

Community Focus Group with: Bengali Women's Group

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Background: Healthwatch Southwark

As part of the Health & Social Care Act 2012, Healthwatch Southwark (HWS) was established in April 2013, delivered through the contract won by Community Action Southwark (CAS). Supported by a National Healthwatch England, HWS is intended to advocate the local patient and public voice and support their involvement to influence, shape and ultimately improve health and social care services in Southwark.

For Healthwatch to be representative of the local community's voice (and needs), we need to engage with a wider and more diverse part of the population, in particularly the seldom heard, or those not typically involved in consultations or statutory engagement structures. Thus, we will be holding an ongoing programme of Community Focus Groups. This is part of our bigger engagement strategy; to engage and involve both community and/user groups, and the wider population.

Programme aim:

- To develop a body of knowledge, insight and issues: across different groups, and/or specific to groups.
- Develop and building relationships to inform and feed into our priorities and activities
- Used to influence and improve specific services, and longer term shaping of local services

Focus group aim:

To explore the key issues within these communities, specifically:

- 'Shine the light' on health and care behaviours
- Gain insight into the challenges they face, specifically and in general

What we will do with it:

Develop ways to address them working in partnership with those bodies responsible for health and care services. They will also be used to inform our priorities, and where appropriate, we will directly engage with specific services.

Profile of the Bengali Community

Based on the latest 2011 census, there are 3,920 Bangladeshis/ British Bangladeshis living in Southwark, which is 1.36% of the total Southwark population. 1,957 Southwark residents speak Bengali (with Sylheti/Chatgaya) as their main language, which is 0.71% of the total. Chaucer ward has the highest number of Bengalis in Southwark, with 4% (612) followed by Faraday, Cathedrals and Newington wards - making up the Borough, Bankside and Walworth locality. Nationally, the majority

of Bangladeshis in Britain are Bengali but there are also Bengalis from India who will not be counted in the above figures. Southwark Council produced a report in 2012/13 to better understand the Bangladeshis. Find out more [here](#).

Southwark Bengali Women's Group: "To educate a woman is to educate a family"

The project is located at Rockingham estate community centre (just off Newington Causeway/Elephant roundabout) based in the Chaucer ward, in the locality of Borough & Walworth in the north of the borough. See the appendix for further information on the Group.

What we did

HWS worked with Southwark Council's engagement team to visit the Bengali Women's Group at the Rockingham community centre to explore engagement opportunities to understand the issues this community faces when accessing health and social care services in the borough.

We met with the Coordinator from the Bengali Women's group to plan how best to run a session, taking into account which day would work best, time of day, refreshments and language support needs so as to ensure that the women felt comfortable and safe to share their experiences. We agreed to run the session together and it was delivered at the Rockingham Community Centre on Tuesday 10th June 2014 where the group normally meet. The Coordinator invited and encouraged the women to attend, ordering lunch for the group and arranging for an interpreter to support the session. Healthwatch planned and brought 2 facilitators to run the session, documented the comments and covered the costs for the programme. A short survey on key topics below took place. Issues raised were explored in group discussion. The key topics are:

1. Key challenges or barriers in accessing health & social care services
2. Needs specific to the community (cultural needs)
3. Ways to offer 'good quality services'
4. Best way to get and obtain information

Overview of the women who attended:

18 women attended in total, although not all took part with some arriving later or leaving early.

- **Age range:** 8 grandmothers aged 50+; 8 mothers aged between 30-49 and 1 lady with no children age 40+

- All lived in and around the Rockingham estate and surrounding areas of Elephant & Castle, Camberwell including two ladies from Kennington, which is part of the borough of Lambeth.
- Over half have long term conditions (heart/pacemaker, diabetic, blood pressure or back pain, or multiple conditions.)

Findings

1. Health services

1.1. Use of primary care services

The findings mainly refer to the core group of 12 ladies (we had 18 women in total attend the session, however 12 were there from start to finish with the other ladies arriving and leaving at different times).

Nearly all of the women used primary care services (GP, dentist, optician, and pharmacies) with over two thirds a frequent or previous attendee as a hospital outpatient. Just under half had been a hospital inpatient. Just under half had used alternative herbal remedies/treatment. *(It should be noted that the Group had recently attended a herbal remedy workshop, and this would/may have influenced this.)*

Over two thirds felt they needed an interpreter to attend GP appointments. Of these, a few felt that if they needed an interpreter they were not able to get one, with one using family members to interpret. One third felt that if there were not able to get an interpreter, it mattered in relation to the quality of care received at their GP appointment. One said it was more about *“having an explanation and being able to understand...”* The few that did have an interpreter felt they received a good service because of this.

1.2. Services outside of GP practice hours

We were aware that the health and care system is difficult to navigate and we consistently hear this, so we asked *if their registered GP was closed, where would they go.*

Attendees were able to choose multiple responses. Over two thirds said they would use an Accident & Emergency, one third said they would use a walk-in centre, and just under a third would use the out-of-hours GP service (SELDOC). In addition, no one was aware of the urgent care centre at Guy’s Hospital.

1.3. Experiences of GP services

We asked attendees to share their experiences of using health and care services with us. Almost all of the experiences focused on GP services. We found that **communication** was the main theme that emerged.

The group felt that the way staff communicated with them had an impact on their experience of the service. When clinicians showed empathy and understanding their experience was improved. This applied when patients raised concerns or issues and wanted to discuss this with their GP. For example one attendee was on long term medication and had some queries to raise about her usage. This was met with dismissiveness and annoyance. Another example was a parent's concern that her young child had been coughing for five days and in response, she was met with dismissiveness and almost "*rudeness*", which affected the patient's/parent's confidence.

Story

"I regularly have blood thinning medication. I feel that I don't need this and said can you stop this for a while and see how I am. The doctor was annoyed and said I will stop medication and not give you medication until you get heart attack."

Story

"Hospital service is very good but last year I went to see the GP because my 5-year-old boy had been coughing for 5 days. The doctor was dismissive and said 'why come, what can I do for you... Okay [maybe I can] put a sign at the front and say if you have flu, cold or cough, don't come in.' He then went to reception and came back and said 'What do you want, calpol/paracetamol? Go to pharmacy.' I felt depressed. Whenever I get flu or cold, I don't want to go to doctor."

1.4. Long term conditions

We asked the group if they had any long term conditions and gave the Department of Health definition. A Long Term condition (LTC) is a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies (Department of Health).

The most common long term conditions were heart conditions (fitted with a pacemaker), diabetes, high blood pressure/cholesterol and long-term back pain. Less than two thirds felt that they were **not supported** enough to manage their condition.

When asked what they would like to see **to support their long term condition**, suggestions included:

- **More support at the GP practice** including around interpreting, being accompanied or supported to build confidence to attend appointments.
- **More help at home particularly for those with long term conditions or issues** - e.g. shopping. One suggested preferably someone Bengali.
- More widely, tackling the lack of **confidence** within the community to attend appointments.

Identified long term conditions included: diabetes (6/12), high blood pressure (7/12), cholesterol (7/12), asthma (2 /12), heart condition (3/12), learning disability (0/12), physical disability (4/12). Mental health (dementia and depression) was discussed in private conversations.

We explored the experiences from those with long term conditions. A few experiences indicated that the care approach taken was not focused on preventative care and seemed to be about maintaining the care or status/quo. i.e. not changing medication or treatment (leaving aside the issue of medication review). Care and treatment was not felt to be based around the individual's needs and there was a reluctance to involve individuals in their treatment, alongside a lack of professional empathy. This goes against the national and local drive on a more personalised and holistic approach.

For example, an experience related to a lady's blood thinning medication which she had taken for a while. She felt that she did not need this and asked her GP if she could stop the medication and see how she was. However, the *"Doctor was annoyed and said I will stop the medication and not give you medication until you get heart attack."*

Another example related to ongoing issue with a lady's bladder and she requested a female doctor because of cultural sensitivities. Upon attending hospital appointments she found there was no woman doctor present- *"if you are lucky, maybe you can get woman doctor."* In the meantime, she is using continence pads, and complained to GP who responded *"you are not incontinent, I said not yet, and he said then wait until you need."*

1.5. Moving between different health services or being discharged from hospital

Generally everyone was happy with hospital experiences, particularly those who are frequent hospital attendees either for themselves or through family members.

Positive experiences focused on clear and easy-to-understand communication, assurance, support, and advice about their care after leaving the professional's

care, and patient information following the patient between services and providers.

Story

“Recently I went to hospital A&E, I had a chest problem and when I was discharged the nurses and doctors were very good and explained everything very clearly and told me I can come back straight away if I have any more pain”

Story

“Good experience, doctor did all the check-ups and saw previous reports” [Doctor at hospital gave advice and wrote to my GP]

Story

“My daughter, she came back from intensive care unit and six days later she had to go to the 6th form college to start....Doctor gave good information and advice about care and treatment.”

Where experiences could be improved, they focused around consistent hospital discharge procedures (particularly for frequent attendees), and family having different views to staff on whether the patient was ready to return home. Furthermore, staff awareness and advice on the practicalities of moving patients around the house was needed and can be overlooked.

Story

“When dad was leaving hospital, they cleared everything and discharge him. They used to observe him like on a one-to-one basis and discharge when they thought he was well enough, but we had to go back again. I was confused, he had infection. [When they saw him again]... they said to take him to a homely environment and said that we should bring him back if there are any problems’ Leaving Hospital, sometimes great, other times it is confusing, when he is in hospital for observation for couple of days and he has to go home and slightly concerned that not quite ready, and few days later we had to come back.”

Story

“...we had to think about how to get her up the stairs, we thought my husband would have to carry her up the stairs to get to bed. In the end, we had one person in front of her and someone behind and she somehow managed.”

2. Social care services

Most of the women did not use social care services, with one Lambeth resident having a paid carer to assist her disabled husband. We differentiated and clarified the difference between a Paid Carer and an Unofficial Carer. Under a half of attendees identified themselves as **unofficial carers**, and no one had received information from professionals that there was potentially help for them to care for someone. Generally, the group unanimously agreed *“culturally, everyone is a carer”*.

However, many of those who acted in an unofficial carer capacity felt they needed help.

3. Cultural needs

We asked the women if there were any different cultural and/or specific sensitive needs that would help staff and professionals, and enable the Bengali community to better access health and social care services.

Key areas highlighted:

- **Gender preferences** i.e. female professionals when possible.
- **Bengali interpretation** although this was on language only, and interestingly it was felt that non-Bengali professionals were more careful, culturally aware, checked thoroughly, and were sensitive to their needs when carrying out consultations and examinations.
- **“Small things that work”** - references were made to mannerisms, a calm and reassuring voice, and listening skills.
- Being aware of when **patients have reasonable capacity to answer requests** and questions, particularly during sensitive examinations.

Some examples of positive experiences

“Can I touch you please?” / “Is it okay to touch you here please?”

“Non-Bengali professionals think about the cultural needs more”

“When he came in, he said that he knew I didn’t want a man to be involved, but that he had to see what was going on, he was very calm and explained to me patiently.” [During labour with potential complications]

“This is an upper body exam and you have to take off your clothes including your bra. I had an English lady who was very respectful and I liked her a lot. She gave

me dignity and said we want to give you dignity and gave me something to cover up.”

Story

One lady recounted her mother’s experience in hospital for an intensive surgery. Her family members acknowledged it would be difficult to keep her hair covered, however she was touched that staff had an awareness of religious and cultural beliefs and sought to address these -

“My mother had a triple heart bypass at Guys...very well known...didn’t expect not to come out of hospital...She was a very religious lady and always wanted her hair to be covered, this was sometimes difficult in hospital and we said for her not to worry about that. I remember going to the ward to visit her one time she had her hair down, combed and neatly plaited into small stands, there was a black nurse who had done this for her and I was so happy, she looked good. The nurse said that she knew she wanted her hair covered and asked if it was ok that when she goes in for surgery, would it be ok for mum to have a surgical cap on to cover her hair, I was so happy that they even offered the idea, they took good care of her”

Some examples of not so good experiences

“During a screening, one squeezed [her breast]...like it was an infection...”

Where the patient could be in a sensitive situation, and staff being aware of when patients are able to or have reasonable capacity to answer questions or requests -

“...asked if I was happy to have a student midwife in the examination, to be honest I was in so much pain and didn’t know what was going on that I think I just said yes. Then I realised that there were 5 or 6 people looking down there with notepads, men and women! I don’t know why they asked me when I couldn’t make a proper decision about what I wanted to happen. My leg was in the air, exposed and I felt very embarrassed.” [During labour]”

4. Quality issues

This section focused on attendees sharing good quality experiences and not-so-good experiences, and their ideas on how services could be made better for them and the Bengali community.

4.1. Good practice experiences

- **Receptionist aware when patients have multiple conditions** and will offer a double appointment
- **Staff mannerisms**, particularly listening, sympathy or empathy (non-clinical treatment) towards patients
- **GPs with an awareness of wider issues that could affect health and wellbeing**, particularly those with chronic conditions e.g. the GP role in benefit assessment.

Some comments:

“Receptionists sometimes see different conditions I have and will offer a double appointment to talk through the issues, this is good.”

“When I book, my record flashes up that I’m diabetic so they suggest that I need a double appointment.”

“My mum has a chronic condition so chronically ill. One time they had a benefit advisor there; GP is meant to pass history to the benefits. But it was difficult to get benefit. But another doctor saw us and said you have a lot of chronic illnesses although you don’t have a disability, but you need help to manage it.”

4.2. Examples of not so good experiences

- ‘Doctor had to **listen** a bit more **patiently**’
- **More time for explanations and information** relating to their care, rather than just instructions.
- The quality of GPs can vary, particularly if you are assigned to a particular doctor or the doctor has a speciality it can be difficult to see another doctor.

Some comments:

“Double appointments or more time with GP, they rush a lot”

“More explanation when in appointment, to explain why I am taking this medication”

4.3. Ideas for improvement

- Information and training days for communities particularly around conditions with a self-management approach.
- Consistent approach across GPs around the GP role in benefit assessments, which particularly affects those with long term/chronic conditions.

- Good mannerisms with good training.
- More explanation and discussion on why they are taking this medication.

Some comments:

“Advice about using the diabetic tool”

“Back home, there was a doctor that used to talk in a really calm voice and really took her time to talk. Just listening to me and the doctor in that way can make you feel better’. In Bangladesh, 50% is about mannerisms and how they treat you...”

4.4. Medication/mental health

When we asked how about any particular issues they wanted to raise, many ladies were concerned around the abundance of medication to treat mental health-related illnesses such as anxiety particularly for young people. One lady suggested counselling and talking therapies as a better treatment.

Furthermore, based on shared experiences from family and friends they observed that after taking medication it seemed to make them more physically and mentally tired.

Another experience related to a mother with children who was unable to sleep after her husband had passed away. She was given antidepressants but she did not want them because she needed to look after her children. She had preferred sleeping tablets or other means that would help without compromising her capacity to look after her children.

Some comments:

“I speak to many young people and a 13-year was upset and spoke to a nurse who told her to take antidepressants”

“Lady, 33 years ago her husband died, she couldn’t sleep, she was forced to take antidepressants, but she didn’t want to because she had children and needed to look after them. They wouldn’t give her sleeping tablets”

“A lot of ladies - are on antidepressants because of anxiety. I can see it makes them sleepy, body tired and mentally tired”

‘People are encouraged to go mostly go onto medication that doesn’t work, talking therapies or counselling works better’

5. Information

When asked where do you turn to or go if you need health and social care advice or information, the women initially did not know where to turn to. After some probing, references were made to:

- Local advice centres (Blackfriars Advice, Citizen's Advice)
- Family members
- Professionals such as GP practices, health visitors, baby clinics and community nurses
- Community centres, including mother & toddler groups / Bengali women's groups
- Friends with experience in the subject are or who have had recent experiences

The most common were free local advice centres, staff professionals who they come into contact with and family and friends.

They also access and participate in other organisations and local services:

- Darwin Court - Swimming and Keepfit
- Southbank University - Keepfit
- Blackfriars - English for Speakers of Other Languages (ESOL) Classes and health workshops
- Waterloo Action Zone for Advice
- Local GPs for physiotherapy
- Dentist
- Local mosque for Islamic Studies
- Bankside Open Space - Gardening Project
- Rockingham Community Allotments - Plots BWG Gardening Project

We found it was quite common that where individuals had similar illnesses, **they would share information on the type of medication they received and the effects.** Consequently, this sometimes led to individuals requesting the same medication that their friend or family had received from their GP. Understandably the GP cannot prescribe medication without taking individual health history and circumstances into account - *"...not to ask for medication that someone else is taking. I will give you what I think you need"* [participant recounting the response received from her GP].

In other cases, after having read leaflets or seeing advertisements, patients will enquire after a particular medication.

6. Giving feedback

When asked how they felt about giving feedback on the services they receive, two key issues were highlighted: **they talk to family and friends about negative** or unhappy experiences with services, and secondly, **they did not know how to complain** to GPs and hospitals. Some comments:

- “[we] talk to other people when they are not happy with services”
- “We just talk to our family member and friends if we have bad experiences”
- “We do not complain to the GP surgery or hospital”
- “We do not know about complaints procedures”

We explored why/ **what stops them from telling/sharing experiences**. The group generally responded that that they compared the quality of services in the United Kingdom with services in Bangladesh and inferred that services here were of better quality - “**so don’t really want to complain.**” They also felt that they may be repercussions if they were to give feedback on services - “**...compare with the services back home and this stops them from giving feedback because they are worried what will happen...**”

Healthwatch Southwark has heard this many times from patients and carers - a common perception amongst patients who are currently receiving care is that they feel that giving feedback, however negative or constructive it is, would affect the quality of their care going forward - “**they are going to do it regardless of our voices.**”

Summary

- General practice was the most widely used service for this group for a variety of issues ranging from long term conditions, to young children. Key issues:
- **What affected the experience and quality of GP services** was both the appropriate need for interpreters through which they could understand or be given an explanation i.e. access to communication, and the ‘softer’ aspects of the interaction around listening, empathy, understanding, sensitivity etc. The ‘softer’ aspects also applied across all interaction across the care pathway from GP/primary care to hospital services.
- Many of **attendees with long term conditions did not feel supported enough** to manage their condition, with some effects on wider wellbeing issues. Negative interactions with health professionals further took away from the patient’s involvement or self-esteem and confidence in their care. Experiences also indicated less of a focus on preventative care but more on maintaining current relationships and care provision.
- Moving between services and providers, the same issues arose that could make either a positive or negative experience. This related to discharge

processes and communication and information. It was also raised that staff needed to be more aware of the practical issues around caring for patients at home, and provide advice.

- General quality issues that could make a good or not-so-good experience were again centred around professionals understanding the patient's needs, e.g. offer double appointments for those with long term conditions, staff mannerisms, wider awareness of welfare advice and information affecting wellbeing, and the varied quality of GPs particularly if there is little choice.
- The group felt that **alternatives to medication around mental health-related illnesses** should be discussed and explored with the patient to find a treatment most appropriate to them and their lives, rather than a primary focus on medication.
- **Key sources of information and advice** were from local advice centres, professionals they had contact with and friends and family. Individuals tended to share information on medication and effects, where they had similar illnesses, and they would bring this understanding, or even informal benchmarking.
- Generally, **the group did not give feedback about their service experiences** mainly based on two factors: they share negative experiences with family and friends and there was concern that there could be repercussions on their care and treatment if they give feedback.

Next steps and considerations

The issues arising from this report will feed into our work plan and activities. These include through our Representatives at strategy and programme boards, particularly the Primary & Community-based Care Strategy and its development, 111 development, and equality and human rights emphasis. References will also be made in our consultation responses and also as part of our feedback to CQC inspections of GP Practices and Hospitals, public forum planning and any other appropriate platforms that arise.

Key considerations:

- **Communication and listening skills across all interactions** from GP services to hospital services is just as important as clinical expertise to increase the quality patient experience. Where a second language is present, patients having access to interpreters or appropriate support to enable communication and understanding.
- **Encouraging confidence in communication**, even if language is an issue. This can mean professionals adopting 'softer skills' around listening, letting

patients speak, explanation so that they can be involved in discussions in their care and treatment.

- All stakeholders to have a role **to increase awareness on where to go for information** on local services, and passing this on to individuals and patients.
- **Professionals should encourage conversations around long term medication and support needed** whereby patients are able to discuss and raise queries and concerns with GPs. Professionals should be receptive to changes such as maintaining the current care or adopting a more preventative approach, and the patient should always be a part of this discussion.
- Professionals being **aware of the influence of family and friends which can affect how others compare services, medication etc**, particularly across different communities.
- **Having a discharge checklist** of communicating information and being aware of patients and carer's practical arrangements including manoeuvring can make the difference between a positive or a negative experience.
- **Staff mannerisms 'the little things' can affect how a service is perceived.** Where staff has been **culturally aware** e.g. a nurse has made sure that an elderly woman's hair was covered when in hospital, female preference etc, this has had a hugely positive effect on patient and family experience.
- **Welfare benefits that may have an impact** on their health and wellbeing, and having consistent and accessible processes in place to support or signpost them to.
- **Alternative approaches to medication needs to be explored** and avoiding an automatic or default medicated approach. Awareness of talking therapies model, where appropriate. More information to the group could be provided where there are disabling side-effects to medication - this could avoid common perceptions of side-effects.
- **Not receiving feedback does not always mean a good experience is provided.** Taking steps to monitor data on who is feeding back or who is not. Encouraging different feedback routes, and creating an environment where feedback becomes the norm. However, this may take a while, being mindful of some community behaviour and concerns around feedback to avoid assuming.
- Public clarity on what is considered a long term condition, from professional and from patient perspective as this can differ, and will manage expectations.
- **Exploring IT tools/systems so that professionals/providers understand their patients more and using this information to give a more patient-centred experience around their needs, e.g. tailoring a patient record to**

inform booking or consultation arrangements when someone with a long term condition is calling and enabling the receptionist to book a double appointment.

Appendix

Southwark Bengali Women's Group - "To Educate a woman is to educate a Family"

Bengali Women's Group formed in 1986 and was established and registered as an independent charity in December 1998 by local Bangladeshi women and their families living in the London Borough of Southwark. It is a grassroots voluntary organisation with charitable aims based in Southwark to help, assist and support disadvantaged Bangladeshi women and their families with their educational, social, health and welfare needs.

The community and family based services are offered within a safe community based environment; enabling women and their families to come together, share their experiences and learn new skills which will help them to develop their opportunities and futures as independent individuals where they are able to build a better future for themselves and their families.

The work of the Group also focuses on to raise awareness, build confidence, provide essential welfare services, education and training support, services that tackles hardship and poverty faced by many Bangladeshi women and their families so that they are able to develop themselves and take more responsibilities for their own lives. Through our work, we aim to empower the women to take control of their lives, to raise their self-esteem and to enhance their life skills.

This report is available at <http://healthwatchesouthwark.co.uk/reports>
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