NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Black, Asian and other minority ethnic groups: promoting health and preventing premature mortality

Date of quality standards advisory committee post-consultation meeting: 24 January 2018

2 Introduction

The draft quality standard for Black, Asian and other minority ethnic groups: promoting health and preventing premature mortality was made available on the NICE website for a 6-week public consultation period between 29 November 2017 and 8 January 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 23 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. The quality standard has statements on specific conditions and on overarching principles for promoting health and preventing premature mortality. Is this approach appropriate and if not what alternative approach would you suggest?

3. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement.

5. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Support for the quality standard and the areas included.
- Concern was raised that some of the quality statements should be applicable to all people not just black, Asian and other minority ethnic groups.
- The quality standard should acknowledge that black, Asian and other minority ethnic groups are not a homogenous population and should not be treated as such when applying this quality standard.
- The application of quality statements should be tailored to the BAME profile of the local population, and assessed separately for the main local BME groups, considering in particular disadvantaged or excluded groups.
- The standard does not seem to reflect on the impact of racism and possible discriminatory past experiences on accessing services in a timely fashion.
- There should be a specific reference to the needs of the Gypsy and Traveller minority ethnic group – this community remains on the margin of BAME politics and practice and can easily be overlooked.
- It should be clarified if this quality standard covers adults only or if it covers children and young people as well.
- The equality impact assessment could be strengthened by providing some more evidence on inequalities faced by the BAME communities and discussing why quality statements and measures were picked up to address those issues. It might also need to discuss the impact of racism on health and well-being.

Consultation comments on question 1

- Mixed response – support for the areas as well as concerns were expressed.
- Concern was raised that the quality standard was too focused on specific conditions rather than reflecting the diverse needs of specific minorities.
- The quality standard would benefit from a stronger focus on effective community engagement.

Consultation comments on question 2

- Support for the overarching principle and specific examples but concerns were raised that some of the statements are relevant to all people with the specified health issue.
- Concern was raised that the quality standard does not pick up the particular needs of specific communities – the needs of marginalised Gypsy and Traveller minority ethnic groups, genetic conditions relevant to other minority ethnic groups such as BRCA 1 and 2 associated cancers in Ashkenazi Jews, Sickle cell anaemia in the black community or thalassemia in the Cypriot, Greek and Turkish communities.

Consultation comments on data collection

- Concerns were raised that current data collection systems do not allow for accurate recording of ethnicity. Issues were raised around ethnic categories currently used such as Gypsy traveller (not included as an option) or Asian (too broad).

Consultation comments on resource impact

- Recruiting people from minority ethnic groups to health and wellbeing programmes will require investment.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People from black, Asian and other minority ethnic groups have their views represented in the setting of priorities and design of health and wellbeing programmes.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- People from black, Asian and other minority groups should be involved throughout the process – planning, designing, implementing, monitoring and evaluating health and wellbeing programmes.
- Setting priorities and design of health and wellbeing programmes should be community led and co-produced with local commissioners.
- Gathering views of people from black, Asian and other minority groups should be done using a structured process.
- Suggestion that Health Equity Impact Assessment (HEIA) should be integrated and applied when designing health and wellbeing programmes and services.
- Past discriminatory experiences may lead to mistrust of public services which can have impact on providing a truly co-produced service with these communities.
- The statement should be expanded to acknowledge the influence of faith, beliefs, expectations and values to help with behaviour change and support that is effective and culturally appropriate.
- The statement could specify that religious or educational community leaders should be invited to be part of the programmes.
- The statement should specify that providers and commissioners should work with local community organisations who already have good relationships with relevant communities.
- The statement should be broadened to cover healthcare services and treatment pathways as well as health and wellbeing programmes.
- The statement should consider inequalities amongst black, Asian and other minority ethnic groups and impact of inequalities on these groups
- Concerns were raised that the statement is hard to measure – what would be classed as acceptable representation?
- Additional measures and data sources:
    - data from non-statutory groups should be used especially on specific or emerging minority ethnic groups which may otherwise be missed.
    - measures should capture more qualitative feedback such as quality of involvement or experiences of people they have involved.

5.2 Draft statement 2

People from black, Asian and other minority ethnic groups are represented in peer and lay roles within local health and wellbeing programmes.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- The statement should emphasise the role of commissioning peer programmes.
- Concern about commissioner's commitment to implement this statement.
- Health and wellbeing programmes need to take account of local demographics and needs.
- People from black, Asian and other minority ethnic groups living in deprived areas and/or from lower socio economic background /groups should be represented in these roles.
- Audits should be used to ensure representation of black, Asian and other minority ethnic groups.
- People in peer and lay roles should be continuously supported through mentoring, support networks and feedback to ensure retention.
- Comments on additional measures and data sources:
    - data from health survey for England and NCMP can be used as source of data on obesity
    - qualitative data should be used to understand service user experience.

5.3 Draft statement 3

People from black, Asian and other minority ethnic groups who are at high risk of developing type 2 diabetes are referred to a behaviour change programme.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Programmes should include well thought out advice on lifestyle changes including diet and physical activity whose information is simple and accessible and made available to raise awareness in community settings.

- Metabolic syndrome would be a better focus for this statement than diabetes.
- The statement should not be limited to risk of diabetes, it should also address risk of CVD.
- Comments on additional measures and data sources:
    - data that would allow measuring the outcomes is not currently collected
    - data should be collected not only on those who started the programme but also those who completed
    - change in BMI, BP, and HbA1c should be monitored as outcomes.

5.4 Draft statement 4

People from black, Asian and other minority ethnic groups referred to a cardiac rehabilitation programme are given choice of time and venue for the sessions and are followed up if they do not attend.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Increasing numbers of cardiac rehabilitation patients who had a baseline assessment would be a better focus for this statement.
- The statement needs to emphasise engagement with family and wider community on a continuous basis as a mechanism to increase engagement, attendance and adherence rates for the programmes.
- Programmes need to be culturally sensitive, flexible and reflective of local needs.
- Programmes should use behaviour change and goal setting techniques.
- Comments on additional measures and data sources:
    - measuring outcomes needs to go beyond level of satisfaction
    - goal settings techniques, participatory tools and service user feedback can be used to measure progress

5.5 Draft statement 5

People from black, Asian and other minority ethnic groups can access mental health services in a variety of community based settings.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Awareness of services among the minority ethnic groups should be the focus of the statement.
- Stigma attached to mental health problems in black, Asian and other minority ethnic groups can be a barrier to accessing services. Non-traditional settings may add to the feeling of stigma and prevent people from accessing the services.
- The role of wider community including faith leaders is important in raising awareness of mental health services and limiting barriers for access.
- It should be clear that accessibility of services means more than accessibility of location/settings. Involving people from black, Asian and other ethnic minority groups in designing the services will ensure acceptability of the treatment and support that is offered.
- Uptake of talking therapies should be added as an outcome measure.

5.6 Draft statement 6

People from black, Asian and other minority ethnic groups with serious mental illness have a physical health assessment at least annually.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- Carers need to be aware of the importance of attending annual health checks.
- Smoking, alcohol consumption and drug use should be monitored as part of the physical assessment. Monitoring would prompt relevant referrals.
- People with serious mental health illness should be regularly assessed for risk of diabetes, receive support and follow up.
- It should be recognised that people from black, Asian and other minority ethnic groups are also at an increased risk of severe mental illness.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Cancer – screening and prostate cancer in black men
- Blood born viruses including viral hepatitis
- Pain management services
- Breastfeeding
- Organ donation

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement	Comments[1]
1	Jnetics	Question 1	The standard seems to focus on a limited number of issues. These may be important but exclude some other issues of high importance to ethnic groups – e.g. recessive genetic conditions. Every ethnic group is at significantly 'increased risk' of inheriting certain genetic disorders relative to the general population. It should be clear that these excluded issues are not generic across all black, Asian and other minority ethnic groups or even within those groups; and the standard should be flexible enough to pick up other conditions relevant to a particular minority or segment thereof.
2	Kidney Research UK	Question 1	Kidney Research would agree that it does in large but that there should be more focus on effective community engagement as highlighted by Kidney Research UK's Peer Educator programme and here, from Diabetes UK: 1) Community champions – People within BAME communities trained to deliver information in a culturally appropriate manner and Tailored interventions for management of Type 2 diabetes in BAME communities; 2) Identifying people from BAME backgrounds that have a high risk of developing Type 2 diabetes and Population and community interventions that are tailored to engage with BAME individuals. Moreover, we would add that more research needs to take place into the causes and inextricable link between socio-economic status and all aspects of ill health, especially the ones under consideration here. Kidney Research UK are progressing with their internal health equalities review to ascertain priority research areas. This will then help guide better practice.

[1]PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

3	Lactation Consultants of Great Britain(LCGB)	Question 1	The draft quality standard currently reflects the key areas for **treatment** to generate quality improvement. **The draft quality standard does not yet address prevention,** to generate quality improvement across many of the conditions that Black, Asian and other Minority Ethnic (BAME) groups face. Infant feeding method, the biologically normal and vital source of nourishment in the first most important months and years of the child's life, that primes all the child's developing systems and functions – is not even mentioned in these draft standards so far. This is evidence of the lack of importance given to normal human milk feeding within the history of the NHS and its standards. Sadly, this also reflects the longstanding conflict of interest within the NHS around protecting and supporting breastfeeding when breastmilk substitute milk manufacturers promote their products to paediatricians, GPs, health visitors and midwives, sponsoring events and providing free gifts, promotional materials and free conference places."Applied in the context of infant and young child feeding, health workers and professional associations whose duties under the Code are to promote breastfeeding should steer away from any interaction with companies whose practices might be detrimental to infant and young child health. Health workers should recognise that they very often are the main and trusted source of information for pregnant women and mothers. Decisions on infant feeding are usually made on the basis of health workers' advice. The attitude of health workers towards the marketing practices of manufacturers and distributors of baby foods, feeding bottles and teats and how they interact with these companies influence the advice they give. That in turn impacts on how successfully mothers initiate and maintain breastfeeding."*Code Essentials 3: Responsibilities of Health Workers under the International Code of Marketing of Breastmilk Substitutes and subsequent WHA resolutions. © ICDC Penang, Malaysia, March 2009*"If breastfeeding with all its benefits is to be recognised as a majority activity, we paediatricians must learn to recognise the elaborate web that is woven around us by formula manufacturers, which currently ensures our goodwill and support for a product that we may acknowledge but would mostly not wish to promote."*Wright, C.M., Waterston A.J.R. "Relationship between paediatricians and infant formula companies" Archives of Disease in Childhood, 91: 383-385, 2006.*There is a longstanding lack of investment and training in providing effective support to enable women from all populations to breastfeed their infants, due in part to the NHS' historical close ties with formula milk manufacturers. WBTi UK Report, November 2016, Indicator 5, Healthcare and Nutrition Systems [health professional training]). The UK Health Service is now struggling under the weight of non-communicable diseases that have their roots in artificial feeding and the lack of immune system and other developmental co-factors that cannot be duplicated in a manufactured product. It is unclear how feasible it would be to put measures in place to protect health workers from influence by formula milk manufacturers through their professional organisations. Many organisations' journals still carry full page adverts from breastmilk substitute manufacturers, although this is changing slowly and becoming less acceptable, in the same way as association with the tobacco industry gradually became unacceptable.
4	NHS England (Equality and diversity council)	Question 1	The proposed standards reflect key areas for quality improvement; it might be worthwhile clarifying for the reader which services are within the remit of the standard and which are not- so for example diabetes, cardiac rehabilitation and mental health issues are included but not cancer;
5	Jnetics	Question 2	Overarching principle and specific examples seems appropriate, but some overarching principles e.g. relating to mental health, seem more relevant to all people rather than specific populations.
6	Kidney Research UK	Question 2	Yes the principles are good but could do with specific examples of case studies/good practice examples like Kidney Research UK's Peer Educators. Kidney Research UK are surprised that CKD is not highlighted as a key risk and that BAME groups can be at 5x greater risk and 10x with diabetes. This echoes the point in the brief and standards about lower triggers for diabetes prevention. Furthermore, to aid with more accurate ethnicity data capture, the Renal Registry collects data on ethnicity in Renal Replacement Therapy (RRT).

7	Lactation Consultants of Great Britain(LCGB)	Question 2	A very large proportion of BAME groups (along with many UK citizens) do not have the enzymes to fully metabolise modified cows' milk protein in infancy. This, and the significant concomitant alteration in the gut microbiome predisposes them to develop chronic inflammatory diseases associated with the BAME groups such as diabetes, inflammatory bowel disease, auto-immune conditions and cardiovascular disease. Human milk feeding supports normal growth and development for all infants, but is especially important to reduce the health inequalities found within BAME groups who are already likely to be marginalised, possibly traumatised if refugee status, and/or subject to racial discrimination. This population is likely to have fewer resources, be living in poorer housing, with limited language understanding and therefore limited access to UK health support services. They are more likely to have compromised health and nourishment and their babies are more likely to be sick or premature, especially if they are living in sub-standard accommodation. BAME groups and particularly those of refugee status are more likely to be isolated from their previous support network of family members and friends, who would normally provide additional postnatal care. Many qualitative accounts state that families and women with infants try to "fit in" to the western culture, which is perceived as bottle feeding, with very little normal breastfeeding seen in public areas. Breastmilk substitutes are often perceived as modern and prestigious, and breastfeeding associated with being poor and unsophisticated, so BAME groups might be more likely to feed their infants artificially if no-one discusses this perception as a fallacy. (Simopoulos AP, Grave GD. Factors associated with the choice and duration of infant-feeding practice. Pediatrics. 1984;74(4):603-14.) Targeting support for breastfeeding among these most vulnerable families would save significant NHS money further down the line in terms of preventing more complex acute and chronic illnesses in both child and mother, poor maternal mental health and hospital admissions. Why invest, and what it will take to improve breastfeeding practices? Nigel C Rollins, Nita Bhandari, Nemat Hajeebhoy, Susan Horton, Chessa K Lutter, Jose C Martines, Ellen G Piwoz, Linda M Richter, Cesar G Victora, on behalf of The Lancet Breastfeeding Series Group* http://www.ilcambiamento.it/files/allattamento2.pdf. Therefore, to address a key area of quality improvement, LCGB would recommend that BAME people are given additional, targeted support with establishing and maintaining human milk feeding, antenatally, perinatally in maternity wards and postnatally in GP community services. Measurable efforts should be made to provide them with someone who can speak their language; is familiar with their cultural practices and can introduce them to support groups within their own and the wider community. Trained outreach workers, peer supporters and translators for communities such as refugees have been found to enable and support breastfeeding well above baseline rates among these vulnerable communities (personal communication, Sally Etheridge, International Board Certified Lactation Consultant, Nottingham) LCGB are all too aware that local systems and structures are in place only in a few areas. Peer support groups that are now financed by local councils instead of the local health authority are being shut down all over the country and those that remain in place are at risk of budget cuts. To quote from the Lancet series referenced in comment 2; "The health and economic costs of suboptimal breastfeeding are largely unrecognised. Investments to promote breastfeeding, in both rich and poor settings, need to be measured against the cost of not doing so. Political support and financial investment are needed to protect, promote, and support breastfeeding to realise its advantages to children, women, and society."It is perfectly feasible to put these measures in place – what is required is the political will and sense of urgency within the NHS. "The stabilization or reversal of declines in breastfeeding are attributed to changes in health service policies and practices"Haaga JG. Evidence of a reversal of the breastfeeding decline in Peninsular Malaysia. Am J Public Health. 1986;76(3):245-51. If they can do this in Malaysia, I'm sure we could do this in the UK. It is feasible; structured peer support training is already available for people within BAME communities to work with the health services and reach out to their peers.

8	Lactation Consultants of Great Britain(LCGB)	Question 2	Many women from BAME groups have nutritional deficiencies in pregnancy, such as zinc, Vitamin D3 and iron that increase their and their infants' susceptibility to prematurity and illness later on in life. LCGB would recommend an approach where these prenatal risk factors should be addressed through nutritional screening, with guidance on diet; spending time outdoors with some skin exposure, and supplementation where required. This would not be restricted to BAME groups, but targeted to areas of social deprivation which is also where many BAME groups are currently housed. This guidance is still likely to apply to more affluent BAME individuals who remain at risk of low Vitamin D or iron, due to diet; culturally mandated or preferred clothing and lack of available sunlight, especially in winter, who should be targeted equally. This sort of intervention could be delivered by health visitors with a little additional training.
9	Lactation Consultants of Great Britain(LCGB)	Question 2	BAME groups and western populations alike have evolved to deal with insecure food sources and a lack of calories. Conservative metabolism then predisposes them to increased risks of visceral adiposity, obesity, cancer and heart disease when exposed to the standard western diet that contains a preponderance of processed wheat, dairy, sugar and high fat products. LCGB would recommend an approach where guidance around culturally sensitive dietary alternatives is provided, and reinforces the excellent food choices often apparent within BAME populations, such as an emphasis on fresh vegetables, legumes, fruit, fish, nuts, herbs & spices and lean meat. This would require a little background research, additional training and materials, but could be addressed nationally as a package of material and guidance, for health professionals already working to provide care with these groups. This material is almost certainly already available within other support organisations.
10	Jnetics	Question 3	We do not have sufficient information on data collection generally, but we have accurate data on the frequency of a number of severe genetic disorders more prevalent in the UK Ashkenazi Community from our community screening programme operated in partnership with the NHS.
11	Kidney Research UK	Question 3	We cannot really answer this question as disease specific in areas which are outside our main focus and expertise.
12	Jnetics	Question 4	The Jewish carrier screening programme that we run in partnership with the NHS demonstrates a viable model for screening across many minority communities – both in terms of cost-efficiency and impact.
13	Kidney Research UK	Question 4	Again, as above, difficult to answer this as we, at Kidney Research UK, are not locally based with Public Health organisations. However, we have consulted with some of our local community staff and volunteers who do perceive a clear lack of resources in their communities to address health inequalities across the board so we would urge much greater investment.Public Health and primary care working with Charities, like Kidney Research UK , would ensure that the crucial resources of people/volunteers to support awareness and behaviour change are available in the numbers required and supported to provide effective engagement to their peers.
14	Kidney Research UK	Question 5	There is a NICE statement: Using evidence-based approaches to community engagement (including collaborations and partnerships and peer and lay roles). An example would be evidence of Kidney Research UK's PE approach such as promoting better management of diabetes (one of two main causes of Kidney failure); some evidence of the effectiveness of Peer Educators can be found in a peer reviewed journal: A peer outreach initiative to increase the registration of minorities as organ donors Jez Buffin; Robert Little; Neerja Jain; Anthony N. Warrens Clinical Kidney Journal 2015; doi: 10.1093/ckj/sfv066.
15	The British Heart Foundation	General	The British Heart Foundation supports the quality standard and the statement areas included.

16	Department of Health	General	In August 2016, Prime Minister Theresa May announced the Race Disparity Audit, with the purpose of: * Publishing clear and authoritative data about ethnicity * Making ethnicity data accessible, by putting it all in one place* Shedding light on ethnic disparities, including in education, employment, health, housing and criminal justice. The Audit developed the Ethnicity facts and figures website launched on 10 October 2017, which presents data about ethnicity collected by government departments. The website covers a wide range of government data on ethnicity. The data highlights ethnic disparities, including between and within ethnic minority groups, and in some cases shows whether they are increasing or decreasing over time. A large proportion of the ethnicity data on the website offers analysis by geographic location, income, gender and a variety of other factors that provide insights into trends and patterns related to people's lives. The data and the disparities are accompanied by commentary information that provide necessary context to help users understand the data to help give a detailed picture of life in the UK for people of different ethnicities.
17	Department of Health	General	**Overall Comment** Although we welcome the NICE Standard we note “Black, Asian and other minority ethnic groups” are treated as a single group. There will be relevant differences in needs between populations of different ethnic groups (for example, in the diabetes standard, South Asian populations would be particularly relevant). If the standards don't distinguish between different BME populations, this will not address exclusion of particularly disadvantaged groups (such as Gypsies, Roma and Travellers, or Bangladeshi women) or address the poor health outcomes of particular ethnic groups. We would suggest this could and should be addressed by a section in the document outlining that black, Asian and other minority ethnic groups are not a homogenous population, and should not be treated as such in applying these standards. The application of these standards should be tailored to the BME profile of the local population, and assessed separately for the main local BME groups, considering in particular disadvantaged or excluded groups such as Gypsies, Roma and Travellers, and ethnic groups with particularly poor outcomes such as South Asian populations when considering diabetes.
18	Department of Health	General	**Gypsies, Roma and Travellers** There is no particular reference to the needs of Gypsies, Roma and Travellers, while protected under Race Equality Legislation, there outcomes in almost all spheres of life are some of the poorest in the country, in particular higher mortality and morbidity rates. Gypsies, Roma and Travellers can also face different problems than other BME groups, which are more complex, due to the extreme and often accepted racism and discrimination that they regularly face over the course of a life time. As well as working to ensure that Gypsies, Roma and Travellers are joined in to Race equality legislation, Friends, Families and Travellers (FFT) have been keen to keep a focus on the Inclusion Health agenda, which focuses on groups of disadvantaged people who often face multiple and chronic disadvantage. Many local authorities and CCGs may support projects working with BME people, and regard Gypsies, Roma and Travellers as part of this group. However, the challenge is that many Gypsies, Roma and Travellers remain on the margins of BME politics and practice, therefore a ‘one size fits all’ often fails to address their specific need. The demographics are also regarded as small so they can easily be overlooked under localism.
19	Jnetics	General	In our view the quality standard is too focused on specific conditions rather than reflecting the diverse needs of specific minorities. In other respects it also sets standards that should be applicable to all not just black, Asian and other minority ethnic groups. It treats black Asian and other minority ethnic groups as homogeneous, when they are disparate, facing different issues between and within themselves.

20	Lactation Consultants of Great Britain(LCGB)	General	*The prevalence of longstanding illness ranged from around two in ten Chinese men (22%) and a quarter of Black African men (24%), to around four in ten men in the general population (43%) and almost a half of Irish men (47%). Similarly, among women, the prevalence was lowest in the Chinese and Black African groups (24%) and highest in the general population (47%) and Irish (44%) groups. Prevalence was also high among Black Caribbean women (44%)*These rates of illness that now manifest in the populations of these groups correlate very closely to their rate of artificial feeding in infancy, with the Irish having the most artificial feeding and the most illness, and the general UK population having the next highest, with the next highest rate of artificial feeding, after the Irish, and the lowest among Chinese and black African populations, who are traditionally more likely to breastfeed their infants. Many of the adults within BAME groups now exhibiting chronic illnesses are more likely to have been fed artificially, due to their mothers being away from their traditional support networks and the misguided perception that artificial feeding is the “modern” British way of feeding infants. (See earlier comments) and is something that British women ‘choose’ to do. The reality is that most women choose to breastfeed and only stop, with intense regret, (often in the early weeks when allegedly they are receiving the most NHS support), when they have not received the support they need to continue. (WBTi Report 2016) This is a contributing factor to the high rates of illness now apparent within BAME groups (and most noticeably the Irish population, from closer to UK shores, who in the last 50 years have the highest rates of artificial feeding in the world) of diabetes, heart disease and cancer, that are also the well-documented long term negative health outcomes of artificial feeding (the Lancet Series, Jan 2016).
21	Lactation Consultants of Great Britain(LCGB)	General	Higher blood pressure is found in children as young as seven who have been artificially fed (Howie 1998)Relation of infant diet to childhood health: seven year follow up of cohort of children in Dundee infant feeding study - Andrea C Wilson, J Stewart Forsyth, Stephen A Greene, Linda Irvine, Catherine Hau, Peter W Howie. http://europepmc.org/articles/PMC2665344/ Arterial plaques in young, apparently fit American military casualties who had been fed artificially as infants. This evidence highlights the root cause of cardiovascular disease. Castelli WP. Making practical sense of clinical trial data in decreasing cardiovascular risk. Am J Cardiol. 2001;88(4A):16F-20F
22	NHS England (Equality and diversity council)	General	The standard does not seem to reflect on the impact of racism and possible discriminatory past experiences on accessing services in a timely fashion;
23	NHS England (Equality and diversity council)	General	The document could benefit from becoming more accessible especially for the BAME communities. The document does not seem to be clear about what the implementation of the standard means for people from BAME backgrounds- you might consider a plain English summary of the standard focusing on would mean for the service user from BAME backgrounds;
24	NHS England (Equality and diversity council)	General	The equality impact assessment could be strengthen by providing some more evidence on inequalities faced by the BAME communities and discussing why quality standard / measures were picked up to address those issues. It might have also to discuss the impact of racism in health and well-being as well as the impact of intersectionality (as suggested on our comments above).
25	Public Health England	General	Are these quality statements intended to cover adults only or all ages of people including children and young people?If children and young people are included, then additional examples are required of ways to involve them in the design of programmes etc. If the statement only covers adults, this should be specified.
26	Public Health England	General	PHE recommends including the NICE guidance 44 Community Engagement https://www.nice.org.uk/guidance/ng44 what is included in this section aligns with the NICE guidance on community engagement.

27	Royal Pharmaceutical Society	General	The Royal Pharmaceutical Society (RPS) welcomes the quality standard for Black, Asian and other minority ethnic groups: promoting health and preventing premature mortality. Community pharmacists through their accessibility are a source of lifestyle advice, health promotion and support with the early diagnosis of various conditions. As experts in medicines, pharmacists provide advice on how to take medicines, adverse effects, possible interactions and cautions, to raise patients' and carers' awareness and increase their understanding of their condition and therapy. Healthy Living Pharmacies have health champions who can promote wellbeing and health improvement. Pharmacies provide a wide range of services to support with the management of long-term conditions. The RPS has produced policy for Improving care for people with Long Term Conditions. This includes examples of services pharmacists deliver to support with the early detection of conditions and ongoing support for people with long term conditions. The policy can be accessed here: https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Policy/LTC%20-%20England.pdf
28	Salford City Council	General	We welcome the entire document and observe that, as our city is changing ethnicity rapidly, the quality standard will be a good reminder on how we need to ensure we take the differing needs of our increasingly diverse population into account in our provision. We collect information about our population but it is not currently clear that this is systematically used in commissioning, providing or evaluating services.
29	University of Surrey	General	I would prefer to see Black and White capitalised. The words describe groups of people, rather than simply a colour.
30	British Association for the Study of the Liver (BASL)	Statement 1	I would disagree. I believe these groups are by and large excluded from these discussions.
31	The British Heart Foundation	Statement 1	We welcome the emphasis on involving people from the relevant communities in the design of services, but the standard should be more explicit about working with local, community organisations who already have good relationships with the relevant communities – otherwise it will be hard for the service providers/commissioners to access them. Most of the quality measures are numerical, e.g. page 5 'Proportion of health and wellbeing programmes that sought the views of people from black, Asian and other minority ethnic groups during setting priorities and the design stage' – Numerical measures only increase the risk for this to be ineffective involvement. it should also be capturing qualitative feedback about the experience of the people they have involved.
32	Chartered Society of Physiotherapy (CSP)	Statement 1	Needs to be more explicit - expanded to acknowledge the influence of beliefs, expectations and values to help offer support that is culturally appropriate.
33	Chartered Society of Physiotherapy (CSP)	Statement 1	Comparisons can be made against the Census 2011 data to see changing trends in the breakdown of ethnic diversity and language support services required.
34	Chartered Society of	Statement 1	As well as focus groups, feedback from participants in pilot health and wellbeing programmes that have then been reviewed and preliminary outcome measures analysed.

	Physiotherapy (CSP)		
35	Diabetes UK	Statement 1	Diabetes UK recommends that for this statement to be achieved it should ensure that people from black, Asian and other diverse minority groups are continuously involved throughout the process from planning, designing, implementing, monitoring and evaluating health and wellbeing programmes around prevention and better management.
36	Diabetes UK	Statement 1	We recommend the practise of using a structured process of gathering the views of people from black, Asian and other minority groups in the programmes.
37	Maslaha	Statement 1	As well as ethnicity breakdown, it can also be useful to understand the role of faith and how that can be a positive tool for behaviour change. Who decides what is culturally appropriate and when a health programme or resource has been successful in understanding cultural needs and context. For example we design health programmes with BAME communities and we constantly hear from patients and families how existing resources are culturally blunt, and usually because communities have not been consulted. Examples include assuming all Muslim communities speak Arabic or can read urdu, or not understanding the importance of aural communication – see our resource Talking From The Heart – www.talkingfromtheheart.org There needs to be greater scrutiny of how the views of local BAME communities are collected and who turns up for public consultations. Again, if it is just a small cohort, larger charities and health providers will assume they will speak for whole communities which of course can be problematic (in our experience larger charities lack an in-depth understanding of BAME communities and will make sweeping generalisations about them). It's also not just about the views of BAME people being represented, but also seeing them as experts and been given the skills and confidence to participate fully in designing programmes. In terms of collecting evidence, it's also probably vital to know who is organising local arrangements, as this will influence how insightful and rich data the is.
38	Mind	Statement 1	We recommend that engagement with communities is strengthened within this statement. Rather than just ensuring that black, Asian and other minority ethnic groups are represented, we believe that effective engagement with communities should enable people to influence the design and delivery of programmes so they are tailored to meet their needs. For instance under 'what the quality statement means for commissioners' it currently states that commissioners "ensure that people from black, Asian and other minority ethnic groups have input into setting priorities and designing health and wellbeing programmes." This could be strengthened to refer to the need for such programmes to be co-produced with people from black, Asian and other minority ethnic groups. This should mean commissioners partner with such groups in the design, delivery and review of such programmes.
39	Mind	Statement 1	We recommend that this statement also refers to building individual's resilience as well as their wellbeing. This supports public mental health programmes seeking to prevent the occurrence, development and/or impact of mental health problems. More information about public mental health programmes can be found in our report Our communities, our mental health.

40	Muslim Council of Britain	Statement 1	This should be community-led and need an appropriately resourced local infrastructure (Co-production). NHS and Local Authorities should assist in establishing this. CQC's should adopt robustness of 'local community engagement' as an indicator to addressing health inequalities. Religiosity plays an important part in the life of BAMEGs . Ministers of Faith / religious leaders have great influence and important role. But need to be trained / educated about health aspects so that they can stress the importance of health - that looking after ones health is not a choice but duty - to ones self and the community. Local authorities and CCGs should develop list of simple projects in consultation with community groups to undertake collaborative research. This approach operates in many resource limited countries. Though operates in the UK but a properly developed infrastructure will bring dividends. Faith-based approach has been successfully applied in relation to HIV/AIDS but applicable to many conditions especially those that require behavioural changes. http://hcfbg.org.uk/about-2/ - NHS Project of multi faith healthcare chaplaincy , Muslim Council of Britain is the Endorsing Authority for Muslim Chaplains. The network will focus on developing mental health chaplaincy work and planning to introduce "Spiritual Support" Service in the community and hospices. Research proposal: A national survey be undertaken to collect information on practices and methods of community engagement in healthcare.
41	NHS England (Equality and diversity council)	Statement 1	Past discriminatory experiences may also lead to mistrust of public services which can have impact on the ambition of providing a truly co-produced service with these communities; what is currently missing is how we can measure the quality of involvement of the BAME community so that it is not simply tokenistic.
42	NHS England (Equality and diversity council)	Statement 1	The statement is also referring to the skills mix of the health professional to provide culturally appropriate care to support behavioural changes. It might be beneficial to discuss the impact of intersectionality- as an one size fits all approach would not necessary address the needs of all communities or indeed the needs of some invisible minorities within BAME communities- for example Lesbian Gay Bisexual and Trans people of BAME backgrounds which can be marginalised from both communities.

43	Public Health England	Statement 1	Public Health England (PHE) welcomes this statement as it supports and aligns to the Community Engagement Quality Standard and the PHE/NHS England guide to community-centred approaches. https://www.gov.uk/government/publications/health-and-wellbeing-a-guide-to-community-centred-approaches PHE recommends expanding this statement by considering inequalities amongst black and minority ethnic groups and impact of inequalities on these groups, especially with focus on care outcomes. For reference, for example see the Department of Health's 'Equality Impact Assessment for National Sexual Health Policy', January 2010 http://webarchive.nationalarchives.gov.uk/20130124053112/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_111231.pdf and the Public Health Outcomes Framework report with focus on ethnicity https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/629563/PHOF_Health_Equity_Report.pdf PHE recommends expanding the standard to include not only health and wellbeing programmes but also healthcare services and treatment pathways. This will ensure that the standard aligns with the National Institute of Health and Care Excellence's (NICE's) guideline NG44 on Community Engagement. https://www.nice.org.uk/guidance/ng44 PHE recommends integrating and application of the Health Equity Impact Assessment (HEIA) when designing health and wellbeing programmes and services. HEIA is a method to assess initiatives and investments to ensure that potential unintended health impacts on populations are considered/addressed to reduce health disparities across vulnerable/marginalised population groups.
44	Race Equality Foundation	Statement 1	The data source should also include reference to data kept by non statutory groups particularly relating to specific or new emerging BME groups which maybe too small for existing data sets or missed. This raises a question about what insight sight data can contribute in the design of health and wellbeing.
45	Salford Royal Foundation Trust	Statement 1	This will be very hard to measure. How do you know if their views are being represented? What is acceptable representation and what is considered to be not acceptable.
46	Solutions4Health	Statement 1	This statement is important, but the details are potentially vague and open to a tick box exercise approach. To ensure that the BAME community is actually involved, it may be worth stating that leaders of the local community (religious, educational etc.) are approached and invited to be part of a consulting group
47	University of Surrey	Statement 1	A hugely worthwhile and important quality standard. This will be valuable to the development of programmes that are meaningful and effective for BAME groups. I hope the effort is put into making this a reality.
48	University of Surrey	Statement 1	Engagement is likely to be difficult and will require significant investment of time, energy and financial resources. Minority groups have been overlooked for a long time and it will take some convincing that they can actually influence the direction of these programmes.
49	University of Surrey	Statement 1	"ensuring local community is represented well" - this is vague, how will this be achieved?
50	British Association for the Study of the Liver (BASL)	Statement 2	I would disagree and believe that these groups are excluded from these areas. Of interest there is under-representation in terms of organ donation particularly with regards to kidney transplantation. There have been previous attempts to engage with this issue and this is something that might be addressed from this consultation.

51	The British Heart Foundation	Statement 2	We welcome the emphasis on service providers and commissioners providing training and support to those taking on peer & lay roles In the definition of ‘peer and lay roles’, it would be good to see peer support mentioned explicitly as a way of encouraging people to take part in health and wellbeing initiatives, and as a way of providing additional ‘informal’ support to help people make long term behaviour changes
52	Diabetes UK	Statement 2	There is also a need to ensure that the programmes take account of the local demographics and needs.
53	Diabetes UK	Statement 2	Diabetes UK welcomes the recognition of peer and lay members and the important role they play in local and health wellbeing programmes, with the need to support them with adequate resources, information and through appropriate mechanisms that are engaging and proactive to reach those that are likely to be excluded. We also recommend that this involves undertaking audits to ensure that representation of black, Asian and other minority ethnic groups are meeting the demands of the local population.
54	Diabetes UK	Statement 2	Diabetes UK would like to stress the importance of supporting lay members in order to ensure retention, provision of feedback, mentoring and support networks should be available.
55	Mind	Statement 2	We recommend emphasising the role of commissioning peer programmes as a public health programme in themselves, rather than just as ensuring representation of different communities within programmes. Peer activity has been found to improve people’s sense of wellbeing, their ability to connect with others, increase their sense of hope and improve their ability to make decisions and take action. For more information about the evidence for peer support can be found in our report Side by Side: Early Research Findings.
56	Mind	Statement 2	We recommend the wording under ‘Rationale’ is amended. Currently it states that “People from black, Asian and other minority ethnic groups should be represented in peer and lay roles within the local health and wellbeing programmes to ensure that the services and support are relevant and acceptable to the community.” This places emphasis on ensuring services are relevant and acceptable on BAME representatives. This should be rephrased to make clear that the responsibility lies with the organisations responsible for the relevant programmes. Engaging BAME people is a necessary part of delivering on this responsibility.
57	Muslim Council of Britain	Statement 2	There is considerable interest in communities to help and volunteer / do social service. There is a significant body of practicing and retired healthcare professionals who wish to offer the benefit of their experience and expertise. They can be a useful resource for community groups to help develop the infrastructure. Local faith and community organisations should be encouraged to identify such experts to help them. Our preliminary survey seeking to document social action projects undertaken by mosques show that many are involved in a range of health-care associated projects. Work is in planning stage to undertake a structure national survey. http://www.muslimdoctors.org/events-past/2017/health-zone-london-muslim-lifestyle-show-olympia-30th-april-1st-may-2016/ http://www.britishima.org/2017/05/11/ramadan-initiative-2017-2/, BIMA Hold Annual Conferences - helps to raise awareness, identify needs and share work undertaken in community settings

58	Public Health England	Statement 2	PHE welcomes this statement as it supports and aligns to the Community Engagement Quality Standard and PHE/NHS England guide to community-centred approaches. PHE recommends that individuals from BAME communities living in deprived areas and/or from lower socio economic background /groups are represented in peer and lay roles.
59	Public Health England	Statement 2	Prevalence of obesity: The Active People survey does not measure adult obesity levels. The Health Survey for England (2015) provides the best national source alongside any local data https://digital.nhs.uk/catalogue/PUB22610. If children are included in this statement, the National Child Measurement Programme provides national and local data on the BMI levels of children aged 4-5 and 10-11 http://content.digital.nhs.uk/ncmp
60	Race Equality Foundation	Statement 2	The overall section is good but it would be helpful if qualitative data is mentioned when looking at experiences as for some communities, it is more likely that the information required to measure the statement will be from qualitative aspect e.g. ‘word or mouth’, as opposed to quantitative. Currently the statement data sources may be perceived to focus only on quantitative.
61	Salford Royal Foundation Trust	Statement 2	People from black, Asian and other minority ethnic groups are represented in peer and lay roles within local health and wellbeing programmes. This could be done in the form of tokenism. Should not the representation reflect the ethnic diversity in the localk population i.e. in terms of proportions. This should be the bare minimum.
62	University of Surrey	Statement 2	Same issue as Comment 3. Recruitment is likely to require significant investment
63	University of Surrey	Statement 2	I am dubious that they will be sufficient commitment to this to provide the resources to prioritise this, recruit and compensate people for their time.
64	British Association for the Study of the Liver (BASL)	Statement 3	This might be of interest. Some of the black, Asian and minority groups have high levels of diabetes but not only that there are high levels of obesity and fatty liver disease. This not only translates into higher rates of morbidity and mortality, but is associated with higher levels of malignancy.

65	The British Heart Foundation	Statement 3	People from black, Asian and other minority ethnic groups who are at high risk of developing type 2 diabetes are referred to a behaviour change programme. Rationale The British Heart Foundation recognises that Type 2 diabetes is on the increase in the UK and having diabetes greatly increases your risk of developing heart and circulatory disease. Premature CVD death rates in England have fallen 80% over the last 40 years, largely thanks to BHF-funded research, advances in treating conditions like heart attack and stroke and the decline in smoking, as well as lifestyle changes. There is a wealth of evidence on the impact of obesity and physical inactivity on cardiovascular disease, however there remains limited evidence to determine which primary prevention interventions can influence lifestyle behaviour change. CVD risk factors such as smoking, physical inactivity and obesity are more common in deprived areas of England and within specific communities. For Bangladeshis, Indians and Pakistanis, and people with an African Caribbean background, cardiovascular risk can be higher than for the rest of the UK population. The prevalence of type 2 diabetes for people of African Caribbean and South Asian ethnicity is much higher than in the rest of the population. To support patients to make lifestyle change we have produced a range of publications including one focused on ethnicity. https://www.bhf.org.uk/heart-health/preventing-heart-disease/your-ethnicity-and-heart-disease We welcome the focus on this within the quality standards and the alignment with key initiatives such as the Diabetes Prevention Programme (DPP). We would also encourage people from Black, Asian and other minority ethnic groups are also referred for an NHS Health Check programme as that would also help to identify high blood pressure in high risk groups.
66	Diabetes UK	Statement 3	Local NHS diabetes prevention programmes should be culturally and language appropriate and continuously supportive so that they acceptable and encourage people from black, Asian and other minority ethnic groups to participate. We also recommend in addition to sourcing data of those enrolled in the programmes there should be consideration to the use of data for those who have completed the programme.
67	Diabetes UK	Statement 3	Diabetes UK recognises the influence religion, cultural beliefs and practices have on behaviour and as such programmes should include well-though out advice on lifestyle changes including diet and physical activity whose information is simple and accessible and made available to raise awareness in community settings.

68	Muslim Council of Britain	Statement 3	Many of the elements of behavioural change programme can be developed in community settings, places of worship and local self help groups. Large national specialist NGOs should do more to connect with 'vulnerable communities' . Infrastructures developed within community settings / places of worship. National community organisations and faith groups are beginning to appreciate the need for local service groups and NGOs to have meaningful conversation / consultation with local communities to identify and prioritise needs to address local inequalities. It is important to have both 'top down' and 'bottom up' approach to achieve positive results. Community and faith groups also need to gain an understanding of how to engage as effective stakeholders with their local service providers. The Muslim Council of Britain (MCB) will be organising a Round Table There is increasing awareness of the need for Capacity building of thinly resourced community institutions and the importance of learning /sharing good practice. Diabetes is one of the three "Ds" identified as an area that requires urgent multidisciplinary stakeholder attention British Muslims in Numbers(https://www.mcb.org.uk/wp-content/uploads/2015/02/MCBCensusReport_2015.pdf) Briefing Papers (http://www.mcb.org.uk/muslimstatistics/briefings/) http://www.mcb.org.uk/wp-content/uploads/2014/07/Ramadan-and-Diabetes-MCB-DiabetesUK-leaflet.pdf https://www.sahf.org.uk/events/2017/9/7/managing-the-complexities-of-diabetes-focus-on-south-asian-people-9grc7 Multifaith group of healthcare Chaplaincy - issue advice/information to healthcare professionals about Ramadan fasting to help them care for Muslim patients.
69	NHS England (Equality and diversity council)	Statement 3	Refers to measures focusing on BAME access to these services. We could not see any comparisons with the general population to measure whether these communities are currently under-represented in these services
70	Public Health England	Statement 3	PHE supports the recommendation but would be grateful for more guidance on why this has been limited to risk of diabetes. PHE supports using the NICEclinical guidance CG181 as a basis for a clinical standard which is also linked to cardiovascular disease (CVD) risk (https://www.nice.org.uk/guidance/cg181). This would serve to enhance NHS England's commitment in the 5 Year Forward View to prevent CVD https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf and PHE's September 2017 publication, 'Action plan for cardiovascular disease prevention, 2017-2018' (https://www.gov.uk/government/publications/cardiovascular-disease-prevention-action-plan). PHE recommends noting that there are clinical systems in place to collect information on CVD risk through the implementation of the NHS Health Check programme. Recent research indicates that data on ethnicity is insufficient http://bmjopen.bmj.com/content/6/1/e008840]. Therefore so having a specific quality standard would help to improve the recording of data in current systems.
71	Public Health England	Statement 3	The statement states 'lose weight' but PHE would recommend rephrasing to 'manage their weight' or 'achieve or maintain a healthy weight' . The same comment applies to the definition of behaviour change programmes on the same page. PHE recommend this amend in order to main consistency with the wording of NICE guidelines, notably PH53 (https://www.nice.org.uk/guidance/ph53) and CG189 (https://www.nice.org.uk/guidance/cg189). This amend also reflects the possibility that an individual from a BAME group may have a body mass index that appears to be in the healthy range but the individual may have greater health risks and therefore weight maintenance may more appropriate than weight loss. In addition, following weight less, weight maintenance is the next stage and often proves challenging.

72	Public Health England	Statement 3	PHE would recommend including the weight management guides PHE developed along with NICE colleagues to support delivery and development of lifestyle weight management services for (i) adults and (ii) children and their families, which includes relevant references to BAME groupshttps://www.gov.uk/government/publications/adult-weight-management-services-commission-and-provide .In addition, PHE have produced data collection tools and for adults a series of key performance indicators (KPIs) which support local consideration of relevant KPIs, including those for BAME communities (page nine): 'https://www.gov.uk/government/publications/adult-weight-management-key-performance-indicators
73	Salford Royal Foundation Trust	Statement 3	People from black, Asian and other minority ethnic groups who are at high risk of developing type 2 diabetes are referred to a behaviour change programme. Should it not be BAME with features of metabolic syndrome rather than stating high risk of developing diabetes.
74	University of Surrey	Statement 3	Excellent idea. I think it should it also state that they would be followed up as well as referred.
75	University of Surrey	Statement 3	No mention here about cultural appropriateness of programmes; this is important for good engagement.
76	University of Surrey	Statement 3	Weak UK-based evidence for higher risk of diabetes among Chinese population
77	University of Surrey	Statement 3	I worry that the data relevant to the numerators and denominators would not be well recorded.
78	University of Surrey	Statement 3	Outcomes would need to reflect change in BMI, BP, and HbA1c to be useful, not simply post-intervention levels.
79	University of Surrey	Statement 3	“trigger action” - too vague to be meaningful.
80	The British Heart Foundation	Statement 4	People from black, Asian and other minority ethnic groups referred to a cardiac rehabilitation programme are given choice of time and venue for the sessions and are followed up if they do not attend Rationale The British Heart Foundation commissions the National Audit of Cardiac Rehabilitation (NACR). The quality standard consultation states that ‘No information on uptake, completion or outcomes of cardiac rehabilitation among minority ethnic groups has been identified’. The NACR audit has produced an ethnicity supplement that shows the breakdown of the UK Cardiac Rehabilitation population by Ethnicity. http://www.cardiacrehabilitation.org.uk/docs/Supplement%205.pdf We agree that further work to examine differential completion or outcomes from cardiac rehabilitation programmes could be beneficial. The 2017 NACR Annual Report will be available published in January 2018.
81	Diabetes UK	Statement 4	We recognise the importance of family and wider community in positive reinforcement to behaviour change and therefore the emphasis on engaging with them on a continuous basis as mechanism to increase engagement, attendance and adherence rates of the programmes.
82	Diabetes UK	Statement 4	Diabetes UK recommends that content of cardiac rehabilitation programmes be culturally sensitive, and delivery of programmes need to be flexible and reflective of local needs.

83	Diabetes UK	Statement 4	To ensure that these programmes are successful, the use of behaviour change and goal setting techniques in this process is essential, taking into consideration appropriate and inclusive monitoring processes and participatory tools are needed to measure impacts and also we recommend to consider other more specific outcomes other than 'level of satisfaction'.
84	Muslim Council of Britain	Statement 4	The choice should also include faith and cultural-sensitive settings. Places of worship provide an ideal setting for these communities. Chronic conditions, disability, diabetes, dementia were identified as main health issues among the Muslim communities. An opportunity to provide 'one-stop shop" for services, wherever possible / appropriate
85	NHS England (Equality and diversity council)	Statement 4	Refers to measures focusing on BAME access to these services. We could not see any comparisons with the general population to measure whether these communities are currently under-represented in these services
86	Race Equality Foundation	Statement 4	It would be useful to add 'service user feedback' as the example which gives emphasis on BME user's role in determine the evidence required. Most of the examples understandably refer to the service level agreements, but this is only one aspect of measurement. Ensuring a service user data sourced is highlighted will assist in using a wider range of evidence to measure and assess the standard quality measure.
87	University of York, BHF National Audit of Cardiac Rehabilitation	Statement 4	The statement proposes the number in the denominator offered sessions in a variety of settings including home, the community or a hospital. This is understandable and would be helpful but a potentially greater effect on the number of patients accessing cardiac rehab would come from capturing the number of patients referred who end up having a cardiac rehab baseline assessment. The greatest drop off of patients occurs between referral and baseline assessment by cardiac rehab teams. This can be over 30% drop off which is much higher than that seen between post assessment and uptake of a cardiac rehab offer. The NACR can help supply data on the original and newly proposed measures.
88	Diabetes UK	Statement 5	Diabetes UK emphasises the need to have appropriate mental health services in place for people from black, Asian and other minority groups and consideration of the stigma attached to mental health problems in this group which should not be a barrier to access for instance certain groups such as women in some communities can often face barriers due to cultural and religious practices. We also recognise the vital role wider community members including faith leaders can play in raising awareness of mental health services and limiting barriers for access. Instances of need for emergency cardiac resuscitation - instances of emergencies during congregations. Need to create a cadre of Community healthcare volunteers (Advocates / Champions) appropriately trained to assist local NHS / social service departments in delivering services. 'Associate Physicians' : what part these trained healthcare professionals can play requires wider discussion. British Islamic Medical Association (BIMA) https://cheadleandgatley.mycouncillor.org.uk/2016/09/01/be-a-lifesaver-learn-cpr-for-free-on-24th-september/This is part of a national initiative spearheaded by the British Islamic Medical Association (BIMA) and has mosques up and down the country opening their doors to educate their local communities (all faiths) in CPR – Cardiopulmonary Resuscitation.
89	Diabetes UK	Statement 5	Healthcare professionals need to have training on how to deal with mental health issues especially if patients also have diabetes. In addition to training of health professionals, they should be made aware of understanding cultural issues surrounding mental health for BAME groups which is likely to impacts on diagnosis and care planning and management and therefore they should be encouraged to work with communities in community settings.

90	Maslaha	Statement 5	Non-traditional settings may be more accessible but also may add to the feeling of stigma from others in the community (this can often be a reason why mental health services are not accessed). Surveys that are carried out to measure satisfaction should be run by individuals and organisations who are trusted by those communities and are able to understand the cultural needs of those communities, otherwise the data will be skewed. For instance we have come across a number of cases of patients getting other family members to fill out surveys on their behalf. Clearly, a survey was not the best way to record that information especially with mental health which can carry stigma. Again, referencing our health resource which focused on depression and anxiety – Talking From the Heart – www.talkingfromtheheart.org - there isn't a direct translation for depression into Urdu, Arabic, Bengali, Punjabi etc, so the process of how data is collected is even more important, and requires a high level of awareness and understanding of those communities.
91	Mind	Statement 5	We recommend that this statement makes clear that services being accessible is broader than accessibility of location/settings. This can be done by further highlighting the importance of influencing service design and the acceptability of the treatment and support that is offered.
92	Mind	Statement 5	We recommend that the 'Rationale' makes clear that all services have a responsibility to engage with these groups and to ensure they are accessible. Whilst in some instances specific provision for particular groups will be valuable and needed, the principle aim should be for all services to be accessible and relevant to all parts of the community.
93	Muslim Council of Britain	Statement 5	Agree and places of worship offer an important setting. Work being developed in conjunction with national NGOs.(MIND, Hepatitis Trust, Hepatitis C Trust, DiabetesUK etc. Some of these NGOs have themselves become to big and need to develop and implement robust, deliverable strategies. Muslim doctors Association: - South Asian Mental Health Stigma Event, 25th March 2014 - Working with MIND in Mosques to create awareness of Mental Health and to engage with communities through places of worship. - A national conference entitled "Our Mosques Our Future" has been organised by the Muslim Council of Britain on 20th Jan 2018. Several stakeholders including PHE, the mental health charity MIND and voluntary professionals will be holding 'surgeries' for delegates and to advise how to engage with their local services. - MCB and its affiliates will be attending the Seminar "Diverse approaches to Mental Health" which has been organised by PHE.
94	NHS England (Equality and diversity council)	Statement 5	We would suggest that the uptake of talking therapies is included in the quality measures
95	Salford Royal Foundation Trust	Statement 5	People from black, Asian and other minority ethnic groups can access mental health services in a variety of community based settings. Again, I think that this will be hard to measure. If the BAME do not know about the services they will not access it then we will not know if there is a lack of resource or not.
96	University of Surrey	Statement 5	Outcomes need to be related to where the BAME groups attended mental health services

97	University of Surrey	Statement 5	Healthcare professionals need to be aware of and sensitive to the additional stigma of mental health in BAME groups and the issues around fear of institutionalisation as a result of discrimination particularly in Black men.
98	The British Heart Foundation	Statement 6	People from black, Asian and other minority ethnic groups with serious mental illness have a physical health assessment at least annually. Rationale The British Heart Foundation research has shown that people with severe mental health problems are two to three times more likely to suffer from cardiovascular disease due to medication and lifestyle factors. This when considered with the ethnicity of patients alongside other risk factors which can significantly increase your risk of developing cardiovascular disease, including age, gender and family history mean this is an important area to focus on. We welcome the focus on inclusion of this quality statement.
99	Diabetes UK	Statement 6	Carers need to be aware of the importance of attending annual diabetes health checks for those with diabetes. Carers, families and the wider community need to be involved in raising awareness of the importance of the risk of developing type 2 diabetes as well as seriousness of the complications of diabetes.
100	Diabetes UK	Statement 6	People from black, Asian and other minority groups with serious mental health illness should be regularly assessed for the risk of developing type 2 diabetes and should receive ongoing support and follow up within the community.
101	Mind	Statement 6	We recommend that as well as stating that black, Asian and other minority ethnic groups are at increased risk of cardiovascular disease and type 2 diabetes, it is emphasised that certain BAME groups are also more likely to receive a diagnosis of a severe mental illness, such as a psychotic disorder. Psychotic disorder is associated with ethnic group, with rates found to be higher in black men than men from other ethnic groups (Adult Psychiatric Morbidity Survey 2014). This further highlights why physical health checks for black, Asian and other minority ethnic groups with severe mental illness is so important.
102	Muslim Council of Britain	Statement 6	This can be incorporated, with advantage, in faith-based mental health set up as a holistic approach to health and well being.
103	Solutions4Hea lth	Statement 6	In the physical assessment checklist, smoking status/tobacco use, alcohol consumption and drug use should be added. These are all causes of the physical symptoms that are being checked for, but by recording them it prompts the practitioner to refer in to appropriate services if required. Smoking, alcohol consumption and drug use are all markedly higher in people with mental illnesses
104	Jnetics	Statements 3, 4, 5, 6	We do not fully understand the thrust of these Statements. We consider they should apply to any person with the relevant need, not just to black, Asian and other minority ethnic groups. Within those groups (as noted in some places) they are not equally relevant issues across and within all groups. If they reflect particular issues of particular groups, perhaps there should be both a generic standard, and a statement that problems particularly relevant to a black, Asian and other minority ethnic group, or segment thereof, should be treated appropriately with specific examples where required.

105	Jnetics	Statements 3, 4, 5, 6	We note that the specific conditions mentioned here do not include screening for genetic conditions relevant to particular black, Asian and other minority ethnic groups. NICE do already have some guidelines in place relating to the management of BRCA 1 and 2 associated cancers that disproportionately affect Ashkenazi Jews (established 10-fold increase in risk of being BRCA positive relative to the general population). There are, however, a number of significantly disabling recessive disorders that are known to lead to premature mortality in minority ethnic groups for which quality standards are absent. For example, in our Ashkenazi Jewish community, we advocate screening for 9 severe, recessive conditions whose aggregate carrier rate in our community is 1 in 5. Similar issues (but with different conditions) apply to many minority groups – e.g. Sickle cell anaemia in the black community, thalassemia in the Cypriot, Greek and Turkish communities. Currently NICE guidelines (as with NSC recommendations) refer only to SCA and Thalassemia but do not include other well established recessive conditions that are known to disproportionately impact people of Black, Asian and other minority ethnic origin. We suggest this is an important area that needs addressing.
106	British Association for the Study of the Liver (BASL)	Additional area	Patients from these groups have higher rates of viral hepatitis (Hepatitis B,C and D) and would benefit from this being prioritized. In addition there are disproportionate rates of hepatocellular carcinoma in these groups as a consequence of hepatitis.
107	Chartered Society of Physiotherapy (CSP)	Additional area	In addition to a specific focus on Type 2 Diabetes, cardiac rehabilitation and mental health, there needs to be an explicit reference to pain management services. There is an established body of evidence which highlights that for patients from black, Asian and other minority ethnic groups, their culture can influence their experience persistent pain conditions, such as Fibromyalgia
108	Department of Health	Additional area	**Cancer** It is disappointing that the draft quality standard does not mention that 1 in 4 black men will get prostate cancer as opposed to 1 in 8 of the general population - see link here to the Be Clear on Cancer campaign: https://prostatecanceruk.org/media/2457622/Be-Clear-on-Cancer-Web-Accessible-Healthcare-Professionals.pdf It is also disappointing that it does not promote cancer screening, where we know there is a lower uptake in some ethnic groups - see the NHS England evidence statement at this link: https://www.england.nhs.uk/wp-content/uploads/2014/02/sm-ft-4-2.pdf
109	Royal College of Physicians	Additional area	The RCP is grateful for the opportunity to respond to the above consultation. We are happy to support but note that we would want to see continued emphasis on bloodborne viruses, to improve the rates of diagnosis and to improve the number of people from BME backgrounds who are treated and retained in care in the UK.

Registered stakeholders who submitted comments at consultation

- British Heart Foundation
- British Association for the Study of the Liver (BASL)
- Chartered Society of Physiotherapy (CSP)

- Department of Health
- Diabetes UK
- Jnetics
- Kidney Research UK
- Lactation Consultants of Great Britain(LCGB)
- Maslaha
- Mind
- Muslim Council of Britain
- NHS England (Equality and diversity council)
- Public Health England
- Public Health England
- Race Equality Foundation
- Royal College of Physicians
- Royal Pharmaceutical Society
- Salford City Council
- Salford Royal Foundation Trust
- Solutions4Health
- University of Surrey
- University of York , BHF National Audit of Cardiac Rehabilitation