healthwatch
Bedford Borough

Hidden Voices

Understanding Health inequalities in Bedford Borough

2022/23

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Contents

Background

The Bedfordshire, Luton and Milton Keynes ICS Inequalities Review (known as the DENNY Review) was set up to improve its understanding of the impact of health inequalities on its local communities. It proposed a listening exercise to hear and understand the lived experiences of residents in seldom heard communities. The aims of this listening exercise were to:

- deepen the knowledge of the healthcare needs and the barriers that people face in accessing care

- support the development of recommendations which could be made to tackle systemic health inequalities in BLMK.

Background to the study

To give a voice to residents from minority or disadvantaged communities in Bedford, Healthwatch Bedford Borough (HBB) were commissioned by the Denny Review steering group to engage with:

1. **The Gypsy and Traveller community in Bedford Borough**
2. **Women from ethnic minority groups living in areas of multiple deprivation in Bedford Borough**

These communities were proposed to utilise and build on the existing relationships between HBB, local communities and Voluntary and Community Sector organisations.

Access to the two settled Gypsy and Traveller sites in Bedford was co-ordinated with the Gypsy and Traveller Liaison Officer from the Bedford Borough Council Team, who was aware of and supportive of this project.

Ethnic groups were selected on the basis of knowledge attained and advice given by supporting Voluntary and Community Sector organisations and areas of deprivation identified from the Bedford Index of Multiple Deprivation 2019.

Queen's Park Community Organisation (QPCO) - works to address social exclusion, relieve poverty, develop the capacity and skills of socially and economically disadvantaged people and provide recreation and leisure activities to help people integrate, participate and improve their life conditions.

ACCM (UK) – a charity working in Bedfordshire and surrounding areas to promote action to bring about positive social change to enhance the wellbeing and to protect the dignity of girls and women.

Where we worked with, and through, groups with established and trusted relationships within the selected communities, women were offered the opportunity to participate in culturally sensitive environments in which they felt safe to talk openly. In the case of our local Gypsy and Traveller community, the HBB Officer concerned had existing strong links within the community that ensured longstanding trust and rapport. This was maintained throughout to offer the community an equal opportunity to have their say in a frank, transparent and safe space.

Community Introductions

Gypsies and Travellers

Despite growing evidence that Gypsies and Travellers are particularly disadvantaged in access to health care, there are very few studies to explore the reasons for this.

Healthwatch Bedford Borough wished to investigate the nature of the social disadvantage that the group experience. For this reason, Healthwatch interviewed 19 members of this community to explore both attitudes and structural reasons behind this health inequality.

Interviews took place over a number of days and were conducted by a member of staff who has a trusted relationship within this community, and a sound understanding of their complex needs. The staff member visited the sites on four occasions. She is aware of the physical layout of both sites and the complex relationships between extended families and networks on the site. Particular to this group were concerns about the distinct lack of facilities on site and health and safety concerns, but participants were able to suggest a number of practical ways by which their care could be improved.

Migrant Women from West Africa

A consistent theme across our review was women's experiences of negative interactions, stereotyping, disrespect, and cultural insensitivity. The stereotype of the strong Black woman who is invulnerable, independent, and caring at first appears harmless or even benign. However, there is a concern that this stereotype may lead health professionals to discount expressions of pain, anxiety, and vulnerability.

Female genital mutilation (FGM) is a traditional cultural practice undertaken in some countries in West Africa (as well as other countries across this continent and worldwide). UNICEF describes FGM as "all procedures involving partial or total removal of the female external genitalia or other injury to the female genital organs for non-medical reasons". In countries where it is practised, FGM is performed on girls in line with their cultural traditions and the social norms of each community. Prevalence varies from country to country.

In Ghana for instance, levels of FGM have always remained low. Whilst in Nigeria, the levels are higher but there is evidence of significant generational change in its prevalence.

This review has focused on experiences that arise at the intersection of both race and gender, as described by 15 Black women from West Africa and accounts of the lived experiences of women supported by ACCM(UK), who have undergone FGM.

Bangladeshi women

The current Bangladeshi population in Bedford is a complex network of people who are the first, second and third generation of families, following immigration into the UK. Language skills, attitudes towards health, and attitudes about how to 'fit in' to mainstream society vary widely.

According to www.gov.uk amongst all ethnic groups living in the UK, people from a Bangladeshi ethnic background were the group most likely to not speak English well, or at all. In addition, Bangladeshi women were 5 times more likely than their male counterparts to speak no English at all.

Previous research also indicates that people outside of the Bangladeshi community do not understand tone of voice and are not aware when someone from this community is distressed, until the level of distress is very high. An investigation based in Leicester suggested that a preference for face-to-face communication is so that people from this community can communicate their distress in body language. A high level of frustration was evident within the group of women who attended the Healthwatch focus group, who used more swearwords than any of the other groups included in this study. They feel this is because they are seen as timewasters with trivial reasons for approaching healthcare.

The intersectionality of both race and gender is thus crucial in understanding how health inequalities for Bangladeshi women can be addressed. Common themes in our review show how interpretation, literacy, lack of access to technology, communication styles and cultural differences create barriers to healthcare.

Bulgarian women

Compared to some of the other ethnic groups in our review, the Bulgarians are part of a more recent wave of immigration following changes in European law in 2014.

Bulgarians have migrated from a country with high cardiovascular disease but where cancer is below the European average. Mental health is not discussed in Bulgaria, and one woman said that she thought it was 'fabulous' to give people a space to talk about these issues. Excess alcohol consumption and smoking in the Bulgarian population are higher than the national average in the UK. This group of women said that they were very busy working, but their priorities include advice on stopping smoking, reducing alcohol intake, healthy eating and where to go to participate in activities.

In contrast to the NHS, hospitals within Bulgaria are described as basic and old-fashioned (www.gov.uk), whilst the World Health Organisation (WHO) describes how the Bulgarian healthcare system can cause financial hardship. As mostly first-generation immigrants from a different cultural background, the women in our study were keen not to criticise and said they were happy when able to access both acute and secondary NHS care. However, they told us that they found the bureaucracy of both primary and secondary care difficult to manage.

The group of women in this study said that they take their UK citizenship very seriously and suggested the idea of 'lessons' on British etiquette.

Methodology

- Recruitment
- Key questions

Methodology

Recruitment

Women from Ethnic minority communities

Recruitment of the Bangladeshi, Bulgarian and Black African women included in this study was co-ordinated by the project lead at Healthwatch Bedford Borough and managed by each of the participating charities. Their advice was used to select the ethnic groups above based on their knowledge of these communities. Areas of multiple deprivation were identified from the Bedford Index of Multiple Deprivation 2019.

Recruitment criteria:

- Women between the age of 18 – 65
- Ethnic background
- Bangladeshi
- Bulgarian
- Migrant women from West Africa

Living in either:

- Castle
- Kempston North
- Goldington
- Queens Park

The women were asked to share their lived experiences of healthcare needs and what matters most to them, either in one to-one interviews or within a focus group. By working with and through these grass-roots organisations, Healthwatch were able to engage with women in settings that were already familiar to them. Conversations were carried out in their first language using Interpreters if/where necessary.

Key questions

Semi-structured interviews were used with each of these communities to explore the key questions of interest to the review steering group:

1. What do you want from health & social care services?
2. Prevention – what can we do better to help you, how could/should we talk to you about healthy lifestyles?
3. Communication – what are the barriers to effective communication? (e.g., language, cultural, health literacy)?
4. What can we do better?

All responses were captured and recorded appropriately. Consent was obtained from participants confirming their agreement to anonymised data being stored, in accordance with The Data Protection Act 2018 and GDPR regulations.

A qualitative analysis approach was used by HBB to organise and analyse the data into key themes identified from within the data. These are reported as findings, with suggested recommendations for service improvements flowing from this.

Healthwatch Bedford Borough values individuals' experiences with, and feelings about, health and care services. Our aim in using this methodology is to reflect those experiences without bias.

Findings

Three overarching themes appeared repeatedly in the responses given by participants in each of the groups, across all the questions discussed:

1. Interpreters
2. Literacy
3. Understanding of culture

When these three issues combined, there was a palpable sense of several barriers with the responsibility for overcoming them being placed firmly on the individual.

Findings

Interpreters

Women in each of the focus groups mentioned language difficulties when discussing what hadn't gone well for them, self-care, and what they wanted from the NHS. All the women said that they could become overwhelmed with information. Only one of the women in the Bangladeshi group said that she was able to read or write in English, whilst only one woman in the Bulgarian group could speak, read, or write in English. All of the women in these two groups said that they needed support from an Interpreter.

Most participants said that health professionals will sometimes use words they do not know. Therefore, even with an Interpreter, they do not understand what is being explained to them. They suggested that photos, diagrams, or pictures could be used to help with this.

The NHS 111 service was mentioned specifically by Bengali women in the Bangladeshi group. Nine out of ten of them said that they were not able to use this service and suggested that there needs to be a way of choosing which language to speak in. They also suggested that Receptionists could assist by identifying language needs and, where possible, by allocating the patient to a doctor who speaks the same language. This, they suggest, would cut down on the number of Interpreters needed. If an Interpreter is needed, this reduces the availability of appointments, as these can only be offered at times that Interpreters are available. Consequently, people needing an Interpreter have to wait longer to see a doctor, therefore adding to the health inequality.

"The Receptionists should do a triage, if a doctor speaks a specific language, patients who speak that language should be allocated to that doctor for consultation."

Three women in the Bangladeshi group gave their own examples of language difficulties they have encountered. One said that she had to organise her own Interpreter, and another said that whenever she needs to ring, she has to ask a friend to sit with her. As this can take up to 90 minutes, she only tries to ring when a problem has got worse. One woman said, "I am frightened to say something wrong."

“I am worried that I will not be able to explain properly my symptoms due to language barrier and I am worried that something will be missed.”

When the Bangladeshi group discussed how to keep themselves healthy and prevent future health problems, the **need for an Interpreter** when talking about health issues came across very strongly. Comments made include:

“Language barrier is an issue.”

“Have Bengali translator available instead of bringing a friend.”

“More appointments for advice in my own language.”

By attending their local social group (ILearn Bedford), Bangladeshi women in Bedford are able to meet healthcare professionals. An Interpreter is provided in these sessions and the women have the opportunity to discuss issues amongst themselves in a safe space. However, none of these women were aware that they could ask for an Interpreter if they needed one in a healthcare setting, to explain their health problem or understand the response given.

Language barriers also came through strongly when discussing communication with professionals. Nine comments made by Bengali women in relation to this include:

“We cannot get help if we do not have Interpreters.”

“Am frightened to say something wrong.”

Several Bulgarian women describe negative experiences due to blocks in the system caused by language difficulties. One spoke of a GP who refused to book an Interpreter. Another had the phone put down on her, before being asked for her date of birth which could have helped to identify her. Three of the women also mentioned poor communication, feeling stuck between departments and organisations that were not communicating with one another. Consequently, their treatment was delayed because of language problems that prevented them from sorting things out for themselves.

Black African women also describe how language issues and accent can become a barrier for them.

“Sometimes Receptionists downplay support, making it difficult to access the right support.”

For some, this was felt as more than just a lack of Interpreters but as a lack of caring as well:

“Language barrier, culture and age. I am old. I am not a priority anymore.”

The Gypsies and Travellers in this study, who have English as their first language, did not describe the same issues in terms of needing Interpreters. However, they did share similar concerns about the use of language which acts as a barrier to them when communicating with health professionals.

Literacy

Almost all of the Gypsies and Travellers who participated in this study described literacy as a barrier to meaningful communication about their health or social care. About half described it as the most important barrier, using terms such as **struggle and embarrassment**. One person describes their feeling of shame in not to be able to read or write. When reading and writing is not an issue, participants still said that they worried about the impact of this on rest of their community. Only two or three people out of nineteen interviewed felt that literacy was not a barrier for them.

“I speak when I need to and read okay.”

When the Gypsies and Travellers were asked about what can be done to help them look after themselves, **health literacy** was raised again as an issue:

“Can’t read or write what they want me to do.”

When this group was asked about texts and advice from the NHS, the majority of people said that they do not have the literacy skills required to read text messages. Those with some literacy skills still experience communication with professionals as hard work and spoke of a need for “something basic”. Only a very small proportion described leaflets and letters as being okay, but others see these as daunting or very hard to understand. Consequently, they often take these to the Gypsy and Traveller Liaison Officer for help.

When Gypsies and Travellers were asked what they want from health and social care, three responded by saying that they:

"Don't really know."

People reported instances of **institutional racism** and **feelings of isolation**. However, rather than these being perceived as a lack of interest in their wellbeing or dissatisfaction with the NHS, their answers are more a reflection of the challenges they continue to face regarding health literacy and an increasing knowledge that is now needed to enable people to move around the health service. For some, this is so overwhelming that they feel lost in the system and don't know what they want. Gypsies and Travellers say that they have described their issues to the NHS, and yet see nothing changing to address or improve these:

"All of those forms, stupid asking."

There was a feeling that the move to online services has resulted in more isolation for the community and, as a result, that the elderly and sick are unable to get help. When they do access services, they continue to experience problems with literacy:

"Need alternatives to electronic boards - we can't read, puts me off going, queue back at desk, and I miss appointment."

The need for **videos** and **voice messages** was mentioned as a way of overcoming literacy issues and the barriers to communication that are experienced by this socially isolated community. However, they currently face additional challenges in accessing information or digital communication due to the lack of a secure Wi-Fi signal on either of Bedford's local authority run sites.

The Bulgarian and Bangladeshi women also describe similar issues with literacy. Of the 8 women we spoke to from the Bulgarian community, **only one** could speak, read and write in English, the rest have limited English but are able to read and write in their own language. Seven out of the 8 women said they were not aware of any NHS messages, attributing this to the language/literacy barrier.

Only one woman in the Bulgarian group said that she uses the NHS app. For her, she feels that the messages are okay but said that she would find it more useful if the app could have **more local ideas** of what can be done.

9 out of the 10 Bangladeshi women who participated in this study are illiterate in both English and their own language. Comments from this group of women included:

"No use to me due to the language barriers."
"No writing in my language - I did not go to school in my country."

"Useless for me as I do not understand in both languages."

For many of these women, literacy was another reason for their reliance on their family:

"I find advice by asking my children."

Social groups such as I-Learn were also mentioned as helpful in reducing barriers.

There was agreement within this group about needing to know what is available, and how this can be accessed. Only one person in the group had a smartphone with internet access. To help overcome this digital exclusion, the group discussed videos which can be shown in GP surgeries, by health professionals or shared with groups and communities.

Cultural understanding

Cultural competency includes an understanding of the visible differences between communities such as dress and the religious significance of events such as Eid and Diwali, and some less visible differences such as tone of voice. Participants in this study describe negative experiences that have arisen due to a lack of cultural understanding and competency, leading to discrimination and unequal treatment.

Institutional racism, arising from systems, structures or expectations established within organisations, is not isolated to discriminatory incidents but also manifests in practices which exclude sections of the community. This includes 'habits of thought' which are not examined deeply.

This study highlights how communities look at events through the lens of the relationships they have within their communities, this being the lens through which they experience relationships with health professionals.

Gypsies and Travellers

For people from the Gypsy and Traveller communities in Bedford, their need to be understood was mentioned when asked that they wanted from the NHS. Two people commented on how difficult it was for them to be away from their community, one was hoping to re-join the community, and another said how difficult and isolating they found it living in bricks and mortar. Being with their community is part of their cultural identity and defines the Gypsy and Traveller way of life. People said that they wanted to **be understood more** and **being listened to** was part and parcel of that understanding.

Cultural understanding was also mentioned by the majority of the Gypsies and Travellers who talked about barriers to communication. They felt people were "clueless" at best and "scared of them" at worst.

"I talk fast and am not understood."

Another person felt the lack of cultural competency could have an impact in some areas of health, for example:

"Female doctors for pregnancy, smear tests. It's against traveller ways for men to be involved."

Only a few said that they did not experience communication barriers:

"I speak when I need to and read okay."

When asked about the impact of being a Gypsy or Traveller on the treatment they receive, **all but two** felt that their cultural identity had a negative impact. Some described how they were **'treated as outsiders'**:

"Turn noses up."

"Act like I'm gonna steal something as soon as I walk through the door."

"Hospital asked about safety in recovery, I felt personally attacked."

“Every time they think I’m a traveller I get treated real bad.”

“Difficult for me to have my say.”

“They don't understand what I'm on about, I hate talking to them.”

West African Women

The migrant women from Africa asked for **greater sensitivity** when providing health care services. Half of this group reported that being a Black African woman had had a negative impact on the care they received. When asked what they wanted, they commented on the way they would like to be spoken to by healthcare professionals:

“Need to be spoken to nicely.”

“No racism.”

ACCM (UK), who were commissioned as part of this study to report on the experiences of migrant women from West Africa, told us of 12 women supported by them (including three from Bedford) who had undergone FGM. Most of these women were under 5 years old when this was done. Over 80% of them were not even aware of having had this procedure performed on them and were told that they would be reported to the police because they had had FGM.

One new mother required counselling from ACCM (UK) after being referred to the Children and Young People’s Safeguarding Team and visited by a Social Worker two days after returning home with her new baby girl. Her daughter was seen as being at risk because the mother herself had had FGM. This young woman was distressed as she did not know what they meant by FGM and was not offered any information or support by the Social Worker to help her to understand this.

The women spoke of being subjected to hurtful and derogatory comments in the UK, such as being told they “looked like aliens” or asked questions such as “how did you get pregnant?” or “did your husband do this to you?”

Word of mouth within the community about such negative experiences in the health service has meant that some women have avoided going to see their GPs or attending hospital for childbirth for fear of being reported to authorities, putting these women's health at further risk.

When asked about talking to the NHS about their lifestyle, the women spoke of **not feeling valued or listened to**, and described a **lack of sensitivity** to cultural differences:

> **“I hate how non-inclusive some services are. They will tell you what works for the average white female without even taking into consideration who you are (African).”**

In contrast one participant described the positive relationship with her GP:

> **“My doctor and I have the same native language and it is great. It makes me feel heard and respected since we have the same cultural background.”**

Bulgarian Women

The Bulgarian women discussed concerns about misunderstandings that can arise from a difference in **‘cultural etiquette’**. One woman describes being unsure about how to speak or behave in front of professionals and expressed her concern about her words or tone of voice being wrongly interpreted. Another woman describes how she is careful when speaking to her child in public as she fears she will be judged. Consequently, the women try to anticipate what would get a negative reaction from health professionals.

> **“It can be interpreted wrongly, and you can have your child taken away. It is a difference in culture.”**

All the Bulgarian women who participated thought that an understanding of the different culture and background of clients or patients should be a requirement for health and care professionals. The notion of **diversity training** and **unconscious bias** was discussed.

At the moment, the women who participated in this study are very concerned about understanding English etiquette and would like to have group classes on this so that they can ‘blend’ in. Their focus is on assimilation rather than integration to avoid negative experiences.

Bangladeshi Women

All of the Bangladeshi women who participated in the study felt that they would get better treatment if they were white. When asked about their cultural identity, they felt it was easy for them to be overlooked and not listened to. When asked what they wanted from the NHS, they were concerned about having to jump through hoops. They also described being talked down to and a patronising attitude from staff which, they say, results in unfair treatment.

Two of the women described not having their health concern taken seriously:

“Give us an appointment when needed not when about to die.”

“The Receptionist was very rude - she didn't listen and talked down to me. They kept sending me to the chemist even though the chemist referred me back to the doctor.”

Another described going for a blood test that would be completely out of date by the time she could get to see a specialist:

“Sometimes it doesn't make sense. I have waited over 12 months to see someone. I had to do a blood test before the appointment. I had to book online and the next slot available was 2 weeks later. Waiting time in waiting room for completing blood tests is quick at the hospital. What was the point of me doing a blood test 12 months before I see someone at the hospital.”

Further Topics Discussed

1. **Effectiveness of NHS and access to services**
2. **Support, safety and stability**
3. **Preventing future health problems**
4. **What can be done better**

1. Effectiveness of the NHS and access to services

All of the groups were concerned about the ineffectiveness of the NHS and access to services. For example, they had not been given information about NHS dentistry and many were attempting to find non-emergency NHS dentistry when such services were not available.

In the Gypsy and Traveller group, the time taken to register with a GP was highlighted, and two people spoke about the slowness of getting a diagnosis for their children. Concern was expressed about how difficult it was working with their local surgery:

> **"Waiting list, no results, surgery don't know anything."**

> **"It would be good 'to ring and get an answer."**

Women in the Black African women also spoke about effectiveness and access to services. One participant suggested that:

> **"The NHS should continue the rendering of care to people especially the less privileged ones."**

Concern was expressed about waiting times and the quality of care given, with women suggesting:

> **"Prompt answers to questions of concern."**

> **"Try as much as possible to diagnose the real cause."**

In the Bulgarian group, women spoke positively about some aspects of the NHS as well as the difficulties they experienced.

Positive comments were made about the efficiency of the NHS included repeat prescriptions, referrals, politeness and organising an Interpreter. Four women mentioned the quality of the care, all of these saying that they were happy with the outcome when they saw the specialist. Two of those mentioned politeness and noting down information from their conversation.

Concerns expressed by the Bulgarian women were focused on inefficiencies in the NHS when trying to access services. Regarding primary care, women mentioned issues with booking appointments with a GP, rushed appointments and only being able to talk about one problem at a time when they finally got an appointment.

Three people wanted to know how to register with a dentist, as they were not aware of any dentists in Bedford at that time who were taking on new NHS patients.

One person commented that it should be easier to book an urgent GP appointment. One person wanted the NHS to inform people who are new to the area about how to book an out of hours appointment.

"Would not know where to go if there was an emergency."

Eight Bangladeshi women who participated in the study also mentioned inefficiencies in the NHS, including 10 comments about how difficult it is to get appointments – from doctors, dentists and physio to the hospital. Six people mentioned not being able to get a GP appointment and another getting a dentist appointment.

"Can't bloody get an appointment to dentist, so I had to go and see a private dentist and it costs £200 even though I am an NHS patient and low income."

Five of the Bangladeshi women expressed a preference for face-to-face and 1:1 appointments. This was echoed by 50% of the Gypsies and Travellers who said that they wanted face-to-face consultations, either with their GP or with someone coming on site.

2. Support, safety and stability

In discussing what they want from health and social care services, two further issues specific to their community were raised by the Gypsies and Travellers:

- **Support needs**
- **The need for safety and stability**

In terms of support, three people asked for help with referrals, writing letters and making calls. It was suggested that the advice clinics, which were running before the COVID pandemic, be reinstated. One person asked for help in moving back on site in order to re-join their community. Within this community, people expressed their feelings of low mood and being "lost" with other problems. Three people commented specifically on how coping with life makes it more difficult for them to contact the doctor. Electricity bills were mentioned, and one person spoke of being "not sure, not much time, I leave (ringing GP) till I have to."

Safety concerns and **plots with stability** were mentioned as things that were needed:

"Our kids to have a nice life, be healthy and safe."

"Where I live in my plot, I am very anxious cos of everything going on. I can't sleep at night and the council are useless. The barrier is dangerous, but nothing's been done. I worry it will come down and me and the babies will be dead!"

3. Preventing Future Health Problems

We asked all participants to tell us about how well they could look after their own health, their views on preventing future problems, and what they think could be done better by the NHS to promote healthy lifestyles.

Three themes emerged from this discussion:

- **Self-care**
- **Staying well**
- **Talking about healthy lifestyles**

Self-care

For the Gypsy and Traveller group challenges arising from their social circumstances, such as isolation and poverty, were mentioned:

"Yes, but in house socially isolated."

"Do what I can but making ends meet."

"Not really sure, just get on with it, treated like we don't matter at all."

"Not a well woman, do my best."

"Yes, I try, despite everything (electric bills and waiting lists) I have to deal with."

One person said that they wanted to look after themselves but felt like a 2nd class citizen when they talking to the Receptionist, who was rude.

Half of the Black African women we spoke to said they look after their own health. For them, the key factor is the availability of information. However, two women said that the information can send them down a spiral or they keep being signposted from one site to another. Another highlighted the need for health care services that are free and easily accessible to all.

One person said that they appreciated being able to go to a doctor, even if it was just something that they were worried about.

The Bulgarian women spoke about mental health, this being something which is not talked about in Bulgaria so felt that it is good that the NHS are doing something. One person said that talking to a GP helps, and another person commented that a website on mental health and living would be useful. Several people had taken steps in stopping smoking, walking more and giving up alcohol consumption. A few of the women said they knew they could do more to look after themselves.

All of the Bangladeshi women mentioned physical exercise, including small walks. One person mentioned how refreshed and energetic they felt after exercise, and another said how exercise has helped to keep arthritis under control. A couple of people said how proud they were of keeping their diabetes under control, one of those for 20 years.

However, one person said that:

“There is a cultural barrier, so I do not get enough appropriate exercise.”

A few of the women suggested that ‘exercising in groups would encourage them’.

Staying well

Two main suggestions emerged strongly from the analysis of data collected from all participants regarding prevention:

- **The need for small groups**
- **Health information and education using digital media**

The Gypsy and Traveller community had face-to-face advice clinics before the pandemic and would like these to start again. Black-African women spoke about the benefits of group discussions, especially through local groups such as the church. All of the Bulgarian group showed an interest in receiving health information in a small group, including information on how to stop smoking.

Two people said that they are very open to the idea of learning about a healthy lifestyle but would need this explained in a group. Amongst the Bangladeshi women, all said that they would like a small group. As mentioned previously, needing an Interpreter was highlighted in terms of looking after their own health.

QPCO told us that many of the women who attend the ILearn group show signs, in their comments, of low mood. This appears to be alleviated temporarily if/when they are able to achieve something, however minimal, such as going for a walk or eating more healthily. However, this needs to be constantly re-enforced to prevent them from becoming detracted by life events.

The use of voice notes and video messages sent via WhatsApp was also suggested. For some, this is seen as an effective form of communication to overcoming their literacy challenges. For example, five people from the Gypsy and Traveller community asked for video messages, general videos and WhatsApp videos on subjects such as stopping smoking. Bulgarian women also requested video information in their own language and Black African women spoke in favour of the internet and text-messages as ways of getting health information.

Talking about healthy lifestyles

Black African – one woman said that she felt proud of how well she managed her lifestyle and one asked for information on the internet. Four people said that they trust their GP – “I just take what the GP gives” and two people mentioned that they have network problems and so can’t find advice on the internet.

Bulgarian – Three people said that they trust their GP and two more said that they would go to them for information. Two people said that they would look on the internet. One person did not have a computer and said that they only knew one number – 999. Two people mentioned how difficult it is to get a blood test to check their own iron and cholesterol levels. This is paid for in Bulgaria but much easier to obtain. Five people mentioned how they managed a healthy lifestyle with two people saying that they did not need additional help and three saying that the current advice is complicated.

Bangladeshi – All the women said that they will go to friends and family or GP to get advice on a healthy lifestyle. This is often because they do not have the I.T. skills needed but one person was aware of the NHS site as a trusted place to go. 4 people said they trusted their GP, professionals and their family but another two people said they do not know who to trust, and that trust has disappeared since the death of a family member. The women said they had not felt able to take any exercise or think about what they ate in the past but with the support of their group (ILearn) they are taking small steps and feeling proud about going for short walks.

4. What can be done better

Amongst the Gypsy and Traveller community there was a strong feeling of improving services with shorter waiting times. Training and a better understanding of their community is also needed, for services that:

- **"Are straightforward" (with them)**
- **"Try to speak in plain English"**
- **"Explain things better, everything in gobbledegook and half of it crap"**

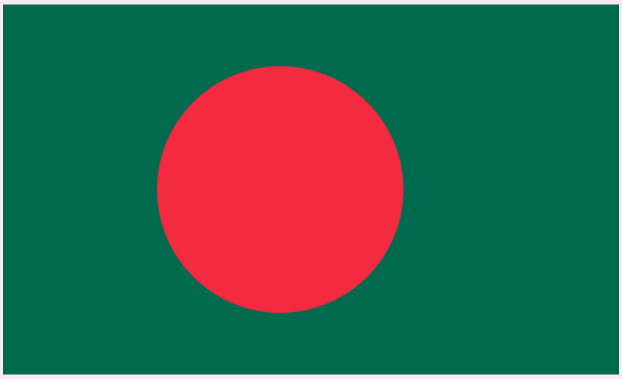
When discussing how to improve services, Black African women asked for:

- **shorter waiting lists**
- **employing more staff**
- **being able to get an appointment**

African women mentioned being able to ask at the hospital or GP's and nurses at their surgeries as helpful ways to get information. However, one woman spoke of the lack of privacy when giving personal information talking to Receptionists and two people mentioned their experience of poor practice during childbirth. One of the Bulgarian women said that a follow-up of written information previously given verbally would be useful.

The need to avoid making assumptions about digital access was also highlighted. One woman explained that a lack of communication when referring had left her unable to get an appointment because of an expectation that an appointment could be booked online, without checking that she had access to a computer.

Case Study 1



Case Study 1

Mrs M is a female Bangladeshi woman, age 59, living in BPHA accommodation in Bedford for over 30 years. Widowed more than 10 years ago, she is a mother of 4 adult children who no-longer live with her. She is in receipt of welfare benefits and is, therefore, living on a low income. She is very dependent on her children and friends. She only speaks Bengali and cannot read and write in her own language.

She is registered with a local GP Practice but does not have a specific doctor. She suffers from Arthritis and Type 2 Diabetes. She is on regular medication for Diabetes and has 6 months check-up with diabetes nurse.

Mrs M caught COVID-19 during the first lockdown. She was hospitalised in Bedford Hospital where she stayed for one and a half weeks. As this was at the very beginning of the pandemic, the doctors had a limited knowledge of the virus and she felt she was left to her own devices on the ward. Other patients around her on the ward was screaming, and it was difficult for her to sleep. She could not communicate at the hospital due to language barriers and she has been traumatised by this whole experience. Since being hospitalised for COVID-19, Mrs M has been suffering from anxiety. She has been prescribed tablets for her anxiety, however she does not take them as she thinks they are going to make her worse.

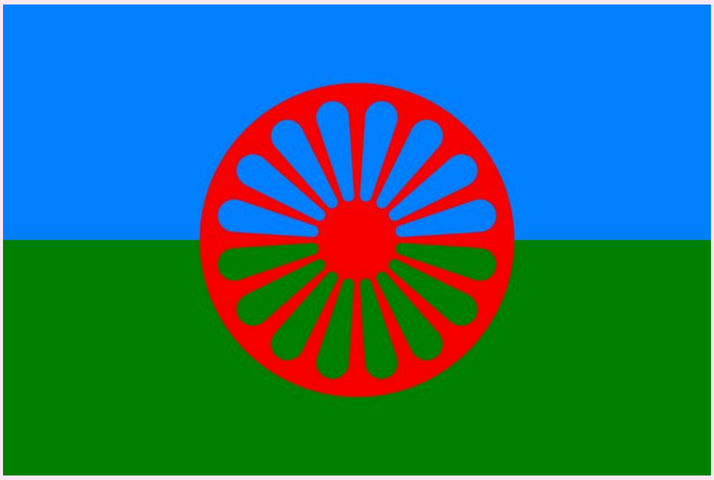
Mrs M was registered with a dentist in Bedford before COVID-19 and is entitled to free NHS dental care because she is on a low income. However, she was unable to get a dental appointment when she needed urgent treatment to have a tooth extracted. Her only option was to go to a private dentist for this emergency procedure. She had to pay £200 for this, which is a lot of money for her.

Mrs M cannot get an appointment with a GP at her surgery due to long queues on the phone and has a language barrier which means that she has to have someone to make the appointment for her. It is always difficult for her to find someone who can spend two hours waiting with her in the queue and she feels embarrassed by constantly having to ask for help from family and friends. She feels that when she does get through to a receptionist, they will ask her 500 questions about the reason why she wants to see a doctor. Therefore, she has reduced the amount of appointment she has made.

She says they can hear the irritated voice of the receptionist making comments such as "We are very busy here". She feels that if it was a white person, they would behave differently. Even if they do not understand the language, the body language and tone of voice of NHS staff in the surgery is nicer to people from a certain background compared to them.

During consultations, the doctor will be looking at his note and will ask her to be quiet while he reads. This makes her feel like being at schools again when the teacher tells you to be quiet. She is made to feel undervalued and not important. This has meant that she is less likely to go to the doctor after COVID-19 than before. Mrs M feels that when she sees one of the male Asian doctors at the surgery, they treat her in an inferior manner (being very impatient and making her feel that she is wasting his time). She believes that they would not speak to a white woman in this way as they think she would go on to complain about this treatment. However, these doctors seem to assume that a Bengali lady would not complain as they think they would struggle to register with another surgery. Therefore, Mrs M would prefer to see a white doctor rather than an Asian doctor.

Case Study 2



Case Study 2

Ms. X is a young woman in her very early twenties. She lives with her partner and young children. She has lived in local authority bricks and mortar accommodation as well as on site and describes the bricks and mortar environment as having **“drunks and druggies”** with inadequate facilities to meet her health needs and the needs of her young family. Something which has been raised with the housing division but to no avail.

They do not have access to information technologies. Her partner has a smartphone, but they do not have a mobile contract and have to put top-up credit on the phone when they want to use it. Ms. X says she is not at all confident using it, even to send or reply to an SMS text. When discussing I.T equipment in general she advised that she **“wouldn’t even understand how to turn a computer on.”** Ms. X has complex medical conditions that she has had from birth which have resulted in specialist surgery and left her with severe asthma. She is registered with a local GP practice.

Ms. X left the SEN educational setting she attended when she was 11, as is common cultural practice within the traveller community. She has moderate learning disabilities. Because of her physical and learning disabilities, her partner is her registered carer, and she is reliant on him and her family for many daily aspects of her life including money matters. They are in receipt of multiple benefits. Neither her nor her partner can read or write. Both are illiterate. Her main presenting condition is complex, and she receives tertiary care from a hospital in London. However, due to literacy issues, they rarely understand written letters and miss appointments. The postal service at Kempston Hardwick has been suspended multiple times due to criminal damage and anti-social behaviour, with Royal Mail refusing to attend the site. This has been intermittent during the past nine months. This puts Ms. X, her family and the wider traveller community residing at Kempston Hardwick at an unfair disadvantage.

She says that being unable to read or write has kept her back all her life and she really struggles to access the NHS properly. She has to get people to read messages aloud to her but when she is unable to access this time-consuming support, it results in missed appointments. She describes missing her children’s vaccinations as she was unable to read the SMS texts sent to them. She says she has asked for WhatsApp voice messages especially for appointments, but the NHS do not cater for this. She describes wanting better for her children.

She says she feels she’s **“treated differently compared to a gorja”** (non-traveller). She feels the NHS turn their noses up at Gypsies because they can’t read or write and are different in their ways. She feels country folk (non-travellers) get everything.

She would like services to be improved, starting with the NHS listening to patients needs and using voice notes and making phone calls about appointments. She is concerned about the long waiting time for a doctor’s appointment even for emergencies and says it’s not good enough. What she would like from NHS and social care services to is to be understood and for them to talk to her as an equal. She says travellers as a group need someone who either is a traveller or has traveller history to explain how things work in the NHS and social care. She says, **“it's pointless at the moment, not like Chinese talking to Chinese”.** This refers to traveller dialects, of which there are many, insisting NHS and council professionals do not understand travellers and travellers can’t understand them.

Recommendations

1. Improve availability of and access to Interpreters
2. Use of digital to overcome literacy barriers
3. Training in Cultural Competency
4. Local Groups
5. Recording of primary/preferred method of communication, language needs and literacy skills

Recommendations

1. Improve availability of and access to Interpreters

Access to Interpreters was highlighted as a significant unmet need by participants in this study, as well as concerns about the inappropriate reliance by service providers on patients' family and friends. The provision of effective and sustainable interpretation is needed to overcome challenges faced by the linguistically diverse population of Bedford Borough when accessing services. This will also reduce the burden placed on individuals and their families and friends.

2. Use of digital to overcome literacy barriers

WhatsApp voice recorded messages should be offered as primary methods of communication to those who are not able to read or write, thus reducing the barriers to care resulting from literacy issues. Information provided should be appropriate to the literacy and language skills of the recipient. Basic Easy Read SMS messaging should also be used for those who have requested this method of communication instead of written letter formats.

To help address digital exclusion, subtitled information videos should be shown in GP practices and other NHS or community settings. Digital poverty needs to be recognised as a contributing factor to digital exclusion. A further explanatory dive should be undertaken at both local authority caravan sites in relation to the installation of Wi-Fi/broadband, to alleviate inequalities within the Gypsy and Traveller community.

3. Training in Cultural Competency

A lack of understanding, leading to problems related to language and cultural issues, was identified by participants across this study. This presents a barrier to effective communication and interaction between individuals and professionals in healthcare settings. Cultural competency training for healthcare Commissioners and providers is recommended to support small groups to provide free activities and facilitate access to advice clinics in the community. Such groups enable the sharing of health education, advice on healthy lifestyles, group discussion and peer support in a safe environment which shows an understanding of their culture and can address their language barriers.

4. Local Groups

Further partnership working between the VCS, healthcare providers and local authority is recommended to support small groups accessing advice clinics in the community. Such groups facilitate the sharing of health education, advice on healthy lifestyles, group discussion and peer support in a culturally appropriate environment that feels safe to those attending.

5. Recording of primary/preferred method of communication, language needs and literacy skills

We recommend that the preferred method of communication, primary language and/or literacy skills are prominently documented on healthcare records to alert Receptionists and Clinicians of the communication needs of their patients and service users e.g., Voice messaging only This should also cover existing patients and service users, as well as new patient registrations.

Acknowledgements and Next Steps

Healthwatch Bedford Borough would like to thank ACCM (UK), Queen’s Park Community Organisation (QPCO), Bedford Borough Council’s Gypsy and Traveller Liaison Officer, and the many women, men and families who participated in this study.

This report will be submitted at the end of January 2023 to the Bedfordshire, Luton and Milton Keynes Integrated Care System (BLMK ICS) Inequalities Steering Group. The group will then review the findings of this study, alongside reports from the other three local Healthwatch in BLMK.

These will be used to develop recommendations that will be taken forward in a report to the BLMK Integrated Care Board (ICB) to tackle systemic health inequalities across BLMK.

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