs and other local partners such as local Healthwatch who access local networks of potentially excluded and vulnerable groups.
- Support and resources, for example as set out in the bitesize guide to <u>diverse</u> and <u>inclusive participation</u> and the <u>Patient and Public Voice Partners</u> Expenses Policy.
- Using a range of involvement approaches, such as health champions and outreach to different groups, communities and organisations. VCSE organisations often work with the most disadvantaged communities - both in geographical areas and with 'communities of interest' (groups of people who have a common interest/need, for example in a particular health condition such as diabetes).
- Including specific reference to the need to consider undertaking an equality and health inequalities analysis in the patient and public participation assessment and planning form.

Following this assessment we have identified a number of short and medium term priorities which seek to further redress inequalities experienced in engaging with NHS England. These include:

- Improving our approach to equal opportunities monitoring across participation opportunities, particularly participation events and on programme boards and committees. This will help us to identify gaps and develop plans to redress these.
- Further development of resources which focus specifically on supporting commissioners and policy makers to engage more effectively with people with protected characteristics and from inclusion health groups.
- Continuing to support commissioners to develop productive relationships with the VCSE sector, particularly those that advocate for people who may otherwise be unable to engage.
- Managing the <u>Involvement Hub</u> which provides access to resources and support for engagement, including opportunities for training for staff and members of the public and promotion of involvement opportunities.
- Actively exploring opportunities for engaging with the 'inclusion health' groups.
- Considering how NHS England can more proactively connect online and offline engagement activity.
- Considering how evidence gaps within this equality analysis can be addressed
- Using a range of communication channels, including <u>In Touch</u>, our newsletter for patients and the public and a range of VCSE networks to promote opportunities for involvement.

Action	Public sector equality duty	Health inequality	By when	By whom
Publication of this analysis alongside the statutory guidance described above.	X	X	April 2017	NHS England
Review progress to improve NHS England's monitoring of equalities data in relation to public participation, subject to successful implementation of the customer relations management system (see Part E)	X	X	March 2018	NHS England

# PART G: Record keeping

27.1. Date draft EHIA circulated to E&HIU	3 March 2017
27.1. Date draft EHIA completed	13 March 2017
27.2. Date final EHIA produced	29 March 2017
27.3. Date EHIA signed off by director	29 March 2017
27.4. Date EHIA published	6 April 2017
27.5. Review date	31 March 2019

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