

**Nottingham City and
Nottinghamshire County NHS
Equality Delivery System (EDS):
Supporting Race Equality for All**

Putting the 'E' into Quality

August 2012

Community Innovations Enterprise

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1. Introduction

Nottinghamshire County and Nottingham City PCT Cluster commissioned this report due to their commitment to making equality a reality. The Cluster also had financial support from the East Midlands SHA. This engagement project was designed to support the roll out of the NHS Equality Delivery System (EDS) and establish race equality objectives for adoption across the PCT Cluster area.

After initial feedback from the first EDS community consultation in July 2011 it was agreed to support a range of minority ethnic and disadvantaged community groups and organisations to run an engagement process between November 2011 and July 2012. The process was coordinated and facilitated by Community Innovations Enterprise under the leadership of Professor Lord Patel of Bradford OBE.

This report presents the findings from the engagement with community groups and makes recommendations on the adoption of race equality objectives for use by the commissioners in their roll out of the EDS. The race equality objectives will support the development of commissioning strategies and the Joint Strategic Needs Assessment for both City and County partners and ensure communities and inclusion is a core value in local NHS commissioning.

2. Aims and objectives

The aims and objectives of the engagement were to:

- ensure 'whole community' involvement in developing the EDS race equality objectives;
- use a variety of methods to enable a diverse range of groups and individuals from minority ethnic and disadvantaged backgrounds to take part;
- provide a report with recommendations which can be used to support the CCGs and the PCT Cluster to incorporate the race equality objectives within their equality and diversity priorities as part of the roll out of the EDS.

3. Methods

The project commenced with a community consultation workshop during which participants representing a range of local ethnic minority and disadvantaged communities were informed about the project. Participants provided feedback on the aims and objectives and the proposed methods of engagement and signed up to the process of supporting access to community members to participate in the engagement.

A small team of engagement workers from CIE working closely with the PCT Cluster equality and diversity lead followed up on the contacts identified at the workshop and arranged a series of focus groups and consultation events.

A total of 85 individuals participated in the engagement. This included a diverse range of ethnic groups representing South Asian, Black African, Black Caribbean, Refugee and Asylum seekers, Gypsy and Travellers and minority white communities. Amongst the respondents 47% were female and 53% male. There was a wide range of age groups including 15% under the age of 24 and 16% over the age of 45.

The focus groups were conducted on the basis of confidentiality and participants were asked to respond to a number of questions about their experiences of using health services and their perceptions about the way in which ethnicity is addressed in healthcare. Information was also provided about the EDS and how the PCT Cluster and CCGs are developing their race equality objectives for the EDS. Participants were then invited to contribute their ideas and recommendations for ways in which these race equality objectives could be developed and which issues they perceived to be a priority.

Data from the focus groups has been used to identify the core issues in terms of the participants' perceptions about access to, experience of and outcomes from using local health services. These core issues have been grouped according to the EDS goals and outcomes framework in order to establish a coherent set of recommendations on race equality objectives.

4. Findings

The findings have been grouped according to core themes relating to access to, experience of and outcomes from healthcare services.

4.1 Access to primary healthcare

Access to healthcare remains an area of consistent concern with respect to Black and minority ethnic communities. Not least because the burden of disease amongst particular ethnic groups is high e.g. rates of diabetes amongst the South Asian community. It is also still the case that Black and minority ethnic communities, in particular young Black men of mixed heritage are significantly over-represented in secondary and tertiary mental health services and under-represented in primary mental health services such as talking therapies. Despite long standing evidence of these issues the barriers in access to healthcare remain stubbornly in place.

While respondents welcomed and appreciated the commitment of the PCT Cluster to listen to and address their concerns they identified a number of critical issues for access including:

- confusion about registration and appointment processes for primary care including inflexible appointment systems and opening times;
- negative experiences amongst family members and friends which feed reluctance in the community to access the same services;
- inconsistency in use of eligibility criteria for refugees and asylum seekers;
- language barriers and general lack of awareness about services.

4.1.1 Appointment systems

One of the key problems experienced by respondents in trying to get an appointment to see the GP is how to negotiate the times and conditions imposed by different practices. Respondents reported that they found the appointment times confusing and that there was a lack of flexibility.

People felt confused by the options provided e.g. being offered a choice of an emergency appointment, one within 48 hours or in three weeks. One respondent said that she had to wait four weeks before she could get an appointment to see the GP.

Respondents also said that restricted opening times created problems for those in work as they could not get an appointment that was outside normal working hours.

"It is difficult for me because the surgery is only open one evening a week and I can't get the time off work."

"Access to GPs is becoming more and more difficult"

One of the consequences of failing to find a GP to register with is that people wait until they become very ill and consequently access emergency services:

"After 5 years I went to A&E – had to wait until I was very ill, but couldn't get help [prior to this]."

"So afraid of getting sick – didn't know where to go."

"The elderly are being excluded till they get to crisis point and end up in hospital"

People who are also homeless experience even greater difficulties in becoming registered with a GP:

"I couldn't get registered with a GP because I was homeless."

"It's hard to get registered, I was homeless, had no money, no phone and no help."

Other groups reporting difficulties in accessing and using GP services include the Chinese, Polish and Gypsy and Traveller communities. For example, Chinese respondents report that their experience of using GPs in the UK differs to that in China. Doctors are normally respected very highly in China and treated with deference.

This is not the case in the UK where a preference for herbal and traditional remedies has resulted in many UK Chinese using herbalists rather than the GP service. Chinese respondents also report that their community is relatively isolated in Nottinghamshire and that many do not access and use mainstream health services.

The Polish community report feeling uncertain about how to access primary care services in the UK and feel that there is very little engagement between health services and the Polish community. People who were new to the UK and refugee and asylum seekers in particular report finding the appointment system confusing:

“Why can’t you see a doctor straight away, why do I have to wait a week for an appointment? I’m in pain now – the system makes no sense.”

Problems with phone systems also extended to cancelling appointments:

“It’s difficult to cancel appointments because people don’t answer the phones.”

Many respondents reported problems with appointments due to language difficulties. For example, a number of GP surgeries now have an automated telephone system and some respondents stated that if they are unable to talk directly to a receptionist they give up trying to access a GP at this point as they are unable to understand what the automated system is asking them to do.

Some GP surgeries are also using 08444 numbers and this can be very expensive to ring so some people are opting not to do so. As one voluntary sector respondent stated:

“We spend a lot of time trying to arrange appointments only [for service users].”

For those without the support of an agency it can be very difficult to get through the system:

“Don’t always have support to make appointments – need to be persistent to get appointments, but if you feel poorly and having a breakdown you don’t have the strength to do this.”

4.1.2 Reception

The experience of reception services at GP surgeries was reported by many respondents to be negative. For example, respondents describe reception staff as being aggressive and rude when they attempted to make appointments or ask questions:

“I’ve had to unfortunately report one receptionist because of her aggression and cheek over the phone.”

“Comments are made that are inappropriate, as if people aren’t bothered about the job.”

Some respondents, who were able to talk directly to a receptionist, felt that they had encountered racism and a negative response due to their ethnicity and limited ability to read and write English:

“Language should be kept simple but that does not happen – staff should consider training around this and keep it simple, think about the words used.”

Respondents also found the experience of being asked about their problems by reception staff was inappropriate or insensitive:

“Receptionist asks you what’s wrong with you – they shouldn’t do this, they shouldn’t be insistent.”

“They don’t treat us as equals or with respect.”

Gypsy and Traveller respondents highlighted the particular difficulties they have had in dealing with staff in GP surgeries:

“At the doctors there been two or three times where phone line staff have occasionally been nasty and I’ve had women come to me where they have been humiliated because they can’t read and write.”

“I asked for help from front line staff who was annoyed that she had to come around the counter to help.”

Respondents also reported being patronised even when their language skills were good:

“[A health card] with some of your details on and if you travel about you can take it to the surgery. I had it in my hand went to the counter to sign in, the little boy in front of me did it fine with his mother, but when it came to me the secretary came flying over to do it for me, and everyone looked at me like I couldn’t read or write, I can read and write I could’ve done it but that was an overzealous receptionist, so you got to have the balance right. She trying to hard to help you couldn’t say anything.....you got to be careful not to pigeon hole people.”

"There should be less patronising staff."

One respondent described their GP practice as being a nurse-led practice i.e. you had to talk to a nurse and describe your symptoms before being able to book an appointment with a GP. One male respondent was clearly unhappy with doing this as most of the nurses were female and he felt this was just another barrier to accessing a GP.

The respondent stated that the system could be bypassed by booking appointments directly on line, but acknowledged that this would be difficult for individuals who did not have access to a computer or for those with language difficulties.

Some of these issues are not restricted to particular ethnic groups e.g. many NHS patients have expressed difficulties in arranging appointments with GPs and have reported difficulties in negotiating the telephone system and early morning calls. However, these issues can be aggravated for some minority ethnic groups as the perception of health services being hard to access is associated with broader concerns about discrimination:

"It makes me feel that they do not want me to use the service, all these barriers..."

"The system is racist and discriminatory."

4.1.3 Cultural insensitivity, discrimination and lack of understanding

Most respondents reported that there was a general lack of awareness about different community groups which went beyond understanding about language and communication issues:

“GPs lack knowledge so just treat everyone the same so things are missed.”

“Doctors need to know their subject – they really don’t know their work.”

One example was with respect to the differing effects of medication for some ethnic groups and GPs being unaware of this:

“The Consultant made her [the patient] aware of this [adverse effect of medication due to ethnic group] and had to write to the GP. But it took the GP a while to make the change [to the medication]. The Consultant had to write to the GP twice.”

These issues appeared to be exacerbated for older people. For example, one respondent felt that they received limited reassurance, dignity and respect as an older person due to their Jamaican dialect. One respondent suggested:

“More eye contact is need by GPs.”

One older respondent stated that GPs do not always listen to her. She cited an example where she fell down the stairs due to psychological health problems, but the GP immediately accused her of drinking:

“The doctor said I should be in a nursing home because I was drinking in the day.”

The respondent made a formal complaint to the Primary Care Trust which resulted in an apology from the GP.

Another respondent who was on numerous medications stated that it was often stopped or alternative medication given but no clear explanation was provided by the GP. Discussion and choice around medication was considered by many respondents as important but many felt such discussions did not take place and they were not given options around their medication:

“They give you medication that has no bearing on your illness and symptoms.”

“Doctors don’t see you as an individual or even as a person”.

Another respondent stated that she was being stereotyped as an Asian woman and assumptions were made that she would ask to see an Asian doctor, however, this is not always the case and she stated that she would like to be given the choice.

The Gypsy and Traveller community report experiencing discrimination by primary care professionals who are perceived to be reluctant to engage with the community especially when confronted with more complex care issues such as older people with dementia:

“Old people need to be looked at in a different light because they are not accessing what they should and that they are not getting the treatment they should be getting - like there is one lady down there with Alzheimer that looks like nobody is doing anything about it you know what I mean”.

A number of respondents outlined the difficulties around explaining and communicating their symptoms:

“My Mother-in-Law is a polish lady and suffered health problems, but the GP didn’t understand what she was saying and dismissed her as having ‘health fatigue’. Later tests showed she had bowel cancer”.

Respondents also stated they had difficulties understanding what the GP was saying to them or how to use the prescription medication that they were given.

“GPs can confuse people by talking about all the options.”

However, a good example of a local pharmacist was cited who was willing to help by placing the medication for patients in medi-wallets at no extra cost, which helped them at least to know what medication to take, how much medication to take, and on what days.

Some respondents felt that GPs simply did not listen to them, especially if they tried to explain emotional issues. As one respondent stated:

“Doctors only want to deal with physical issues – they don’t pick up the emotional issues.”

4.1.4 Refugee and asylum seekers

Refugee and asylum seekers report conflicting information and lack of consistency when trying to register with a GP e.g. one respondent, who originally entered Britain on a 6 month visa, was told by a GP that she could not register with their practice due to her short term visa, but another GP was happy for her to be registered with their practice in spite of the visa.

Others report being treated differently on the basis of their refugee or asylum seeker status and there is a general lack of awareness about their rights in accessing healthcare:

“Don’t get equal treatment as refugees and asylum seekers.”

“People are not aware of their rights and what is available.”

“Lack of knowing where to go and which services they can use especially asylum seekers.”

The lack of consistency by GPs on whether to allow asylum seekers or people with refugee status to register for healthcare is creating confusion and fear. Respondents also report that once they have found a GP who will allow refugees to register it can still be difficult to do so because of the myriad of forms that need to be completed:

“Make registration with GPs simpler. Filling in forms for refugees is difficult and time consuming – many drop out.”

4.1.5 Gypsy and Traveller communities

Gypsy and Traveller respondents reported that around 85% of their community are not registered with GPs. They also said that 80% of Gypsy and Traveller women have never had a smear test despite large rates of cancer within the Gypsy and Traveller communities:

“Women in Gypsy community don’t talk about healthcare issues – seen as shameful.”

Gypsy and Traveller respondents also report difficulties with respect to screening and inoculation services:

“...expectant mothers need to be seen to and their inoculations and their children and all that.”

Gypsy and Traveller respondents said that the result of poor treatment over many years has been very negative for the community resulting in people choosing not to access primary health services:

“Gipsies don’t use NHS – scared about how they’ve been treated over the years.”

For some this resulted in only using A&E or paying for private care:

“Lack of access to basic healthcare is enormous – only place used is A&E.”

“Some will go private if they can afford it.”

Problems with literacy are often not recognised:

[Gypsy and Traveller women have been] “refused antenatal care – mid-wives are terrified of communicating with them so give out leaflets but many are illiterate.”

“Expressing themselves is difficult and they are worried about wrongly communicating symptoms to GPs.”

4.1.6 Access to mental health services

Many respondents reported feeling afraid of mental health services and were concerned that inappropriate diagnoses were being made. Some respondents thought that false assumptions and diagnosis were being made due to misunderstanding about cultural and ethnic differences. This was highlighted by a number of respondents, who had received a mental health diagnosis, for example:

“I've noticed that it's typical, predictable, it's like I walk in ...and they're going to look at the book and say you've got this diagnosis. It was mental health and they give you specific diagnosis, specific drugs right now. I'm not sure if that drug is going to be beneficial to me. I'm not sure if the diagnosis is right in the first place....”

Some respondents also felt that this stereotyping was taking place because some GPs lacked knowledge and experience around key issues, such as mental health, alcohol and drugs and their impact on people of different cultural groups and races:

“Tackle stigma and challenge some GPs attitudes around mental health issues.”

“ ... they made assumptions [around mental health diagnosis]. The attitudes need challenging.”

These Respondents felt that they were not being listened to by GPs and not being given the opportunity to have a discussion about their condition or offered a choice of treatment, for example:

“I walk in, I say I hear voices and I'm seeing things, that doctor will say your paranoid and you're a schizophrenic. I would say I might be a little bit paranoid and I might have two minds going on but I am in control of them, but the doctor will say you need help in this position and I will say well do I need to take medication and that doctor will say there is no other choice so that's kind of like is a problem. I would like talking therapies, sports, running, books reading, educating the people about what is happening to them.”

“Can’t share with GPs – they don’t understand, they don’t give you any choice, it’s like talking to a computer.”

“Services are black and white, no greys.”

Depression and mental health issues were cited as major problems by a number of male respondents in a range of communities. Examples were cited of men who had avoided seeking NHS help until suicidal thoughts were being considered.

One respondent described a friend who had sunk into depression and after many months finally went to the GP for help. He was told he would be referred for talking therapies but the referral could take 6 months, however, within a week he had committed suicide.

Another respondent described supporting his friend in a similar state:

“I’ve took him to the doctors along with his wife of course who didn’t know what he wanted to do, I think he was reaching being suicidal...”

There was concern amongst a number of male respondents that the waiting times for talking therapies of around 3-6 months was just too long for these men and the severity of their conditions were not being recognised:

“Quicker access to mental health services, especially talking therapies, people shouldn’t have to wait 6 months for support.”

A number of male respondents felt that they were being discriminated not only in terms of race but also in terms of their gender. They believed that women with stress and/or depression would receive medication from a GP, but some felt that there was still an attitude that men should “pull themselves together” and so did not receive medication from GPs.

The MOT for Men was viewed as extremely positive where men of a certain age were sent reminders to go to the GP for a basis health check, as one respondent stated:

“This raises our awareness about health issues and is beneficial.”

4.1.7 Language barriers and interpreting services

Language clearly remains a barrier to accessing services, in particular amongst older Black and minority ethnic people especially South Asian and amongst newer migrant groups. People describe being expected to provide their own interpreters from family members including children as a common occurrence:

"I had to interpret for my mother which was embarrassing for her and me."

"You have to ask your children to interpret for you, there is no other option."

"We need a more supportive approach to tackle language barriers."

"BME groups have multiple needs that are not being met and on top of this there is a problem with communication, the problems are exacerbated with dementia, depression and isolation especially with South Asian elders".

The problems caused by language difficulties in understanding what GPs were saying left many respondents feeling they had no choice but to use younger family members to attend appointments with them and to act as interpreters. However, this practice is viewed as problematic:

"Not everyone wants family members to interpret – this can be dangerous. Domestic violence is being missed around BME communities. GPs and nurses are not picking this up and not seeing this as their business – they are not willing to ask questions or raise the issue."

Moreover, if patients with language difficulties did bring a family member or supporter along, it was said that some GPs would ignore the patient and talk only to the family member or supporter. This can unsettle or even frighten the patient who may not clearly understand what is being discussed:

"Some people need support to hear and interpret what is said."

As Good as Your Word: A guide to community interpreting and translating in public service (Sanders, M. 2000. London: The Maternity Alliance) identifies three models for interpreting services: linguistic; professional team; and client centred or advocacy model. The different models highlight the variations in issues and responses that are relevant across health services:

Linguistic

This model is appropriate when the only barrier is being understood i.e. the person is confident, articulate and understands the service they are trying to access. An example of a linguistic model response is using a telephone interpreting service such as language line. The advantage of these services is immediacy of use and cost savings. The disadvantages are that some people are not comfortable using the telephone which can seem impersonal and it is not possible for the interpreter to see non-verbal behaviour.

Individual interpreters can also be employed as part of the linguistic model. In this instance it is common for the interpreter to be booked in advance which can restrict immediacy and is not always helpful when people present without having identified a language barrier. Problems can also arise when the interpreter does not have sufficient technical language skills e.g. understanding about mental health diagnostic terms.

Professional

This model refers to the use of face to face professional interpreters who are employed directly for this purpose such as link workers. The use of a professional model is directly linked to service improvement with the added benefits of having a team member whose role is to work in the community and raise awareness about the service and also raise awareness about the community amongst staff. The model is less effective when it is ad hoc or existing staff who happen to speak a particular language are being relied on to perform the link role on top of their normal duties.

Client centred or advocacy

This model is used as part of a managed care plan to ensure that the person is supported throughout their treatment and for the duration of their care including key transition points such as movement from hospital to community. The model is predicated on conceptions about culturally appropriate healthcare and learning and adaptation in service delivery and quality. The problem with this model comes when there is confusion between the role of interpreter and advocate. This confusion in roles can lead to professionals rejecting the model and having a poor understanding about the respective value of using interpreters and advocates.

Respondents in this consultation report primarily experiencing the linguistic model with varied degrees of success e.g. respondents talking about their elderly relatives describe the interpreting service as being poor:

"My mother didn't understand the interpreter, they did not know she was a Mirpuri dialect speaker."

"The GP appeared to be reluctant to see us with an interpreter, I think they thought it would interfere with things."

"Would prefer to ask doctors questions directly i.e. translation services need to be available".

Respondents also reported the lack of link worker services and that there should be more to establish engagement and increase awareness between services and the community:

"They do not engage with us, they do not understand the community."

"We need a worker who is part of the GP team and a member of our community."

"Voluntary services should promote their services to communities."

"Develop peer support services for BME communities."

This was thought to be an issue that transcended language barriers for example, amongst the Gypsy and Traveller communities there was a view that link workers were needed who came from the community and could increase access because they would be trusted.

The issue of trust and engagement between communities and services represented another significant barrier to access. Respondents commonly expressed the view that they were not understood by health services i.e. the needs and preferences of their community were not understood by healthcare professionals.

The prevalence of these views meant that choice and continuity were very important to minority ethnic communities. Where a healthcare professional was trusted and perceived to understand the community respondents wanted to be able to see that person each time they accessed health services. System inflexibilities and capacity make this unrealistic but this can have a detrimental impact on access especially when the issue of choice and continuity includes other factors such as gender.

4.1.8 Choice and continuity

Given the varied experience of primary care services and perceptions of cultural insensitivity, choice and continuity of care were viewed by respondents as being especially important. Many respondents reported being unable to choose the GP they wanted to see which influenced their willingness to seek help. This was viewed as important from the perspective of confidence that the GP understood their cultural and ethnic background but also related issues such as age and gender. For example, one female respondent said that there was only a single woman doctor in her surgery and that she could not guarantee being able to see her.

Being unable to exercise choice also affected perceptions about continuity of care:

“They won’t assign a regular GP in my surgery – it took me 6 years to find a GP I liked and felt safe with.”

“Need consistency with GPs and counsellors but don’t always get this.”

“GPs need training and to look at things more holistically, but there is a lack of continuity in GPs.”

These problems were further compounded by the perceived lack of time that GPs had to see patients. On average respondents said that appointments lasted for 6 or 7 minutes and they felt under pressure to explain their symptoms and needs in such a short amount of time. Respondents felt that the lack of time was disrespectful and that it meant they were not being valued:

“NHS is getting it really wrong – there is a real lack of time and empathy in the medical profession.”

“People feel rushed and that they are not important.”

“Leaves people thinking they’re not worth very much because they are only seen by the doctor for 7 minutes.”

“Younger doctors are better – the older ones have no patience, you’re in and out in five minutes”

Some men felt they had little choice in terms of seeing a male or female doctor:

“My practice has been taken over by all women – GPs and nurses. I feel awkward going there and think they don’t understand me.”

Having access to a male doctor was seen by some community groups as an important issue in terms of their *“pride and honour”* and could have an impact on whether they actually approach NHS services. For example, in the Gypsy and Travellers communities, it was stated that:

“Travellers are easily frightened towards health, they’re frightened of the C (cancer) word, terrified of that, so a lot of men will ignore their health because they are bread winners they are weakened down with the knowledge that they have got something serious wrong with them they’d rather just go on and by the time they need help it’s too late..“

4.2 Experience of health care in hospitals

There are wide variations in the reported experience of using hospital services with many respondents describing poor experiences which they relate as being discriminatory. These concerns relate specifically to poor experiences such as lack of appropriate food, negativity of staff members, poor understanding about procedures and medication regimes and uncertainty about aftercare.

Respondents also reported lack of cultural sensitivity amongst doctors and hospital staff and lack of appropriate interpreting services. One of the most damaging perceptions was that hospital staff could be racist resulting in detrimental and discriminatory treatment:

“.....a lot of the travellers are not saying that they are travellers so that they get the treatment that everyone else gets, and, I think that's very important, they need to be careful with that or you going to get people not using the NHS just for that reason.”

One respondent reported needing an operation and having turned up to the hospital and then told the operation was cancelled as there were no beds on 7 separate occasions. Finally, after making an official complaint on race grounds to the hospital a bed was found and the operation finally took place. The respondent perceived this be evidence that the motive for the previous lack of treatment was racist:

“I wasn't convinced by the excuses given in response to the complaint – I felt white people had priority.”

Getting to and from hospitals for appointments and around hospitals, was highlighted as a major problem for those with language difficulties and/or those who were elderly, had financial difficulties or had disability issues:

“I had no ways and means to get to the hospital because I was in debt.”

“I had to get a bus so used to get up at 5.00 a.m. to get to the hospital in time for a 7.00 a.m. appointment.”

An elderly Polish lady with language difficulties who lived 8 miles away from the hospital was reported as receiving appointment letters, but failed to attend because she did not understand them. Also, there was no follow up when she failed to show up for repeated appointments:

“Things should be done for the patient – the system should work for the patient, not the patient for the system.”

It was reported that some elderly Indians view going ‘back home’ to India as a safer option than to be operated on within the NHS, as they have a different relationship with the doctors at home. The situations they are hoping to avoid were clearly described by a South Asian respondent who spoke of her mother’s experiences in hospital. She felt there was a total lack of care, no choice of food – in fact because she was Indian she was given the spicy food although she did not want this and no interpreter was offered.

The lack of availability of interpreters within hospitals was widely perceived to be the norm and respondents described a number of examples. For example, one person attended a secondary care clinic but could not communicate her needs as no interpreter had been provided. In another example the person was due to have a breast screening but did not understand the procedure or what was being asked due to the lack of an interpreter.

Respondents reported feeling that many hospital staff appeared to be lacking in confidence when dealing with people from different ethnic backgrounds such as not knowing how to ask questions that may be about culture or ethnicity:

“Staff are frightened to ask questions around race.”

“Staff are not equipped enough to deal with the differences in people.”

“They should not be afraid to ask questions.”

One respondent stated that there was limited Asian staff workforce and thought that a wider variety of staff from different background would help to improve the language barriers and the cultural knowledge of staff:

"More staff from ethnic minority communities to be more visible."

"Need to increase of Asian staff in NHS premises."

The lack of diversity in staffing was thought to be indicative of negative attitudes to different cultural and ethnic groups. This was especially the case for Gypsy and Traveller communities:

"Yeah it's in hospitals too, I went to the hospital recently, my grandchild, daughter and grandchild, the nurse she came to treat my grandchild, when asking the details of how he injured himself we said that we were from a certain lane, her attitude just changed, it stunk her attitude, nothing was said to her, we carried on being polite because you don't get anything back from being nasty because you know you never get anywhere with attitude but yeah even in hospitals with certain nurses."

Perceptions about racism amongst hospital staff had a detrimental impact on perceptions about the quality and standards of care. For example, one respondent cited the experience of her mother who was admitted to hospital and rapidly deteriorated due to a lack of food drink eventually dying:

"The nurses wouldn't let her go to the toilet. She would have lived a lot longer if she hadn't gone into hospital"

Other respondents expressed similar perceptions about negativity and poor care in hospital:

"Nurses spoke to people like they are lesser human beings – there is a lack of respect and dignity. They should be taught respect. They don't converse with patients – there is no interest in them at all."

"Anybody at 60 or 70 years is written off."

Some of these perceptions were related to historical experiences and respondents recognised that there had been improvements but it was hard to change these attitudes and beliefs amongst older community members.

It was also reported that people often do not complain about the lack of interpreters as they do not understand the system for making a complaint and this is not explained in a way that they understand.

On the whole respondents were unaware of their rights and even when they did have this awareness reported being reluctant to make official complaints for fear of reprisal or because they did not understand the complaints process.

None of the respondents were aware of the various systems and processes for improving patient experience such as enhancing the healing environment (Kings Fund), Pacesetters (Department of Health) or Experience by Design (NHS Institute for Innovation and Improvement).

This does not mean to say that Black and minority ethnic patients have not been involved with these or similar initiatives but awareness about these approaches to health services and hospitals was low amongst respondents.

Experience by Design (EBD) provides a useful framework by which Black and minority ethnic patient experience could be improved. The EBD model uses patient experience to design improvements in services. There is a strong focus on capturing and understanding patients', carers' and staff experiences of services. This goes beyond process issues such as speed, efficiency and counting bed nights. The model specifically seeks to use subjective, personal feelings from patient and carers at crucial points in the care pathway.

There are three elements to the EBD model:

- *encouraging and supporting patients and carers to 'tell their stories';*
- *using these stories to pinpoint those parts of the care pathway where the users' experience is most powerfully shaped (the 'touch points');*
- *working with patients, carers and frontline staff to redesign these experiences rather than just systems and processes.*

4.2.1 Supporting patients and carers to tell their stories

The consultation process invited respondents to tell their stories about using health services. The value of this approach is that individual, personal insights are recounted and that respondents feel listened to. The process of asking people to recount their experiences is itself part of the process of changing experience as people can start to believe that their experience is being validated and that something will be done to change negative experiences.

There is a need for a community focus to this work i.e. the EBD approach needs to go beyond individual patients and recognise the importance that people place on their identity in describing experiences of healthcare. There is a complex interaction between the various ways in which people identify with their communities and the experience of being a patient within a large healthcare system which often leaves people feeling de-humanised.

It is important not to challenge people's experience. Health professionals sometimes find this difficult to do as the first instinct is to defend what can be perceived as an attack on their professionalism and standards of care. Respondents describe encountering this defensiveness in their attempts to raise issues with staff:

"I didn't feel that they believed me, my experience didn't seem to matter, I was just another bed and not a person."

"Staff were defensive, it was as if I was attacking them when all I wanted was to get proper food for my father in hospital."

"I didn't want to make an official complaint, but no one seemed to care what I was trying to say, my views were just dismissed."

Having a targeted programme for encouraging Black and minority ethnic patients and carers to tell their stories would provide a bridge between formal complaints processes and service improvement initiatives.

4.2.2 The 'touch' points

Touch points are critical points in the care pathway which are often the salient points in determining whether the experience is perceived negatively. It is possible from the consultation findings to identify touch points which relate specifically to different communities. For example, end of life care with the Gypsy and Traveller communities can be a critical time as large numbers of the community will want to visit the dying person.

“A hospital stay can be awkward! What happens with travellers is if we've got someone that is about to pass away then you'll get a hell of a lot off Travellers gathering which is unfair on the staff which I understand that fully and it's quite embarrassing. You've got about 25 sat outside in the corridors all waiting and they want to see the person for the very last time, the person, the loved one and the nurses are going mad, 2 to a bed or 3 to a bed or whatever, and the travellers get annoyed.”

This can be challenging for hospital staff when there are restrictions on the numbers of carers able to visit a patient at any one time. This is a touch point for the community where they perceive inflexibility in what is an emotionally charged situation as being indicative of wider rejection and discrimination against the community.

Another touch point concerns discharge from hospital and how well medication and follow-up is explained. This is reported to be something that elderly South Asian patients experience as poor with people being sent home without adequate understanding about how to take their medication.

Other touch points in the hospital pathway include:

- **personal care** - Black Caribbean and Black African patients being unable to access appropriate hair treatment in hospital;
- **nutrition** - South Asian patients being unable to eat an appropriate diet;

- **communication** - lack of interpreters at key points e.g. during ward rounds
- **care planning** - failing to take adequate account of specific cultural and religious needs e.g. being able to pray while in hospital.

These touch points are not complex to understand and constitute what can be considered basic care and yet they continue to be areas that respondents describe as being insufficiently addressed. It is often the seemingly simple things such as being able to look good, eat properly and communicate that can determine someone's impression of whether the care they receive is good or bad.

4.2.3 System redesign

Taking action when people raise issues and talk about their experiences needs to be addressed in a way that directly encompasses the experiences being described. This is especially important for communities and groups who are already feeling left out and ignored. The need for things to change and be seen to change is demonstrated by respondents in this consultation who report feeling 'over consulted' and that 'nothing ever changes as a result of these consultations'. Some community group agencies were reluctant to engage in the process due to their negative perception about health service consultations with Black and minority ethnic communities.

There is a need to ensure that Black and minority ethnic communities feel able to influence service redesign and improvement initiatives. Moving from consultation to action requires commitment and resources and communities need support and guidance on how to be effectively involved.

The advantages of taking this approach are that negative perceptions in the community which also influence access as people avoid services they do not perceive to be acting in their interest, can be changed into positive affirmations.

4.3 Outcomes from healthcare

Respondents were very much aware of the differential health needs experienced by some minority ethnic groups and the impact on outcomes:

"We have much higher rates of diabetes in our community."

"Gypsy and Traveller communities have very poor health compared with other groups."

"Doctors do not understand the health problems in our community like Sickle Cell."

Respondents also expressed concerns that members of their communities with chronic conditions were being neglected and suffering poor outcomes.

Some of these examples relate to general poor care quality such as cases of dementia where people have very low levels of community support or missed appointments not being followed up. Others are specific to the minority ethnic group i.e. medications being prescribed without being checked for efficacy with particular ethnic groups.

In many respects it is not possible to differentiate outcomes from access and experience as the latter clearly influence outcomes. However, awareness and concerns about outcomes that are specific to the community or ethnic group have a strong influence on perceptions about health services more broadly.

These perceptions are based on personal experience rather than research or evidence i.e. whether the person themselves or a family member felt better and in more extreme cases whether someone died.

Many of the issues identified under access and experience of health services influence the interpretation of outcomes i.e. negative outcomes are perceived as being linked with discrimination and poor service experiences regardless of the quality of treatment that may have been given:

"We had problems getting the right service, things took too long, my brother would not have become so ill if he had been seen sooner."

"The nurses on the ward were rude and impatient; I became more ill while in hospital."

Outcomes from the community perspective differ from that which clinicians and public health professionals identify. For example, some communities express a preference for medication when the clinician may prescribe counselling. Previous studies have shown how some minority ethnic communities express feelings of depression somatically i.e. they will describe the symptoms in terms of tummy pains.

This can cause problems when the symptoms are misunderstood and depression is not identified. Conversely, counselling can be perceived to be inappropriate when the person is expressing physical pain and they perceive the doctor to be ignoring this.

Also awareness and understanding about health care systems and processes can influence the degree to which people perceive outcomes as being positive or negative. For example, respondents from newer migrant community groups found the short duration of GP appointments challenging. They lacked understanding about primary care services and also experienced difficulties in explaining themselves in appointments of short duration.

Community groups also expressed concerns that services could be inappropriate for minority ethnic communities. There is a perception that many treatment models are Eurocentric and do not take adequate account of alternative models based on cultural differences. This was thought to have implications for some screening and public health services e.g. attitudes about gender amongst some minority ethnic groups meant that people would not be honest or frank with someone of the opposite gender.

Some health screening and advice programmes were not thought to be suitable for minority ethnic groups e.g. education about obesity that failed to take account of South Asian diets and smoking cessation programmes that ignored some groups habits of chewing tobacco.

Other community specific health issues were perceived to be ignored e.g. use of Khat amongst some African communities and drug interactions with herbal medications used by the Chinese community. There were also significant concerns that minority ethnic communities did not know enough about substance misuse problems and services:

"Tackle barriers to accessing drug and mental health services."

"Raise awareness of long term effects of taking drugs."

"NHS need to raise awareness to Asian parents to look for signs of drug abuse in their children as Asian parents do not always understand addiction."

There is a need for responses to the public health outcomes framework to take adequate account of minority ethnic community health and disease prevalence. This is further complicated by the failure of research to adequately take account of ethnicity and health. For example, there are problems with evidence based practice care which relates to the lack of adequate evidence encompassing smaller population groups:

" While there is considerable evidence supporting the efficacy of the psychological therapies (e.g. Lambert & Ogles, 2003; Roth and Fonagy, 1996), there is still relatively little evidence for specific age groups, ethnic minorities, or large service areas, such as primary care. Data sufficient for precise estimation of effects for small subpopulations requires the availability of much larger datasets than those which will accumulate through prioritized RCTs and traditional research-driven studies¹".

¹ Evans, C; Connell, J; Barkham, M; Marshall, C; Mellor-Clark, J. 2003. Practice-Based Evidence: Benchmarking NHS Primary Care Counselling Services at National and Local Levels. *Clinical Psychology and Psychotherapy Clin. Psychol. Psychother.* **10**, 374– 388 (2003)

The onus is on commissioners, providers and academics to work together to ensure that appropriate account is taken of ethnicity in consideration of public health outcomes.

4.4 Summary and conclusions

The Equality Delivery System (EDS) is designed to encompass healthcare improvements across all nine protected characteristics. However, this project was commissioned in recognition of the fact that there is a need to focus on the specific factors that are affected by race and ethnicity due to the population demographics for these groups and the history and evidence of poorer access, experience and outcomes from healthcare amongst different minority ethnic communities.

The respondents identified a wide range of healthcare issues which they perceived to represent poor quality care and reduced access to services on the basis of their ethnicity e.g. lack of interpreters and insensitive and discriminatory attitudes amongst healthcare staff. Other issues were identified which were not *per se* discriminatory on the basis of ethnicity but contributed to a perception that services responded poorly to the needs of different minority ethnic groups e.g. rigid and inflexible administration systems and restrictions in choice of healthcare provider.

A variety of issues were identified by respondents in their experience of using primary care services including problems arranging appointments, access to interpreters and appropriate language support, difficult relationships with surgery reception staff, cultural insensitivity and lack of understanding about communities. Respondents also reported negative experiences of using hospital services including perceptions about discrimination and negative attitudes, poor understanding about ethnic and cultural differences and language and communication problems.

Respondents did acknowledge that there have been some improvements but it is difficult to overcome the poor reputation of some health services due to the history of perceived discrimination. Some of the good practice cited by respondents included pharmacies providing clearer instructions on medications and the men's health screening initiative in primary care. However, on the whole there is a significant gap between minority ethnic communities and health services which limits their ability to access these services and benefit from improved experience and outcomes.

Bridging the gaps between health services and communities in order to overcome barriers to improving access, experience and outcomes requires specific actions on the part of health service providers and commissioners.

Some of the solutions identified by respondents on ways to address this include:

- **outreach** - services need to reach out to communities and take the first steps in establishing a relationships of trust and understanding;
- **training and development** - healthcare staff including reception staff need to understand the diversity in their local communities including different cultural norms and preferences, language needs, catering and religion;
- **appropriate community profiling** based on evidence of health need - services should be targeted at those communities where there are known health problems and poor access;
- **improved data collection** - some groups do not appear on standard demographic statistics or health needs assessment e.g. Gypsy and Traveller communities, BME lesbian, gay, bisexual and trans-gender individuals etc.
- **data systems need to be inclusive** to take adequate account of the diversity in local communities and to present an inclusive picture of access amongst these groups;

- ***engagement and language support services*** - there needs to be a comprehensive plan for providing engagement and technical support services such as link workers, advocacy and interpreting.

It is insufficient to rely on linguistic models in order to make improvements in access and there needs to be an approach that combines health care planning and improvement with raising community awareness and understanding about health services.

The PCT Cluster commissioned this project because they are committed to service improvement and want to demonstrate that will listen to community concerns and will take on board the learning and feedback.

The PCT Cluster takes the issues of race equality very seriously and intends to adopt the specific race equality objectives in order to ensure improvements in service commissioning and delivery.

5. EDS Assessment Framework

This consultation specifically sought views from respondents on the goals of the EDS (See Appendix A for the full tables). It was not possible to include the EDS Goal 3 on empowered, engaged and well supported staff as respondents did not have direct knowledge of this. However, respondents did have views about the kind of training and development they thought staff groups needed based on their experiences of using health services.

5.1 Better Health Outcomes for All

There are five outcomes for this goal:

5.1.1 EDS Outcome 1.1 Services are commissioned, designed and procured to meet the health needs of local communities, promote well-being, and reduce health inequalities

The key factors for this outcome include meeting health needs of specific communities, addressing gaps in health inequalities, engaging with communities on health needs including disadvantaged groups; promoting health and wellbeing for different communities through mainstream processes and having clear plans with milestones to progress to the next stage of the EDS assessment.

This consultation provides evidence that the commissioners are developing these outcomes. The report highlights a number of ways in which services need to be commissioned, designed and procured to meet the health needs of local minority ethnic communities that will promote well-being and reduce health inequalities:

Outreach

Services should be able to reach out to different communities where they are known to be experiencing lower access:

"NHS staff need to consider going out to local communities if some BME groups will not come to see them in their local surgeries e.g. Gypsies and Travellers".

Contract monitoring

Provider services should be held to account on the degree to which they are meeting the needs of target minority ethnic groups through the contract monitoring process.

"People should be held to account, services should have to show what they are doing."

Increased understanding about communities

This report goes some way towards increasing understanding about the needs of minority ethnic communities. This needs to be part of mainstream processes whereby community engagement is undertaken regularly and continually extended to include more groups.

5.1.2 EDS Outcome 1.2 Individual patients' health needs are assessed, and resulting services provided, in appropriate and effective ways

The key factors for this outcome include having individual health needs assessment and resulting appropriate and effective services that are comparable to those for all patients, engaging with communities on this including disadvantaged groups, improving patients and carer health outcomes through mainstream processes and having clear plans and milestones to progress to the next stage of the EDS assessment.

Individual health needs assessments need to take account of the range and diversity of cultural factors for minority ethnic communities. This report highlights a number of areas where individual health needs assessments are falling short of meeting the needs of minority ethnic communities including:

- barriers to accessing services so that some minority ethnic communities do not receive an individual assessment;
- poor understanding by clinicians about minority ethnic communities meaning that assessments do not reflect the full range of needs;
- language barriers preventing a full and adequate assessment;
- lack of appropriate targeting in service delivery to improve health outcomes for particular minority ethnic communities e.g. South Asian community and diabetes.

5.1.3 EDS Outcome 1.3 Changes across services for individual patients are discussed with them, and transitions are made smoothly

The key factors for this outcome include comparisons with community groups on transitions and service changes with patients as a whole, preventing breakdowns in care pathways; engagement with communities on service changes and transitions including disadvantaged groups, improving service changes and transitions for communities using mainstream processes and having clear plans and milestones to progress to the next stage of the EDS assessment.

There are a number of instances where service changes and transitions for some minority communities are less effective than for patients as a whole. These include:

- minority ethnic elder people experiencing more problems in understanding health care due to language issues;

- refugee and asylum seekers experiencing differential access problems to primary care and follow-up services;
- transient communities such as homeless and Gypsy and Traveller communities experiencing greater degree of problems during service changes and transitions.

5.1.4 EDS Outcome 1.4 The safety of patients is prioritised and assured. In particular, patients are free from abuse, harassment, bullying, violence from other patients and staff, with redress being open and fair to all

The key factors for this outcome include prioritising and assuring safety of community groups including comparisons with patients as a whole, engaging with community groups including disadvantaged groups, improving patient safety through mainstream process and having clear plans and milestones to progress to the next stage of the EDS assessment.

The key area regarding patient safety relates to the experience of mental health services amongst Black African and Black Caribbean communities. Fear and stigma continue to affect access and use of services and there is concern in the community that safety is not adequately addressed:

"I would not use the mental health service, can't trust that they would keep me safe."

"Black people are discriminated against in mental health services"

"Black people die in these places [mental health hospitals]"

In order to mainstream better responses to patient safety concerns amongst minority ethnic communities there is a need for critical incident monitoring to be broken down by ethnicity. These data should be reviewed regularly and reported as part of mainstream reporting processes.

5.1.5 EDS Outcome 1.5 Public health, vaccination and screening programmes reach and benefit all local communities and groups.

The key factors for this outcome include ensuring public health, vaccination and screening programmes reach community groups and benefit them in the same way as for all communities as a whole, engaging with communities including disadvantaged groups, improving the efficiency of public health programmes for community groups through mainstream processes and having clear plans and milestones to progress to the next stage of the EDS assessment.

There is evidence in the report that some minority ethnic communities do not receive screening routinely and can miss vaccinations. There are various factors which influence this including:

- lack of awareness about screening programmes;
- children being removed from school at times of vaccinations e.g. for extended periods of holiday abroad to visit home countries;
- health care professionals making false assumptions about communities e.g.
- Gypsy and Travellers not agreeing to have vaccinations;
- poor access to primary care.

5.2 Improved patient access and experience

There are four outcomes for this goal.

5.2.1 EDS Outcome 2.1 Patients, carers and communities can readily access services, and should not be denied access on unreasonable grounds

The factors for this outcome include having ready access to services and not being denied access on unreasonable grounds, comparisons on access with patients groups as a whole, engagement with communities on access including disadvantaged groups, improving access through mainstream processes and having plans with clear milestones to reach the next stage of the EDS assessment.

There is evidence that refugee and asylum seeker groups in particular have experienced differential access with some having been denied access to primary care unreasonably. It would appear that there is confusion amongst primary care staff about eligibility criteria resulting in inconsistencies and mixed messages.

Other groups experience differential access due to a variety of factors including language barriers, lack of awareness about how systems operate, confusion over forms and registration procedures, difficulties negotiating appointment systems etc.

Some of the barriers to access are generic and others are specific to particular groups e.g. all patient groups have reported problems with GP appointment systems and telephone booking arrangements. Gypsy and Traveller communities feel unwelcome by services resulting in their opting not to attend appointments and some South Asian older people and new migrant communities with poor or no English fail to understand processes or are unable to respond to letters and other communication in English.

5.2.2 EDS Outcome 2.2 Patients are informed and supported to be as involved as they wish to be in their diagnosis and decisions about their care, and to exercise choice about treatments and places of treatment

The factors for this outcome include individuals being informed and supported to take part in decisions about their care and to exercise choice in available treatments and location, comparisons on decision making and choice with patients groups as a whole, engagement with communities and disadvantaged groups about involvement and choice, making improvements in information and support on diagnosis and treatments and having plans with clear milestones to reach the next stage of the EDS assessment.

Respondents report feeling confused about treatment options and having difficulties understanding care such as use of medications. There are more general concerns about choice in particular being able to see a clinician of their choice and continuity of care when can't get an appointment with the same GP.

Information and support to be involved in decisions about care needs to extend to language support and inclusion of family members and carers. Negative perceptions about services and discrimination can influence the degree to which people feel adequately involved.

5.2.3 EDS Outcome 2.3 Patients and carers report positive experiences of their treatment and care outcomes and of being listened to and respected and of how their privacy and dignity is prioritised

The factors for this outcome include patients and carers reporting positive experiences including being listened to, respected and having dignity and privacy prioritised, how experiences compare between community groups and patients groups as a whole, engagement with communities and disadvantaged groups on experience on making progress, improving patient experience and having plans with clear milestones to reach the next stage of the EDS assessment.

Minority ethnic communities report many negative experiences of care and treatment and feel that dignity and respect are compromised by discriminatory and insensitive care:

“Dignity and respect has massively slipped and is shocking from nurses.”

“People have become just patient numbers.”

Perceptions about cultural competence and capability influences people's experience. These factors result in minority ethnic experience being less positive than comparisons with all patient groups.

5.2.4 EDS Outcome 2.4 Patients' and carers' complaints about services, and subsequent claims for redress, should be handled respectfully and efficiently

The factors for this outcome include handling complaints from community groups respectfully and efficiently, how treatment of complaints compares between community groups and patient groups as a whole, engaging with communities and disadvantaged groups on how complaints are handled, improving the way in which complaints are handled through mainstream processes and having plans with clear milestones to reach the next stage of the EDS assessment.

Minority ethnic communities report low awareness about how to use complaints systems and also being reluctant to do so for fear of reprisal. Some do not want to report to a formal complaints system but feel that their views are ignored and that staff are unwilling to engage with them on how to make improvements.

Amongst those making complaints on the basis of discrimination or actual racism there is a view that this is not taken seriously and that their experiences are discounted or ignored:

“They were unwilling to talk to me about what happened, I was seen as a trouble maker.”

“They don't want to know about racism, it's like they can't face up to it.”

Complaints systems need to be explained better including more information about how people can use informal systems to raise issues. Greater involvement of minority ethnic communities and patients in service improvement initiatives would help to address these issues.

5.3 Empowered, engaged and well supported staff

Respondents did not have sufficient knowledge of staffing systems to comment on this goal. However, general views on training and development issues were reported:

Cultural capability and understanding

Respondents thought that staff training should include cultural capability and that this should be mandated:

"They should implement mandatory awareness training of cultural needs to healthcare professionals to tackle cultural barriers".

"NHS staff need to have greater understanding and consideration of religious beliefs."

Cultural sensitivity

Respondents wanted to see staff being confident to ask questions about culture and individual preferences:

"Training to get doctors to ask the right questions."

"Staff training needs cover treating people with dignity and respect as part of cultural awareness such as not asking people to undress in front of medical staff".

Reception

Particular concerns were raised about reception staff and that these groups of staff needed to be included in development training:

“Training also for receptionists – they need basic communication skills.”

5.4 Inclusive leadership at all levels

There are three outcomes for this goal. Not all factors can be assessed from this consultation as do not all relate directly to the engagement areas being addressed.

5.4.1 EDS Outcome 4.1 Boards and senior leaders conduct and plan their business so that equality is advanced, and good relations fostered, within their organisations and beyond

The key factors for this outcome include senior leaders communicating the vision for services and workplaces that are fair and diverse, taking steps to develop diverse teams, advancing equality and fostering good relations as part of personal objectives, engagement with communities in decisions making and review, engagement with staff side, demonstrating the importance of using the best evidence in decision making and service review, dealing with personalisation, fairness and diversity in mainstream processes.

There was awareness about the vision for fairness and diversity in services and the way in which this relates to the NHS Constitution due to the engagement work undertaken by the lead for equality in the PCT cluster. This was perceived to be a good example of a senior manager taking steps to come out and talk with different communities about their needs and experiences. However, this was not perceived to be more broadly replicated amongst other senior leaders and there was a perception that this did not feature prominently as part of people objectives.

Respondents did not view commissioners as having used the best evidence with respect to minority ethnic community health needs and that the evidence was not taken account of fully in service reviews and decision making.

Respondents raised particular issues with respect to personalisation reporting that personal budgets were being less used amongst minority ethnic communities. Perceptions about discrimination in services meant that respondents had negative views about the degree to which services were fair.

5.4.2 EDS Outcome 4.2 Middle managers and other line managers support and motivate their staff to work in culturally competent ways within a work environment free from discrimination

The key factors for this outcome include middle managers creating high performance and diverse teams, advancing equal opportunity and fostering good relations included in middle managers objectives, middle managers motivate and support staff to understand and work with diversity, working in culturally competent ways, engaging with communities to respond to their needs, capturing and disseminating examples of good practice in cultural competence.

While respondents did not have direct knowledge about middle managers there were perceptions that not enough was being done to develop and manage staff appropriately so that their attitudes and standards were in keeping with the vision for fairness and respect for diversity.

Respondents did not feel that staff were skilled in cultural capability and reported experiencing poor service responses on the basis of discriminatory attitudes and behaviours. There was a perception that managers did not address this fully and minority ethnic communities would be reluctant to speak to managers directly as they did not feel they would be listened to.

5.4.3 EDS Outcome 4.3 The organisation uses the Competency Framework for Equality and Diversity Leadership to recruit, develop and support strategic leaders to advance equality outcomes

The key factor of this outcome is whether the organisation uses the competency Framework for Equality and Diversity Leadership. Respondents were unaware of this framework or its use in services.

6. Recommendations - race equality objectives

Based on the findings from this engagement and consultation, the analysis of race critical issues and mapping of the findings to the goals and outcomes from the EDS assessment framework it is possible to make recommendation on race equality objectives that should be adopted by the PCT Cluster and CCGs.

6.1 Race equality objective 1: Access to healthcare

The PCT cluster recognises that access to healthcare must be fair for all communities and that where there are known gaps action should be taken through commissioning, service delivery and procurement systems to improve access for those communities experiencing barriers. This report highlights gaps in access to health services for:

- refugee and asylum seekers
- new migrant communities
- people whose first language is not English

It is recommended that specific actions are taken to address these gaps.

Refugee and asylum seekers

There are inconsistencies in the approach taken by primary care services about the eligibility criteria for refugee and asylum seekers. The PCT cluster should take action to ensure that all GPs and primary care services staff understand the eligibility criteria and that this is applied consistently across the City and County CCGs.

New migrant communities

New migrant communities such as the Polish community are experiencing problems accessing primary healthcare services. The administration systems for registration and making appointments are viewed as confusing and inflexible. The PCT cluster should ensure that easy to read instructions are provided for new migrant communities explaining how to register with a GP.

CCGs should undertake a review of appointment systems to ensure that these are reasonable and take due regard for the needs of communities who may need to access services in more flexible ways.

People whose first language is not English.

Not understanding English is one of the main barriers to access amongst minority ethnic communities, especially those who are older. The PCT cluster should ensure that there is adequate provision of interpreting services across all health services. Clinicians should have a clear understanding about how to use these services including policy and practice guidelines which seek to avoid the use of family members and especially children being used as interpreters.

CCGs should develop a range of models for addressing language barriers including telephone and face to face linguistic support systems and community link workers. The role of the link workers should be clearly prescribed as providing a bridge between communities and services in order to raise awareness and increase access for those whose first language is not English. Link workers should be based in primary care health teams within localities where there is a higher density of South Asian communities. It would be helpful if this service was developed in partnership with the Black and minority ethnic voluntary sector.

6.2 Race equality objective 2: Experience of healthcare

Experience of healthcare services differs across minority ethnic groups with some reporting negative experiences which they perceive to be the result of discriminatory and racist attitudes and behaviours amongst health services staff. There are particular concerns with respect to mental health services and the experiences of Black African and Black Caribbean communities.

The voice of minority ethnic patients and carers needs to be more prominent in health service improvement programmes with specific actions being undertaken by service providers to ensure these groups are able to contribute effectively.

The PCT cluster should ensure that minority ethnic voices are heard in service improvement programmes by requiring service providers to report on the inclusion of minority ethnic patients and carers within service improvement projects. CCGs should ensure that provider services contracts include requirements to report patient experience data by ethnicity and establish baselines by which comparative data may be used to measure this experience between all ethnic groups.

CCGs should require mental health services to develop outreach programmes and link work with Black African and Black Caribbean communities in order to increase trust between mental health services and these communities.

6.3 Race equality objective 3: Outcomes from healthcare

Some minority ethnic communities have higher prevalence of particular health problems e.g. Diabetes and learning disabilities in the South Asian community, morbidity and chronic conditions in the Gypsy and Traveller communities. Problems with access and experience of health services can influence the outcomes from these services. This results in health inequalities for minority ethnic communities.

The PCT cluster should prioritise action to address the most prevalent diseases and health conditions in minority ethnic communities. These priorities and actions should be part of each of the CCG health strategies and discussed and agreed with the Health and Wellbeing Boards. Specific programmes should be developed which are based on the available evidence, target particular minority ethnic communities with tailored service initiatives and engage those communities in the design and monitoring of the services being developed.

6.4 Race equality objective 4: Mainstreaming the race equality objectives

This work will take place against a background of unprecedented change in health services. However, this also provides new opportunities to ensure that race equality is embedded in the new systems and architecture for health service commissioning and delivery.

The findings and recommendations from this report should be shared with the CCGs and the Health and Wellbeing Board to ensure that there is full discussion of the issues and that all the relevant stakeholders are engaged in the process of making the race equality objectives part of mainstream developments going forward.

The EDS requires health commissioners and providers to mainstream their responses to equality. This means that the development, implementation and monitoring of race equality objectives should be part of core business planning and strategies and not ad hoc or supplemental.

The PCT cluster should ensure that the authorisation process and subsequent performance monitoring for CCGs includes the requirement to mainstream the race equality objectives. This could be evidenced through CCG business plans and strategies, Board commitment and development programmes and staff training and development.

Progress reporting on the race equality objectives should be at the highest levels of governance and be made available for the public through publication on CCG websites and in other media such as Foundation Trust membership bulletins. There should be a clear link between performance on the race equality objectives and contract management including the use of financial rewards and penalties. This could be further supported by incorporating the race equality objectives within QulPP and CQUINs.

All commissioners and service providers should be required to take steps to improve their equality monitoring systems so that there is a robust evidence base which encompasses all minority ethnic communities in the area. These monitoring systems should be supplemented where necessary to ensure that where gaps in data exist steps are taken to address this e.g. community engagement programmes with targeted groups.

Appendix A. The EDS assessment framework

The evidence from this consultation has been mapped to the EDS assessment framework.

EDS Goal 1 – Better health outcomes for all

EDS Outcome 1.1 Services are commissioned, designed and procured to meet the health needs of local communities, promote well-being, and reduce health inequalities.

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|--|-------------------------|
| Through the use of best available evidence, for how many protected groups can the organisation demonstrate that the health needs of patients & carers are being met, and well-being is promoted? | <p>Health needs of some minority ethnic communities are not being met appropriately.</p> <p>Public health promotion models do not take full account of ethnic differences.</p> | Under developed |
| Through the use of best available evidence, how does the health and well-being of patients & carers from protected groups compare with the health and well-being of all patients & carers? | <p>Ethnic minority community groups perceive themselves to be faring less well than other groups.</p> <p>The evidence base lacks sensitivity to include all ethnic groups.</p> | Under developed |

| | | |
|--|--|------------------------|
| <p>Through the use of best available evidence, what is the extent of the gap in health inequalities between patients & carers from protected groups and patients & carers as a whole?</p> | <p>Ethnic minority communities perceive the gap in health inequalities to be greater than for groups as a whole. Some groups report experiencing more health inequalities e.g. Gypsy and Travellers, new migrant communities.</p> <p>Black African and Black Caribbean groups report greater discrimination in mental health services.</p> | <p>Under developed</p> |
| <p>Does the organisation engage with patients, carers & communities (and for foundation trusts, with members and governors) from protected groups on how health needs can be met, well-being promoted, and inequalities reduced?</p> | <p>There is evidence of engagement including this consultation. There is a need to undertake additional engagement with specific ethnic minority groups on particular health issues e.g. mental health and Black African and Black Caribbean communities.</p> | <p>Developing</p> |
| <p>Does the organisation take account of key disadvantaged groups in the above processes?</p> | <p>This consultation is evidence of taking account of ethnic minority groups.</p> | <p>Developing</p> |
| <p>Does the organisation aim to meet health needs & promote well-being of protected groups, and reduce health inequalities, through mainstream processes?</p> | <p>Ethnic minority communities perceive that more needs to be done to mainstream cultural sensitivity and ensure staff are adequately equipped and trained to address diversity.</p> | <p>Developing</p> |
| <p>Does the organisation have plans in place to progress to the next grade, with milestones?</p> | <p>This report contains plans and recommendations for minority ethnic communities - race equality objectives</p> | <p>Developing</p> |

EDS Outcome 1.2 Individual patients' health needs are assessed, and resulting services provided, in appropriate and effective ways

| EDS outcome factor | Consultation feedback | Grade assessment |
|---|---|-------------------------|
| Through the use of best available evidence, for how many protected groups can the organisation demonstrate that patients from protected groups have their health-needs assessments, and resulting services, provided in appropriate and effective ways? | Health needs assessments for some minority ethnic groups are reported to lack sensitivity e.g. not taking account of specific cultural factors. | Developing |
| Through the use of best available evidence, how do the health-needs assessments, and resulting services, for patients from protected groups, compare with the health-needs assessments, and resulting services, for patients as a whole? | There is a perception amongst some minority ethnic groups that they receive poorer quality health needs assessments in comparison with patients as a whole. | Developing |
| Does the organisation engage with patients (and for foundation trusts, with members and governors) from protected groups about how health-needs assessments, and resulting services, may be provided in more appropriate and effective ways? | This consultation fulfils some of this for minority ethnic groups. | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Homeless asylum seekers and women who have been abused were included in the engagement. | Developing |
| Does the organisation aim to improve on patient and carer outcomes for protected groups through mainstream processes? | Recommendations from the consultation with minority ethnic groups seeks to do this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | This is part of the recommendations in this report. | Developing |

EDS Outcome 1.3 Changes across services for individual patients are discussed with them, and transitions are made smoothly

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|--|-------------------------|
| Through the use of best available evidence, how do service changes and transitions for patients from protected groups compare with the changes and transitions for patients as a whole? | Minority ethnic groups report being uncertain about transitions and service changes. Some groups such as Chinese and new migrants communities feel isolated and not engaged. Individuals with poor or no English report being confused about healthcare changes. | Developing |
| Does the organisation have adequate procedures to prevent breakdown of care pathways for patients from protected groups when transferring across services? | Breakdowns in care pathways are reported to occur for minority ethnic groups due to difficulties with language support. | Under developed |
| Does the organisation engage with patients (and for foundation trusts, with members and governors) from protected groups on how service changes are planned and transitions made smooth? | Minority ethnic groups do not feel engaged on these issues. | Under developed |
| Does the organisation take account of key disadvantaged groups in the above processes? | Not part of this consultation | N/A |
| Does the organisation aim to improve on service changes and transitions for protected groups through mainstream processes? | This report provides recommendations to achieve this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | This report makes recommendations to achieve this | Developing |

EDS Outcome 1.4 The safety of patients is prioritised and assured. In particular, patients are free from abuse, harassment, bullying, violence from other patients and staff, with redress being open and fair to all

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|--|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that patients from protected groups have their safety prioritised and assured? | Minority ethnic groups report experiencing racist and discriminatory behaviour within health services. There is a reluctance to use formal complaints systems. | Under developed |
| Through the use of best available evidence, how does the safety of patients from protected groups compare with the safety of patients as a whole? | Black African and Black Caribbean groups report feeling less safe in mental health services. | Under developed |
| Does the organisation engage with patients (and for foundation trusts, with members and governors) from protected groups on how patient safety procedures can be improved? | This engagement is part of this | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Homeless asylum seekers and women who have been abused were included in this consultation. | Developing |
| Does the organisation aim to improve patient safety for protected groups through mainstream processes? | This report has recommendations to address this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Outcome 1.5 Public health, vaccination and screening programmes reach and benefit all local communities and groups

| EDS outcome factor | Consultation feedback | Grade assessment |
|---|---|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that public health, vaccination and screening programmes reach and benefit all protected groups within local communities? | Minority ethnic groups report being missed for screening and vaccinations | Under developed |
| Through the use of best available evidence, do public health, vaccination and screening programmes benefit protected groups in the same way that they benefit communities as a whole? | There are reported variations for minority ethnic groups | Under developed |
| Does the organisation engage with patients, carers, staff & communities (and for foundation trusts, with members and governors) from protected groups on how public health programmes can be improved and inequalities reduced? | This report achieves some of this for minority ethnic groups | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Homeless asylum seekers and women who have been abused were consulted in this project | Developing |
| Does the organisation aim to improve the efficiency of public health programmes for protected groups through mainstream processes? | This report has recommendations to address this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Goal 2 – Improved patient access and experience

EDS Outcome 2.1 Patients, carers and communities can readily access services, and should not be denied access on unreasonable grounds

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|---|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that patients, carers & communities from protected groups can readily access services, and are not denied access on unreasonable grounds? | Refugee and asylum seekers report particular difficulties accessing GPs and report having been refused registration | Under developed |
| Through the use of best available evidence, how does the access of patients, carers & communities from protected groups compare with the access of patients, carers & communities as a whole? | Some minority ethnic groups compare less favourably | Under developed |
| Does the organisation engage with patients, carers & communities (and for foundation trusts, with members and governors) from protected groups about access to its services, and how to make progress? | This report achieves some of this for minority ethnic groups | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | This report has recommendations to address this | Developing |
| Does the organisation aim to improve access for protected groups through mainstream processes? | The recommendations in this report seek to achieve this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Outcome 2.2 Patients are informed and supported to be as involved as they wish to be in their diagnosis and decisions about their care, and to exercise choice about treatments and places of treatment

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|---|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that patients from protected groups are informed and supported to be involved in decisions about their care, and to exercise choice about treatments and place of treatment? | Some minority ethnic groups experience limited choice and report finding it difficult to be involved in decisions about their care. | Under developed |
| Through the use of best available evidence, how does the information & support needed by patients from protected groups to help them to be involved in decisions about their care, and to exercise choice about treatments and place of treatment, compare with the information & support provided to patients as a whole? | Minority ethnic groups have lower awareness about their rights and about how services operate compared to patients as a whole. | Under developed |
| Does the organisation engage with patients (and for foundation trusts, with members and governors) from protected groups about how they are informed and supported to be involved in decisions about their care and make choices about treatments and place of treatment, and how to make progress? | This report achieves some of this for minority ethnic groups | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Some disadvantaged groups included in this engagement | Developing |
| Does the organisation aim to improve information & support on diagnoses and treatments for protected groups through mainstream processes? | The recommendations in this report seek to achieve this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Outcome 2.3 Patients and carers report positive experiences of their treatment and care outcomes and of being listened to and respected and of how their privacy and dignity is prioritised

| EDS outcome factor | Consultation feedback | Grade assessment |
|---|---|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that patients & carers report and enjoy positive experiences of the organisation, including being listened to and respected, and having their dignity and privacy prioritised? | Minority ethnic groups report negative experiences. Cultural and religious needs are reported to be poorly accounted for. Minority ethnic groups do not feel listened to or understood by health professionals. | Under developed |
| Through the use of best available evidence, how does the experience of patients & carers from protected groups compare with the experience of patients & carers as a whole? | Minority ethnic groups report less favourable experiences compared to patients as a whole. | Under developed |
| Does the organisation engage with patients & carers (and for foundation trusts, with members and governors) from protected groups about their experiences of the organisation, and how to make progress? | This report achieves some of this for minority ethnic groups | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Some disadvantaged groups are included on this consultation | Developing |
| Does the organisation aim to improve on patient & carer experience for protected groups through mainstream processes? | The recommendations in this report seek to achieve this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Outcome 2.4 Patients' and carers' complaints about services, and subsequent claims for redress, should be handled respectfully and efficiently

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|--|-------------------------|
| Through the use of best available evidence, can the organisation demonstrate that complaints by patients & carers from protected groups, and any subsequent redress, are handled respectfully and efficiently? | Minority ethnic groups do not want to use complaints systems for fear of reprisal and also report not understanding how to use these systems | Under developed |
| Through the use of best available evidence, how does the handling of complaints by, and subsequent redress for, patients & carers from protected groups compare with the handling of complaints and subsequent redress for patients & carers as a whole? | Minority ethnic groups report less favourable experience compared to patients as a whole | Under developed |
| Does the organisation engage with patients & carers (and for foundation trusts, with members and governors) from protected groups about how their complaints, and subsequent redress, are handled, and how to make progress? | This report achieves some of this for minority ethnic groups | Developing |
| Does the organisation take account of key disadvantaged groups in the above processes? | Some disadvantaged groups are included on this consultation | Developing |
| Does the organisation aim to improve how complaints are handled for protected groups through mainstream processes? | The recommendations in this report seek to achieve this | Developing |
| Does the organisation have plans in place to progress to the next grade, with milestones? | The recommendations in this report seek to achieve this | Developing |

EDS Goal 3 – Empowered, engaged and well-supported staff

EDS Outcome 3.1 Recruitment and selection processes are fair, inclusive and transparent so that the workforce becomes as diverse as it can be within all occupations and grades

N/A

EDS Outcome 3.2 The NHS is committed to equal pay for work of equal value and expects employers to use equal pay audits to help fulfil their legal obligations

N/A

EDS Outcome 3.3 Through support, training, personal development and performance appraisal, staff are confident and competent to do their work, so that services are commissioned or provided appropriately

N/A

EDS Outcome 3.4 Staff are free from abuse, harassment, bullying, violence from both patients and their relatives and colleagues, with redress being open and fair to all

N/A

EDS Outcome 3.5 Flexible working options are made available to all staff, consistent with the needs of the service, and the way people lead their lives

N/A

EDS Outcome 3.6 The workforce is supported to remain healthy, with a focus on addressing major health and lifestyle issues that affect individual staff and the wider population

N/A

EDS Goal 4 – Inclusive leadership at all levels

EDS Outcome 4.1 Boards and senior leaders conduct and plan their business so that equality is advanced, and good relations fostered, within their organisations and beyond

| EDS outcome factor | Consultation feedback | Grade assessment |
|--|--|-------------------------|
| Do Board members and senior leaders communicate their vision for services and workplaces that are personal, fair and diverse within the organisation and beyond to the wider health and care system? | Good awareness of the visions for fairness communicated by PCT cluster equality lead and team. | Developing |
| Do Board members and senior leaders actively take steps to create high performing diverse teams and develop diverse talent in the organisation? | N/A | N/A |
| Do Board members and senior leaders include advancing equality of opportunity and fostering good relations in their personal objectives and ask the same of their staff? | N/A | N/A |
| Do Board members and senior leaders demonstrate the importance of engaging with patients and communities, across the protected groups, in their decision-making and service review, and require the same of all parts of the organisation? | Minority ethnic groups report feeling less well engaged and unable to be involved in decision making about services. | Under developed |
| Do Board members and senior leaders demonstrate the importance of engaging with staff-side organisations and staff, across the protected groups, in their decision-making and service review, requiring the same of all managers? | N/A | N/A |
| Do the Board and senior leaders demonstrate the importance of using best available evidence, across the protected groups, in its decision-making and service review, requiring the same of all managers? | Minority ethnic groups do not feel that the evidence on health needs for their communities are used effectively | Under developed |
| Do Board members and senior leaders deal with issues of personalisation, fairness and diversity, across the protected groups, as part of mainstream business and internal assurance processes? | This report makes recommendations on this | Developing |

EDS Outcome 4.2 Middle managers and other line managers support and motivate their staff to work in culturally competent ways within a work environment free from discrimination

| EDS outcome factor | Consultation feedback | Grade assessment |
|---|--|-------------------------|
| Do middle and line managers actively take steps to create high performing diverse teams and develop diverse talent in the organisation? | Minority ethnic groups report that services are mainly white | Under developed |
| Do middle and line managers include advancing equality of opportunity and fostering good relations in their personal objectives and ask the same of their staff? | Minority ethnic groups report that there is discrimination in services in how they are treated and that staff do not address this directly | Under developed |
| Do middle and line managers motivate and support their staff in understanding and responding to the different needs of patients, carers, communities and colleagues from protected groups? | Minority ethnic groups report that staff do not understand the needs of their communities | Under developed |
| Do middle and line managers use a range of evidence to gauge the extent to which they and their staff are working in culturally competent ways and that the work environment is free from discrimination? | Minority ethnic groups report that services lack cultural sensitivity | Under developed |
| Do middle and line managers engage with staff from protected groups to identify and plan responses to meet the needs of diverse patients, carers, communities and colleagues from the protected groups? | N/A | N/A |
| Do middle and line managers actively take steps to capture and disseminate examples of good practice demonstrating how to work in culturally competent ways across protected groups? | N/A | N/A |

EDS Outcome 4.3 The organisation uses the Competency Framework for Equality and Diversity Leadership to recruit, develop and support strategic leaders to advance equality outcomes

| EDS outcome factor | Consultation feedback | Grade assessment |
|---|------------------------------|-------------------------|
| Does the organisation use the Competency Framework for Equality and Diversity Leadership? | N/A | N/A |