

United Women's Affiliation: #SpeakUp project report

Exploring the experiences of African women living in Sheffield, and their access to health and social care



#SpeakUp: United Women's Affiliation

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of £2000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care. By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.



United Women's Affiliation (UWA)

UWA help women from African countries, or with African heritage, living within underprivileged communities in Sheffield, surrounding areas and internationally, to reach their full potential. We focus on raising awareness, building resilience, providing support and enabling underprivileged people to make full use of the services and support available to them to enjoy their right to improve their life, their family and community.



Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Introduction

What did we do?

Our #SpeakUp project was a collaborative effort aiming to capture the views and experiences of people we support about health and social care services through activities. We conducted focus group discussions, outdoor activities, home visits and educational group discussion meetings. We explored how women and young mothers feel about accessing care and support, as well as talking about previous experiences and their hopes for the future.

We focused on various elements of health – specific topics like medication, mental health, and sexual health, as well as wider determinants of health like access to green space and good quality housing. Some sessions were attended by healthcare workers and other professionals, to help us deliver important health information to participants. Meetings were facilitated by UWA volunteers and sessional workers.

We ran 15 events across summer 2022, with 147 attendees in total – we support around 90 women living in the area, with some coming to more than one session to talk and learn about different topics.

What did the sessions focus on?

Date of session	Discussion topic	Professionals present	Number of participants
13 th July	Long term conditions, nature connections	Lecturer from Sheffield Hallam University	7
20 th July	Landscape and health	Lecturer from Sheffield Hallam University	6
27 th July	Cold and housing issues	NHS Health Education	10
1 st August	Experience of diabetes	Dr Hawa	4
3 rd August	Long term health conditions and medications	Community Health Nurse	12

8 th August	Youlgrave visit – connect with nature	Maxwell	16
10 th August	Emotional wellbeing and hospital experiences	Health education & community development mental health worker	6
11 th August	Environment and health	Maxwell	6
17 th August	General/social wellbeing	Legal advisor	11
24 th August	Home environment and wellbeing	Maxwell	11
31 st August	Emotional/ mental health	Dr Hawa	8
7 th September	Respiratory health	Community health education England worker	15
14 th September	Women’s health/family planning	GP – Women’s health specialist	11
21 st September	Women’s health/sexual health	GP – Women’s health specialist	15
28 th September	Emotional wellbeing	Dr Hawa	9



Findings

Across the different sessions, many women shared similar concerns or obstacles. We are therefore presenting our findings as key themes, rather than breaking down conversations that happened in each meeting.

Medication

People feel they are prescribed medication too quickly

Many women expressed frustration that medication is offered as the first (or only) choice when they present to their GP with a health issue. They don't always feel this is the best option for them, but aren't offered alternatives such as talking therapies, or spoken to about lifestyle changes:

"We need counselling, social support to alleviate our anxiety and loneliness"

People also expressed concern about the number of medications they are now taking, and how these might interact:

"When I go to GP I'm prescribed new medication. Like now I'm taking more than ten tablets I'm worried if this is right"

Sometimes a particular medication doesn't work for someone or has an unexpected side effect. However, when people don't believe their GP will help them explore other options, some choose to stop treatment altogether:

"I suffer asthma and I was given inhaler that was not helping me and other tablets. When I take them I feel bad and tired. Went back to the GP they added more dose more dose no investigation now I'm worried and I don't go to them any more I would rather die rather than be overdosed"

Medication is not always explained well to people

Most of the women we work with encounter a significant language barrier when they go to the GP, which makes understanding the medication they are prescribed even more difficult.

People tell us they do not always know how often to take their medication, what the correct dose is, or how long they should take it for. They say that GPs do not always take the time to explain this, perhaps assuming that people can read the instructions, but this is not always the case.

Access to interpreters

Appropriate interpreters are not always provided

Accessing interpreters is a common issue with the women we support in most settings (health and otherwise). Interpreters are often not provided at all, and when they are, they often do not speak the same dialect as the women.

The women we support speak Congolese-Swahili. When they attend GP or dentist appointments, the interpreters that are booked are often from a different country (such as Kenya or Tanzania) and speak a different dialect of Swahili. This means there are many words and phrases the women do not recognise, and the interpreter cannot fully help them to understand the appointment. It also means the interpreter cannot fully convey what they want to say to the GP:

“Interpreters not understanding them instead they interpret wrong info which affect my compliance [with health advice]”

People told us this leads to frustration and a lack of trust between the patient, the interpreter, and the health professional. It can also cause delays to people getting the healthcare or other outcome that they need. One woman said she needed to see a dentist, but several months later she has still not had an appointment as a suitable interpreter could not be found.

When there is a language barrier, people need more time to talk about their issues

Even with an interpreter present, effective communication can take more time when there is a language barrier. When we asked what changes they need to see for GP appointments, most women asked for more time:

“To be given time and be listened to”

“To be given time to say my problems”

“GP to talk slowly and give me time to say”

“GP explain to me slowly what I need to do with my health condition”

People also need more time and support in other settings where they are faced with a language barrier, including practical support:

“In hospital – A&E tell you to go elsewhere in the building. When they don’t understand the language and are told to go left or right, they don’t know which. They are not supplied with anyone to guide them, let alone an interpreter”

Access to GPs and dentists

It can be difficult to get an appointment

Many women told us they had struggled to get an appointment to see a GP or dentist. GP booking systems can be even more difficult to navigate where there is a language barrier, and NHS dentistry waiting lists are long.

During one session, we asked how phoning up services for advice or to book an appointment made people feel. One person said “I am listened to” and that there is “minimal time to wait on the phone”. However, most people felt less positively about the experience:

“Frustrated”, “Worried”, “Not listened to”, “Been picked out”, “Angry”,
“They just put the phone off all the time, so I want the people on call to be monitored and give service equal even if I can’t express myself well”

People still felt concerned after they managed to book an appointment. We asked people how they feel when they attend a health appointment, and everybody in the group shared negative feelings:

“Shame”, “Don’t have confidence”, “Stumble in speaking”, “Can’t express myself well”, “Worried”, “Anxious”



Some people don’t feel they are listened to by health professionals

Many of the women told us about times they didn’t feel their concerns were taken seriously by their doctor or other health professionals:

“GP not listening us when trying to express our problems”

In some cases, this meant that patients could not get referrals to specialist services. One woman asked her GP for a referral to gynaecology and was refused.

She tried to book a private consultation instead, but couldn't access this either as the private clinic said they would still need a GP referral letter. She now says she feels at a loss about what to do. Another woman could only get a referral when someone from United Women's Affiliation came with her to act as an advocate:

"I'm diabetic my sugar level is high over and over more than five years now. Been prescribed many tablets and insulin injection. I have developed incontinence problems which I didn't have before but when I ask GP to review my medication she refused until when Dr Hawa [from UWA] come with me and ask for consultancy referral my medication was changed and I feel happy"

In other cases, women felt that health professionals don't take their choices and preferences into account, including choices about birth control:

"I was told to keep the rod [implant] and not to have more children rudely I was not happy at all. I struggled until they took the rod [out of] my arm"

There was a perception amongst some people that new health concerns are quickly put down to mental health conditions, and not explored in their own right:

"Because of my mental health problems I can not get support of other things because when I express myself I'm told 'it is your mental health flare again do you take your mental health medication' then they prescribe me more medications. I'm tired and not happy but I don't know what to do if I don't take medication".



Finance

There's a lack of clarity about NHS dental charges

Some of the women we support receive benefits, and said they believe they have been charged for NHS dental treatment incorrectly. The funding structure for NHS dental treatment can be confusing, with people in receipt of some (but not all) low income benefits being entitled to free care. However, people told us that staff at dental practices have not taken the time to explain people's rights to them or fully understand people's circumstances, so some women have been asked to pay and don't think this is correct. Some women felt they were being purposefully taken advantage of because they didn't understand the rules. People shared examples of this:

- Some women have been refused treatment because they couldn't pay
- One woman said she had needed tooth extractions but the dentist had refused to do so. She had been asked by the dentist for payments towards treatment despite being in receipt of benefits. It was not explained to her why she had to pay
- Some families have been charged for children's NHS dental care
- One child needed a cap on their tooth and the dentist asked the mother to pay, despite them being under 18 and the mother receiving benefits.

Charges at the pharmacy

NHS prescription costs are another area that can become confusing for people, as costs can depend on the type of low income benefit you receive. Some women told us they are charged for their prescriptions even though they think they shouldn't be. We heard the following story at one session:

"One woman was told she couldn't collect her entire prescription as she was under a 'budget' of around '£20-30' which it would take her over this so she couldn't collect it. She is on benefits and should get free prescriptions. It was not explained why she couldn't have it from the pharmacy. She is left confused and without resolution or reason."

Home and the surrounding environment

Housing issues impact on health and social wellbeing

At many of the sessions, women spoke about wider issues that impacted on their health and wellbeing. Many people who live in council housing told us that problems in their homes were impacting them significantly.

They told us that their homes had major issues with damp which was causing breathing and respiratory problems, but language barriers were an obstacle to raising or reporting this. They also said that when the Council does send people out to look at and resolve the issue, this doesn't lead anywhere – issues are marked as 'fixed' despite no action having been taken. Many women also felt they were treated disrespectfully by the people who came to see them.

"My house condition is bad really bad, it is damp and dripping of water. I ask council to help every time when they come they say I can't understand what you are saying I show them but they ignore me they write something and go. Not doing anything when I ring again for follow up they say we sent and engineer said that have repaired. This is wrong and I know because they didn't do anything"

Lack of security was also mentioned; people feeling unsafe in their homes and on their streets has a huge impact on their social wellbeing and ability to leave the house:

"I live in area where every day me and my neighbour because we are the elderly black in that street we are threatened by people we don't know. Our houses outside no light, no fence. We can not go out by ourself UWA helping us but we want council house to help us get some lighting and security. Loneliness is bad"



Access to green space is important

Some of our events were outdoor activities and walks, or educational talks about nature. The groups fed back that these sessions helped them to “connect with nature and find other ways of managing long term health and wellbeing”.

Nearly everyone said the sessions “felt very rewarding and inclusive” and that “this kind of visit can be part of their physical health management plan”.

Access to green space was felt to be important, but many people felt they couldn’t access it alone and needed support – “because of limited language expression are isolated and not engaged much”.



The need for education and support

The women we support shared extremely positive feedback after these #SpeakUp sessions – especially the information sessions attended by professionals. They told us that being able to ask questions in the sessions and have someone listen to their experiences was very powerful for them. They wanted decision-makers and clinicians to understand the day-to-day experiences and barriers that they face.

When a GP attended sessions, the women found it particularly valuable to have extended time to ask questions that they aren't able to in appointments, and have someone take the time to explain things to them. This can also help to build trust – a key thing many women felt was lacking in their interactions with health professionals and something they wanted to improve – “[people we can trust to support our private health problems](#)”.

Because of the lack of trusting relationships with professionals, and the barriers people face accessing care and information, it is easy for misinformation to spread. At one session some of the women had conversations about childhood vaccinations and autism – and had encountered misinformation that they perhaps would not have if health professionals had been able to engage with them more actively. They all felt it was important for professionals to come out and speak with them, and provide an opportunity for further learning.



Recommendations

Based on the experiences women shared with us across the 15 sessions, and the changes they said they would like to see, we have made several recommendations for health and social care services.

Some of the findings were about specific services – such as GP or dental practices – but people were facing similar barriers in a variety of settings, so many of these learning points are relevant across a wide range of services.

1. People need support to better understand the medication they have been prescribed
2. People should be involved in decisions about their care – including whether to take medication, explore alternative treatments like counselling, or a combination of approaches
3. Access to interpreters who speak the correct language and dialect is crucial – records kept in healthcare settings should specify the dialect spoken by people, and interpreters should be booked for all appointments
4. Where a language barrier is present, people need more time for appointments to support the discussion and ensure the patient and professional both understand what is being said
5. Clear and accessible information about NHS prescription and dental charges should be made available to people – and patients should be supported to understand why they have been charged
6. People do not always feel listened to or respected by medical professionals. From the experiences people have shared with us, this is often linked to the cultural appropriateness of the care they receive – services should reflect on their cultural competency, and ensure there are good routes for patient feedback regarding this
7. Services should consider increased outreach activities in community settings – providing information to support people’s health and wellbeing, as well as building more trusted relationships with communities
8. People need more information about how to report issues with their housing – including damp, mould and repairs. People facing a language barrier may need support in order to raise these concerns
9. People need more information about what will happen when they report an issue – including a way to give feedback on the process