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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The Denny Review - Engagement Project

December 2022

CDS

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The Disability Resource Centre

healthwatch Central Bedfordshire

Content...

Introduction

Bedfordshire, Luton and Milton Keynes Integrated Care System (BLMK ICS) commissioned The Denny Review; *'A rapid evidence review of the health inequalities experienced by the local communities of Bedfordshire, Luton and Milton Keynes'* in April 2022. It aimed to improve its understanding of health inequalities in its local communities and good practice to address them. It identified priorities for areas of focus for engagement and co-production with individuals and communities to agree actions to reduce inequalities.

The Denny Review demonstrated that the wider determinants of health, including socioeconomic deprivation, psychological, cultural and individual factors affect health and wellbeing. All these factors intersect and have a cumulative effect on an individual, family, social group or community. The review evidenced that the communities affected by the health inequalities in BLMK include ethnic minority groups, including Gypsy, Roma, and Traveller communities, people living in deprived neighbourhoods, people with disability, and people experiencing homelessness, migrants, and LGBTQ+. These groups experience health inequalities from unfair distribution and the impact of wider determinants of health to access health care services.

The ICS aims to understand the nature, causes and potential solutions to inequalities in health through a whole-system approach to understand and inform and tackle health inequalities affecting BLMK local communities.

Working together on an action research project, Healthwatch Central Bedfordshire (HWCB), The Disability Resource Centre (DRC) and Community Dental Services (CDS CIC), known for the purposes of this report as 'the partners', engaged with residents, identified with physical and/or learning disabilities, of all ages inwards of deprivation, across Central Bedfordshire, Luton, Bedford Borough and Milton Keynes, to learn more about their experience of accessing health and social care services. Their feedback will help to improve services and better meet the expectations of people across BLMK.

Executive Summary

The project aimed to highlight the health inequalities for those that may be disproportionately impacted due to a physical and/or learning disability, living in deprived areas of Bedfordshire, Luton and Milton Keynes.

A survey was created and widely distributed which generated **1298** responses. In addition, within the survey, respondents were asked if they would be willing to take part in a more in-depth study, either a focus group or individual case study, and over **850** positive responses were received.

The survey questions sought to understand what specific services work well for individuals and which ones do not, and how those services could be improved. People were also asked what was most important to them in the way they are treated by healthcare professionals, and what they think are the barriers to accessing healthcare services that do not work so well for them. They were also asked how communications could be improved to access services more easily, and if they knew which preventative services were available to them.

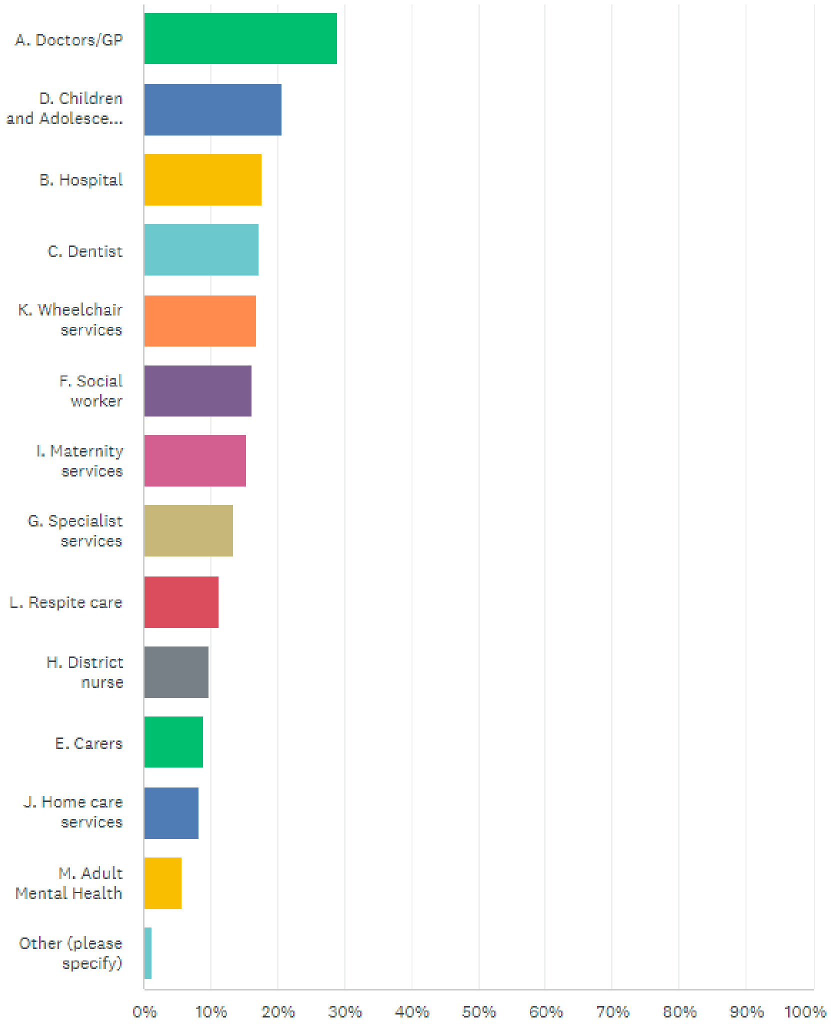
Responses to the questionnaires included both positive and negative feedback about accessing health and care services across Bedfordshire, Luton and Milton Keynes (BLMK). A full copy of the survey questions can be found in Appendix A.

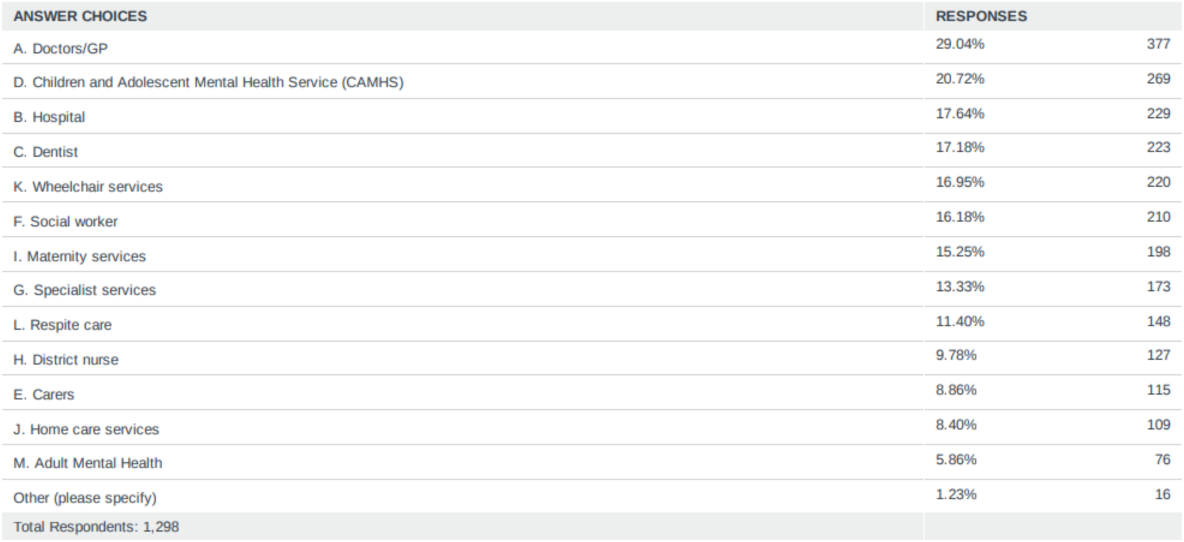
The majority of negative feedback from service users related to GP services, which is unsurprising given current national concerns involving access for all patients to GP services, and the Children and Adolescent Mental Health Service (CAMHS), with **29%** of respondents selecting the Doctors/GP service, and **21%** CAMHS respectively.

See below a bar chart demonstrating the results of the question asking which services do not work well.

What specific services do not work well for you? (List all that apply)

Answered: 1,298 Skipped: 0





ANSWER CHOICES	RESPONSES	
A. Doctors/GP	29.04%	377
D. Children and Adolescent Mental Health Service (CAMHS)	20.72%	269
B. Hospital	17.64%	229
C. Dentist	17.18%	223
K. Wheelchair services	16.95%	220
F. Social worker	16.18%	210
I. Maternity services	15.25%	198
G. Specialist services	13.33%	173
L. Respite care	11.40%	148
H. District nurse	9.78%	127
E. Carers	8.86%	115
J. Home care services	8.40%	109
M. Adult Mental Health	5.86%	76
Other (please specify)	1.23%	16
Total Respondents: 1,298		

Additional comments with regard to this question included, ***"Doctors are generally still not dealing with patients."*** and ***"Contacting and gaining an appointment with a GP is beyond a joke. This results in us having to visit hospital more with minor issues"***

Respondents were asked in what way services needed to improve (question 5). For Doctors/GP services, the two most popular responses were '**easier access to appointments'** with 24.5%, and '**staff to be more helpful'** with **22.6%.** The same two responses were also the highest for hospital services, with **24.6%** and **24%** respectively. One respondent commented, ***"My GP seems to rely on 111 to screen patients and arrange appointments. Also I am deaf so they don't seem to understand that a phone appointment is useless, I need face to face but cannot get this".***

In addition, the key statistics that stood out for us, were that **26.3%** of people responded saying that '**more interpreters available'** is a needed improvement for hospitals, and **22.5%** responded saying that there needs to be '**more available appointments with a Disability Champion'.** This may suggest a lack of understanding and disability awareness within this environment.

The majority of respondents (**30.2%**) clearly indicated they wanted to be **'listened to',** closely followed by **'to be involved in decision making'** at **24.3%,** and **'to be treated equally'** at **19.4%,** as the most important ways in which they wanted to be treated by healthcare professionals. One respondent commented, ***"Not to be spoken to as if you are stupid. Talking over you as you are trying to explain. Dismissing your concern without even listening to you".*** A more in-depth study would need to be undertaken to better understand how service users and patients feel they are currently treated by healthcare professionals.

More importantly, respondents viewed the biggest barriers to accessing services as the, **'difficulty in securing an appointment'**, **'long waiting lists'**, **'shortage of staff'**, and equally as important **'No disabled access'** and **'a lack of interpreters'**.

A mother commented, ***"I have a great doctors surgery that go out of their way to help my handicapped daughter. Sadly once seen by the doctor it takes months for a hospital appointment, even phoning the surgery to find out why".***

Asked what could be done better to improve communication with patients, a fairly large majority of respondents would like **'hearing loops'** installed, closely followed by **'longer appointments'** and **'interpreter services',** as mentioned earlier. Interestingly, **'Understanding individual needs'** was also popular which could be related to their particular disability.

Many people responded positively to awareness of preventative services, the most popular being **'Exercise and Active Lifestyles'**, closely followed by **'Screening Services'**, although one of the least well-known was **'Social Prescriber'** which may indicate that more promotional work needs to be instigated to help inform the public of self-management or self-care options available to them.

See a table of results for the most selected improvements and services on page 15.

Methodology

The partners gathered the views of the target group through a variety of methods designed to gather feedback about their experience and examples of best practice to share with BLMK ICS and key stakeholders.

Working with BLMK ICS we initially designed a short survey of qualitative and quantitative questions to gather feedback from local residents to explore the socioeconomic deprivation, psychological, cultural and individual factors of their experiences, including the barriers and aspirations for fair and accessible health and social care services. The survey was launched on 12th October 2022 and closed on 7th November 2022. A copy of the survey questionnaires can be found in Appendix A.

We also engaged with our existing volunteers with lived experience including DRC Experts by Experience, Carers Panel and Young Healthwatch.

We aim to follow up the launch of the survey with group and individual conversations within areas of deprivation across Central Bedfordshire, Luton, Bedford and Milton Keynes and to facilitate focus group discussions to further explore the key questions asked within the survey.

Distribution and selection Process

The survey was shared through a variety of channels:

- Our websites
- Our social media platforms
- Targeted emails to our distribution lists in excess of 8500 people
- Our newsletters
- Via Beds, Luton and Milton Keynes Integrated Care System(BLMK ICS) communication channels such as social media and regular Ebulletins
- Hard copy through community engagement
- Hard copies distributed to community and health settings
- Distribution via wider organisations including condition-specific, health and community organisations

Survey responses were collected via Survey Monkey which included demographic details, and whether they would like to volunteer for group and/or one-to-one sessions for a more in-depth study.

We received nearly 900 requests from those who indicated within the survey that they would like to take part in a case study. These individuals were subsequently sent an additional survey to determine the specific area of Bedfordshire, Luton or Milton Keynes (BLMK) they lived in. Selection will be based on whether they live in areas of high deprivation across BLMK. All participants who agree to take part in a focus group or case study will be offered a £25 gift voucher for taking part.

Demographics

Demographic questions were included in the survey relating to; age, gender, ethnicity and religion. People were also asked if they considered themselves to live with a disability or additional need, and whether they lived in Bedfordshire, Luton or Milton Keynes.

From the feedback received, interestingly **53.5%** of people who completed the survey were within the 18 – 30 age bracket. The second most popular age bracket was between 31 – 50, with **39.2%** of responses.

61.9% of people who completed the survey identified as being female, and **36.5%** identified as male. A very small minority of people preferred not to say (**10 people**), or identified as non-binary or intersex (**5 people each**) which made up **less than 1%** of respondents. However, **7 of the 10** people who selected non-binary or intersex were aged **18 to 30 years**. As the figure for this cohort of people is very low this could suggest that this group are vastly unrepresented when accessing services.

A range of ethnic groups were indicated in the survey although 'white/white British' was the most dominant at **76.4%.** Other ethnic groups represented were Black/Black British (**16.09%**), Asian/Asian British (**5.68%**), and Arab/Arab British (**0.63%**). Six individual respondents identified as multiple ethnicity groups or other, with responses either being mixed ethnicity or unknown.

79.1% of respondents indicated 'Christian' as their religion. Other religions represented were Hindu (**6.1%**), Jewish (**1.74%**), Muslim (**1.27%**), Buddhist (**0.95%**), and Sikh (**0.4%**). Two individual respondents selected 'other', with one person saying 'Spiritualis't and the other 'Islam'. However, the second most selected response was 'no religion' with **10.29%** and **130** responses.

More than half of the respondents who completed the survey (**54.8%**) indicated that they considered themselves to live with a disability or additional need, and **61.6%** of respondents were from the Bedfordshire area.

Data tables with full information have been added to the relevant questions in the survey results section of this report.

Survey Results

A total of 10 questions were asked in the survey relating to what specific health and care services work well for individuals and which ones do not, and how those services could be improved. People were also asked what was most important to them in the way they are treated by healthcare professionals, and what they think are the barriers to accessing healthcare services that do not work so well for them. They were also asked how communications could be improved to access services more easily, and if they knew which preventative services were available to them.

The results of the survey and each question are detailed below.

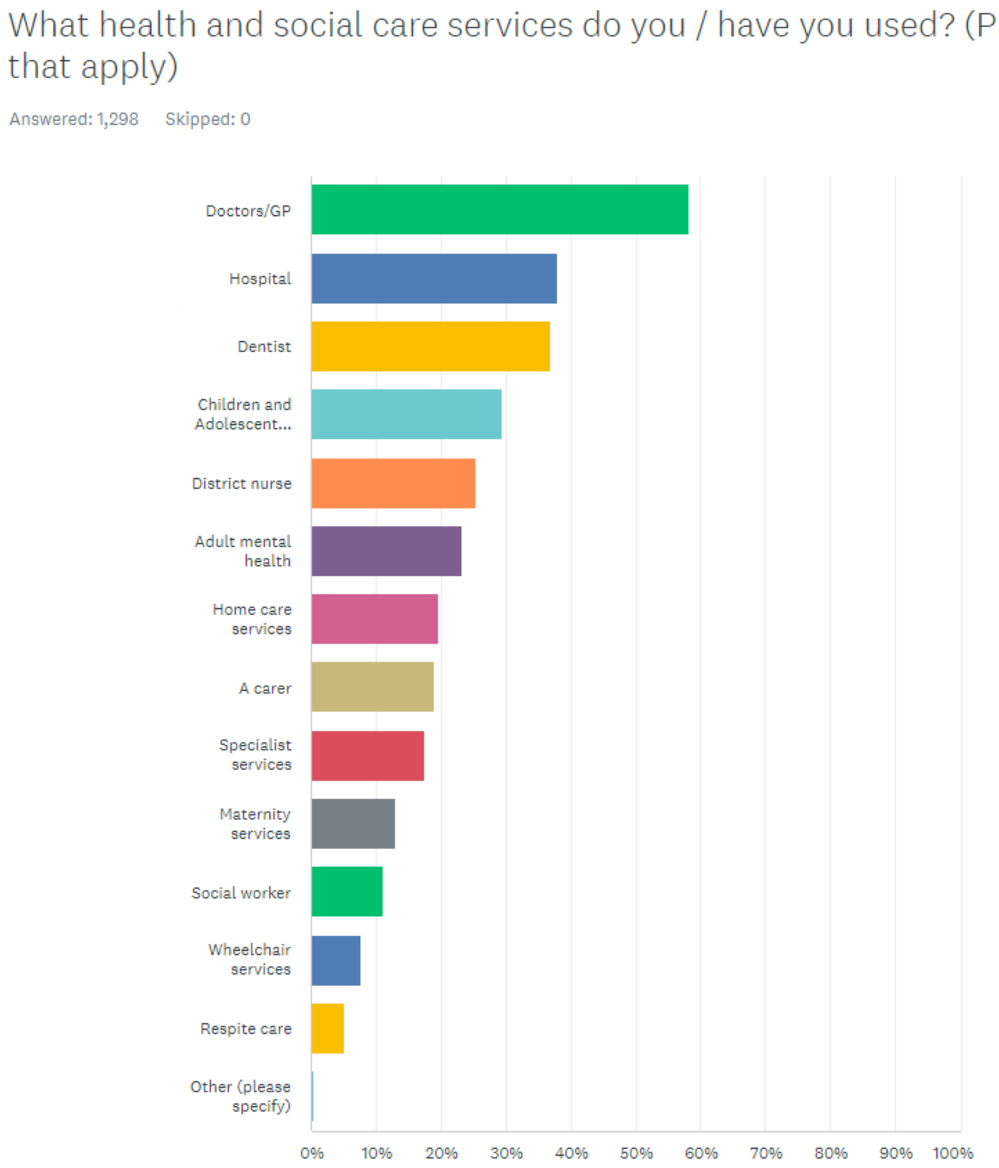
Question 1

Service users were asked what health and social care services have they used.

A range of healthcare services were indicated, but unsurprisingly the majority of respondents (**58.2%**) had accessed a GP Service. Many indicated that they had also accessed dental (**36.8%**) and hospital services (**38%**) too. Mental health services were also registered amongst the highest services accessed. Children and Adolescent Mental Health (CAMHS) services were accessed by **29.5%** of respondents, and adult mental health is accessed by **23.3%**

Over 25% of people had used the District Nursing services and many indicated using specialist services too **(17.4%).**

See the full table of services and results below.



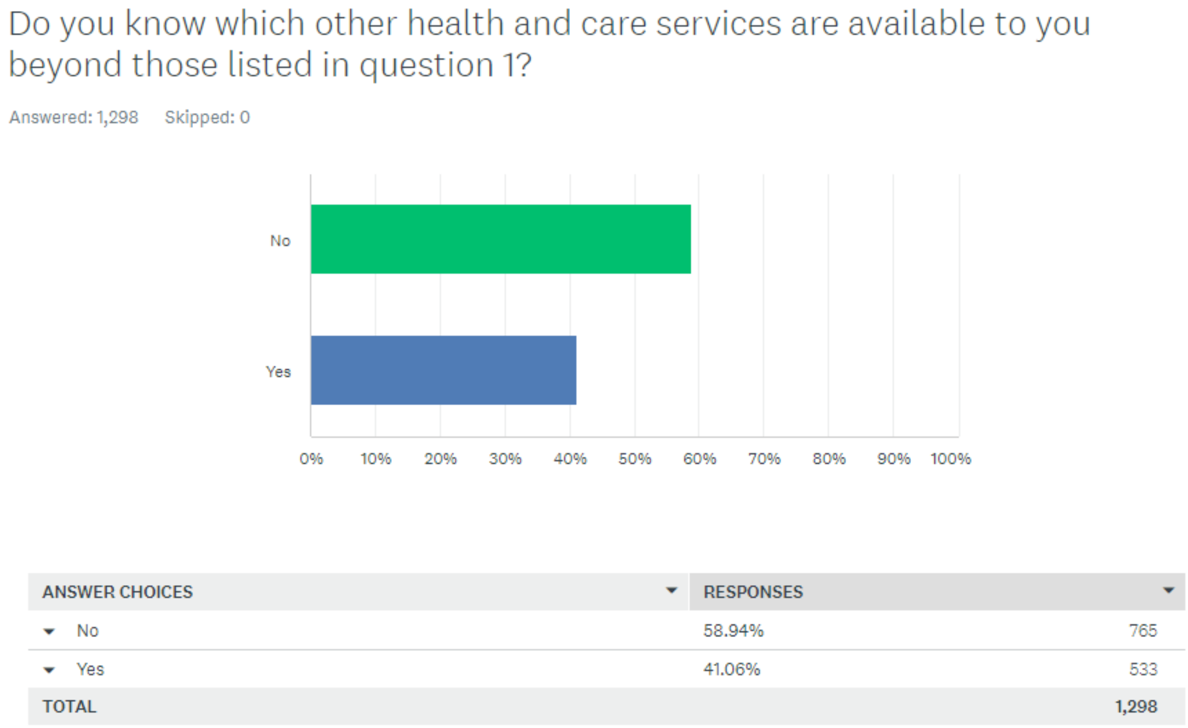
What health and social care services do you / have you used? (Please tick all that apply)

Answered: 1,298 Skipped: 0

Question Two

Service users were asked if they knew of other health and care services available to them which had not been listed in question one.

Interestingly the result of this question indicated that respondents were mainly unaware of any other services, with just **40%** saying they ***did*** know of health and care services other than those listed. This meant that **59%**, a fairly large majority of respondents, were ***not*** aware of other services. This would suggest that there is a need for an industry-wide marketing campaign to raise awareness.



Do you know which other health and care services are available to you beyond those listed in question 1?

Answered: 1,298 Skipped: 0

ANSWER CHOICES	RESPONSES	
No	58.94%	765
Yes	41.06%	533
TOTAL		1,298

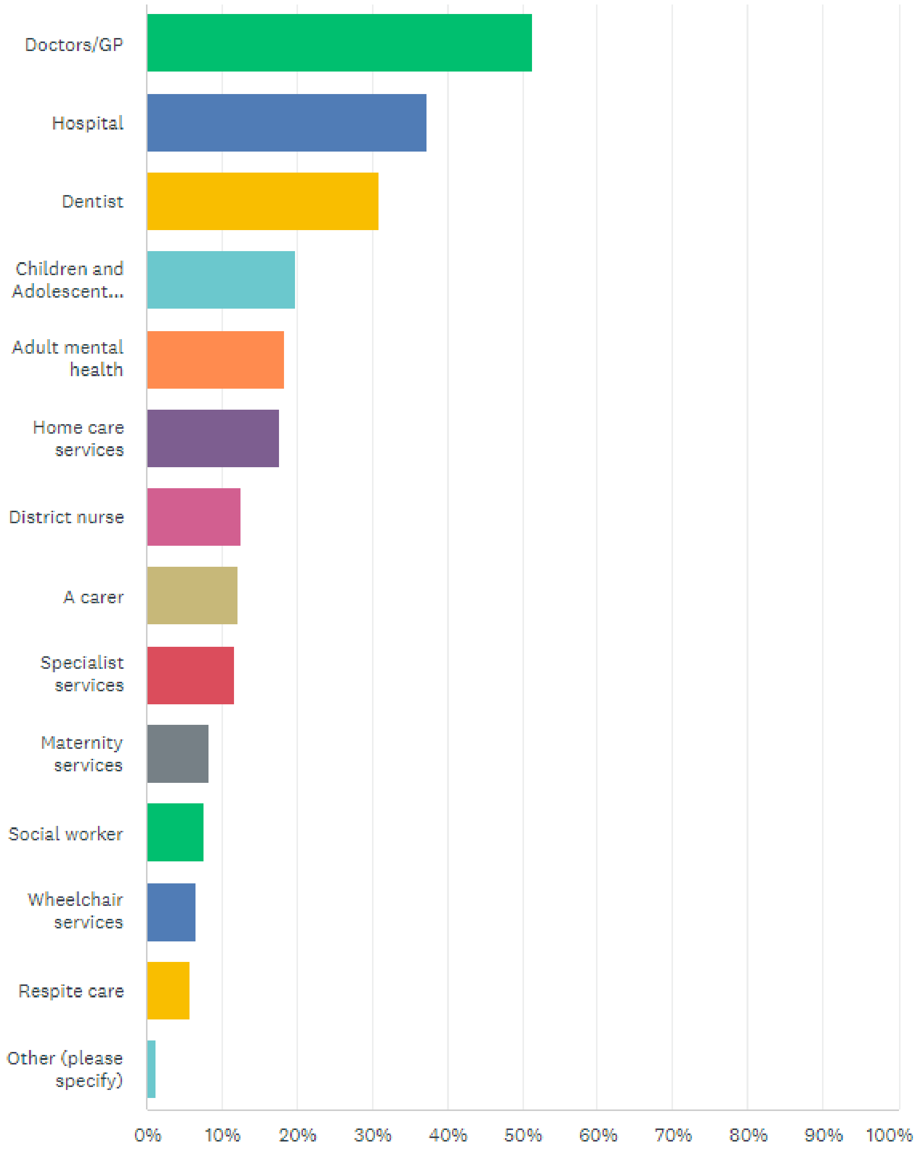
Question 3

We asked service users which specific services work well for them, and to select one or more that applied to them.

The four most popular responses were the Doctors/GP (**51.3%**), the hospital (**37.3%**), the dentist (**31%**), and the Children and Adolescent Mental Health Service (CAMHS) (**19.8%**). These results are of particular interest when reviewed in line with responses to question 4. It would appear that as wheelchair services only received **6.6%** of the votes, this could indicate that either the service is not used by many people, or it is well used and people are not happy with its level of service. Either way, there is something to explore there.

What specific services work well for you? (List all that apply)

Answered: 1,298 Skipped: 0



Question 4

This question was the opposite of question 3, as people were asked what specific services do not work well for them. Again, they had the option to select one or more services that applied to them.

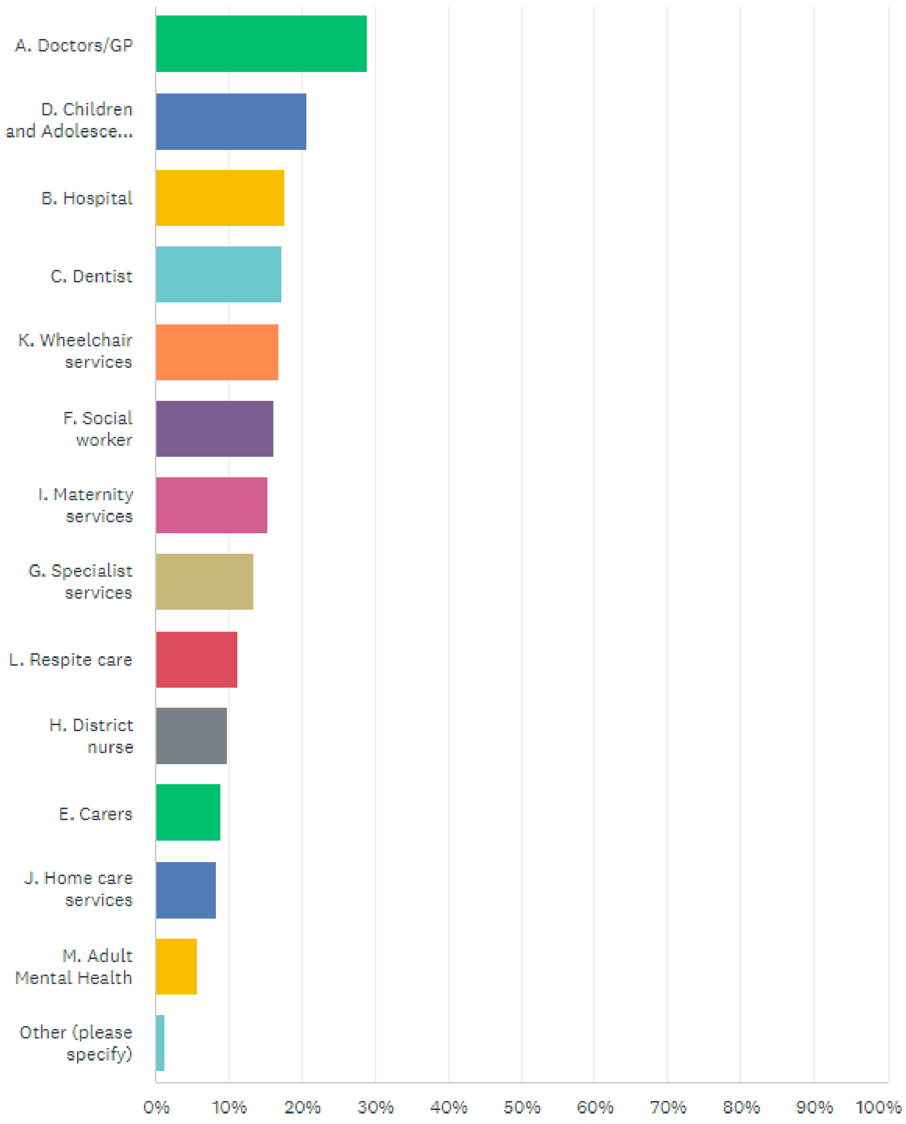
Surprisingly, and in contrast to the responses in question 3, the top four most popular answers were the same as in question 3. Doctors/GP received **29%** of the votes, Children and Adolescent Mental Health Service (CAMHS) **20.7%,** hospital services **17.6%,** and dentist services **17.2%.** This shows a very mixed opinion of the services people access but would also indicate that these services are used by many people who are not entirely happy with the quality of service provided.

Additional comments were received about the Doctors/GP service in particular, with a reoccurring theme, summed up by one service user, as follows, ***"GP appointments need to be easier to arrange and more admin staff to actually answer the phone instead of long waits to get through with irritating music to listen to."***

When looking at the wheelchair services results, it was the fifth most selected option, with **17%** of the votes. In question 3 it was selected only 86 times, but in this question, it was selected 220 times. This would indicate that more people are not happy with this service compared to those that are.

What specific services do not work well for you? (List all that apply)

Answered: 1,298 Skipped: 0



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L. Respite care	11.40%	148
M. Adult Mental Health	5.86%	76
Other (please specify)	1.23%	16
Total Respondents: 1,298		

Question 5

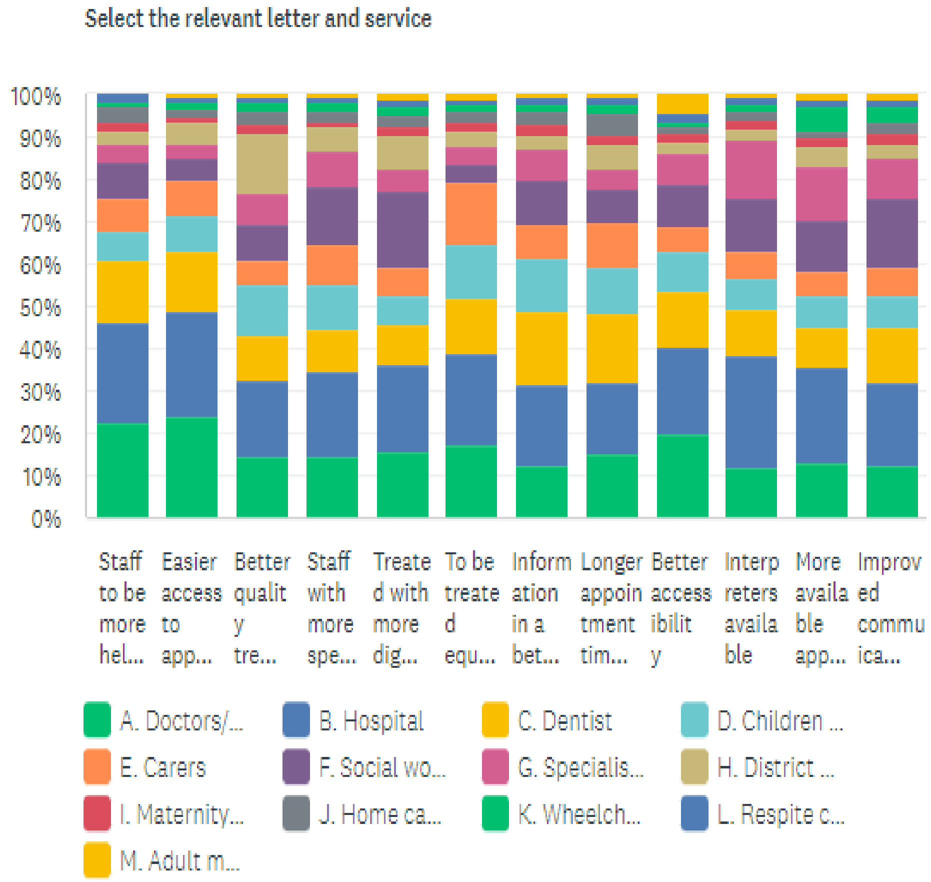
In this question, we asked service users to tell us what they thought needed to be improved for each service. We listed possible improvements, and the service users could select the letter of the service that required improvement the most (see chart below).

In addition to the analysis of this question on page six, another statistic that stood out specifically was the **18.9%** and **17.3%** of votes from people that would like to see the hospital and dental services have information in a better format to help them understand, e.g. large print. This indicates a disadvantage to service users who have a visual impairment. This perhaps links to another stand-out statistic, with **21.7%** of people stating they wish to be treated equally within the hospital service, indicating a possible need for development in equality, diversity and inclusion.

Once again, a fairly large percentage of people (**26.3%**) would also like more interpreters available within hospitals to better support those whose first language is not English.

Select the letter of the service (from question 4) next to the way these services could be improved. For example, if the improvement to the Doctors/GP service is to have better accessibility, then select A next to this improvement. Only select those reasons that apply to you

Answered: 1,298 Skipped: 0

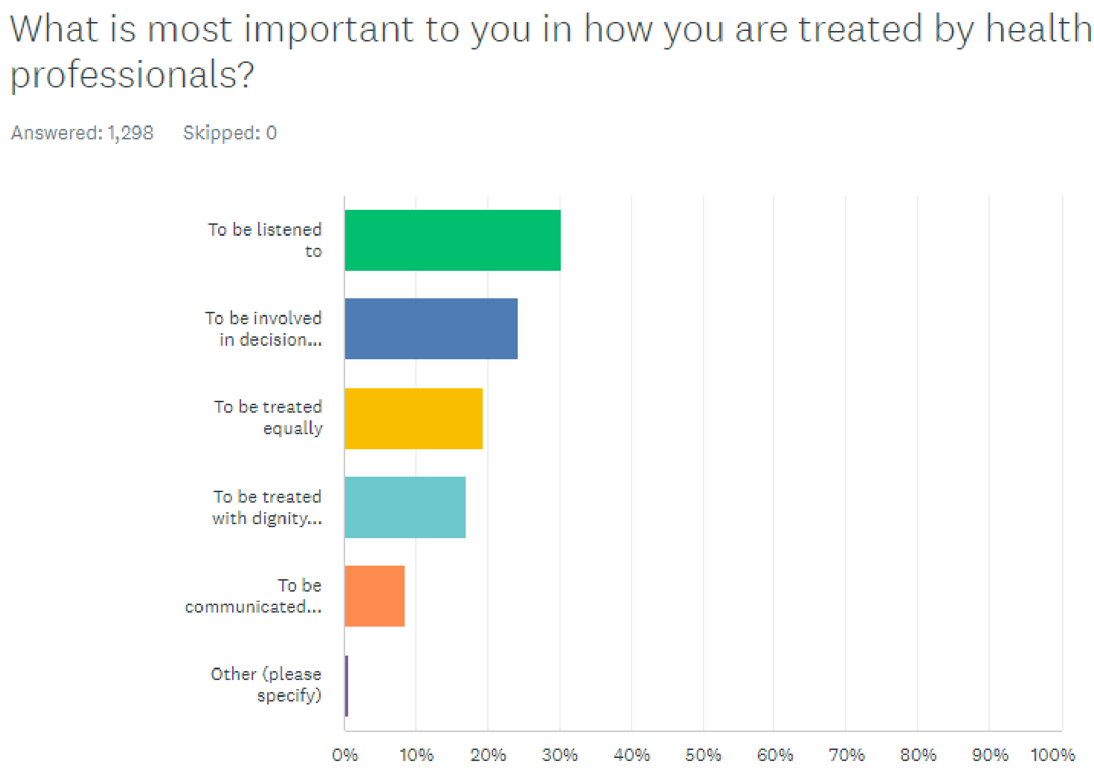


	A. DOCTORS/GP	B. HOSPITAL	C. DENTIST	D. CHILDREN AND ADOLESCENT MENTAL HEALTH SERVICE (CAMHS)	E. CARERS	F. SOCIAL WORKER	G. SPECIALIST SERVICES	H. DISTRICT NURSE	I. MATERNITY SERVICES	J. HOME CARE SERVICES	K. WHEELCHAIR SERVICES	L. RESPITE CARE	M. ADULT MENTAL HEALTH	TOTAL
Staff to be more helpful	22.59% 281	23.95% 298	14.31% 178	6.83% 85	8.12% 101	8.44% 105	4.10% 51	2.97% 37	2.57% 32	3.22% 40	1.21% 15	1.45% 18	0.24% 3	1,244
Easier access to appointments	24.43% 311	24.67% 314	14.30% 182	8.41% 107	8.33% 106	5.34% 68	2.83% 36	5.26% 67	1.41% 18	1.96% 25	1.41% 18	1.18% 15	0.47% 6	1,273
Better quality treatment	14.65% 182	17.79% 221	10.95% 136	11.76% 146	6.04% 75	8.45% 105	7.25% 90	14.01% 174	2.25% 28	2.98% 37	2.09% 26	1.21% 15	0.56% 7	1,242
Staff with more specialist training	14.68% 182	20.24% 251	9.68% 120	10.48% 130	9.92% 123	13.47% 167	8.31% 103	5.73% 71	1.29% 16	2.66% 33	2.02% 25	1.05% 13	0.48% 6	1,240
Treated with more dignity and respect	15.95% 196	20.26% 249	9.68% 119	7.00% 86	6.59% 81	17.90% 220	5.45% 67	7.65% 94	2.36% 29	2.28% 28	2.44% 30	1.63% 20	0.81% 10	1,229
To be treated equally	17.20% 211	21.68% 266	13.12% 161	12.63% 155	14.67% 180	4.24% 52	4.32% 53	3.75% 46	2.28% 28	2.20% 27	1.55% 19	1.39% 17	0.98% 12	1,227
Information in a better format to help you understand, e.g., large print	12.83% 155	18.87% 228	17.30% 209	12.50% 151	8.20% 99	10.10% 122	7.53% 91	3.23% 39	2.57% 31	3.31% 40	1.24% 15	1.57% 19	0.75% 9	1,208
Longer appointment times (for more support time)	15.29% 189	17.07% 211	16.02% 198	11.00% 136	10.60% 131	7.93% 98	4.85% 60	5.83% 72	1.78% 22	5.26% 65	2.02% 25	1.86% 23	0.49% 6	1,236
Better accessibility	19.80% 243	20.86% 256	12.80% 157	9.54% 117	5.87% 72	9.86% 121	7.66% 94	2.53% 31	2.36% 29	1.30% 16	1.30% 16	1.71% 21	4.40% 54	1,227
Interpreters available	12.27% 146	26.30% 313	10.76% 128	7.39% 88	6.39% 76	12.61% 150	13.70% 163	2.61% 31	2.18% 26	2.02% 24	1.51% 18	1.68% 20	0.59% 7	1,190
More available appointments with a Disability Champion	13.37% 162	22.52% 273	9.16% 111	7.59% 92	5.61% 68	12.46% 151	12.46% 151	4.79% 58	2.15% 26	1.57% 19	5.69% 69	1.49% 18	1.16% 14	1,212
Improved communication	12.40% 151	19.46% 237	13.22% 161	7.47% 91	6.90% 84	16.58% 202	9.44% 115	2.71% 33	2.71% 33	3.04% 37	3.20% 39	1.97% 24	0.90% 11	1,218

Question 6

To further understand how service users would like to be supported, we asked what is most important to them in how they are treated by healthcare professionals.

The most selected option was that they wanted **"to be listened to"** with 30.2% of the votes. One person added an additional comment for this question stating that she is not listened to properly by the Doctor' and Dental services. This may be linked to why people voted for longer appointment times for Doctors/GP and Dental services in question four, receiving **15.3%** and **16%** of the votes respectively.



What is most important to you in how you are treated by healthcare professionals?

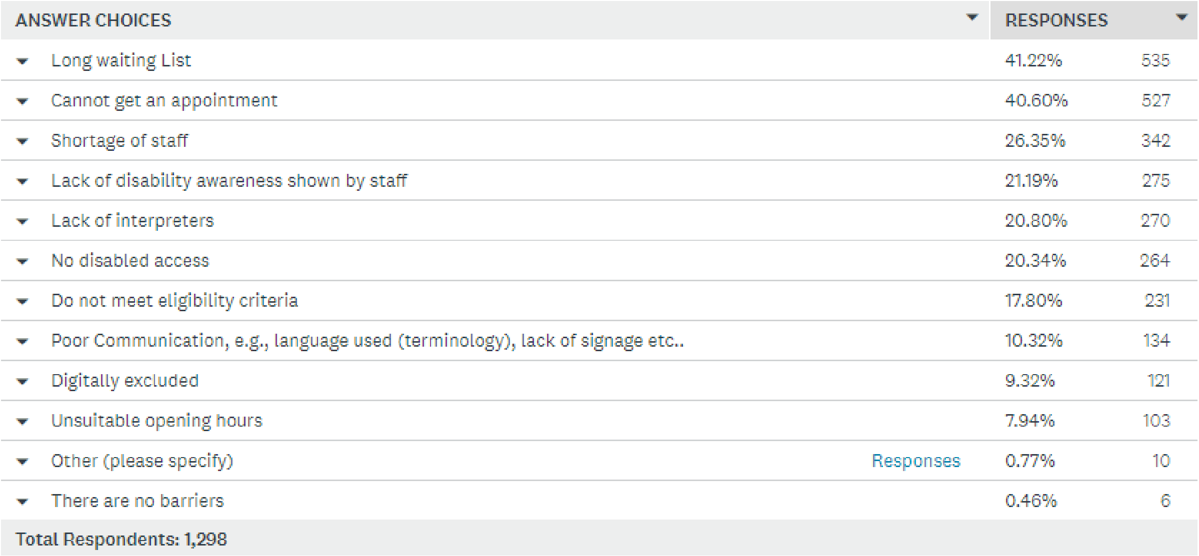
Answered: 1,298 Skipped: 0

Question 7

To consolidate our understanding of questions that focused on issues that stopped people from using healthcare services, we asked them to tell us their biggest barriers to accessing different services.

They were asked to select a maximum of three options. The two most selected options were ‘cannot get an appointment’ (**40.6%**) and ‘long waiting list’ (**41.2%**), which does consolidate service users' frustrations, based on feedback and analysis in previous questions. The third most selected option was ‘a shortage of staff’, which received **26.4%** of the votes.

Other noticeable statistics that stood out were ‘no disabled access’, ‘lack of disability awareness shown by staff’, and ‘lack of interpreters’, which were all selected by over **20%** of respondents. This links to the data highlighted in previous questions. Less than **1%** of service users selected the option, ‘there were no barriers’.



ANSWER CHOICES		RESPONSES	
Long waiting List		41.22%	535
Cannot get an appointment		40.60%	527
Shortage of staff		26.35%	342
Lack of disability awareness shown by staff		21.19%	275
Lack of interpreters		20.80%	270
No disabled access		20.34%	264
Do not meet eligibility criteria		17.80%	231
Poor Communication, e.g., language used (terminology), lack of signage etc..		10.32%	134
Digitally excluded		9.32%	121
Unsuitable opening hours		7.94%	103
Other (please specify)	Responses	0.77%	10
There are no barriers		0.46%	6
Total Respondents: 1,298			

Question 8

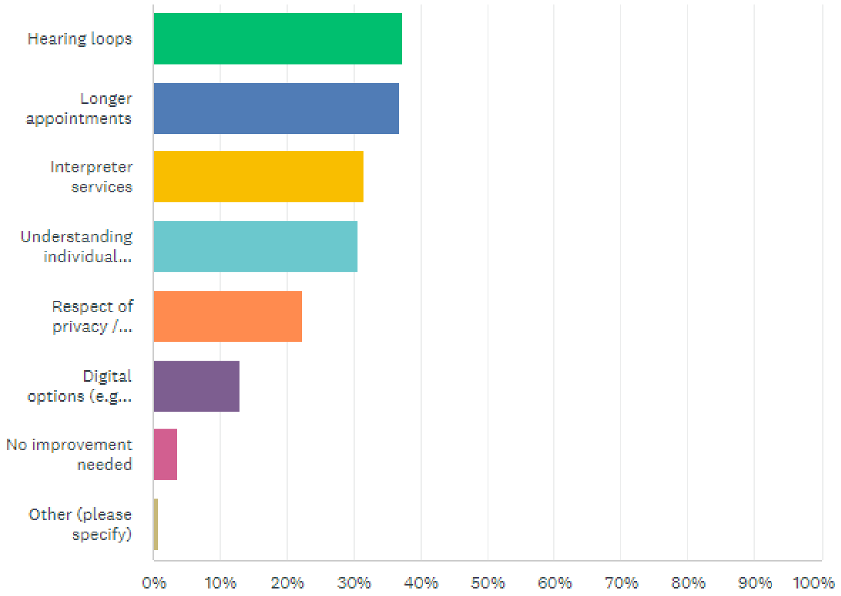
For this question, we wanted to know what possible solutions could be looked at in relation to communication. We asked what can be done better to improve communication with patients, Carers, and relatives.

Respondents could select one or more options, whichever they felt would apply to them. The two most selected options were ‘hearing loops’ (**37.2%**) and, again linking to appointment issues as a reoccurring theme, ‘longer appointment times’ (**37%**). One service user left an additional comment in answer to this question, ***“Not rushing – taking time to explain terminology”.***

Closely following ‘longer appointment times’, was ‘interpreter services’ at **31.6%,** and ‘understanding individual needs’ at **31%**.

What can be done better to improve communication with patients, carers and relatives? (Tick all that apply)

Answered: 1,298   Skipped: 0



Question 9

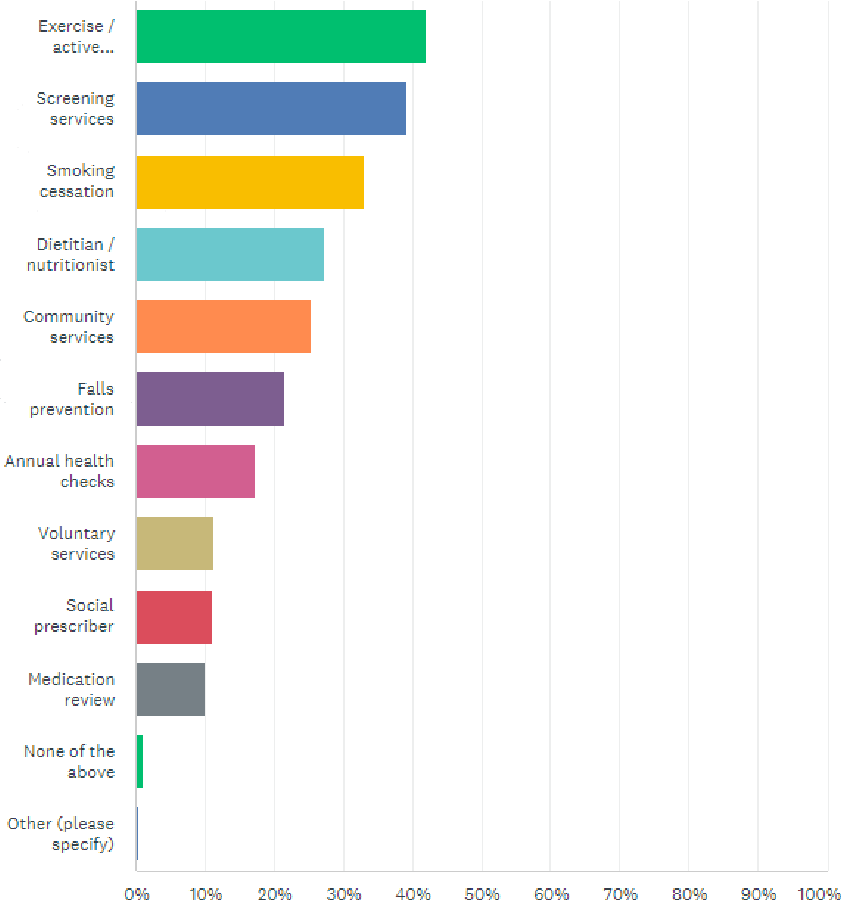
To further explore which services people are aware of that can help prevent a decline in their health and wellbeing, in question 9 we asked people to indicate, from a list of services, which preventative services were known to them.

Respondents could select one or more choices from the list given, and the most well known was 'Exercise / Active Lifestyle' with **42%** of service users choosing this option, closely followed by 'Screening Services' (**39%**) and 'Smoking Cessation' (**33%**). The least well-known preventative service was 'Medication Review' which only **10%** of respondents chose, this was closely followed by 'Social Prescriber' and 'Voluntary Services' (**11%**) each. As Social Prescibers are able to connect people to community groups and statutory services for practical and emotional support, it is concerning that the majority of respondents were unaware of this unique service.

As an additional comment, one service user said, ***''Better and more professional medical services will bring the greatest guarantee to our health'',*** and another said, ***''Some help, any help, would be appreciated''***.

Which services are you aware of that can help prevent a decline in your health and wellbeing? (Tick all that apply)

Answered: 1,298   Skipped: 0



ANSWER CHOICES		RESPONSES	
Exercise / active lifestyle		41.91%	544
Screening services		39.29%	510
Smoking cessation		33.13%	430
Dietitian / nutritionist		27.27%	354
Community services		25.35%	329
Falls prevention		21.57%	280
Annual health checks		17.26%	224
Voluntary services		11.40%	148
Social prescriber		11.17%	145
Medication review		10.09%	131
None of the above		1.16%	15
Other (please specify)	Responses	0.39%	5
Total Respondents: 1,298			

Question 10

People were asked if there were any other comments they would like to include about their experience of health and care services.

Of the many comments given, some were about the support they need now, one service user said, ***"Need to get More mental health support, Autism support, and hard of hearing support, and there is a lack of supported employment to secure permanent employment for disabled people'.*** Another service user was frustrated with the lack of support for their disability, they said, ***"My condition is rare so the doctor knows little about it. I am often left with GPs that make assumptions about my rare genetic disorder based on their medical training x years ago. Medical science has changed since and the way my condition is conceptualised and treated by my consultants is changing all the time. They are blocking my access to a healthy life because they are so out of date"***

Other comments from service users were about lack of communication, ***"Having the stress of getting finance demands to pay towards care because my PIP was increased, given an extra £120 and now they want £400 a month. I'm on universal credit for disability and can't afford this. So now I'm going to have to cancel my care and there is no social worker to help with any of this. Disgusting that no one is communicating with me about this, so I have no option but to cancel the care I need".***

Another service user was very clear about how they feel they are spoken to by healthcare professionals, they said, ***"Not to be spoken to as if you are stupid. Talking over you as you are trying to explain. Dismissing your concern without even listening to you".***

Unfortunately, the majority of comments were negative which is a reflection of the frustrations many service users have experienced when accessing health and care services. A full list of comments received can be found in Appendix B.

Question 11

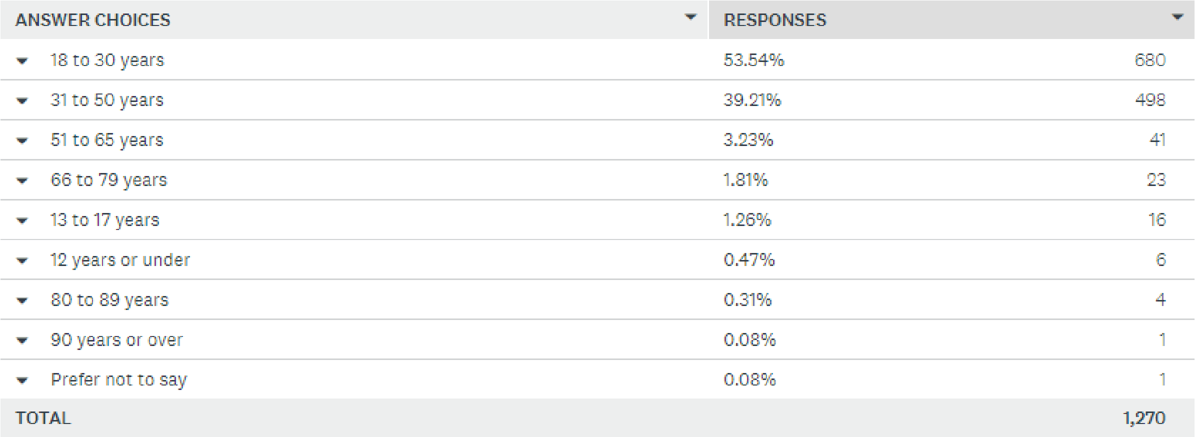
To further explore their experience of health and care services, respondents were asked, following completion of the survey, if they would like to take part in an individual case study and/or focus group.

90% of respondents answered 'yes' to this question which is a staggering response. As we were particularly interested in speaking to individuals who live in areas of high need, a further survey was developed to determine the area individuals resided.

Questions 12 - 17

The remainder of the survey referred to demographic questions such as age, gender, race/ethnicity, religion, location, and whether respondents considered themselves to live with a disability or additional needs. Answers to these questions can be found on page **9-10** of this report under 'Demographics'.

Respondents age

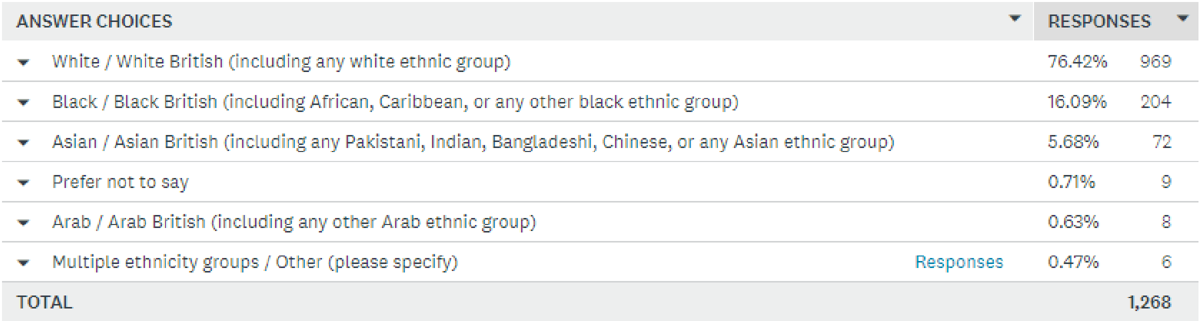


ANSWER CHOICES	RESPONSES	
18 to 30 years	53.54%	680
31 to 50 years	39.21%	498
51 to 65 years	3.23%	41
66 to 79 years	1.81%	23
13 to 17 years	1.26%	16
12 years or under	0.47%	6
80 to 89 years	0.31%	4
90 years or over	0.08%	1
Prefer not to say	0.08%	1
TOTAL		1,270

Respondents gender

ANSWER CHOICES	RESPONSES	
Female	61.88%	784
Male	36.54%	463
Prefer not to say	0.79%	10
Non-binary	0.39%	5
Intersex	0.39%	5
Prefer to self-describe	0.00%	0
TOTAL		1,267

Respondents race/ethnicity



ANSWER CHOICES		RESPONSES	
White / White British (including any white ethnic group)		76.42%	969
Black / Black British (including African, Caribbean, or any other black ethnic group)		16.09%	204
Asian / Asian British (including any Pakistani, Indian, Bangladeshi, Chinese, or any Asian ethnic group)		5.68%	72
Prefer not to say		0.71%	9
Arab / Arab British (including any other Arab ethnic group)		0.63%	8
Multiple ethnicity groups / Other (please specify)	Responses	0.47%	6
TOTAL			1,268

Respondents religion

ANSWER CHOICES		RESPONSES	
Christian (including Catholic, Protestant and all other Christian denominations)		79.10%	999
No religion		10.29%	130
Hindu		6.10%	77
Jewish		1.74%	22
Muslim		1.27%	16
Buddhist		0.95%	12
Sikh		0.40%	5
Other (please specify)	Responses	0.16%	2
TOTAL			1,263

Respondents living with a disability or additional need

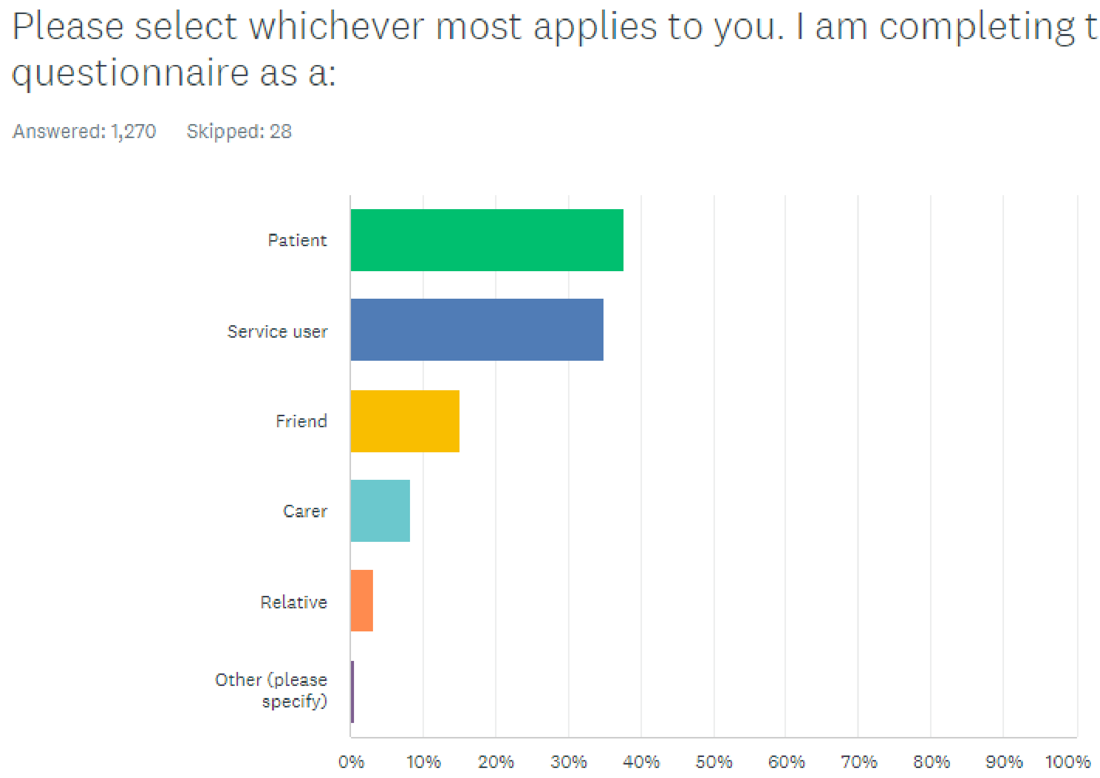
ANSWER CHOICES	RESPONSES	
Yes	54.76%	690
No	34.37%	433
Prefer not to say	10.87%	137
TOTAL		1,260

Respondents area they live in

ANSWER CHOICES	RESPONSES	
Bedfordshire	61.56%	780
Luton	26.12%	331
Milton Keynes	11.76%	149
None of the above	0.55%	7
TOTAL		1,267

Question 18

To get an indication of whether the service user, a patient, Carer, friend or a relative had completed the survey we asked respondents to select their answer from the list given. Results showed that the majority of respondents considered themselves a patient (**38%**) or a service user (**35%**) when completing the survey. Only **15%** described themselves as a 'friend' who was completing on behalf of a patient or service user, **8%** considered themselves a Carer and **3%** a relative.



Please select whichever most applies to you. I am completing this questionnaire as a:

Answered: 1,270 Skipped: 28

Conclusion

We received a very good response to the survey which provided a wealth of quality feedback from service users, patients, Carers and their family members who access health and social care services.

Many additional comments were provided in answer to the set questions, with some of them being highlighted throughout this report. It clearly shows the depth of feeling particularly for those that are unhappy with service provision.

From the responses received, the main issue that needs to be addressed is the need for an easier booking process for Doctors/GP services, and longer appointment times, which is unsurprising. However, evidence can also be seen of health inequalities for those that may be disproportionately impacted due to a physical and/or learning disability. For example, the Deaf community need 'face to face' appointments with their GP, and hospital consultants, but are struggling to do so due to the current appointment systems and the impact of long waiting lists. In addition, the majority of people would like to see more Interpreters available in GP and hospital settings to help support them, and to be able to more easily secure an appointment with a Disability Champion.

Another barrier to service provision highlighted within the survey, in addition to securing an appointment and lack of Interpreters, was the lack of disabled access to premises. Clearly, this only has a major impact on people with a physical disability and may not affect, or even be a consideration for the able-bodied, but it is preventing disabled people from accessing the services they need.

In addition, evidence showed that service users were unhappy with how they are treated by healthcare professionals, highlighting the importance of being listened to, and always being involved in decision-making. A key requirement was to be treated equally, and therefore to vastly reduce health inequalities, this needs to be a priority for all commissioners and providers of healthcare services. In conclusion, the majority of people would like to experience more understanding of their individual needs when accessing health and care services, to improve services and better meet the expectations of people across BLMK.

Next Steps

Those respondents who indicated they would like to take part in a more in-depth focus group or individual case study, were sent an additional survey to determine the specific area of Bedfordshire, Luton or Milton Keynes (BLMK) they lived in. Selection for the focus groups and individual studies will be based on whether they live in areas of high deprivation across BLMK. All participants who agree and are chosen to take part will be offered a £25 gift voucher. We intend to hold the focus groups and individual interviews in January 2023, and a further report will be produced showing the results of their experience.

From the initial survey results given in this report, follow-up actions need to be discussed by key stakeholders to address the health inequalities highlighted and to prevent people from being disproportionately impacted due to a physical and/or learning disability.

Initial feedback suggest further consideration should be given to the following areas:

Interpreters - Hospitals Trusts to urgently review the provision of Interpreters within the Trust to determine quantity and availability to ensure patients' needs are catered for. In addition, all service providers to comply with Accessible Information Standards (AIS) to ensure that nterpreters are readily available, and to be more proactive in ensuring they are available when and where required, for as long as required. Better access to Interpreters would increase a Deaf person's confidence, and reduce anxiety before and during an appointment with a health and/or social care professional.

Disability Champions – Healthcare professionals to receive training and guidance to understand the role of a Disability Champion and be prepared to offer more appointments to service users who may benefit from this service.

Healthcare Professionals – training and recruitment to include 'listening to patients/service users' to better understand their needs and to make adjustments where necessary to enable better access to services.

Hearing Loops – installed across all healthcare establishments.

Disability Access – urgent review of **all** healthcare premises to ensure disability access is available at all times.

Industry-wide marketing campaign - to raise awareness for more self-care/self-management and the availability of support services or preventative services available to the public.

Thank You

Healthwatch Central Bedfordshire (HWCB), The Disability Resource Centre (DRC) and Community Dental Services (CDS CIC) would like to thank all the residents who took the time to complete the survey, and who took part in a focus group, or more in-depth case study, to share details of their experience of accessing health and care services.

We would also like to thank our colleagues from the Denny Review who commissioned this project and for their continued support throughout the process.

Organisations involved:

Healthwatch Central Bedfordshire (HWCB) are part of a network which aims to ensure that the views and feedback from patients and carers are an integral part of the design and delivery of local services.

Healthwatch Central Bedfordshire is the local consumer champion promoting choice and influencing the provision of high-quality health, social care and wellbeing services for all across Central Bedfordshire. We are independent, professional and the voice of local people.

The Disability Resource Centre (DRC) is a charity led by people with lived experience that has those affected by health and disability at the centre of its decision-making. Their vision is to empower people of all ages with pan-disability, health conditions, mental ill-health and carers to fulfil their potential and aspirations. The cornerstones to the services are professional, emotional and practical support including information and advice, equipment, training, employment support, wellbeing, and personalisation services

Community Dental Services CIC (CDS CIC) is an employee-owned social enterprise delivering special care, paediatric dentistry and Oral Health improvement across Bedfordshire, Essex, Norfolk, Waveney, Lincolnshire, Leicestershire, Nottinghamshire, Derbyshire, Oxfordshire and in Her Majesty's Prison services in Norfolk, Suffolk and Hertfordshire.

We are a referral only specialist dental service, bringing dental care to people who cannot be treated in general dental practice; including patients who have learning disabilities, mental health, or are in situations or locations that traditional dental services cannot reach. Our social purpose is to *'improve oral health in evermore communities'* we serve.

Appendix A

- Survey questions

1. **What health and social care services do you / have you used? (Please tick all that apply)**

☐ Doctors/GP
☐ Hospital
☐ Dentist
☐ CAMHS
☐ Carers
☐ Social worker
☐ Specialist services
☐ Adult mental health
☐ District nurse
☐ Maternity services
☐ Home care services
☐ Wheelchair services
☐ Respite care
☐ Other (please specify) ....

2. **Do you know which other Health and care services are available to you?**

☐ Yes ☐ No

If you answered yes to this question, please give an example:

....

3. **What specific services work well for you, e.g., GP surgery? (List all that apply)**

☐ Doctor/GP
☐ Hospital
☐ Dentist
☐ CAMHS
☐ Carers
☐ Social worker
☐ Specialist services
☐ Adult mental health
☐ District nurse
☐ Maternity services
☐ Home care services
☐ Wheelchair services
☐ Respite care
☐ Other (please specify) ....

4. What specific services *do not* work well for you (List all that apply)

☐ Doctor/GP
☐ Hospital
☐ Dentist
☐ CAMHS
☐ Carers
☐ Social worker
☐ Specialist services
☐ Adult mental health
☐ District nurse
☐ Maternity services
☐ Home care services
☐ Wheelchair services
☐ Respite care
☐ Other (please specify) ....

5. Select the letter of the service (from question 4) next to the way these services could be improved. For example, if the improvement to the Doctors/GP service is to have better accessibility, then select A next to this improvement. Only select those reasons that apply to you

☐ Staff to be more helpful
☐ Easier access to appointments
☐ Better quality treatment
☐ Staff with more specialist training
☐ Treated with more dignity and respect
☐ To be treated equally
☐ Information in a better format to help you understand, e.g., large print
☐ Longer appointment times (for more support time)
☐ Better accessibility
☐ Interpreters available
☐ More available appointments with a Disability Champion
☐ Improved communication
☐ Other (please specify) ....

6. **What is *most* important to you in how you are treated by healthcare professionals? (Please tick all that apply)**

☐ to be listened to
☐ to be involved in decision making
☐ to be treated equally
☐ to be treated with dignity and respect.
☐ to be communicated with in a way that suits me
☐ Other (please specify) ....

7. **What are the biggest barriers to you accessing different services? (Select up to 3 options)**

☐ Cannot get an appointment
☐ Shortage of staff
☐ Long Waiting List
☐ No Disabled Access
☐ Lack of Disability Awareness Shown by Staff
☐ Unsuitable Opening Hours
☐ Digitally Excluded
☐ Do Not Meet Eligibility Criteria
☐ Lack of Interpreters
☐ Poor Communication, e.g., language used (terminology), lack of signage etc.
☐ Other (please specify) ....

8. **What can be done better to improve communication with patients, carers and relatives? (Tick all that apply)**

☐ Hearing loops
☐ Interpreter services
☐ Longer appointment
☐ Respect of privacy / Confidentiality
☐ Digital options (e.g., text message, video conferencing)
☐ Understanding individual needs
☐ No improvement needed
☐ Other (please specify) ....

9. **Which services are you aware of that can help prevent a decline in your health and wellbeing? (Tick all that apply)**

☐ Screening services
☐ Smoking cessation
☐ Exercise / active lifestyle
☐ Dietitian / nutritionist
☐ Community services
☐ Voluntary services
☐ Social prescriber
☐ Falls prevention
☐ Annual health checks
☐ Medication review
☐ Other, please state ....

10. **Are there any other comments you would like to include about your experience of health and care services?**

....

....

11. **Would you like to take part in a case study and / or a focus group to share further details of your experience?**

Name: ....

Email: ....

ABOUT YOU (only add service user details):

12. **What is your age category?**

☐ 12 years or under
☐ 13 to 17 years
☐ 18 to 30 years
☐ 31 to 50 years
☐ 51 to 65 years
☐ 66 to 79 years
☐ 80 to 89 years
☐ 90 + years
☐ Prefer not to say

13. **How would you describe your gender?**

☐ Female
☐ Male
☐ Non-binary
☐ Intersex
☐ Prefer not to say
☐ Prefer to self-describe
☐ Self-description: ....

14. Which race/ethnicity best describes you?

☐ White / White British (including any white ethnic group)
☐ Black / Black British (including African, Caribbean, or any other black ethnic group)
☐ Asian / Asian British (including any Pakistani, Indian, Bangladeshi, Chinese, or any Asian ethnic group)
☐ Arab / Arab British (including any other Arab ethnic group)
☐ Prefer not to say
☐ Multiple ethnicity groups / Other (please specify) ……………………………………………

15. Select which best describes your religion?

☐ Christian (including Catholic, Protestant and all other Christian denominations)
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Buddhist
☐ No religion
☐ Other (please specify) ……………………………………………

16. Do you consider yourself to live with a disability or additional needs?

☐ Yes

☐ No

☐ Prefer not to say

17. Please select whichever most applies to you. I am completing this questionnaire as a:

☐ Service user ☐ Patient ☐ Carer ☐ Friend ☐ Relative
☐ Other (please specify) ……………………………………………

Thank you for taking part in this survey

Appendix B

- Comments

Withdrawal of services for the disabled will not be continued as private treatment is very expensive, as little or no disposable income/ cash

Be sure to go to a regular hospital

Make sure you choose the hospital you usually go to

Better and more professional medical services will bring the greatest guarantee to our health

I feel it is necessary to choose a more appropriate way to communicate with patients in a variety of ways

Dentist services (teeth pulling, over 2 years wait) is dire. GP access is awful. Hospital wait time (6 months for neurologist) is a joke

When there was cut backs, I was left stranded with no support with my father back in 2015. The social workers were quite rude & difficult to deal with. It was impossible to get a social worker order assigned, an agency social worker visited my father on one occasion in a care home, he was unable to communicate his needs. It appeared to be a tick exercise, to show action was done. He died in 2019 from bladder cancer. The hospital did Not seem to ask why he was ill and sent us on a wild goose chase. The care system is broken. The worrying aspect younger staff make decisions which are incorrect because of lack of experience & double checked by senior staff.

It's extremely difficult to get appointments with all services within a timely manner.

Some help any help would be greatly appreciated

Respite care facilities are too few and too costly. I am in my 80 s and sole carer for my disabled husband. I receive Â£80 per month carers allowance. 1 week respite care will cost me £900+!!!

Show compassion to individuals really choose the most appropriate support.

Insufficient care at present for my daughter who has been suffering with knee pain for over a year now. She has had a ultrasound scan and MRI and a Bakers Cyst was found she can hardly walk now due to healthcare professionals not deciding on the next plan of action.

My condition is rare so the doctor knows little about it. I am often left with GPs that make assumptions about my rare genetic disorder based on their medical training x years ago. Medical science has changed since and the way my condition is conceptualised and treated by mu consultants is changing all the time. They are blocking my access to a healthy life because they are so out of date

My husband and I have repeatedly been let down by social services. Hospital communication needs significant improvement for those with dementia. There needs to be closer communication between professionals, for people who live in Central Beds but whose GP is in Buckinghamshire and whose nearest hospital is L&D, or other cross county issues.

Contacting and gaining an appointment with a GP is beyond a joke. This results in us having to visit hospital more with minor issues.

Need patient contact in GP to diagnose illness or injuries

All health care and hospitals communicate with each another

More alternative treatments and easier access to living requirements.

Lack of social care, support & facilities, signposting etc in Dunstable area.

Having the stress of getting finance demands to pay towards care because my PIP was increased, given an extra £120 and now they want £400 a month. I'm on universal credit for disability and can't afford this. So now I'm going to have to cancel my care and there is no social worker to help with any of this. Disgusting that none is communicating with me about so no option but to cancel the care I need

Quicker, referrals when advised by professionals and able to get to see or speak to doctor to enable this.

GP appointments need to be easier to arrange and more admin staff to actually answer the phone instead of long waits to get through with irritating music to listen to.

I would like to see mature reception staff who listen well and experience.

Need to get More Mental Health Support and need to get Autism Support and Hard of Hearing Support and lack of Supported Employment for secure Permanent Employment for Disabled People which I am now on Zero Hours Contract while on Universal Credit insecure employment and thinking moving to Scotland or Republic of Ireland because they got stronger worker employment rights up there in these countries compared to East of England

My GP seems to rely on 111 to screen patients and arrange appointments. Also I am deaf so they don't seem to understand that a phone appointment is useless, I need face to face but cannot get this

Need more long term support for CFS / ME patients and more understanding when having appointments with this condition

Lack of thorough overall review during year following stroke

Have not had very good communication between social workers and my family

Train staff to be more friendly and mainly improve customer service as we are human as well.

Lack of duty of care

I have a great doctors surgery that go out of their way to help my handicapped daughter. Sadly once seen by the doctor it takes months for a hospital appointment even phoning the surgery to find out why.

Not to spoken to as if you are stupid. Talking over you as you are trying to explain. Dismissing you concern without even listening to you

More help for autism children

Just to say that the Surgeries need to employ and train people properly for their jobs. To make front of house staff more friendly, helpful and knowledgeable. I accept that the Surgeries are under a lot of pressure but so are the patients who are trying to access their services.

Please add disability transport services (bus drivers and escorts) to the list

Stop using medical jargon and treat people according to their individual needs.

They need to more diverse

They seem to be disjointed with different communication systems ie electronic records and the information is often not shared between the different services involved with the same patient.

Have to continually remind staff that a hoist is required

Haematology at L&D is frustrating I am changing hospitals to the one where I am at Uni.

Being told that there are NO appointments after having been waiting on the phone for a long time

Generally all health practitioners do their best to be helpful. However, you can hear in their voices how frustrated they are with the limitations put upon them, due to lack of staff or other resources.

Mental Health Services were very challenging. Different healthcare professionals, so no continuity.

COMMUNITY ACTION: MK

Community Action: MK Research Project for the Denny Review
Final Report
December 2022

Contents

Background and Introduction

Following the initial phase of Denny Review research across Beds, Luton and Milton Keynes (BLMK), Community Action: MK were commissioned to undertake engagement at Place level (Milton Keynes) to find out more about the reasons why the communities identified in the Denny Review face such health inequality, and begin to explore what could be done to address this.

The initial phase of the Denny Review was a rapid evidence review to improve understanding of health inequalities in communities within BLMK and identify good practices to address them. The evidence collected confirmed that the communities most affected by health inequalities in BLMK include ethnic minority groups, including Gypsy, Roma, and Traveller communities, people living in deprived neighbourhoods, people with disability, and people experiencing homelessness, migrants, and people who are LGBTQ+. These groups experience health inequalities from unfair distribution and the impact of wider determinants of health to access health care services.

As the local Infrastructure Organisation in MK, we have strong relationships with a range of voluntary, community and social enterprise (VCSE) sector organisations working across the City at grassroots level. We know these organisations possess a great deal of knowledge about the challenges the people they work with face, as well as the ideas the communities they support have around solutions. Grassroots VCSE groups are often uniquely placed to gather such insight, and this research aimed to ensure this information was collected and used within the Denny Review.

Community Action: MK identified key groups working within the communities of focus, and arranged one to one interviews with them to talk in detail about the health inequality the people they work with experience. The information we gathered helps to create a clearer picture of the specific challenges faced by each group and enables us to identify some tailored solutions based on real community needs and lived experience.

Below is a summary of the findings, followed by more detailed information from the interviews broken down by community, recommendations for future work to address health inequality in MK and the actions we have taken as a result of the research.

The information gathered from the VCSE groups we spoke to was fascinating and insightful, and really helps us to understand why the health inequality we see in some communities exists. It also uncovers some really practical steps that could be taken to address some of the issues faced, in the short, medium and long term. It offers health providers the opportunity to take action that will start to reduce health inequality, focusing not only on how to improve access to services, but also how services need to change so they are appropriate for all groups of people. As one VCSE group simply put it, “If services are designed for the mainstream, they won’t work for people that sit outside of that and unless this changes those groups of people will continue to experience health inequality.”

Summary of Recommendations

The research produced a set of recommendations relating to each population group. Although the details of many of the recommendations are specific to individual communities, they fall within three categories:

1) Adapting services and spaces to be appropriate and accessible (Reasonable Adjustments), and Service Gaps

Many of the recommendations outlined in our report relate to making reasonable adjustments to existing services so they are appropriate, welcoming and accessible to the communities this research focused on. Many of these adjustments would be relatively quick and easy to implement. The report also highlights some of the gaps in health services experienced by the communities of focus, and highlights what additional services would help reduce health inequalities within the population groups that experience them the most.

- Some examples of desired reasonable adjustments we heard included:
    - Providing a comfortable waiting area for people with autism that have sensory sensitivities (dimmer lighting, less noise and crowds etc)
    - Providing alternative ways to make appointments for those who cannot c early morning phone calls etc
    - Ensuring patients within certain communities are supported to understand the information / medication they are given within health appointments by providing a written summary, a post appointment 'de-brief' (perhaps via a staff 'champion') and by being given time and encouragement to ask questions within their appointment).

- Some examples of gaps in service that need to be filled included:
    - Need for much more advocacy support across a range of communities
    - Specialist support needed for people with autism around eating disorders
    - More outreach health workers and taking services (eg vaccinations) into certain communities / community hubs is required
    - Need for more 'in home' support to combat social isolation and provide practical assistance (like that provided by Homestart and to support people with learning disabilities and other disabilities etc)

2) Training, education and increasing awareness

Many of the recommendations outlined in our report relate to training for health providers that would support them to increase their awareness of cultures, needs and conditions relating to the focus population groups. It is important that the content of any training be co-produced and informed by members of the focus communities.

- Some examples of training topics included:
    - Terminology and pronouns relating to members of the LGBTQ+ community
    - Understanding of different cultural norms and needs relating to some ethnic minority groups
    - Understanding of autism and neurodiversity, physical disability, mental health conditions and learning disability (eg ensuring 'do not resuscitate' isn't wrongly applied to some people in hospital with learning disabilities, understanding the specific needs and challenges relating to certain mental health conditions and recognising the difference between neurodiversity and personality disorders)
    - Understanding of the communication needs and challenges relating to some communities

3) Communication / information

Many of the recommendations outlined in our report relate to changes and improvements around communication and the presentation of information.

- Some examples of recommendations relating to communication include:

        - Co-producing communication materials with the focus communities so they are culturally appropriate and accessible
        - Ensuring the communication needs of each individual are explored and logged (eg for those with hearing or sight impairment, learning disabilities or autism)
        - More opportunities for community members to express their needs, challenges and ideas to health providers
        - More time given in appointments to people with certain needs and /or from certain cultures
        - Greater availability of translators

Summary of Common Themes

Although the experience of, and reasons for health inequality are different within each of the focus communities, there were some common themes across many of the groups we spoke to. These were:

- **Cultural Competency**
    - The lack of understanding of different cultures was raised as a big issue that impacts health inequality as services provided are often not appropriate or welcoming for all communities.
    - The needs and norms of different ethnic minority or faith groups are not always known or considered by health professionals / services.
    - Terms and experiences relating to the LGBTQ+ community are not always known or considered by health professionals / services.
    - Specific training for health providers was recommended, as well as adjustments to make services more appropriate.

- **Advocacy**
    - The need for and lack of advocacy services was something that came up again and again across a range of groups, including people with physical disabilities, people with autism and neurodiverse conditions, people with mental ill health and people with learning disabilities.

- **Lack of proper understanding of conditions and needs**
    - Many groups reported instances of their service users' health needs not being understood by health professionals, including autism and neurodiversity, physical and learning disabilities and mental illnesses (for example autism being misdiagnosed for personality disorders, mental health issues 'shadowing' other illnesses and benefit assessors lacking sometimes basic knowledge relating to disability).
    - More training on key needs and conditions recommended to decrease inequality.

- **Food and healthy eating**

    - Diet and food was something that came up across a range of groups as causing health issues.
    - Tailoring diet advice depending on foods eaten within different communities is needed to make it accessible.
    - Understanding of the complex relationship with food that people with autism can have is needed, and bespoke services are required as eating disorders and unhealthy eating are extremely common in this group, and mainstream services do not effectively support.
    - Management of weight, diet and diabetes needs intensive support within the learning disabled community.

- **Accessibility**
    - Transport was a big issue amongst many of the groups we spoke to preventing people from accessing health services
    - Environments and processes within some health services are not suitable for some people (eg people with autism because of noise, bright lighting, crowds etc, those with disabilities because of long waiting times that cannot be endured with some disabilities, or ambulances not being able to accommodates individuals' wheelchairs and roadside Gypsy, Roma and Traveller community members not being able to access same day appointments before they move on).
    - Fear of discrimination or being made to feel uncomfortable is a barrier for some in terms of accessing health services (eg within LGBTQ+ and Gyspsy, Roma and Traveller communities).
    - The process for booking GP appointments is difficult or impossible for many of the people the groups we spoke to work with (early morning telephone calls, online bookings etc)
    - We heard that for many of the members of the communities of focus, accessing healthcare has a negative impact on their health - causing extreme anxiety and stress. Processes need to change to prevent this.
    - The need for services to go out to where people are more often was recommended time and again across most of the focus communities.
    - Affordability of healthy choices or activities (eg food, wellness activities, transport to activities)
    - Dental and mental health support are hard to access.

- **Lack of bespoke services**
    - Many groups highlighted the need for services to be tailored in order to be effective for individuals and communities.
    - Recognition that this is difficult, but is absolutely key if we want to reduce the inequalities faced by the communities highlighted in this research.
    - Impersonal, quick and/or virtual/phone appointments and services are just not suitable for many people that need more time to process information, understand, build trust and communicate etc.

- **The need for lived experience to steer services**

    - The groups we spoke to told us that in order to ensure health services are accessible and effective for communities, members of those communities need to be enabled to feed in their lived experience, express the barriers they face and work with health providers to design solutions and amended services.
    - VCSE groups that work at grassroots level can facilitate some of this work if supported to do so.
    - Feedback needs to go somewhere and when communities give their time and knowledge, they need to hear back about the impact it has had. Circular communication and equal partnerships between health services asking for input and people with lived experience need to be set up.

- **Opportunities for prevention work and early support**
    - Throughout the research, opportunities to prevent ill health are highlighted. This work would mean that pressure on health services are reduced in the long run.
    - The importance of supporting people as early as possible was highlighted (whether this is by managing diabetes, early counselling for refugees that have experienced trauma, or by creating an understanding and culture of healthy living in creative ways that are meaningful to different communities).
    - The need for long term relationships to be formed within communities to build trust, tackle barriers, address wider determinants of health and increase confidence to take action on solutions is required. This means long term, embedded community development work.

- **Communication**
    - Communication was a big issue across focus communities and ranged from language barriers, methods of communications being inaccessible, medical terms causing confusion, difficulty speaking to health professionals and a lack of access to information. Extreme situations such as giving birth on floor and 'do not resuscitate' measure nearly being wrongly imposed are examples of the dangers of miscommunication (see below),
    - The need to adapt communication depending on the individual was highlighted.
    - Communication is complex and sometimes people from different cultures need to be communicated and cared for in specific ways to feel comfortable.
    - Some people process information differently, so need to receive information differently.
    - Information is not reaching all communities, so people do not know what services are on offer (eg migrants, some ethnic minority groups and Gypsy Roma and Traveller communities)
    - Digital and written communications aren't right for everyone.

Autism and Neurodiversity- Detailed Report

The main VCSE groups we spoke to that specialise in support relating to autism and neurodiverse conditions were Talkback and Talent Unlimited. We also had some input from MK Centre for Integrated Living and the Disability Resource Centre, as well as drawing on information within the CA:MK Team from their experience of working with VCSE groups that support autistic and neurodiverse people, and the information that has been added to the MK Community Data Tool.

Talent Unlimited provides a safe place for autistic adults to socialise, share and develop their skills. They also market what users produce through their website.
Talkback aims to improve the lives of autistic individuals and those with a learning disability by giving them the tools to thrive through a range of services. They provide the opportunity for continued personal development, help build meaningful friendships and create the confidence to embrace new experiences.

Communication

A lack of face to face GP services is an issue as we learned that people with autism often prefer these to virtual appointments and they often don't like to speak on the phone or via automated systems. Unexpected phone calls are also particularly stressful for some people with autism and sleep patterns can be different.

"For some people with autism, 8am can feel very early, so having to call GP surgeries at 8am to get an appointment is impractical and excludes them. This shouldn't be the only way to get appointments as it is in many surgeries" ***- Talent Unlimited***

Also, some people are not comfortable discussing or disclosing their autism diagnosis on the phone in front of people they live with. All of this can mean they avoid making the phone call and do not seek medical attention when they need it. It was suggested that PCN's could have an autism champion that manages the communications with the autistic clients e.g. emails and phone calls and has dedicated time to meet individuals at the door and undertake a debrief of their appointment after speaking with the GP.

"Citizens Advice MK have set up a vulnerable persons helpline - can there be an autism champion within these networks who can speak directly with individuals, as well as avoiding having to use automated systems?" ***- Talkback***

It is important that people with autism are supported to communicate effectively when attending health services, in terms of being understood and understanding the information being given. We were told that it's often beneficial if people with autism have advocates in health appointments with them, and the right to take a trusted person with you to appointments should be promoted.

"Visiting the Doctor can create anxiety due to not wanting to 'feel stupid' in front of a GP by asking 'silly' questions" ***- Talkback***

We were told that often individuals with autism can feel intimidated by medical professionals, and lack the self esteem or confidence to ask questions.

> *“Not asking questions during the appointment can lead to individuals ‘beating themselves up’ when they get home as they feel they should have asked questions, when they get home and don't know what their new medication is for, for example.”* ***- Talkback***

We were advised that providing honest answers and not just saying what they think the Doctor wants to hear requires trust between the individual with autism and the professional. Processing information can also take longer for people with autism, so conversations and appointments will take longer than those for people without autism. Working with health providers to allow people with autism the time to ask questions would be beneficial, as would specialist training for GPs, receptionists and other health providers around autism and how to make services more accessible, welcoming and helpful.

> *“Health professionals should understand that their patient has autism and may only process information after the appointment. Therefore, staff should simplify language, take time when speaking, be mindful of tone of voice and allow the patient in the room the chance to understand. Having the ‘whys’ and ‘because’ conversations during appointments are important”* ***- Talkback***

If GPs and other health providers had a system that made them aware the patient they were calling or seeing was autistic, this could be helpful. It was also suggested that communication preferences should be gathered and noted, or asked to the individual by receptionists, GPs etc.

> *“If GPs had an electronic system that flagged up if a person is autistic, and if information has been collected and noted on the ways that individual prefers to be communicated with, they could tailor their approach accordingly.”* ***- Talent Unlimited***

We were told that people with autism often have difficulty remembering and processing spoken information in a medical appointment. Having a written summary to take away with them would be very helpful. We learned that online communications of health messages can be effective for many people with autism, but websites need to be simplified otherwise some people with autism will become frustrated and give up. Written information must be accessible. Talkback says that health information is welcomed, but it needs to be in an easy to understand format that is not off-putting for people with autism. Consultation with individuals about what information they already access and what information they would like to access would be beneficial - along with discussions around putting health advice into practice.

"Providing easy read information as Mencap recommends would help to increase people with autism's confidence with medical services. So a letter with a picture of a clock and calendar to communicate the appointment time for example. Paragraph after paragraph is not appropriate. The National autistic Society has an easy to read website version. Can this model be used for health information? " ***- Talkback***

Medical communications can be ignored due to lack of understanding by some people with autism, for example not following up on a Doctor's letter, or for other reasons.

"They need to be more lenient with the '3 strikes and you're out' rules when it comes to not responding to appointment letters etc. - reach out to people as things may be going on. Reminders, texts etc can also be useful." ***- Talkback***

We were told it is important that commitments are kept with people with autism, otherwise this can cause a lot of stress.

"Delivering on what we say we'll do goes a long way - e.g. ensuring you contact someone with autism when you say you will. Autistic minds can be very literal. The anxiety caused by not receiving a call when expected could negatively affect someone with autism for the whole day" ***- Talkback***

A single 'place' where all autism related resources are available in MK (not restricted to but including health) was suggested as something that would be really useful. This could include support options, services, information about autism etc. Currently everything is separate and difficult to find.

Accessibility

Transport is an issue for some people with autism and often there is limited access to community transport. We were told that some specialist appointments given outside of MK, for example in Oxford, are often impractical. In many cases individuals do not meet the criteria for community transport initiatives (e.g. dial a ride) but still have difficulties accessing appointments.

"If health specialists could come to MK and see all people with transport issues on a designated day in a dedicated clinic that would help to solve the problem." ***- Talent Unlimited***

Using a taxi service to travel to the medical appointments can cause anxiety for some autistic people as they may not want to speak to a stranger at the taxi company or will be very worried about the taxi being late.

“Providing arranged transport for people that need it in order to attend the appointment would be great. Let's do everything we can to empower people to get to their appointment” ***- Talkback***

We were told that for some people with autism, medical environments, particularly waiting rooms within health centres, hospitals and other health care settings are unsuitable for them due to sensory sensitivity. A large, bright, busy, noisy room is difficult for some people with autism to tolerate, and they may be put off going back for further support with their health, or from attending appointments in the first place. A small quiet room with adjustable lighting for people with sensory sensitivities would help with this.

“A person with autism was restrained in A&E because she couldn’t cope with the waiting room. She told us all she needed was a broom cupboard to reduce the sensitivities” ***- Talkback***

Measures to reduce the stress experienced by some people with autism when attending medical appointments would be welcomed by Talkback.

“Can reception staff meet people before they walk into the GP surgeries perhaps.” ***- Talkback***

Lack of understanding of autism and neurodiversity

It is felt that often GP receptionists lack understanding of autism, and can ‘block’ appointments.

We were told that autism is sometimes mis-diagnosed and mistaken for a personality disorder. In other cases patients have been told they are too old to be diagnosed with autism. More training to healthcare providers to increase understanding of autism was recommended.

“It all comes down to understanding and education of professionals. Seeing each person as an individual.” ***- Talent Unlimited***

Talent Unlimited’s current avenues to express issues and lived experience of their beneficiaries is the MK Mental Health Alliance and CA:MK. They used to have the Health Partnership, but this is no longer operational.

"There are good signs in mental health services that these messages are getting across - whether that filters down to the GPs? It's very varied." ***- Talent Unlimited***

Talkback told us that the Hospital put a lot of effort into working with them to ensure the needs of autistic people are met, for example creating easy read documentation and sending text reminders, but that more can be done. Better links need to be made with PCNs, but the work Talkback is involved with through the Mental Health Alliance provides opportunities to link with The Bridge and The Crown PCNs as a start. The opportunity for people with autism to have 'their say' is very important, it was stressed.

"The 'experts by experience work' with the hospital was great - certainly pre pandemic we have been invited to the hospital a couple of times as a group to consult on out-patient waiting rooms. Etc. The hospital have attended our group 3 or 4 times this year to get views on documentation for example, and MK hospital Chaplaincy and PALS have engaged with us too. The hospital are great, they have really embraced us but there is lots of work to do... there is a lot of work, but there is a real chance." ***- Talkback***

There are existing opportunities for engagement with autistic people in MK, where a greater understanding of lived experience could be gained and co-design facilitated. Talkback's bi-monthly user meetings would be a great option, and professionals providing support are welcome here.

"An example of good 'consultation' and involvement with people with Autism in MK was a sensory garden project at The Campbell Centre." ***- Talent Unlimited***

Common Health Issues

We heard that people with autism are more prone to intestine related health issues and being overweight or underweight. In some cases this is due to complex issues relating to food that are specific to people with autism and specific to individual people with autism (as the underlying reasons are not always the same).

"Some foods make some people with autism sick, and to some, foods taste rotten, or disgusting. This can lead to having an unvaried diet, eating unhealthily, becoming ill, and being under or overweight. Food addiction can also be an issue" ***- Talent Unlimited***

> *“Some people with autism have a complicated relationship with food - ‘healthy living’ is huge and texture and taste is a big part of it”* ***- Talkback***

We were also told that around one third of people with anorexia are on the autistic spectrum.

Cooking healthy food was highlighted as a support need within the autistic community.

> *“Some people with autism may struggle with cooking a meal. Takeaways and ready meals are very accessible and are often chosen over cooking food. Education regarding food and support to cook meals would be beneficial - via social worker assistance perhaps.”* ***- Talkback***

Despite all of these diet related issues and eating disorders, there is no specific support for adults with autism to help them address their specific needs around food issues, and because of the complex autism specific causes of issues, mainstream services are unlikely to be effective.

Anxiety was flagged up as a common issue for people with autism, with certain situations causing a great deal of stress, as well as general mental health issues.

> *“The mental health side of autism can be traumatic including the diagnosis or lack of it.”* ***- Talkback***

Recommendations

Adapting services and spaces to be appropriate and accessible

- Avoid out of area appointments for autistic/neurodiverse people with transport issues, and/or consider if specialists could come to MK and see all people with transport issues on a designated day in a dedicated clinic. Could this be facilitated by the ICS?
- Autistic specific support is required relating to diet, healthy eating/cooking (potentially via social workers), food issues and eating disorders. This is an urgent matter and is perhaps something that the ICS could investigate.
- Better access to community transport, or new initiatives involving VCSE, Private or Public sectors that can help people with autism / neurodiversity access transport more easily. Could ICS investigate this?
- Alternative ways for autistic people to access appointments aside from the early morning call to GP surgeries (as early mornings are difficult for some with autism, as are phone calls).
- More face to face appointments for people with autism as often they do not like to speak on the phone, and/or may not be comfortable discussing their diagnosis on the phone at home in front of the people they live with.

- Ensure that phone calls with people with autism are scheduled at a particular time so they are not unexpected and stressful, and pay special attention to ensuring they are undertaken on time. The same goes for appointments.
- Follow up on missed appointments and lack of response to medical letters by people with autism to explore the reasons for this. Text reminders etc may also be useful.
- Reasonable adjustments to be made to medical waiting rooms and other medical environments for people with autism such as providing a small, quiet room with adjustable lighting. Could work be done with PCNs and hospitals to achieve this?
- More advocates to attend appointments with autistic people, and promotion of the right to take a trusted person with you into appointments.

Communication / information

- A single 'place' where all autism related resources are available in MK (not restricted to but including health) would be useful. This would include support options, services, information about autism etc. Currently everything is separate and difficult to find. Could the ICS support this, linking with VCSE Local Authority and linking with MK Council's Midos initiative?
- Consultation with individuals about what information they already access and what information they would like to access would be beneficial - along with discussions around putting advice into practice
- Work could be done with GPs to allow people with autism the time to ask questions - processing information can take longer so conversations and appointments will be longer than those for people without autism. Trust between the individual and the professional also needs time to build so individuals are responding openly and honestly, and do not feel intimidated.
- Receptionists, GPs etc asking the individual about their communication needs and preferences and receptionists or other staff meeting patients with autism before they walk into GP surgeries to make them feel more comfortable.
- Systems that flag up a person's autism and notes (gathered beforehand) around their communication needs and preferences so that receptionists, GPs and other health providers can take this into consideration when communicating would be helpful.
- Written summary of what is discussed in medical appointments for people with autism to take away with them. Could a simple template be designed for GPs to use for this? Can VCSE work with PCNs?

Training, education and increasing awareness

- Training for health providers, including GPs and GP receptionists etc, on autism and neurodiversity generally, and how to support and communicate effectively. This could include how to make sure autistic / neurodiverse people understand the information given in medical appointments and that they are supported to feel comfortable and able to ask questions. Could this be something facilitated by ICS or that the VCSE are funded to do?
- Training to GPs and other health professionals on diagnosing autism and the differences to personality disorders. Also, that people of any age can be diagnosed (never 'too old').
- Promote Talkbacks user meetings as a place for health service providers (NHS, Local Authority, VCSE) to connect directly with autistic and neurodiverse people.

- Mencap has easy read recommendations and the National Autistic Society has an easy to read website version. Can these resources and model be used for health information?
- PCN's could have an autism champion that manages the communications with autistic clients e.g. emails and phone calls and avoiding automated systems, and has dedicated time to meet individuals at the door and undertake a debrief of their appointment once they have left. Citizens Advice MK have set up a vulnerable persons helpline - perhaps a model to replicate?
- More opportunities for organisations working with autistic/neurodiverse people, and for autistic/neurodiverse people individually to directly communicate with health providers to feed in lived experience and co-design services. Build on work with the Hospital. Initiate links with PCNs.

Community Action: MK and VCSE Actions Taken

- Community Action: MK raising the need for specific eating disorders and diet support for people with autism to ICS.
- CA:MK has linked Talent Unlimited to MK Dons SET to provide specialist advice in tailoring their diet and healthy living sessions for people with autism within their Health Inequalities project funded through CNWL.
- Community Action: MK has flagged the need for specific eating disorders and diet support for people with autism to CNWL - and explore potential funding in the future.
- Talent Unlimited is exploring funding for collating autism related information, resources and services on their website.
- Community Action: MK has asked the team developing the Midos database to include autism and neurodivergence as a category in their cross sector database for the area that we and other VCSE organisations will use.
- Community Action: MK has a neurodivergence section on our signposting directory on our website
- Talkback delivering a 'wellness course'

Living in Deprived Communities - Detailed Report

We spoke to Sonal Mehta, currently working with the ICS to create stronger partnerships with the VCSE across BLMK, and previously having worked as a community pharmacist in The Lakes Estate (one of the most deprived estates in MK and the country) to gather information around health inequalities in deprived areas generally.

The first phase of the Denny Review revealed that living in deprived areas and being from an ethnic minority community or having disabilities led to particularly bad health outcomes. We therefore also asked specialist organisations working with those groups specific questions about experiences the people they support have of living in areas of deprivation.

Accessibility

We were told that sometimes individuals living in deprived areas, that are in a mental health crisis, and have School aged children, found accessing appointments difficult. They would often prioritise getting their children to School over attending appointments.

Sometimes access to green space is limited, as are community spaces making it difficult for positive activities to run in deprived areas.

We heard that having a pharmacy within deprived communities is a positive.

> *"There was a lot of anger when the pharmacy was going to be taken away. There was a pharmacist that worked on the surgery side, she was very good at advising people about what they can access via their surgery"* ***- Sonal Mehta***

We were told that many people living in The Lakes Estate don't want to leave the estate, so taking health and wellbeing services or activities into the estate is very important.

It was highlighted that a lot of health inequality experienced by people living in deprived areas is complex and due to the wider social determinants of health, and the lack of access to all sorts of things across many aspects of life and over generations. We were told that whilst people might have the knowledge about what to do to stay healthy, they may not have access to them.

Important that the assets within deprived communities are appreciated and that community members are involved in initiatives to ensure they are effective, appropriate and accessible.

> *"You need to work with local people and piggyback off what they already do. Don't go and do things 'to' them do them 'with' them."* ***- Sonal Mehta***

Taking advantage of opportunities such as the regeneration initiative in MK was highlighted, as well as looking at what can be built upon.

> *"There's plenty of things that you can build on on the Lakes Estate instead of reinventing the wheel. When you stop looking at the community as a problem that*

needs to be solved, you'll be able to see there are lots of good things that have gone before." ***- Sonal Mehta***

Communication

We were told that some people living in deprived areas may pick up and believe information relating to health that isn't based in fact or from a trusted source, but that it is important that healthcare providers handle this situation sensitively.

"People need to be treated as humans. For example childhood immunisations, even if the information they have is based on information that isn't factual or not from the NHS, professionals still need to be sensitive towards the questions and where the original information comes from. Being listened to and taking people's concerns on board may impact people's ability to have conversations with healthcare professionals and feel comfortable doing so. You have to validate someone's feelings even if the information they base their feelings on are wrong. Being respectful that people have opinions." ***- Sonal Mehta***

Using the fact that taking certain actions may increase how long you live isn't always the most effective incentive when communicating with people living in deprived areas, we were told, as sometimes people lack a sense of hope and purpose.

"Some people may feel their life isn't enjoyable and therefore, do not see the point in living longer. For example giving up cigarettes. If you haven't got any hope then you might not want to 'live for longer" ***- Sonal Mehta***

Common Health Issues

We were told that people living in disadvantaged areas tend to suffer from chronic pain more, and access to holistic treatment options are often not affordable in the same way they may be for others.

"Some people may access addictive pain relief for the numbing effect." ***- Sonal Mehta***

Sometimes people living in deprived areas lack confidence and self esteem, we were told.

"Need to build people's confidence first in response to criticism around not having aspirations to leave the Lakes Estate" ***- Sonal Mehta***

Intersectionality - people with autism and neurodiversity living in deprived areas

When we asked whether people with autism / neurodiversity living in deprived areas experience greater challenges relating to health inequality, we were told that they do by the specialist organisations engaged in this research.

Noise is often particularly difficult and uncomfortable for people with autism to tolerate. Noisy neighbours are a big issue in areas where anti-social behaviour is more prevalent or where properties are poorly soundproofed.This leads to distress, complaints and animosity with neighbours.

There was also concern for autistic people that are vulnerable.

> *"Some autistic people are vulnerable and can be taken advantage of. For example befriended and stolen from, bullied etc. In areas where people are more desperate for money due to economic disadvantage, or under more stressors themselves this may be more likely."* ***- Talent Unlimited***

We were told it is difficult to get moved when issues arise, and difficult to get complaints listened to early on.

> *"Often if people with autism were supported early, and issues with neighbours addressed early, they would not escalate."* ***- Talent Unlimited***

It is also more difficult for economically deprived individuals with autism to afford transport to access specialist appointments, exacerbating health inequality and disadvantage.

> *"Living in deprived communities increases anxiety around safety"* ***- Talkback***

We heard that navigating and accessing online services can be a barrier to people living in deprived areas. Some people within these communities may be on a low income or may not be willing or able to use the internet, this then makes accessing online services really difficult.

Anxiety about safety may also be higher among people with autism living in deprived neighbourhoods. This concern could be a mental health 'trigger', resulting in people living within certain neighbourhoods, not wanting to go outside due to the concerns about 'what' could happen. We heard that the environment you live in can affect one's mental health. Anti- social behaviour in a neighbourhood can have a big impact also.

Intersectionality - people with disabilities living in deprived areas

When we asked specialist organisations engaged in this research whether people with disabilities living in deprived areas experience greater challenges relating to health inequality, we were told that they do.

> *"People living in deprived communities may not have endless use of a telephone or internet facilities to access support. This is even worse post Covid now more services are online or over the phone"* ***- Talkback***
>
> *"I tend to think the worst of the areas are the ones that can't communicate so well. They haven't got endless use of a telephone or they don't have endless use of internet facilities. Automatically that is going to knock them back."* ***- MK CIL***

We heard from a former health trainer of the benefits of community based roles when working in areas of high deprivation with mixed population groups.

The Disability Resource Centre told us that the people with disabilities living in deprived areas often struggle to understand how to access the services they need, where to go and how to navigate the system. We also heard that disabled people lib=ving in deprived areas are often experiencing financial difficulties.

Intersectionality - ethnic minority communities living in deprived areas

In terms of whether people from ethnic minority communities living in deprived areas experience increased challenges relating to health inequality, we were told that yes, they do. It was stated that all areas of life will impact health inequalities - whether this is caused by living in deprived areas or other factors. Some of the wider determinants of health mentioned include perinatal issues, neurodiversity, finance, cost of living, discrimination at work and the legal issues relating to this, engaging with Police (if more able to, could help prevent issues) and domestic violence.

We also heard that among the Somali community, diet can be an issue and in particular for young men, smoking and the consumption of khat.

Intersectionality - people with learning difficulties living in deprived areas

Isolation is also a big issue within the LD community, and we were told that individuals that are isolated are often not picked up quickly enough. Isolation is particularly prevalent amongst those living in more deprived areas of MK.

> *"Those living in social care settings can become extremely isolated - especially if neighbourhoods are intimidating.."* ***- Camphill Communities MK***

Recommendations

Training, education and increasing cultural awareness

1. Education to professionals about the importance of listening and respecting patient's reactions and opinions on health matters, even if the basis of opinion isn't factual, in order to build a positive relationship and help to educate.
2. 'Good things' can provide online courses to update people's skills - There are also initiatives to provide funding for equipment in order to access the internet https://www.goodthingsfoundation.org/

Adapting services and spaces to be culturally appropriate

- Stop looking at deprived communities as a problem that needs to be solved, look at the assets, opportunities (Regeneration) involve residents in solutions and action rather than 'doing things to' people and build on the good things that exist and have gone before (don't 'reinvent the wheel').
- Support people in mental health crises to access appointments, when also caring for children (especially if appointments clash with school runs etc)
- Take services out into communities where possible, as there is often a reluctance to travel outside the estate or area. Including holding health events within communities
- Recognise the value of pharmacies within communities and use them to support and promote community health and available services
- Provide accessible and affordable health and wellbeing activities, access to green space, confidence/self esteem raising activity and holistic treatments. Including more community spaces to run positive activities in.
- Providing housing for people with autism in quiet neighbourhoods and within homes that are well soundproofed.
- Early support for people with autism around and issues with neighbours so they are addressed early and do not escalate.
- Wider provision of safeguarding and support for vulnerable people with autism to prevent them being 'befriended and potentially stolen from'.
- Quicker moves arranged for autistic people living in unsuitable homes (e.g. with antisocial neighbours etc).
- Reduce digital exclusion - current or new initiatives to provide sim cards

Communication / information

- Appropriate communication for people who are digitally excluded

Ethnic Minority Groups

- The Wisdom Principle
    - The Wisdom Principle (TWP) is a BAME-led organisation working in Milton Keynes. They are members of MK Mental Health Alliance and MK Intercultural Forum. The Wisdom Principle have been involved in extensive engagement and outreach within BAME communities

within MK to understand more about Health inequalities, what causes them and how they could be reduced.

Communication

We were told that both verbal and non-verbal communication can be difficult for some ethnic minority community members. Some non-verbal communications are not always understood, and the ways sentences are constructed can be difficult to understand with gaps being filled by assumptions. It was suggested that a way to overcome this is ensuring that health services have professionals within teams from such communities so they can understand and facilitate understanding.

In terms of what sources of health communication are most trusted, we were told that being told something verbally is effective, as opposed to leaflets etc. Stories are much more effective in some ethnic minority communities rather than purely factual information. Many people need real stories and examples to be added to communications. The opportunity to discuss the information is also vital to check that it has been translated and understood correctly.

Accessibility

We were told that not knowing how to get help or what help is available is a big barrier to accessing health services amongst ethnic minority groups. It feels as though there is no definitive place to get all of the information across the piece and many don't know where to begin as it is such a complicated picture.

> *"Not knowing where to get help or understanding the different segments of the service is an issue. For example, the routes and where referrals go to."* ***- The Wisdom Principle***

Fear of harm, experiencing discrimination or abuse, and fear of authority can all lead to some people from ethnic minority groups avoiding accessing health services and support. This is exacerbated by the fact that Community members are often quick to share stories relating to negative experiences of visiting GP or other health providers. TWP advised us that now is an opportune time where people from ethnic minority communities want to arm themselves with information. Topics include health conditions such as perinatal, neurodiversity and HIV but also information linked to the wider determinants of health such as information about pro bono support and domestic violence. The interaction between health and the law is really complicated and can be difficult to negotiate. It likely has more layers of stigma attached to it than other topics.

Going to where ethnic minority communities are was explained as important to increase access to health services. Introducing services in a familiar, informal space can help to remove fear and normalise the idea of accessing them before people need them, so if and when they do need support they will feel able to access the right services.

The Wisdom Principle would welcome more opportunities to be able to directly communicate the issues faced by ethnic minority groups relating to health care to health providers and decision makers.

> "There is so much we would want to say to specific service providers e.g. through stories we have heard.
> We would like to find a footing to sit at that table and say we have heard from this many individuals about this and this is what their recommendations are and these are our thoughts".**- *The Wisdom Principle***

The Wisdom Principle told us that they meet groups that are really organised, and function really well for their communities but stay parallel to the mainstream services. However, they do wonder what unintentional barriers may be there due to these groups working closer to the mainstream services.

We were told that there seems to be ethnic oriented community groups that provide feedback to mental health charities such as Mind BLMK and Rethink Mental Illness as opposed to mainstream groups. TWP did wonder why this was and the challenges present to result in this.

It is felt that there are not enough opportunities for individuals from ethnic minority communities and support organisations to feed in experiences to health providers and take part in co-designing solutions and services.

> "How do these very organised communities that are self run, self funded who are constantly in this knowledge base, able to access service providers? Is there something that says if you are a group of more than 100 people that you can approach a GP and write to them [about a particular issue] - something structured, something that has a pathway that feeds back" ***- The Wisdom Principle***

There is also a lack of feedback when information from ethnic minority communities is collected. People give their information and time and don't hear what, if anything, happened as a result of it. There needs to be pathways for that circular communication from service providers to communities, as well as from communities to service providers. At the moment it feels there is a lack of openness from service providers.

“When all of this research is done, often it does not return to the community. Therefore you (people from ethnic minority communities) feel, well I fed into it, I'm not yet seeing the change and we understand that change takes time but sharing the progress of the journey does not.

Doing this [sharing the progress] is very transparent, immediate and clear and gives people grace and patience to endure the slow pace [of change] that is necessary as it is a big piece of work/change that is interconnected and there is so much to consider.” ***- The Wisdom Principle***

Unfortunately, we were told that there were many issues and barriers with providing feedback. Feedback being effective requires both parties involved to be on a common footing, including shared language and shared sense of power or impact of feedback. This footing or connection between people from an ethnic minority community, and mainstream services rarely exists impacting effective feedback. The person providing feedback and the service collecting the feedback do not share the same aims, language and pre-understanding. This impacts both parties, making both the request for feedback from services ineffective and the response or engagement with feedback by people from ethnic minority communities less likely.

Additionally, the type of feedback that services want to collect is chosen by them and this may not provide opportunities to include the type of feedback that service users/ community members want to provide/feel the service provider needs to hear.

“Another reason feedback isn't always given is because services ask for feedback about the point of care but people want to provide feedback about the structure and strategy of the service - they want to say things like is your service diverse in your workforce? Are there people who look like me in your service? Rather than answering, was the greeting okay? What makes that service okay is making sure the service feels like it is representing you and is presented in a way that works for you - there is a reluctance to to expand feedback to not just be about transactional paths of services but to be more about how we structure services, how we fund services and how we locate services.” ***- The Wisdom Principle***

There doesn’t seem to be an openness from service providers towards welcoming different types of feedback as quoted above or a template to change in regards to feedback. It was felt that there is a way to go around the area of system change.

We heard that there are challenges around bringing service providers and community members together to provide feedback on services due to the expectation and accountability attached to meeting in person. For example, we were told that there have been great turnouts from service providers at events to hear communities' voices and learn. But service providers did not attend the event that was held to allow community members to voice their opinions directly to these service providers.

The Mental Health Alliance provides an opportunity for The Wisdom Principle to feed information to health services (CNWL and Transformation Board) but there needs to be the opportunity for organisations to be honest about what is working and what isn't and health providers and other organisations need to be held to account around what they are doing with the information they are hearing about health inequality and the changes that are required and how funding is used. There is a keenness for structures to be co-designed that allow this honest, two-way, productive communication that results in real action and change.

> "If a space is facilitated well, there is space to harness some vulnerability into it, there is a willingness to share accordingly but holding it to account is where things are let down. How do you keep the conversation going as change progresses? It can't just be a one way information flow, it can't carry on like that. People aren't going to want to keep giving feedback without anything in return, without seeing any progress" ***- The Wisdom Principle***

There are a great deal of community led activities happening within ethnic minority communities in MK, which are community led. Covid really highlighted and brought out community led responses,activities, expertise and skill. Therefore, there are a lot of incredible activities to link in with in terms of working jointly to engage with the community and address health inequality.

Cultural differences

We were told that the 'white coat effect' can come into play within some ethnic minority groups, and that patients need to be given permission to give their opinions / suggestions, be advised that they are part of their own treatment and can say yes or no and have their responses acknowledged and respected.

> *"Individuals may come from countries or regions where the professional tells you everything you need to know. However, within the UK, patients collaborate with the professional and can decline the service or interventions. To challenge a professional requires courage.."* ***- The Wisdom Principle***

If a GP is trained to expect patients to participate etc, as this is the majority cultural norm, they may not probe further in order to draw out issues amongst ethnic minority individuals that may be reluctant to communicate with Doctors. For example, if an individual does not tell a GP that they are feeling stressed, the GP may not explore this.

Some ethnic minority groups expect and need a more personal experience when seeking medical help in order to build trust, it was explained. This might include the professional asking about wider aspects of their life e.g. how their family are. They need a relationship or connection with one person, a face not just a service. They need to feel they are being treated as an individual. Often this familiarity and friendly interaction will 'warm people up' to speaking about their health concerns. The whole person, including their religion, needs to be considered.

"People want to speak to a person, not a service. By putting a face to the service, knowledge and trust may be increased, which would improve individuals' experience of the service. " ***- The Wisdom Principle***

The Wisdom Principle explained that they appreciate time is pressed for the NHS, but if certain cultures value this so much and they are not getting it, it creates health inequality. It was explained that for some ethnic minority groups, time equates to care, so being rushed through an appointment can lead individuals to feel the service is not there to care for them and their health, reducing trust and increasing reluctance to access services.

Younger people within ethnic minority communities are becoming more willing to speak about health and the barriers they face and The Wisdom Principle hopes that this will eventually have a positive impact on those experiencing health inequality.

Although there may be a good level of understanding around being healthy, some ethnic minority communities may not go to service providers for help. They may use natural remedies instead of mainstream remedies. There is huge self reliance within some ethnic minority communities and often individuals only seek support when issues are critical. There may also be a different perception of what healthy and unhealthy is, and in some Communities taking actions to prevent ill health is not a common practice.

It was suggested that more funding should go into supporting ethnic minority communities to co-create non-medical health services. That way Communities are involved from the inside and access isn't such a big jump. It is also the only way to redesign a system that was created for the mainstream, so that it is also fit for purpose for those people and communities that fall outside of the mainstream. Designing services that are appropriate, welcoming and accessible for ethnic minority communities is the only way to ensure they are effective and support the reduction in health inequality.

"The system wasn't made for me, so it's never going to work for me" ***- The Wisdom Principle***

Mental Health

We were told that the term ‘mental health’ does not translate into some languages, as it is just not a concept in some ethnic minority groups, although the same experiences in terms of mental health are being felt. A translation may not have the same meaning and translation can be over simplified when it is actually a complex task. Mental health issues and experiences may be communicated differently, which may lead to some symptoms or mental illnesses not being picked up, or individuals not accessing appropriate services. Some ethnic minority groups may think of spiritual health instead of mental health.

> *“Some ethnic minority groups might express feeling stressed or anxious as a sense of feeling out of balance for example, but because they don’t use the word stress the individual may never access services to help with stress.”* ***- The Wisdom Principle***

We learned that some mental health issues in some ethnic minority groups can just be thought of as normal to experience, e.g. PTSD in migrant communities, and support to deal with such issues will not be sought.

Common Health issues

We learned that stress is a common health issue experienced by ethnic minority communities. Often they may be working a number of jobs, have a high number of children and get very little sleep - but this becomes the norm for them.

Other health issues that were highlighted included headaches, rashes, long term health conditions,muscle strain, high blood pressure (hypertension) kidney and liver issues.

In terms of weight, diet and food, we were told this is a complex issue. There are cultural differences in the way health and healthy weight are defined - and this might not relate to being overweight or having a high BMI, but whether weight allows a person to do the things they want to do.

> *“A person might not see their weight as an issue just because they have a high BMI. If their weight starts to stop them dancing at church however, they may then see it as an issue”* ***- The Wisdom Principle***

Recommendations

Adapting services and spaces to be culturally appropriate

- Workforce diversity within healthcare services
- It was suggested that more funding should go into supporting ethnic minority communities to co-create non-medical health services
- Mainstream/statutory services to link in with pre-existing activities to work jointly to engage with communities and address health inequalities.

- Designing services that are appropriate, welcoming and accessible for ethnic minority communities is the only way to ensure they are effective and support the reduction in health inequality
- Further research to explore barriers ethnic minority groups working parallel to mainstream services may experience
- Services can try to ask people what is going wrong, without the people receiving the feedback feeling like they have ownership of the feedback they are collecting
- Services should go out into communities where possible

Training, education and increasing cultural awareness

- Cultural competency training for GPs and other healthcare providers and staff teams.
- Culturally sensitive education about what being healthy is and raising awareness of some health conditions not being 'expected' e.g. diabetes during pregnancy or stress
- Culturally sensitive approaches to weight, weight management and weight education

Communication / information

- The Wisdom Principle would welcome more opportunities to be able to directly communicate the issues faced by ethnic minority groups relating to health care to health providers and decision makers
- The Wisdom Principle would like to co-produce something that allows groups to voice their views
- Include real stories and examples to outgoing communications
- Opportunities to discuss information to ensure information has been translated and understood correctly
- Sensitively and politely discussing current healthcare time constraints to avoid people feeling that services do not care
- Make appointments more personal when people are seeking medical help e.g. healthcare professionals to ask about wider aspects of a patient's life.
- Raise awareness of seeking help earlier - before crisis
- Raise awareness of seeking help for conditions such as PTSD
- GP's to facilitate deeper conversations. Just because someone does not mention something doesn't mean they are not experiencing it
- Structures to be co-designed that allow honest, two-way, productive communication that results in real action and change.
- Develop ways to discuss mental health and mental health symptoms/conditions if translations do not easily facilitate this
- Services to allows services users the opportunity to provide feedback on a range of issues, not just what the service provider wants to receive
- Reduce barriers that people from ethnic minority communities may feel when providing feedback as highlighted within the report

- There needs to be pathways for that circular communication from service providers to communities, as well as from communities to service providers. At the moment it feels there is a lack of openness from service providers

Ethnic Minority Groups - Cancer Care Focus

- MacMillan Cancer Support Research, Phase One, Project workers from Community Action: MK
    - Community Action: MK undertook research on behalf of Macmillan cancer care to understand why take up of their services is lower within ethnic minority groups, including what barriers are faced and what could help services become more accessible

- MacMillan Cancer Support Research, Phase Two, Project workers from Community Action: MK
    - Following the initial research, Community Action: MK undertook a second phase to dig deeper into the experience of faith communities within ethnic minority groups in terms of access to and experience of cancer support.

Person centred and inclusive

We heard that more culturally appropriate advice is needed in regards to diet and access to food within hospitals. When health professionals discuss ‘healthy eating’, it was often felt that this advice was only related to narrow diets and did not provide specific advice around how to make food from all cultures healthier. People were often advised to eat ‘healthy’ diets but when provided with information around healthy food, were not offered culturally appropriate nutritional advice or meals - resulting in an increased difficulty to stay healthy. We heard that the approach currently used was not person centred enough. In regards to access to food in hospitals and nutritional advice, food could be offered along with meal plans or suggestions regarding cooking but they were only based on one culture. This included meals that people from some communities and cultures would not eat.

> *“Healthy food, healthy diets, healthy lifestyle - it wasn't the food they (people from ethnic minority communities and faith groups) were eating - how can I change the food I already eat and make it healthy? - it caused some alienation and feelings of not fitting in. [Professionals] need to be aware of different cultures and religions and what is appropriate. ”* ***- CA: MK Staff member***
>
> *“Their family member was bringing them food due to their lack of interest in hospital food - this meant they weren’t eating 3 meals a day.”* ***- CA: MK Staff member***

Cultural awareness was discussed to help ethnic minority communities and faith groups feel better supported when connecting with health services/professionals in the future. We heard that cultural awareness training would be beneficial for health professionals and that cultural awareness of appropriate interaction between genders would help to alleviate barriers to interacting with some communities. Additionally, health professionals need to be aware of different cultural and religious aspects of healthcare. For example, a smear test and the cultural implications of this procedure.

We also heard that health conditions such as cancer can be stigmatised in some cultures and faiths. Therefore, privacy is important. If a health condition is stigmatised, it was advised that loneliness may be increased.

> *"More cultural awareness - cultural training for specific groups. A barrier that we had when talking to groups as women, there may have to be a champion that meets the criteria of those in the group you are interacting with - males may not talk to females and females may not talk to males."* ***- CA: MK Staff member***

Current service provision

We were told that there feels to be a lack of personal connection with service providers including cancer support such as fewer nurses and having a different GP on each visit. It was also reported that issues relating to healthcare do not seem to be heard and that when issues are raised, they are not followed up.

Additionally, in regards to current cancer care services, it was reported that these services seem to be tailored towards a single demographic. For example, we were told that breast prostheses are not inclusive enough.

> *"When a lady had breast cancer and had her breast removed, prostheses in general, there wasn't anything for her body that suited her skin tone. So you've already got this alien thing that you've had taken away from you and you have this alien thing to be using to help you move on from this - she said 'you think when you've had cancer, you think you'll get better and you think you'll be the same as you were before but your not the same'. It's a different feeling and a different life that you're living. Especially if you have a body part offered to you that's not your skin colour, then that's really difficult".* ***- CA: MK Staff member***

Communication and Language

We were told that health terminology can be a barrier faced when accessing cancer support for some ethnic minority community members. Complex information can create difficulties in understanding especially if english is a second language. Additionally, services may need to explain medical terms, especially if a child is translating for their older relative. Additionally, some information sheets are unavailable in different languages, creating a huge barrier to accessing and understanding health information.

> "In a lot of families, the only person that can translate is a child, this isn't always appropriate. [The translator] needs to be able to translate from English and also explain the medical terms. It can be difficult to find someone" ***- CA: MK Staff member***

In regards to translation, this can also be a barrier when accessing cancer support in 2 different ways. 1 using a translation service and 2 when using a family member. It was reported that although services may offer translation services, interpreters aren't always readily available. In regards to using a family member to translate, it was reported that sometimes females with English as a second language rely on males to translate. However, this may not be possible and/or cause the female to feel uncomfortable if the topic that needs to be discussed was a personal, female health condition.

> *"Often if english isn't your first language, you may have a male family member take you to the appointment but how can you feel comfortable if the appointment was to talk about a female thing e.g. personal female issue?."* ***- CA: MK Staff member***

Additionally, sometimes community members rely on the 'head of their community' for translation of health information due to a lack of English language skills. This reliance can be problematic and at times, information may not be passed on such as the need for health checks. The term 'gatekeeper' was heard and although community leaders are a great way into communities, sometimes leaders can become 'gatekeepers' and do not pass information on.

> *"Education about the need for health checks for individuals would be beneficial - sometimes it (information) just goes to the gatekeepers and the other members are not even aware they should have it."* ***- CA: MK Staff member***

We heard that awareness of Macmillan services were varied with some people having great knowledge of and supporting Macmillan and others having never heard of them before. Overall, it was found that knowledge of Macmillan cancer support services is better known amongst people from faith groups whose first language or household language is English.

Accessibility and Trust

It was suggested that NHS services should allow time to build trust with people in a long term manner. Building trust takes time and developing trust to develop relationships with communities and understand what they need will require a long term commitment. It was suggested that trained volunteers or employed staff to help with this could be beneficial. Additionally, we were also told that age can sometimes correlate with how trusted a person's opinion or advice is and how well it is received. For example, within some communities, if a younger professional provides advice, it may not be as well received due to their age.

> *“The second part of the research was about faith - you need to build trust, you can't just go out and ask sensitive questions e.g. about cancer. Not everyone wants to talk about it. You need to allow the time to build trust, not just putting in a service and expecting it to work or people to attend. .”* ***- CA: MK Staff member***

We also heard that within some communities, there is a reluctance to ask questions of, or challenge health professionals. Such as Doctors as they can be very highly respected. Furthermore, sometimes people may not ask health professionals questions as they may be unaware of the support available.

In regards to accessing services, we were told that health support needs to go into communities to reach people and that outreach work is important.

> *“Services need to go out into the community rather than the communities reaching out to the services. That could increase access. One of the recommendations was working with the existing networks.”* ***- CA: MK Staff member***

Faith

We were told that faith and/or spirituality are not always well understood or considered by health staff/services. Some people from ethnic minority communities and faith groups feel that the NHS do not take consideration and care about the importance of spirituality in healing in relation to cancer. This is an aspect that is important for emotional wellbeing for people using a service and different cultures and faith groups do this in a different way. It was reported that this lack of consideration can make service users' healing process more complicated. Additionally, there may not always be appropriate spaces or support for service users to pray.

> *“Not being able to pray may make them (patients with cancer) lose hope and they may just want to stay in hospital and sleep.”* ***- CA: MK Staff member***

Praying was mentioned during both interviews. It was reported that some faith communities have beliefs that cancer is a punishment or a test from God and faith leaders can advise people that praying is the only treatment. However, the person with cancer may have wanted to bring up their belief that God also provided Doctors and therefore, they pray and work with the Doctor. We heard that the recommendation to pray only, can prevent or delay people from accessing treatment. Therefore, there needs to be research into ways that faith, including prayer, can be used alongside medical interventions. Additionally, service users can feel that nursing staff not being allowed to pray for them can affect their healing.

Recommendations

Training, education and increasing cultural awareness

- Cultural awareness training for health professionals to maximise staff awareness of all cultural and religious aspects of healthcare. This training could be tailored around demographics of the area in which the service operates, and help them to take a faith and culturally sensitive approach to cancer care including recovery.
- Raise awareness of the importance of asking questions within health decisions/consultations - promote this way of interacting with healthcare staff

Adapting services and spaces to be culturally appropriate

- Research/exploration into ways that faith, including prayer, can be used/included alongside medical interventions.
- Greater support and more availability of space for patients to engage in faith based activities e.g. praying within healthcare settings
- Wider variety of foods offered in hospitals/inpatient settings
- Named GP's for people with cancer to enhance their patient journey experience and maximise rapport
- More inclusive prostheses
- Outreach work and taking services to communities
- Trained volunteers or employed staff to help with building trust within ethnic minority communities

Communication / information

- Health information to be available in a range of languages including leaflets and online resources, and in easier to read and understand formats that do not include complex medical terminology
- Greater use of culturally adapted eat well guides, and multicultural nutrition websites for healthcare services such as here
- Provide feedback during the stages of complaint management
- Greater availability of translators and promotion of these services in particular for female related health conditions e.g. gynaecology departments
- Share information around health checks and available services with community leaders as well as community members individually (as in some cases community leaders can withhold information / gatekeep)

Actions

Gypsy, Roma, and Traveller Communities - Detailed Report

Finding VCSE organisations to speak to that engage with Gypsy, Roma, and Traveller (GRT) Communities in MK was challenging. However, we were able to gain some insights from other professionals with experience of working with GRT groups in the City:

- Danny Conway
    - Danny worked for many years as a Local Authority Social Worker. He also worked as a Commissioner within Children's Services in MK. Danny's work has seen him focus on engaging with traveller communities in MK through Chairing the Gypsy Action Forum, which brought together Gypsy Travellers and agencies to co-produce action.
- Ethnic Minority Achievement Team - MK Council
    - We received written responses to our questions from the Ethnic Minority Mentor working with GRT communities in MK

Serious, long-term investment is needed to engage with GRT communities and tackle health inequality

The need for long-term investment to properly and helpfully engage with MK GRT communities was a point that was very strongly made. We were told that if GRT communities are supported consistently over a long period of time by trusted, named visitors into their communities, and supported to access health services, experience has shown they will. However, without this special provision that builds trust and offers tailored support, it was felt that health access will continue to be poor and health inequality will persist. This work may take years of effort and long-term investment, but have substantial health benefits.

> *"GRT communities will engage and access health services if they are helped to. The last time I saw anything that really worked in MK was 2002-2006 when Health appointed a full time health visitor to the GRT communities, based out of Hilltops Surgery on Great Holme. Two of her notable successes were the complete re-building of the Calverton site and setting up of the Gypsy and Traveller Action Group. I fondly recall the inaugural meeting when a leading voice from the Irish Traveller Community said she didn't mind joining a group, as long as it had ACTION in its title. Most important was that the health visitor got the trust of the three communities: English Gypsies; Irish Travellers and those on the Roadside. This role was discontinued in budget cuts"* ***- Danny Conway***

The long term engagement required includes social work, support to understand what health services are available and support and guidance to access it. The EMA Mentor told us that GPs are accessed by most GRT community members that need them, and the service is good when accessed, but there is a lack of knowledge around what GPs can provide.

> *"Knowledge around health is improving, but they (GRT Communities) often need to be told to see a GP/ Dentist by another professional as they do not know what services GPs etc can offer and do not engage with Family services etc"* ***- EMA Mentor***

We were told there is a great need for services (e.g. dentistry, physical and mental health services) to go out into GRT communities to engage directly, and take their services into those communities where possible. We were told that there are no current programmes or activities within GRT communities in MK around improving health. However, interventions during the pandemic were successful.

> *"In the pandemic I supported and encouraged as well as myth busting with the NHS which worked well but there are no programmes in place to the best of my knowledge now"* ***- EMA Mentor***

Communication

In terms of health communication, we were told that anything that is written can be an issue as levels of literacy are low within the GRT community. Any health services that require something to be read or written can be problematic and a potential barrier to access altogether.

> *"They (GRT Communities) usually ask me, or a school staff member they know well, to read any letters to them and explain what it means."* ***- EMA Mentor***

Having the level of verbal communications to have health issues understood when communicating with health services is also difficult. It was also suggested that 'jargon' used by health practitioners can be difficult for GRT communities to understand, and 'strong accents' can make understanding information given over the phone difficult.

We learned that online information relating to health is rarely accessed by GRT communities, although social media is sometimes used, along with 'word of mouth'. Lack of online communications in the GRT community is also an issue in terms of having their voices heard around health.

> *"There are options (to feedback re. health) through Healthwatch and if they raise any concerns I will signpost to PALS, CCG etc if needed, but as these are mainly online I suspect that they do not utilise the schemes."* ***- EMA Mentor***

We were told that getting in contact with the right services at all is difficult, and referrals for specialist health support beyond the GP can be difficult as some GRT families 'don't know what to say and waiting lists are very long'. A better understanding of how referrals work, how to get them and how long they take would help.

General barriers and issues

Particular support is required for roadside GRT communities (often made up of English Gypsies and Irish Travellers). Because they often don't know how long they will be able to stay in one place before being moved on, accessing local health services is very difficult.

We learned that there is often a perception amongst GRT communities that health centres 'look down on them', which can put them off visiting their GP or other health service and/or it is a stressful experience when they do.

> *"[There is] a feeling like if you (GRT Community Members) go to the health centre, they (staff) are looking down on you and looking at you as an outsider like what are you doing here?"* ***- Danny Conway***

We were told that often GRT community individuals or families tend to try to solve health problems themselves before asking for help from the NHS. This means that when they tell a GP or other health provider they need help, it is very likely they do and that the issue needs addressing ASAP.

Again, we were told that the building of trust over the long term is crucial. This is the only way to gather lived experiences to truly understand the issues and barriers GRT communities face relating to health. This would also allow GRT community members to express ideas for change that would really work, and be part of co-designing solutions that will actually help them. However, we were told that GRT communities within MK are currently very disengaged.

> *"It is only a few months ago that I was asked to approach the Gypsy and Traveller communities on the matter of access and barriers to health. I then met a thank you, but firm no… My general comment is these two communities, (that doesn't even include the people with no right to even temporarily put down in BLMK) are so disengaged that they do not even want to talk to anyone about their health needs and experiences, even though they still trust me"* ***- Danny Conway***
>
> *"We did try to organise a multi agency meeting for the community but none attended on 2 occasions, this had a representative from Police, MH team both adult and child, community nurse and education."* ***- EMA Mentor***

Common health issues

Danny Conway told us he believes the health inequality experienced within GRT communities is amongst the worst of any population group in MK. Health data and statistics would seem to back this up[1] with life expectancy thought to be 10 to 12 years less than that of the non-Traveller population. In 2011 14.1% GRT people rated their health as bad or very bad compared with 5.6% nationally. 42% of English Gypsies are affected by a long term condition, as opposed to 18 % of the general population. Gypsies and Travellers are nearly three times more likely to be anxious than the average for the general population and just over twice as likely to be depressed. One in five Gypsy Traveller mothers will experience the loss of a child, compared to one in a hundred in the non-Traveller community.

Health was reported as generally poor across the board, with environmental conditions exacerbating this.

We were told that mental health issues are common for GRT children, and quicker access to support from CAMHS would help, along with more regular visits to home educated GRT children to check on both attainment and mental health.

> *"Although there is no written evidence to support this, I am aware that most of the GRT Community in MK wish to retain their heritage and values without the persecution that goes with this, my experience shows that the retention of the accent and poor regard for education, together with the expectation they will be discriminated against is a big problem for the school age children and appears to lead to the behavioural issues towards the end of year 5 through to year 8 where most have withdrawn from school.*
>
> *There still appears to be a lack of aspiration with the youths believing that they are only good to run a home or undertake manual labour. There is a belief that they do not require an education as they will get work or enter college at 18. NEET is an issue within the community as are issues surrounding technology as the parents do not understand or allow themselves to be shown how to protect children online. Sadly this has not improved since the Covid pandemic and many older children are subjected to online bullying. At present I am aware of about 25% of the children aged 12-18 being subjected to significant bullying (racial abuse, threats of violence, sexual explicit content). This relates to the cases I have been made aware of by the parents or school."* ***- EMA Mentor***

Mental health issues were also cited as common amongst adults, and it was explained that stress is a big issue across the GRT community. We learned that violence is often used to settle disputes within some

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[1] Statistics from:
- Gypsy, Roma and Irish Traveller ethnicity summary - GOV.UK Ethnicity facts and figures (Gypsy, Roma and Irish Traveller ethnicity summary - GOV.UK Ethnicity facts and figures (ethnicity-facts-figures.service.gov.uk))
-Tackling inequalities faced by Gypsy, Roma and Traveller communities - Women and Equalities Committee (Tackling inequalities faced by Gypsy, Roma and Traveller communities - Women and Equalities Committee (parliament.uk))
-University of Bedfordshire (Written evidence - University of Bedfordshire (parliament.uk)
-Census data

parts of the GRT community, which again makes for a stressful situation, and statistics show that 20.4% of the GRT community is made up of lone parents compared with 7.2% nationally. 55% of the GRT communities the EMA Team support are living in a house/flat. At least 30% of these would prefer to live on a site but there is not space. 6 families were driven off of the site they were resident at, outside of Milton Keynes.

Stress is a particular concern for roadside GRT communities, as they never know how long they will be able to stay in one place. Their options are limited as when they apply for legal rights to use land they are refused, so their lifestyle is being made illegal. Ancient, cultural ways of life have been eroded making the lifestyles of Roadside GRT communities very difficult, with the Local Authority moving communities on via Environmental Health. All of this means that life as a roadside GRT community member is stressful, and makes some aspects of leading a healthy lifestyle more difficult (e.g. cooking healthy meals).

> "That uncertainty of lifestyle is so difficult - the government is trying to make their lifestyle illegal. Originally this would have been solved by the planning laws as people would be able to apply to stay at a site but the council would decline them" ***- Danny Conway***

We were told that gynaecological issues seem to be common for women within the MK GRT community, with one suggestion being that this may be caused by women being encouraged to marry and have children very young in order to 'keep them pure'. There is also a reluctance amongst females in the community to talk about intimate health issues.

Dental health is poor and dental issues are common. We were told that dental care is very difficult for GRT communities to obtain.

Early cancer deaths has been a trend observed with GRT communities in MK.

We learned that mobility issues are often experienced amongst over 40 year olds in GRT communities, and the GRT community would benefit from knowing what support can be offered at home (e.g. for older people with dementia or other issues).

Access to fresh food is difficult for GRT communities, as many cannot afford it. We were told many community members are on benefits, and the cost of heating for example, for many on sites is extremely high (£150-200 p/w).

Access to support around parenting was suggested as a need in GRT communities:

> *"I also feel they (GRT Community Members) would benefit from parenting skills/ new parent support as I see the same mistakes in child care being repeated time and time again as parents raise their children the way they were raised without much*

*exposure to alternative ways." **- EMA Mentor***

The EMA Team told us that around 30% of the school age children they support have mental health issues and/or are autistic, with 5% of children having a learning disability and one child a physical disability. There may be more adults supported by the EMA Team with physical disabilities (aware of 6) and mental health conditions (aware of 3) but they may not have disclosed this. We were told that in primary School males struggle with education more than females, and about 80% of the boys the EMA Team support require intensive additional support. In secondary school those struggling academically are evenly split between male and female. The EMA Team are aware of adults with physical disabilities.

*"Most adults seem to have health issues that are being managed by GP & local hospital but they do still struggle to make GP's understand what the issue is due to barriers on talking about bodily functions." **- EMA Mentor***

The GRT community are spread across MK, housed on either the site at Willen or at Calverton. Neither site has a footpath to link it to the main thoroughfares making walking the children to school dangerous and difficult.

Recommendations

Fixed sites and housed travellers, - health visitor, and GRTs passing through.

Trusted long term engagement, flexible health provider and outreach to sites / individuals

Training, education and increasing cultural awareness

- Specialist analysis and a deeper trawl of the health data relating to GRT communities is needed to get a real grasp and more detailed understanding of the situation. Concern that the extent of health inequality within the GRT community is unknown and the situation is likely to be alarming. More data would allow the biggest issues to be understood and explore the reasons for them.
- Training for health providers around GRT lifestyles to increase cultural competence and understanding of people's perceptions and experiences (so health professionals 'get where they are coming from'). I.e. understanding that GRT people are only likely to ask for help if they really need it, and females may be reluctant to speak to health professionals about intimate health concerns etc.
- Support GRTs to increase understanding of what health services can offer (e.g. GPs), how referrals work, how to get them and how long they take and what services are available at home.
- Training and support for GRTs around parenting skills.

Adapting services and spaces to be culturally appropriate

- Long term, consistent, named visitors to GRT communities are needed to achieve positive engagement, trust, and to use lived experience to understand issues and support community members to co-design solutions that will work for them to reduce health inequality.
- Special provision for roadside GRT communities to access health provision, for example same day appointments to make access possible.
- Special work to make health settings more welcoming to GRT communities (to combat feelings that they are not welcome or 'looked down on').
- Services (eg dentistry, physical and mental health services) going out into GRT communities to engage directly.
- Digital exclusion is an issue - more ways to access information and services and feedback about services that aren't online or written would be beneficial.
- CAMHS support being available earlier and quicker, as mental health is a big issue for young GRT people.
- More visits to GRT children that are educated at home to monitor attainment and wellbeing (mental and physical)
- Make it easier for GRT communities to apply for legal use of land, including appropriate transit sites.
- Specific support to female GRTs to combat high prevalence of gynaecological conditions

Communication / information

- Avoiding written communications or need to write as literacy is a common issue in the GRT community and could form a big barrier.
- Services communicating with GRT communities in 'simple English' and not using complex jargon or phone calls from professionals with strong accents.
- Forms for GRT communities being simplified (12 pages or more for Paediatric referral with terms that are not in everyday language is very difficult for example)
- Keeping GRT families updated on health issues in a verbal or very simple written way.
- Increase awareness of available services, including wider support such as Foodbanks, Community Fridges etc to increase access to healthy food, support to decrease heating bills and/or financial support.
- Communicate the importance of good dental health and how to access services

The LGBTQ+ Community

- Q:alliance are the LGBTQ+ support charity for Milton Keynes, and are particularly well placed to feed into this report as they are currently involved in research and pilot projects related to mental health inequality in terms of access and experience for LGBTQ+ people in MK. The below also includes input from the CA:MK team gained from speaking to a range of groups with LGBTQ+ users or directly to LGBTQ+ people in MK, as well as via some insights recorded on our MK Community Data Tool.

Lack of knowledge and understanding relating to the LGBTQ+ community

One of the biggest issues facing LGBTQ+ people in MK relating to health provision is lack of knowledge and understanding. This includes a lack of knowledge around the LGBTQ+ community itself, as well as the issues they face. For example, poor knowledge around appropriate use of pronouns and what certain terms mean relating to sexuality and gender identity (a lack of cultural competency). It was noted that pronouns and terms are particularly important to younger LGBTQ+ people as a way to communicate who they are and how they feel - so a firm understanding and recognition of this is vital if health services want to support young LGBTQ+ people. A lack of understanding of specific issues such as gender dysmorphia and the gender reassignment process were mentioned in particular, with poor communication around what the transitioning process will involve to transgender people in MK.

Reluctance to access health services

This lack of knowledge within healthcare settings around LGBTQ+ specific needs and lack of cultural competency all add to the reluctance many LGBTQ+ people in MK have around accessing health services. Many LGBTQ+ people say they struggle to communicate with their GP for example, with some anecdotal evidence suggesting some GPs respond to gender identity issues inappropriately.

“One young person we work with, biologically a boy, told us they confided in their GP that they were questioning their gender identity, and were told to, ‘play more football, that will sort you out’...” **- MK YiS - recorded via MK Data Tool**

“We have had several young people come to us throughout the last year or so saying that their GP has been dismissive of their issues around gender identity. One young trans woman was told she should start playing more football and that would sort it out by her physician..” - **MK YiS - recorded via MK Data Tool**

GPs can also assume a patient is heterosexual, and treat them as though they are in a male-female relationship, making some feel uncomfortable in correcting them. Many LGBTQ+ people are scared of accessing mainstream services for fear of LGBTQ+ phobic responses and Q:alliance feels the LGBTQ+ community don’t access health support early enough. “Gender and transgender education for GP's” has been recorded on MK Community data tool as something that is very much needed.

“In some cases LGBTQ+ people avoid interacting with GPs altogether because they fear the worst - lack of understanding or an LGBTQ+ phobic response...” ***- Q:alliance***

Health care relating to the transitioning process for transgender individuals can be stressful

The issues facing people who are transgender, particularly around the transitioning process, was highlighted as a big concern. It has been reported that there is a lack of clarity and understanding following interaction with health services around what the transitioning process will involve, and what the timeframes are. This can be extremely stressful, confusing and isolating for transgender patients.

Mental Health

Some of the most common health issues users of Q:alliance mention are anxiety and depression, so appropriate mental health counsellors are extremely important. However, Q:alliance have found that there are a lack of specialist counsellors with lived experience, or at least a good knowledge of the LGBTQ+ community and the specific mental health support they need (e.g. around gender dysmorphia, gender reassignment etc). This means mainstream mental health therapy does not meet the needs of some LGBTQ+ people.

Intersectionality

Q:alliance told us they estimate around 30 - 40% of adults that attend their activities are neurodiverse, or are awaiting a diagnosis. Those with a diagnosis reported having to wait a long time to obtain it.

Health equality challenges are likely to be more keenly felt by LGBTQ+ people that are also part of the other communities of focus identified within the first phase of the Denny review. There are some particular complexities surrounding LGBTQ+ people from some ethnic minorities and faith communities (for example, according to Government research a large portion of the conversion therapy offered or administered to LGBTQ+ people originated from a faith group) and as mentioned above, a large proportion of Q:alliance activity users are neurodiverse.

Communication

Q:alliance believe that most of their users know the NHS website and resources are reliable sources of information, but more training to the LGBTQ+ community about what information sources are not trustworthy would be beneficial. If there were strong enough NHS resources relating to LGBTQ+ health issues, they wouldn’t need to seek information out elsewhere and potentially become misinformed.

Communicating lived experience, co-design and co-production

Q:alliance told us that the only active route they feel they currently have to interact with the health sector, and communicate the lived experiences of MK LGBTQ+ people, is via the MK VCSE Alliance and the MK Mental Health Alliance. They find these groups really beneficial in terms of linking and working with a range of groups, and in making some headway in communicating the health needs of the MK LGBTQ+ community. A recent survey showed that 80% of MK LGBTQ+ respondents had never been part of a steering group but that 73% would like to be. This shows there is an appetite for involvement in co-designing / co-producing services, and in expressing lived experiences to affect change, but few opportunities to do this in a focused way.

Recommendations

Adapting services and spaces to be culturally appropriate

- To overcome the fear and mistrust associated with mainstream services, health providers should consider working with an LGBTQ+ specific organisation to reach LGBTQ+ people, and support them to access healthcare. Such organisations are trusted by the community because (unlike mainstream services) they feel they will be understood and not discriminated against.
- Sometimes Q:alliance users speak about health issues (physical and mental) at Q:alliance's social activities, however this space isn't always appropriate. Opportunities for LGBTQ+ people to speak about health in a designated setting with specialist support would help.
- Particular activities or services that support LGBTQ+ people with intersecting vulnerabilities in terms of health inequalities, e.g. those that are neurodiverse. Long term and careful support for LGBTQ+ people from ethnic minority and faith communities may also be helpful.

Training, education and increasing cultural awareness

- Training around LGBTQ+ cultural competency and specific healthcare issues. Q:alliance provides training around cultural competency, trans awareness and pronoun use for example, and this kind of training has been used by many organisations (including Thames Valley Police) in order to ensure staff have an appropriate level of knowledge and can therefore provide accessible, welcoming and useful services for LGBTQ+ people. Training to ensure healthcare providers have a good understanding of the experience of trans people and of how the transitioning process works would be beneficial.

Communication / information

- Q:alliance would like to explore any opportunities to work with Healthwatch around supporting LGBTQ+ individuals to voice their experiences re health.
- Resources and communications regarding health and wellbeing being more 'fun' would be welcomed.

Actions Taken So Far

- Q:alliance have teamed up with Talkback to create a safe space for LGBTQ+ people who are neurodiverse
- Q:alliance training MH alliance and other MH / health / wellbeing groups
- Q:alliance joint work with crisis cafe - suicide prevention.

- Q:alliance are engaged on projects to reduce health inequalities within the LGBTQ+ community, particularly focussing on mental health, working with The Crisis Cafe (a high proportion of attendees at the Crisis Cafe are transgender).

Mental Health Conditions - Detailed Report

- We spoke with Jon MacPherson who has extensive experience of supporting and working with people with mental health conditions. Jon was previously the Service Manager at Rethink Mental Illness and has worked as a health trainer within Milton Keynes within areas of high deprivation with mixed population groups.

Health professionals understanding of mental health conditions

We were told that health professionals such as GP's have a lack of understanding around mental health conditions and how they may affect a person's life. This lack of understanding can lead to what is known as shadowing - the proposition that a health professional will put ailments or illness down to a person's mental health condition and therefore, dismiss it. Additionally, GP's may not always have a great understanding of how a mental health condition can affect a person's ability to access and interact with healthcare services.

> *"GP's not having a good understanding of how mental health affects people. The anxiety of waiting for a phone call or going to a GP practice. Also, because of mental health, some people cannot manage a diary or calendar. They will miss 3 appointments and then be under the threat of being discharged from the surgery."* ***- Jon MacPherson***

Communication

Poor communication was an issue highlighted during our discussion. We were told that in terms of communication, there is a lack of trying to meet personal needs in the way in which people want to speak with health professionals and receive information.

> *"[a client] did not want to speak over the phone due to having family around and requested to receive information by text or online but this was declined. "* ***- Jon MacPherson***

We heard that one way to improve the experience of connecting with healthcare services could be by letting people know what services are available. There seems to be a communication barrier around the variety and availability of services.

Common Health Issues

We learned that a poor diet is often experienced by people with mental health conditions and heard that one approach is to take a holistic view with the promotion of healthy diets being important. In terms of mental health, we were told that there is a difference in having self awareness and being able to recognise that you are becoming unwell. We also heard that older adults with diabetes can have difficulty managing their condition such as medication management due to their mental health.

Accessing health information/services

Accessing health information online can be affected by one's income, willingness or ability to use the internet. Raising understanding about skill and confidence may reduce digital exclusion within communities. We also heard that current NHS services should provide outreach to existing groups. Unfortunately, this way of working seems to have declined significantly over the last few years but if implemented, would be beneficial.

> *"[A mental health charity] had a nutritionist come into the service and people talking about diabetes. 'Rather than people being expected to go to the specific healthcare provider or service?' yes."* ***- Jon MacPherson***

When accessing healthcare services, finding an advocate for a client with mental health conditions can be challenging. Historically, mental health charities would offer services whereby support workers could accompany clients with severe mental health conditions to appointments such as GP or benefits appointments. This service allowed clients who had reported having difficulty with understanding information the support of having someone else there with them. However, due to funding cuts, there is less 1:1 support available. Additionally, accessing prescription reordering services can be an issue and result in missed appointments such as support sessions. We heard that service users had to cancel support sessions due to needing to sort out issues related to repeat prescriptions. Not only did this result in missed appointments, it also heightens stress and anxiety.

> *"Our support worker (Mind BLMK) would accompany them if need be, but the nature of the service has changed. So that sort of 1:1 support, as far as I understand, has greatly reduced. So having someone to advocate for you is quite difficult to find now."*
> ***- Jon MacPherson***

We also heard that there can be a considerable perception that if a person with a severe mental health condition asks for help as they are 'struggling', they could be forced to visit an acute mental health ward.

> *"There is a considerable perception that if people ask for help and said i'm struggling, that they would get locked away in the acute ward in the Campbell Centre, which isn't true. I mean we would say look it's really difficult [to visit an acute mental health ward] but that prevented them quite often from saying what they were experiencing."*
> ***- Jon MacPherson***

Additionally, previous research looking into health inequalities around mental health and physical health highlighted the lack of involvement people with mental health conditions feel they have in their own care.

> *"Rethink Mental Illness did a project two and half years ago looking at health inequalities around mental health as well as physical health. One of the themes that came out was that people didn't feel involved in their own care, sometimes it's done to people, without proper discussion of issues in treatments. Also, a lack of encouragement for people to be involved in their own care."* ***- Jon MacPherson***

We were told that there used to be opportunities to connect with health services such as when the partnership board introduced separate sessions for service users which then fed into a further meeting between professionals and the NHS. In essence, it was a forum for people to voice their needs. Healthwatch Milton Keynes supported this but unfortunately, it stopped. Additionally, we were told that people can be reticent about being involved in opportunities to directly feed their experiences to health services, and/or to co-produce services or solutions to issues, even with Patient Participant Groups (PPG's). This reluctance can be due to a lack of confidence.

Recommendations:

Adapting services and spaces to be appropriate and accessible

- Non-mainstream ways to help people with mental health conditions manage their appointments e.g. send the appointment to the service user and a NOK
- Services to highlight services users can have accompaniment when accessing appointments e.g. GP receptionist to mention that a friend/family member can attend if the nature of the appointment is regarding mental health
- Allow free communal opportunities to access internet services in order to access online health information/services

Communication / information

- Reinstate sessions for service users to voice their needs as part of the partnership board
- Requests for personalised communication to be better acted upon
- More education about healthy diets as part of mental health support
- Sharing information about available resources for mental health within Milton Keynes

Training, education and increasing awareness

- GP surgeries/PCN's to explore patient experiences and views of Patient Participation Groups (PPG's) to understand how to better use them
- Further research around people with mental health conditions' perceptions of healthcare staff's understanding of mental health
- Education co-produced and co-delivered by mental health professionals and people with a mental health condition to staff working in mental healthcare including GP's
- More mental health education within GP training - "During their training, GP Specialty Trainees (GPSTs) spend 18 months in clinical placement posts, and a further 18 months in general practice. There is a single opportunity for GPSTs to do a mental health placement within this three years, which is through a placement in psychiatry" Mind (2018)
- Education around diabetes management during periods of worsened mental health
- Education around being able to recognise when you are becoming unwell
- Tailored computer training courses focused on accessing online healthcare systems/services run by VCSE organisations linked to specific GP surgeries/PCN's across Milton Keynes to reduce digital exclusion within communities
- Reach out to private companies to obtain donations to reduce digital exclusion e.g. computers, sim cards etc.

Actions:

- CA: MK staff to liaise with ICB staff responsible for Patient Participation Groups (PPG's) to share insight
- CA: MK to liaise with VCSE organisations that offer computer training to tailor service to accessing online healthcare systems/services

Migrants - Detailed Report

Welcome MK are the VCSE organisations that have been supporting refugees from Afghanistan in Milton Keynes. Afghan refugees have been living in hotels in the City since they came to the UK. The CA:MK Team has also worked with volunteers and Harben House, and The Wisdom Principle engage with migrants through their work.

Communication

One of the biggest challenges in supporting refugees and migrants to access health services and stay healthy is communication.

> *"For migrant communities, there isn't anywhere that fully explains how to access services and what their roles are. Knowing what is available is a challenge."* ***- The Wisdom Principle***

When arriving in England, refugees are given information about health services including education about 111, the emergency services and A&E. This information is provided by Welcome MK or MKCC. There are also medical posters within Harben House, the hotel where the Afghan refugees are living. These are all helpful, but just the start of the support needed.

The most obvious communication issue is the language barrier, and we learned this can cause miscommunication in all levels of care. Understanding what health services and information is available can be made easier by simply having a good level of interpretation.

"[When discussing difficulties with communicating well and being understood when discussing health and care with staff in health and social care services] Language and appointments, understanding what is available, but if they had a good interpretation, then they would understand what is available and what different things mean." ***- Welcome MK***

Simply booking appointments is difficult, as is trying to describe an ailment without misunderstandings causing misdiagnosis.

"An Afghan lady ended up giving birth standing up with her child delivered on the floor due to miscommunication regarding her pregnancy" ***- Welcome MK***

Using a telephonic translator can be uncomfortable when discussing personal medical problems. There is also the issue that translation can be complex as in Afghanistan, there are some languages that only some parts of Afghanistan speak and that other Afghans don't speak. This means that in some cases the lesser spoken language is translated by a family member or friend into the more common Afghan language to be translated into English. This causes concern that information regarding health will be misunderstood as there's more chance for it to 'get lost in translation'.

"A double translation was required for a client and the NHS cancelled it because they were worried that it would be mistranslated. In the end it was reinstated but how can we ensure we support this moving forward?
How can this translation be effectively facilitated in health services? I don't have the answer but we need one. Are there examples from other languages, areas, countries…?" ***- Welcome MK***

In terms of supporting refugees to learn English, this can be more challenging for some. For example, some Afghan women have not been educated as they grew up under Taliban rule, so they have a very difficult starting point. Developing the knowledge and skills to learn a new language would require a lot of time and support.

> *"Groups that Welcome MK provide are about empowering the ladies and increasing their mental wellbeing so that they can function independently."* **- Welcome MK**

Vaccinations in the UK, once explained to Afghan refugees, have been well received. However, there have been issues in accessing medical records and information on what vaccinations have already been received and what they were for, for example by Afghan children.

Finding alternatives to medication refugees are already taking can be challenging, this is difficult if the GP cannot understand the medication packaging or medical notes. Equipment used can also be different and incompatible with UK items, adding another layer of challenges.

> *"An individual required something for their diabetic machine but this couldn't be sourced. Therefore, the client then needed a new machine and had to learn how to use the new machine."* **- Welcome MK**

The Health Centre closest to the hotel Afghan refugees are staying in has been helpful in setting up systems to support access and communication and has set up a dedicated phone number for refugees to call.

> *"People's starting point is different. The key to anything is knowing where the person comes from and building from that - finding alternatives to what they would have accessed in their home country and trying to meet their needs."* **- Welcome MK**

Common Health Issues

Dental Issues

Welcome MK told us they estimate common health problems are a 50/50 split between mental and physical health including high blood pressure and depression.

Dental health is a big problem for Afghan refugees with the majority having dental issues, and access to dental services has been difficult. People are advised to contact 111 but the closest emergency dentistry services are in Luton and Northampton, which is impractical as refugees will not be able to travel there. There is a lack of knowledge around dental hygiene (e.g. refugees needed to learn that toothbrushes are not disposable, single use items) and support to understand how the system in MK works in terms of GPs Vs Dentists. However, this education has been difficult with the dental services available to signpost to, as many are not accepting new clients.

Mental Health and Trauma

Welcome MK told us there is a lack of mental health support, with MK Talking Therapies only having become involved in the last few months, when Afghan refugees have been in MK for 16-17 months. They told us that refugees came to MK having experienced severe trauma, some with gunshot wounds for example, so trauma teams and mental health support needed to have been in place from the start. We were also told that there has been no involvement from CAMHS.

> *"Children were experiencing night terrors during November due to the fireworks"* ***- Welcome MK***

It was expressed that the need for ongoing mental health support is a big need, with individuals having gone through so much and many having family and friends back home, so they are constantly worried and anxious about their safety.

There is a concern that some mental health conditions can come to be thought of as normal.

> *"Some migrants are experiencing PTSD, but it goes unrecognised and is normalised"* ***- The Wisdom Principle***

Cultural differences

People living in Afghanistan are used to queuing for services and being seen that day, so the concept of waiting lists, or pre-booking and waiting for an appointment are unfamiliar. There has been a need to explain that this situation is not because they are refugees, but rather just how the system works in the UK.

Many Afghan refugees have large families (6-8 children for example), and in Afghanistan they would live with relatives so childcare was never an issue. However, as they have come to the UK without that support network, they struggle to access appointments as taking 8 children with them is impractical. If a father is working, there is often a fear that if they take some time off to support with childcare to enable wives or children to attend medical appointments, they will lose their jobs. More education is required around this, and there needs to be more childcare support for refugees with large families.

Female refugees being supported by male doctors can be an issue, especially when accessing support on specific issues.

Harben House have worked with refugees to ensure the food being provided is culturally appropriate, with one refugee having gained part time employment as an advisor as a result.

Recommendations

Training, education and increasing cultural awareness

- Programmes to support Afghan women, who may not have been educated previously, to develop skills and independence.
- Support to health providers around understanding current medication and medical records of refugees, and accessing alternatives.
- Education around dental health for Afghan refugees
- Afghan culture and health system / norms training for service providers, as well as similar education support to refugees around UK health system and cultural norms.
- Education for Afghan Refugees on rights to take time off work to support families access health care.

Adapting services and spaces to be culturally appropriate

- More joint work with health providers, VCSE groups working with refugees / migrants and refugees / migrants themselves to make services more accessible and effective.
- Ensuring access to dentists is available to Afghan refugees.
- More and ongoing mental health support to refugees, adults and children including specific support relating to trauma.
- More support with childcare to allow Afghan Refugees to access to health care
- Access to female GPs if and when female refugees require this.

Communication / information

- Research and development around appropriate solutions to translation issues. Including allowing refugees that don’t speak English to access translation services that make them as comfortable as possible in sharing personal information, and around how to overcome the significant challenge of translating uncommon languages spoken in Afghanistan without mistranslation occurring through information being translated twice for example.

Voice of LGBTQIA+ Luton Residents

Healthwatch Luton's report for the Denny Review

January 2023

Contents pg

1. Glossary - Stonewall

LGBT stands for Lesbian, Gay, Bisexual or Transgender and the plus sign stands for a range of other descriptions people may choose to use. HWL have opted to use the term LGBTQIA+
The charity Stonewalls definition of these terms is below:
Lesbian Refers to a woman who has an emotional, romantic and/or sexual orientation towards women.
Gay Refers to a man who has an emotional, romantic and/or sexual orientation towards men. Also a generic term for lesbian and gay sexuality - some women define themselves as gay rather than lesbian.
Bi is an umbrella term used to describe an emotional, romantic and/or sexual orientation towards more than one gender. Bi people may describe themselves using one or more of a wide variety of terms, including, but not limited to, bisexual, pan, bi-curious, queer, and other non-monosexual identities.
Trans is an umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth. Trans people may describe themselves using one or more of a wide variety of terms, including (but not limited to) transgender, transsexual, gender-queer (GQ), gender-fluid, non-binary, gender-variant, crossdresser, genderless, agender, nongender, third gender, two-spirit, bi-gender, trans man, trans woman, trans masculine, trans feminine and neutrois. TGD – Trans Gender / Gender Diverse
Q is Questioning or Queer – intermittently used
I relates to Intersex
A is Asexual
+ Stands for other terms, such as but not limited to 'non-binary': An umbrella term for people whose gender identity doesn't sit comfortably with 'man' or 'woman'. Non-binary identities are varied and can include people who identify with some aspects of binary identities, while others reject them entirely.
MOM – Man on Man (Sexual encounters)
Cisgender or Cis Someone whose gender identity is the same as the sex they were assigned at birth. Non-trans is also used by some people.
Transitioning The steps a trans person may take to live in the gender with which they identify. Each person's transition will involve different things. For some this involves medical intervention, such as hormone therapy and surgeries, but not all trans people want or are able to have this. Transitioning also might involve things such as telling friends and family, dressing differently and changing official documents.
Other terms: (https://www.stonewall.org.uk/help-advice/ glossary-terms)
SMW – Sexual Minority Women
HWL – Healthwatch Luton
VCSE – Voluntary and Community Sector

> *'If there truly was no stigma in 2022 – you would not be seeking my views. I don't represent everyone, but can only ask you just see this as my view – a human, a person, who is struggling because I don't know where to go for support. That, - that is the part I hope you can help with.'*

2. Methodology of Engagement and Feedback

This report was commissioned by the BLMK Integrate Care Board.

The Denny Engagement Project was commissioned by the BLMK ICS after the Denny Literature Review was completed, to look at those disproportionately affected by COVID-19 across Bedford, Luton and Milton Keynes.

The Denny Literature Review had three distinct stages:

Stage one - A literature review to assess the existing information about health inequalities and their impact on BLMK Communities. This review pulled together the common themes and identified the gaps and understanding of good practice relevant locally – and used this to inform strategy and service change
Stage two - An engagement exercise listening to individuals and communities about their experiences of health inequalities and working together to think about how to address them effectively
Stage three – the development of co-produced practical recommendations for action by the whole health system; its partners and communities, supporting the achievement of the ICS Strategic Priorities and targeted resources to making positive difference collectively.

This report outlines the Stage Two section organised by Healthwatch Luton, within Luton, with their Collaborating Partners:

Healthwatch Luton had already begun a project to gather views from those within the LGBTQIA+ community in Luton, which from prior year's feedback had been shown to be lacking. With this project already underway, Healthwatch Luton were commissioned to support the Denny Steering group, with questions from the steering group to determine how to analyse thematic responses to feed into Stage 3.
Healthwatch Luton began this work in July 2022 – and did not find a suitable and collaborative partner until September / October 2022. These partners are now:

- Penrose (x 5 LGBTQIA+ Ambassadors and connections)
- Pride in Luton (Committee and Contact connections)
- Individual Collaborators (x 4 individuals)

Healthwatch Luton, after doing an initial findings survey, realised we could not 'partner' with one individual group / community led support service in Luton. Many people within Luton provided feedback that they were not attributed nor represented by just one partner, and so we opted to partner with two community organisations and individuals we called 'Collaborators' who provided personal insights.

Healthwatch Luton used the following methods to gather the feedback:

- Individualised Interviews to create supporting Case Studies for the report
- Healthwatch Luton's own survey – for initial findings
- Initial Statements reviewed by Partners for discussion
- Denny Engagement Survey – using questions confirmed by the Denny Steering Group
- Healthwatch Luton's Listening Events – online forums on a arrange of topics
- Individual phone-call discussions; interview style
- Feedback centre – generalised feedback Healthwatch Luton had gathered
- Healthwatch network events and discussions with other Healthwatch and their feedback

Healthwatch Luton also did a review of the Healthwatch networks' reports to determine other leading themes which co-existed in Luton, and those which the feedback from the Denny Partners would be solely regarding Luton residents.

In total, Healthwatch Luton, in 2 months gathered feedback in some form from just over 50 (52) Luton residents and people who were happy to respond to our engagement, either via survey, interview, email or phone call. Some residents no longer resided in Luton, some reflected views outside of Luton, but all had heard of our work through the Collaborators we worked with on this project about Luton and BLMK.

All views are anonymised and not associated with any individuals, and cannot be attributed to any person. All likeness in Case Studies have been removed for anonymity and where people have disclosed their data, we have sectioned them out. Where a name has been attributed to a quote this has been done with full consent and all who took part have fully consented for their views to be used by the ICB Denny Steering group and engagement and Healthwatch Luton for ongoing use.

All images used are from Healthwatch England's stock images (BrandStencil) and not attributed to the views relayed to Healthwatch Luton – but have been used to reflect the reporting in a more stylistic approach.

3. Report Statement – Limitations

Report limitations within our engagement

- Healthwatch Luton worked with two organisations for this project. Due to timescales, the deep relationship management usually considered in our engagement was unable to be completed, but we hope to carry on working with individuals from those community groups in to 2023 to gain further views
- Individual collaborators and people who contacted us 'offline' outside of our usual routes were quite enlightening to our findings; including terminology discussions, non-aggressive training and outlining of 'stereotypes' and general support in continuing the conversation with the health and care system
- The term 'community' was one of the most common themes, particularly during interviews and case study discussions during the course of this work. People felt very much there was a difference in the 'community' which tended to be 'out and proud' and those who identified as LGBTQIA+ and not associated with an organisation or group; this terminology is used within this report for those who found the terminology important.
- There was an over-riding review of support being held or led by 'gate-keepers' – who tended to want to lead in supporting people with similar views; but also resulted in other LGBTQIA+ residents not associating or being able to engage with community 'support' organisations; particularly from non-white non-British collaborators
- The timescales for this work has, for Healthwatch Luton, outlined that further work is needed regarding understanding more from how we can support people who identify as LGBTQIA+. **This report should be the starting of a conversation that can help change and improve service delivery.**
- HWL worked with two partner VCSE groups – Penrose, and Pride in Luton. Due to timescales, these organisations have provided a wide range of input into this work – but both have stated those contributing views do not reflect all the voices needed to be gathered in order to make this a BLMK overview; further work is needed.
- It has been made clear from those we have spoken to that each individual's journey and experiences only represent their own; and should not be taken as a reflection of all those who identify as LGBTQIA+ across a regional area; and more in-depth work would be needed at each Place area
- Most willing to 'speak' to Healthwatch were mostly white and British. Views captured of Asian, Black and Ethnic minorities were harder to receive in the timescales provided. Through developing our approach, and with longer timescales, we believe we could collate more views to represent the ethnically diverse population better.

'You keep referring me as part of a 'Community' – which I am not. I am just me, trying to figure out what I am and how to navigate my life. The less the system tries to pocket us into groups would be a start to understanding half our needs.'

"The approach is always – ask 'them' about this one topic– so we know how to deal with them. Why doesn't the system recognise, if they changed *their* approach, we wouldn't be a 'them'.

'Most of the support groups I am aware of – or are signposted too – are run by middle-aged white men, who may or may not be gay. That doesn't reflect me, my life, my history and who I need to connect with. It's another mis-hap, and I don't know what to do to change that.'

"I don't know if they even realise half of us are also just trying to figure it out. It's great to be asked my opinion, but I am willing to give you my views. It's those I know who won't step up that need to be heard, and I am not sure, unless the world changes to support them entirely, whether they ever will be.'

'For those of us who do refer to the 'community', it is entirely invaluable; without having what I class as my community; which are virtually my family now; I am unsure of what I would do. I know not everyone feels the same – but for me – it has been all the support I needed.'

4. Overall Summary Findings

From the people who identified as being Lesbian, Gay, Bisexual, Trans, Queer/ Questioning, Intersex, Asexual or Other + - these are the overall summary statements taken from the responses we have been provided.

- Older and younger people (throughout the feedback) reflected on their **feelings of anxiety and isolation** which had been exacerbated through the COVID lockdowns; but is also driven by micro-aggressions and experiences throughout their lives
- **Anxiety was outlined as a 'baseline' feeling** for many young LGBTQIA+ people, stating that 'as they start the day they probably worry more about how that day will be' than their straight peers; within this – many knew of the offering of self-referral mild / moderate mental health support, but none had engaged with the service due to not feeling it would be supportive; reflective; knowledgeable
- There was a **distinct lack of culturally appropriate support** for varying ethnicities and identities; generally health services and community support services that were most funded / most awareness, were not culturally reflective of many of those we spoke to
- There was a common theme of **diagnostic overshadowing** – a term used by a few people we spoke to, referring to feeling dismissed or there experiences being 'downplayed' or dismissed
- **Cis-normative communications** in health and care was a large theme discussed throughout the project, and that a change in terminology in data gathering would be beneficial and supportive, and even lead to discussions that may support health and care needs
- **First contact care** affects lifetime of health and care interactions; and people discussed if their first interaction (at any age) with a health or care provider was negative, cis-normative, or un-engaging to allowing them to express (or not) their identity, it had a lifetime effect on how they continued to engage / trust the health and care system.
- Some medical professionals still made some people feel like **'medical curiosities'** and this will have a profound effect on how they engage with health and care ongoing. This approach needs addressing particularly for the trans / transitioning community
- **Medical identity** needed to remove the 'tick boxing' element in continuing care or referrals. Some residents expressed seeing sight of their medical notes which referred 'Lesbian / Gay' at the top – regardless of the health condition, which would not be consistent for 'straight' patients.
- It was discussed on a few occasions, and highlighted in a few survey respondents that the **'gate-keepers' to community** support could sometimes also create division and cultural disparity – leading to particular some younger (black) residents not associating with statutory or community support.

- ‘**Concealment’ factors** were particularly raised in the Black (British) and Black (Caribbean) feedback, highlighting stigmatisation within their own community (cultural stigmatisation) led to some not being able to raise their views due to fear of community rejection.
- Many from non-white ethnicities (mainly Pakistani / Bangladeshi / Hindu feedback but also noted in Black Caribbean) discussed **cultural disparity in seeking health and care support** – where when unable to see culturally ethnically reflective health and care staff, could cause dis-engagement and lack of trust
- Many young people outlined the **lack of age -appropriate support for young people** ‘questioning’ their identity. Some felt the ‘appropriateness’ of the information was set by those outside of their age range without discussion – leading to some young people not feeling guided
- Some **young people reported ‘self-education’ and ‘educating down’** was happening among young people (particular in the White / and South Asian young feedback). Because of a lack of appropriate support, young people were researching and teaching young people, and felt this could be improved
- One family discussed the lack of support they perceived whilst transitioning from male to female – for their children. The reflection was provided anonymously, **asking for more support for trans children, or children from Trans parents.**
- For those who had positive experiences, they thought that **general staff / workforce attitudes were improved** than from historical experiences when younger; they found stigmatisation to be limited, and for those with positive experiences – found the **health and care system supportive and empathetic**
- **Access to services –** was generally deemed as needing more up to date and appropriate timescales – for most health and social care settings
- **Understanding different cultural perceptions and backgrounds –** key to addressing cultural competency and awareness; many different ethnic minorities displayed concern for general mis-understanding of their general cultural differences; which affected accessing health and care
- **Terminology understanding –** use of the correct terminology goes a long way in providing assurance and trust for people experiencing different gender affirming /dysphoria expressions. Understanding terminology supports people’s interactions with the health and care services (binding, packing etc) and training would be recommend to update health and care workers on this terminology

- **Sexual Minority Women (SMW)** – already feel displaced and 'invisible' as minority women in white towns, feel dis-engaged when discuss 'women's health' due to feeling unsupported. Combined wider determinants (being ethnic minority and gay/lesbian) increases lack of feeling heard, empowered or supported in health and care journey through their life.

Luton Sexual Health services was mentioned by over half of all those we spoke to, and nearly all rated the service positively / had positive interactions with the provision. I-CASH was another sexual health provider that was rated highly.

Of those who did not rate the service highly – the theme was around needing more funding / more outreach in younger audiences / more cultural groups / sessions held / more extended hours in availability.

5. Findings from the Denny Project:

The main topics of the Denny Engagement for the ICB were situated around the following themes and questions:

- What worked well?
- What didn't?
- What and how could it be improved?
- Communications and being understood
- Tools and messages for self care
- Support around self care
- Trustworthy messaging and advice
- Health prevention

Healthwatch Luton used these questions as agreed by the Steering Group from the ICB outlined in the project proposal. We also however, adapted some of our interviews and forum questions to understand information further from the Denny Collaborators and participants.

We included questions around

- Communications general and inclusive messaging
- Training and staff competencies; beyond cultural competency
- Access to services and awareness of services
- Stigmatisation in health and care

Outside of the two Voluntary organisations who supported this work (Penrose and Pride in Luton), and aside from the individual Collaborators, toward December 2022 we began to receive individual anonymised phone calls relaying experiences to us. We amalgamated these views with our Denny respondents and thematically analysed along with our formal partners.

Allowing individuals to feed into this project alongside our partners ensures we capture as many diverse views as possible; and seemingly black and Asian responders mainly preferred the interview and phone call route to providing input.

What works well?

- Generally feedback highlighted **staff and staffing attitudes** more favourable (in over half of those who responded) – words used were, 'caring, respectful, empathetic, responsive'
- Therapist using **inclusive language** and being supportive opened up more honest dialogue between health and care clinicians and patients; resulting in more trusting relationships for ongoing care
- **Luton Sexual Health services/ I-CASH** – many mentioned this provider and service favourably in support; for content provided, knowledge and educational information
- **Hospital support was 'great'** from a few respondents; 'non discriminatory' and 'empathetic' when sexual health was affected
- For those who are engaged with health and care services, many had similar issues to general population concerns (like GP access, dental access etc) and few found their orientation was involved in this
- **Health prevention messages** (on general health) were clear – but could be advertised more in more appropriate places; digital forums, apps etc
- **Digital access to clinicians where available –** worked best for a lot of responders, to support anonymity (for those where this was important) and choice of appointment

What wasn't working well?

- **Waiting for gender identity psychoanalysis** before turning 18 – or receiving under 18 information lacking; more general information on this would be helpful
- **GPs** – many felt not enough time to discuss issues available, being seen face to face, continuity of care lacking by never seeing same GP – made it harder to have honest open conversation; online and phone were generally working well, but needed longer time to open more
- **CAMHS** – no follow up after referrals, – resulting in admissions; more than a few respondents outlined waiting times for support being an issue for young people

- **Staff shortages** – resulting in long waiting times, lack of resources, and no time to provide good health or care;
- **Referrals / Hospital Discharges** – not much support
- **Feeling misgendered** – or dismissed '2nd class citizen' or 'ignored'; some outlined challenges in correcting gender representation on more than one occasion; resulting in fatigue and irritation
- **Lack of awareness of support service** – or lack of culturally or age appropriate groups; with culturally appropriate staff and workforce
- Those who were not engaging in health and care had psychological **and deep routed traumatic experiences which dis-engaged** them and would most likely never recover to engage with HSC
- **Advice outlet** for young people / older people / people from different cultures to have sexual health information and guidance; more than just in sexual health clinics
- **Diagnosis and symptom management information –** available at outlets such as Sexual Health services but if not engaged with these services, feel limited communications (e.g. HIV diagnosis)

What could be improved?

- **Access to sexual health services –** to be more appropriate for the working person; sometimes staff shift / opening hours are not appropriate for people in various age/ cultures
- **GP or General Health support access** – to be more available, time allowing for more person centric and honest discussions
- **Health Literacy –** for younger people to be more available in more accessible places (such as schools) and for older to be more available for aging members who identify as LGBT+
- **More education on Gender services –** these are well known by those who use the sexual health services but those who do not know, need to be promoted further, and more outreach options available
- **Inclusive language –** to be used more in general health and care paperwork/ data collation –
- **Cultural competency –** felt generally competency was there, but actually more in depth signposting and training on behaviours, relationships and ongoing health support
- **Comprehensive assessments –** to be more widely available for all with regards time of assessments, length of assessments and where assessments take place
- **Gate Keepers within the community –** should not be used as always representative and the term 'community' to not always be used as a tick

box summary of those who are LGBT+; understanding language usage important for engagement

- **General Communications on Sexual Health** – to be more apparent in general society – not just allocated to sexual health service provisions
- **Extending opening times** – for information outlets and providers – to ensure working well are able to use as well as within day / 7 day service
- **Local people refer to local services** – whilst have opportunity to attend town wide / regional wide support – for those who cannot access, need online / digital versions available more

6. Recommendations for the Denny Steering Group

The recommendations below on the next page reflects the overall recommendations suggested by collaborators, either individually or thematically analysed as part of this engagement; as well as overview from Healthwatch Luton.

These recommendations are based on the work completed through September – December 2022 and ongoing engagement with these collaborators, but the main recommendation for the Denny Engagement Steering Group would be to **develop further engagement more sustainably** to ensure co production can be achieved in the future.

Many collaborators felt this engagement was 'a good start' to understanding some issues faced by some people; but that overall the general health and care system needed to continue to develop engagement in this process in order for residents to trust sharing their views made a difference.

Many praised the overall staffing and staffing attitudes in health and care; and many acknowledged general issues in health and care unaffected by someone's sexual orientation or gender identity (such as GP access) However, the reasons for being affected by GP access outlined some specific issues for people who are LGBTQIA+, such as how they build trust to explore and discuss sexual or orientation health and care concerns.

The recommendations are outlined – but are brief due to the nature of this short-timed programme of work. **Healthwatch Luton would recommend**

- The Denny Steering group review this report in full and review the thematic **changes which can be made at Scale**
- Healthwatch Luton would like to share this report at Luton Place and Health and Wellbeing – **to review what can be supported at Place**
- We would also recommend this report be taken as a '**start' of a process;** and that these recommendations are not a representation of everyone in BLMK who is or identifies as LGBTQIA+

- SCALE – ICB
    - Healthwatch Luton would recommend that the ICB review the approach to engaging with the Luton community regarding seeking experiences of a 'set piece' work – and start to adapt their communications and engagement to be more inclusive and less cis-normative generally;
    - Digital support to be progressed; for anonymity and time – many supported a digital strategy of progression allowing more people to access health and care; for anonymity
    - ICB to review approach to engagement at both scale and place; one Luton resident review does not reflect those across BLMK – and need to ensure steps for planning engagement going forward at scale
    - ADVICE LINE – for all health, before 111 or after GP access tried – for general concerns but also for health related to gender / YP / Isolation / - for advice and info – not for diagnosis or referral (could be non clinical)
    - Training and development in LGBTQIA and approaches to languages when used in diagnosis / coding etc / not being seen as medical curiosities or dismissed – leads to dis-trust in honest health conversations – cis normative languages
    - Challenge the view of systemic racism and homophobia within the health and care institutions –many viewed this to be a priority
    - Provide funding / support for different ethnic minority led awareness / support groups – need to be racially / ethnically appropriate or supported
    - Just over half of responders felt stigmatised when accessing health and care – needs to be addressed; and deeper work undertaken to review why this is
- PLACE – Luton
    - More funding to be allocated to support services that are currently working well and engaging with communities (Luton Sexual Health / iCash – Dunstable etc)
    - Extending hours of clinical assessments to be more appropriate for 2022-23 needs; extended clinics; available workforce for sexual health needs outside of 9-5
    - Culturally targeted support for different cultures / ethnicities – relevant to language used, workforce appropriate representation; support groups to be supported with funding in Asian and black communities
    - Luton Place Board to review findings and discuss potential local action plans; to feed into wider ICB plans for support. Luton JSNA outline HIV diagnosis concerns, and Engagement outlines access to diagnosis lacking from those we spoke to
    - Trans community small but apparent in Luton – research wider network shows more who won't come forward.
- Healthwatch Luton and Collaborators recommendations to provider / commissioners:
    - Training to staff / workforce around informing health and care staff on how to advise and support 'behaviours' and 'relationships' – not just general awareness
    - Trans people felt much more work was needed in general awareness of individual needs; as much as for culturally competent language and acceptance; stigma was noted most within / from these responders
    - Cultural competencies to be reviewed; most competent but need further work in workforce on signposting for behaviour / relationship information
    - Reviewing all generalised areas of working well and not working well to be constructed into action plan to review at SCALE< but also, at PLACE
    - Mental health Services known of generally – being appropriate for gender / sexuality not found so much

Further Report Details

7. Case Study 1

Profile: 24, Female, Pakistani, Queer/Questioning

We spoke to one lady who outlined various barriers she had faced in her own community regarding her own identity. She was very articulate and welcoming of having the opportunity to speak about her experiences, but highlighted the need to spend more time developing trust from any members of Luton residents to ensure more views could be captured.

All our case studies have been summarised, edited and stylised to produce an outline of the hour interview conducted.

Young female, Questioning, Asian (Pakistani)

"Being an Asian woman in a white British town creates, for some, a particular sense of invisibility when it comes to health and care anyway.

If you grow up seeing white women who don't reflect your family or self, in every image, text book or media image, you learn to dis-engage very early on. Having said that, I have to admit more cultural appropriate images have been seen on health messages more recently – but I wouldn't say it's the norm.

With this early dis-engagement and invisibility, layered with being queer, or questioning your sexual orientation or identity, just adds so much aloneness to feeding into anything that you think may change. We are constantly told Luton has more Asian people than other towns, and yet everything I still encounter is white – white messaging, hetro-normative messaging – nothing that ever speaks to me as a young questioning Pakistani.

I think white people also can't or won't grasp deeply held cultural and religious and societal views which we hold in our families, and in our sense of selves.

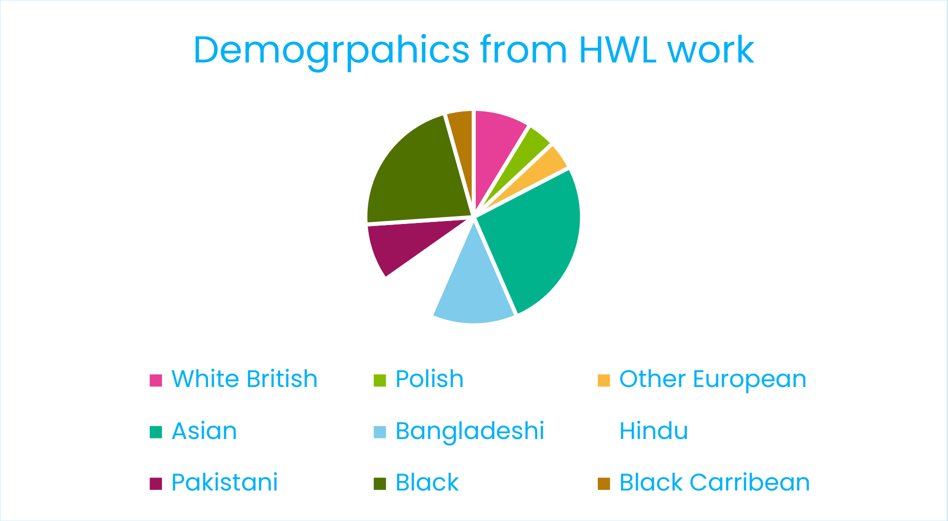
To be honest, you could change everything to be culturally appropriate and it would still take a generation before I would even feel comfortable being 'out and proud' as so many seem to be.

There is a lot about cultural understanding which seems fixed in a competency workshop but if you talk to young people, like me and my friends, we could share a world of understanding, or lack of, which infiltrates all parts of my life. You can't fix things by changing the hours of service to be more appropriate – you need to really address the wider deeper issue of how health is delivered to everyone in this country.

I have felt stigmatisation in my own community for being female, I could never have the 'out and proud' motto others profess. Just to be able to access information online, discreetly and anonymously would be so beneficial. And to have in my language would make it so much easier. But I know there isn't resource for that.

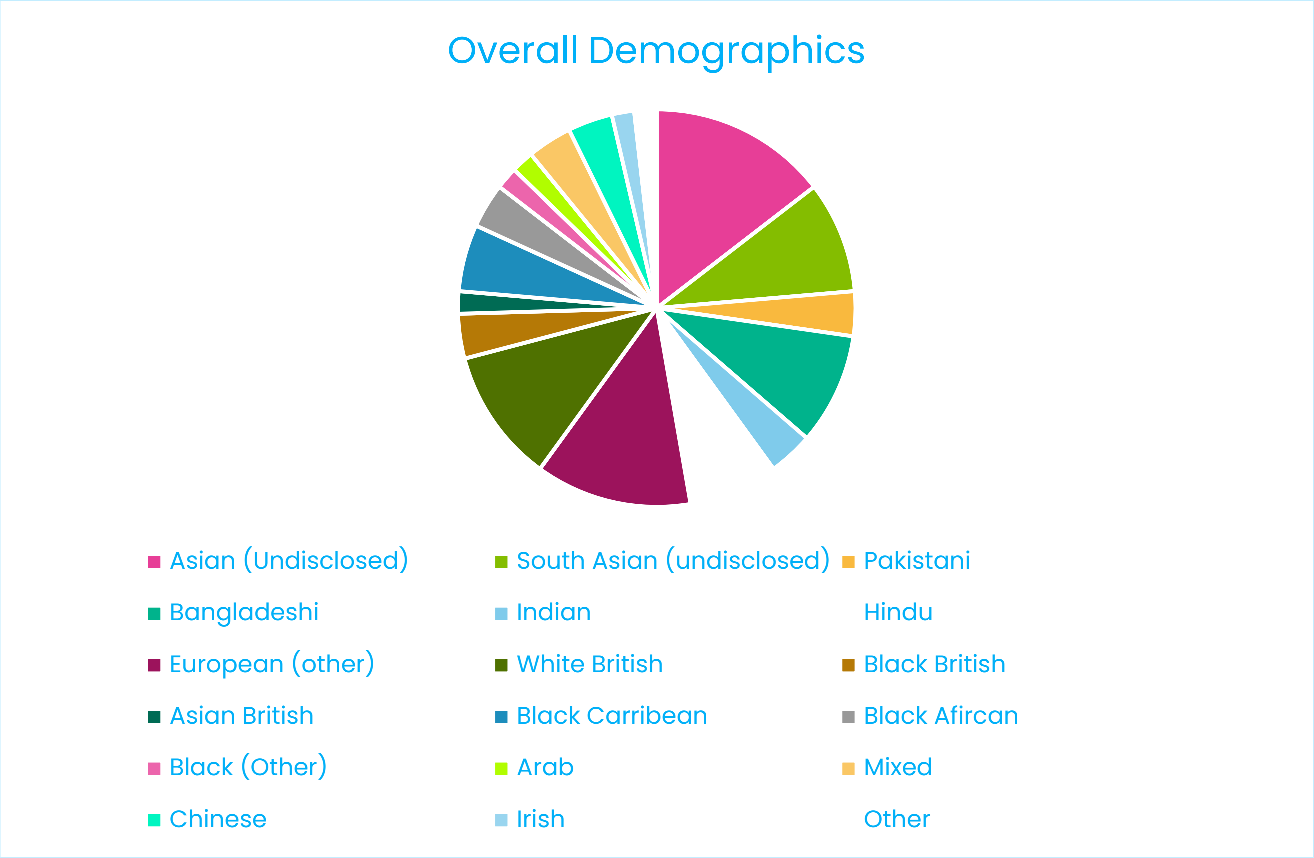
I think the approach of asking us how things are for us is a great start and appreciated, but I hope as I grow up there will be less need to ask us – as we will be catered for as just other humans are catered for, no matter the identity.

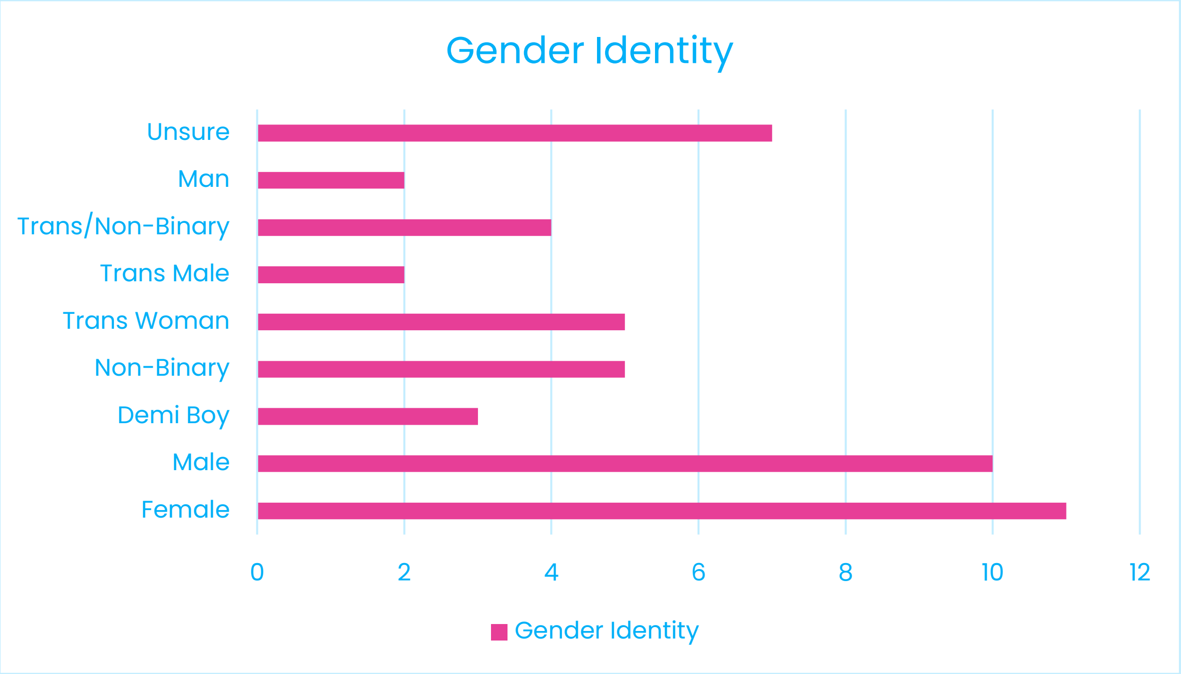
8. Demographics from Collaborators



The above demographics are from the Collaborators who took part in our survey for the Denny Engagement. Due to one of the partners main demographics being white/male – Healthwatch Luton used other approaches such as inviting individual collaborators for anonymous interviews and case study pen portraits (allowing people to send their views in anonymously) to ensure we had full representation reflective of the Luton community. Most participants affiliated themselves with their ethnicity and we added those factors to our data.

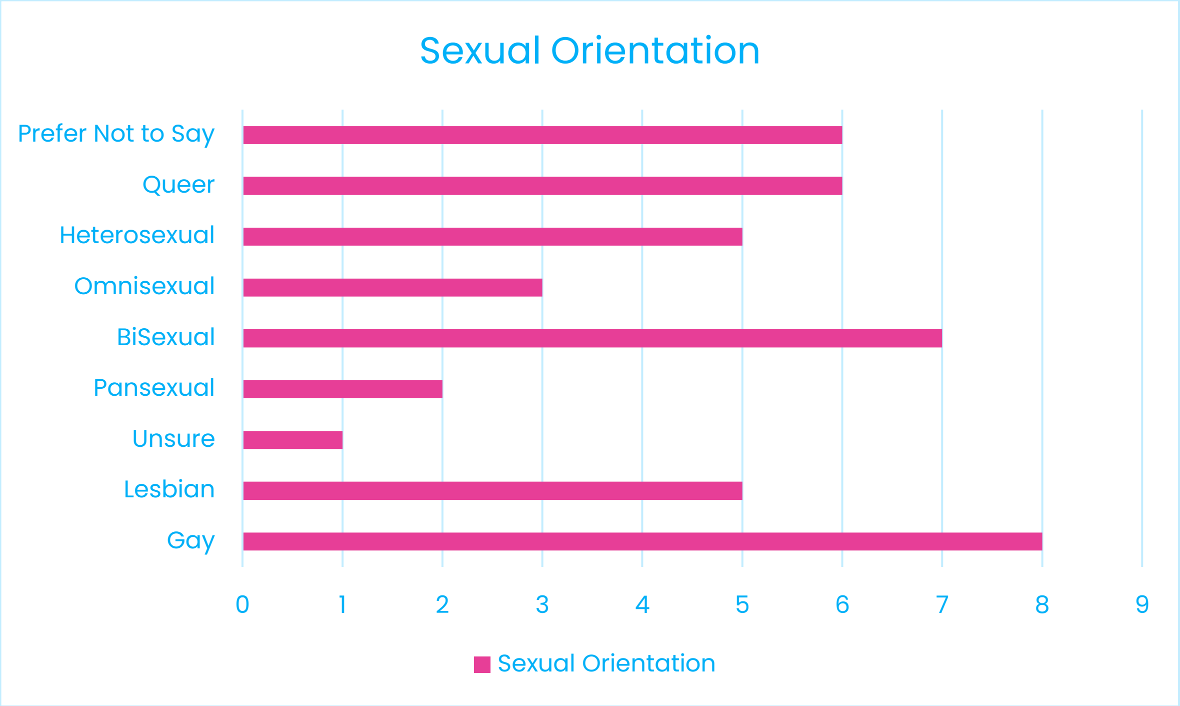
Demographics from all Collaborators / Survey / Forums / Interviews / Individuals





Most of the responders (particularly on survey) were female. The majority of our overall feedback was from females, but our interviews options for partners and collaborators were more male.

We felt a succinct lack of Trans/ Transitioning individual feedback, although the ones we received were massively informative. We also lacked Asexual, Intersexual and many other orientations / identities and with more time feel we could capture and hear more views.



9. Case Study 2

Profile: Male, White, British, Gay

We spoke to one gentleman who was adamant his view was not representative of others within Luton. And whilst he provided an insightful overview of his experience wanted us to outline the difficulty in generational views of white British people within those he knew to be LGBT+

The gentleman agreed to meet post interview to continue conversations on supporting the health system develop care for people who were LGBT+

All our case studies have been summarised, edited and stylised to produce an outline of the hour interview conducted.

Male, British, White, Gay

"My experience will in no way reflect all those I know who are also Gay in Luton. It can't. I have my experience and history and suspect it won't be the same for all.

I have had many positive experiences of health and care over the years and have to say I have felt limited stigmatisation in general health settings. There have been more issues in my wider life, such as socially and with my colleagues at work, but for health, it hasn't generally been an issue.

If I have had to declare my sexuality it tends to still come with some shame, or awkwardness, but mainly on my part. Most I have encountered have accepted and not perceptibly judged or changed their level of care, from what I can tell. The only reason I wouldn't openly declare my sexuality would be for insurance and record purposes which they could expose me in a different environment.

It is hard to discuss openly with my GP – so I tend to revert to the Sexual Health clinic for all manner of support, as I trust them.

Communications these days should be better but actually a long time ago a leaflet / flyer in the right pub or place went a long way to bringing together the community. If it wasn't for my work I wouldn't know half of the events going on for people in the LGBT community.

Calling the community a 'community' is paramount to me because essentially they became my family when I moved away when younger. You can't say it is so for everyone though and do feel the younger generation have their own way to interact and explore with each other.

Training on sensitivities of language would be good – if you get the language right or try, you're half way there – some people just show disrespect with not even attempting to find the right words. It can make interactions quite closed if you don't have that respect in health and care

I worry about the Trans community now more – more like how I felt about the gay / bisexuals in the 80s. It seems they lack a lot more support, so that would be beneficial.

The most important part of all of this is making everything inclusive – the moment you divide it up and target it is the moment people withdraw. Just make everything accessible to all and most will find that the most helpful thing.

10. Thematic Findings from Initial Statements

These statements were thematically collated from Healthwatch Luton's initial survey sent from April – September 2022. HWL wanted to discuss these thematic statements with the collaborators of the Denny engagement – and gave options to review or amend these statements. Most responders agreed with all initial statements made from our initial survey – with amends in the final column to be added to for evidence.

Statement	Agree / Disagree	Amend / Own Experiences
1.**Training and information** for GP Surgery staff and frontline health care workers was suggested to challenge their approach and knowledge of health concerns around different aspects of LGBTQIA+ and how that affects health – e.g. MOM sexual encounters can be stigmatised	Agree	None directly but most sectors are still coming to terms of the evolving LGBTQIA+ facets.
2 **Wider social determinants affect general health and care, such as older LGBTQIA** community and housing support – screening at health access areas for wider special determinants such as stress, housing etc	Agree	Empirical research suggests that LGBTQIA+ Community have accumulated numerous unresolved trauma incidents which often impact on ability to trust and be fully transparent about presenting social needs.
3.**Cis-normative approaches to communications** and language immediately makes young people find it hard to be honest about health and care ongoing for their life; cis-normative language can be confusing for young people and general LGBTQIA+ community	Agree	Cis-normative language can create a sense of isolation across the age spectrum and often trigger passive or overt aggressive reactions.

4. Dismissal of acknowledging the LGBTQIA focus on health and care leaves a blockage ongoing through life support and se**eking honest overviews of someone's health** – however, being ticked at LGBTQIA was not well received or wanted	Agree	Being labelled by a group who have minimal lived experience can cause additional engagement obstacles regardless of how well intended the gesture was.
5 Mainly, people only used 1 or 2 outside statutory services available to support life and care ongoing; and had **limited knowledge of other services available to them in the local area**	Agree	It's a common trend in most Boroughs'.
6 **Gender diversity should not be pathologized**, and gender diversity is not synonymous with a clinical diagnosis of gender dysphoria	Agree	The use of language often is a key indicator of if a relationship based on trust and respect can be built/sustained.
7 **Gender identity** evolves and develops across the lifespan of all individuals, and this developmental process may not follow a linear progression along any set gender affirmation or expression pathway; continuous dialogue should be encouraged with health professionals and members of the community	Agree	Gender identity like most other life perspective is fundamentally driven by emotions and opinions which are by nature fluid.
8 **Distinct lack of support for young children /paediatric**	Agree	This is just one of many examples of groups who have been adversely affected by the last 12 Years of sector under investment.

support of TGD families – and the stigmatisation		
9 **Social** isolation for older community more explicit – more likely to not share identity or sexual orientation even in private lives	Agree	Elder Community Members have been forced to accept marginalised positions in society and may never fully be trusting in this new age of comparative transparency to present authentically.
10 **Younger mental health – particularly in some cultures (raised in Bangladeshi / Pakistani/)** serious psychological distress in non-acceptance (1 in 7 people in ELFT feedback[1] identified as non-straight in ELFT in-patient ward work)	Agree	The highlighted statistic is influenced by having the additional psychological hurdle of religious definitions around lifestyle choices to address.
11 **Intersex community still viewed as medical curiosities** – and the inappropriate expectation for investigation with students and many professionals causes distress	Agree	This comment underlines many of the emerging themes around statutory subject knowledge gaps that really needs to be meaningfully addressed.
12 **Black and Ethnic Minority communities – concealment factors,** cultural disaffirmation, homophobia contribute to health disparities; support networks led and managed by white British not representative of selves	Agree	As with a number of protected characteristics' the absence of support facilitators with lived experience can adversely impact on the level of support accepted.
13 **Black and Ethnic Minority Communities – heightened**	Agree	Despite the high profile of GDPR legislation, accountability approaches

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[1] Taken from MH Perspective report demographic collation

concerns to confidentiality within the health system; leading to avoidance; stories of shared information with family members causing stigma		in regard to confidentiality breaches are not generating appropriate professional responses.
14 **Cervical screening for lesbian and bisexual women** – just as likely to get cervical cancer as heterosexuals, but less likely to be screened or attend screening; cis-normative approach to screening; wider social issues affecting need to screen	Agree	Health providers need to look at existing information sharing strategy and consider the merits of tapping into platforms such as Terrestrial Tv Channels, YouTube & Radio Stations to get the correct information into key communities.

Collaborators and partners were asked to add any further comments and those we received, outside of these initial statements above in the table, but to be added were:

- Access to health provision such as Monkey Pox Vaccinations etc has been difficult for many with people having to travel to London to receive the vaccine
- Point 13 on trust in the health system is prevalent in the Trans community particularly as well as the black community.

11. Case Study 3

Profile: Male, Black, Bisexual

We met anonymously with a gentleman who provided some insight into his experiences (outside of case study / collaborator interaction)

All our case studies have been summarised, edited and stylised to produce an outline of the hour interview conducted.

Male, Black Caribbean, Bisexual

"The largest thing I can say is how much being different affects your general mental health from the moment you wake up – to how you interact with every element of your life.

Accessing culturally appropriate services cannot be under-rated. Watching particularly young people I know trying to navigate their own identity journey in a world where all we see is white – cis normative people, it is more highly damaging than I can express.

Being from the culture I am, being how I am is viewed so differently to how British people view it. But if you want to really understand how it makes us feel, then change some how you present the world to us.

My mental health has not ever been in crisis state but I could have appreciated some more culturally relevant support – having British white women or men sympathise with me, has not been conducive. Not everyone who is Black and Bisexual will feel the way I do – I hope this review and report highlights that – I can only speak for me. And for me, I don't trust many things, because you always start everything on defence, in case you are attacked.

It is better these days, but in Luton – with all its multi-culturalisms, you don't even know how that affects trying to access and be honest with services. Telling my Doctor from a different culture to mine, who has his own views on what I am and what I do – just makes for a very un-honest approach. I would never go to him for health advice and would only use online.

You're asking us to outline what could improve – but until I feel that society itself improves I feel limited in what I can offer to suggest change. I do feel society is still racist and bigoted, so its hard to suggest one thing that could help that feeling of insecurity in all interactions I have. When discussing my health I feel the UK has one of the best systems in the world, but that's for if I had a crisis need that needed fixing. Like everything else, the nuances of wanting to 'be better' comes with probably more resource and funding the health system has. I just need to feel heard and unguarded.

I think reaching the younger generation is the key to real change now – it feels with covid they have been left in isolation, and trying to figure the world out without direct contact and face to face interactions. Using online is amazing, and helped so many, but we have to support people talking and listening to people. We have to get the young people out in the community again, we need their fresh thinking and innovative minds to help change the world.

12. Thematic Findings from Healthwatch Luton's Survey (April – December)

- Digital
    - People generally felt more digital access was needed; for anonymity and time and access to services and information
- Inequality
    - Most felt there was an inequality to someone being heterosexual to homo / other – and this inequality was found in all walks of life, not just health and care
- Communication
    - Communication for those with different identities and sexualities did need to be reviewed; when medically needed people generally agreed better to disclose, but didn't understand why system 'generally' needed to know what sexuality / identity they were
    - Communications needed to be accessible more online with online options
    - Communications needed to be reflective of culture / sexuality etc
- Access
    - Most people worked / were students – and found access to all general health and care difficult in working hours – and thought extended hours for most services, including sexual health knowledge and information would be beneficial
- Competency
    - Most found most staff competencies fine, but mentioned cultural and sexual competency and sensitivity training could be improved
    - Knowledge training wasn't a requirement, but how to support beyond knowledge, such as behavioural support / mental health support etc would be beneficial
- Awareness
    - Most are aware of sexual health services locally, but not regionally or nationally (some are aware nationally but not locally)
    - People generally felt more awareness of needs of people who are LGBTQIA+ would be beneficial in helping them access services
- Accessible Language
    - Most felt most health and care language was accessible – but the term cis-normative was commonly mentioned throughout the project in communications and language
    - Clinicians tended to assume people were heterosexual in first approach – and many found this in-accessible

- Stigmatisation
    - Older people we spoke with found stigmatisation less with more gay / bisexual orientations and health and care
    - Younger people (YP) felt this was more apparent with 'transitioning' or 'trans' community
    - YP stated more national guidance affected way YP approached health and care settings with queries or questions
- Cultural Disparity
    - Majority of black and Asian respondents found cultural disparity in health messaging – usual use of one black / Asian person in comms publications
        - Suggestion of usage of more targeted messaging or co designing of messaging
- Trust / Confidentiality
    - How people's first interactions with health and care are experienced tended to affect their outlook to ongoing health and care experiences (for life)
    - Transitioning / identity questioning was life-long transformation and adaption – needing more flexibility in health and care recording and stigmatisation
- Co-Morbidity Care
    - Some mentioned having co morbidity health needs affected whether they disclosed further sexual information which may affect their health and care – the more consultants / departments and people they were reviewed by – the less likely they felt comfortable continuously sharing private information
- Isolation and Anxiety- knowledge of services, but being appropriate to needs of micro-aggressions and psychological trauma
    - Many expressed micro-aggression experiences throughout their life / and health and care journey -which did result in quite a few respondents having anxiety issues on the health and care interactions
- Self care
    - Many liked the digital route for self care and wanted to access sexual health necessities to practice safe sex and have information provided for them. Some were unsure what self care meant and how young people accessed information and advice on this area
- Advice Line – Potential suggestion
    - Some suggested having a formal / clinical and updated advice line / website where information could be provided which was local,

supportive and non-judgemental on health and care for different ages. Some suggested adapting a page on the 111.nhs.uk page (January 2023 input)

- Health prevention
    - Many were involved and engaged about health and care prevention but with self care / found accessing updated and correct information on prevention limited
- Digital Support progress
    - Many referenced digital support to support working people being able to access prevention, self care and ongoing updated messaging on sexual and general health
    - Many referenced digital for young people to access broader range of information and care without having to attend a sexual health clinic
    - Discussions around different platforms being invested in – many responders mentioned websites, apps, and forums etc to be used on online functions. Young responders mentioned further digital support such as mobile, applications designed and provided for YP to be separate from other platforms.
    - Digital approaches allowed for anonymity and time for people to access / review / and use health and care information and advice.

13. Case Study 4

Profile: Teenager, White, Female, Questioning, Catholic

We met anonymously with a teenager who provided her insights into her experiences

All our case studies have been summarised, edited and stylised to produce an outline of the hour interview conducted.

Female, Teenager, Questioning, Catholic

"There is apparently less stigmatisation for young people these days – but that is mostly the view of older people about us.

I think that there is more information out there possibly than before – and that is great – but it is like it is all written by people who don't really know or understand what it is like to be LGBTQIA+

There is a lot even in the NHS guidelines that refer to all questioning or queer young people as 'transient' as though its not for all of us something sustainable, or real. It is something we may even 'grow out of' and some may. But you can't have guidelines stating that and then expect young Questioning people to come forward to share their experiences and feel like they are being heard. They can't have local support offering something and national guidance pertaining something else.

As a young person from my background, it has been hard to even be honest to family. Sometimes if that part is hard – it is hard to know who you are and what you should be. The support for young people with their mental wellbeing is so old-school and face to face – we need the online anonymous digital support to really support us in navigating our way through who and what we are feeling.

Have you heard the term 'binding'? I am in a position now where I am teaching younger people than me what they should and shouldn't be doing – because there is no access to this information elsewhere. An 18yo shouldn't be explaining what she knows to a 14yo. It should be more readily available. But a lot of the guidance is written by straight forty-somethings who want us to just not feel mental strain. If you have kids teaching kids – it is a strain. I worry all the time what I am saying is it right or wrong? I should be able to signpost them to a website where this real information can be discussed.

I think most of my experiences are okay – there is a lot that could be changed, but I think just understanding we are not all a 'group' goes a long way. The groups that I am part of come from being built a certain way to want to help others – if you're not built that way it really is a dark lonely path to be questioning yourself and not know where to turn.

I think this is great to be asked my opinion but it can't be reflective of all the young people in this area. Again, I think it is great the 'health people' are asking for our opinion – but they must know a few case studies and surveys can't make the difference. It will take time and more talking and understanding and real change for us to feel there is a health system built on knowledge, care, sensitivity and support for us all.

14. Next Steps

The next steps of this programme of work are for the four Healthwatch (Bedford, Luton, Central Bedfordshire and Milton Keynes) to submit their Denny reports to the ICB. Once this has been done (by end of January 2023) the next steps are:

- Denny Steering Group to review reports (Jan-March 2023)
- An amalgamated report to be completed by Lloyd Denny for the Steering group and the ICB to review (tbc)
- The LGBTQIA+ Luton Collaborators to reconvene, discuss elements of project with Healthwatch Luton for 2023 workplan (Feb – March 2023)
- Stage III (3) of the Denny Review: Co production support for ICS on working toward implementation plan on service delivery

Healthwatch Luton have made recommendations within this report which relate to both system-wide Integrated Care System approach (Scale), as well as some aspects which may need to be reviewed regionally within Bedfordshire (Care Alliance) as well as more service-provision and commissioning reviews to take place at Place level (Luton Health and Wellbeing, Scrutiny and Luton Place Board).

The collaborators who invested time and energy and shared experiences to produce this report would expect to receive

- Response to the thematic findings from the ICB / ICP – and action plans on what could / can't be amended / altered/ improved
- Introduction to further co production and discussion on community and people involvement in service delivery for this cohort of people (LGBT+)

Other steps to be reviewed would involve:

- Training of staff on behaviours / cultural competency / mental health around LGBTQIA+ people (assumptions / judgement / stigmatisation / young people's views etc)
- Diversity and cultural appropriate communications / engagement – if real understanding is to be met from this community; understanding language, tone, wording and diverse/cultural references and language support should be reviewed.

- ICB = Integrated Care Board
- ICP = Integrated Care Partnership
- ICS = Integrated Care System

Home - Bedfordshire, Luton and Milton Keynes (BLMK) Health (blmkhealthandcarepartnership.org)

Appendix

a) Biography of partner organisations

Penrose

Penrose Housing Association was set up as an Industrial & Provident Society, an exempt charity, in 1969 by two ex-offenders and several volunteers to provide housing for ex-offenders. It became a company limited by guarantee, registered with the Charity Commission and changed its name to Penrose Options on the 28th of March 2013.

It traded as Penrose and joined the Group on the 1st of October 2014. Penrose strives to address inequality of access to health, employment, training, and social care support for people with complex needs. People that struggle with daily living, mental illness, personality disorders, trauma, substance and alcohol issues, homelessness, offending backgrounds, facing everyday challenges or needing support to overcome difficulties because of their complex, chaotic life.

We specialises in working with people excluded from other services as they present personal or public safety risks. It provides practical social support and health care solutions, supported housing in residential accommodation, resource centres, floating support and Housing First services. Penrose also provides specialist rehabilitation and technical and therapeutic support that aids recovery, reduces reoffending and changes behaviour. Penrose currently operates across London, Bedfordshire and Luton and has the ambition to grow.

Penrose services are as far-reaching as our resident and participant profiles. We strive to address inequality of access to health, employment, training, and social care support for people with complex social and health care needs. People who struggle with daily living, mental illness, personality disorders, trauma, substance and alcohol issues, offending backgrounds and experiencing homelessness face everyday challenges or need support to overcome difficulties because of their complex, chaotic life.

We provide practical social support and health care solutions, supported housing in residential accommodation, resource centres, floating support and Housing First services. We specialise in working with people excluded from other services as they present personal or public safety risks. We offer specialist rehabilitation and technical and therapeutic support that aids recovery, reduces offending and changes behaviour. Penrose operates across London, Bedfordshire and Luton and is ambitious to grow.

Pride in Luton

Pride in Luton formed in November 2022 out of focus group conversations with the LGBTQ+ community in Luton. Their aim is to support the LGBTQ+ community in Luton and the surrounding area by providing events, social activities, advice and guidance and a support network for the community. Pride in Luton are supporting the development of the LGBTQ+ community as they evolve, based on lived-experience and shared beliefs.

a) Data Collation Thematic Tables from Surveys / Forums

Culture and Religion	Communication Barriers	Understanding / Knowledge of Health services	Cultural Competencies of NHS Staff	Accessible Language about health prevention
Social isolation; particularly in Asian community; but noted in black British community / elderly and young people both mention isolation being exacerbated by COVID – 19; where progress was being made publicly, no more	Cis-normative language creates ongoing lifetime dis-honesty in approach to health and care	On average, individuals only knew of 1-2 outside statutory services available to support their needs; once engaged with one service tended to stick with (Luton Sexual Health services for example)	Training and Information to front line health and social care staff – challenge approach and knowledge of health concerns – and how it affects health outcomes	Cis-normative approach leads to dis-engagement about all aspects of health and care – including prevention
Younger Mental Health – particularly in Pakistani YP mentioned more psychological distress in non-acceptance (1 in 7 on ELFT MH Inpatient Wards were from Ethnic Minorities and under age of 25)	Assumptions from clinicians and system wide engagement / communications leads to dis-engagement with services	Distinct lack of support for TGD families and stigmatisation – including lack of paediatric support for children of TGD families and awareness groups	Cis-normative approaches to languages when engaging associated with dishonesty ongoing through life cycle of engagement with health services	MOM individuals fear disclosing information regarding lifestyle choices in relation to health and care' affecting preventative measure of illness / disease – underlying

				cause around stigma
Concealment factors particularly in the Black (other) communities and South Asian communities led to cultural disaffirmation, and homophobia	Engaging with community views on aspects of health needed to become continuous conversations with community – and not a one off sound bite piece	Support networks and most health services run by white British / not representative of own community; result in dis-engagement	Gender diversity tended to be pathologized – not synonymous with clinical diagnosis of gender dysphoria	Cervical screening for lesbian and bisexual women – just as likely to get cervical cancer, but less like to attend screening *wider social issues affecting need for screening
Heightened concerns from Ethnic minority (Asian – Other) regarding confidentiality and distrust – leading to avoidance of interaction with services			Gender identity evolves over lifetime; development doesn't fit the linear health and care structure of support; continuous dialogue needed	
Inability to relate to support services due to ethnic disparity – need more ethnic appropriate support groups (most WB led)			Intersex community mentioned being medical curiosities and still reviewed as such; leading to distress and exclusion from	

			service provision	

b) Thematic responses to the Forum / Interview / Case Study reviews:

Communication	Training / Competencies	Access to HSC services	Stigmatization / Focalised Issues in LGBTQIA community	Other
Approach to develop targeted or non-Cis-normative language when engaging and communication to general public	Information support and awareness around gender affirming hormone therapies available – policy funding and information to be more widely available to staff and public	Most respondents found accessing both primary care and secondary care as hard / easy as non-community members – outline not effective in their community – however – they did feel once accessed they could not disclose their gender identity inline with their care, as not always appropriate but could be ongoing	Trans community reported more isolation within COVID-19 and transcending into post – COVID	Division within the LGBTQIA community was felt during the course of this project and mentioned by few collaborators and contributors to the survey. This division within the community leads to more difficulty in approaching trying to help change or collaborate moving forward.

		effective to their health outcomes		
Request for more fluid apps / websites regarding availability of services and information to be provided. NHS trusted – but limited in appeal and lacks local source and knowledge	Co-morbidities are not dealt with holistically or joined up with national data – those with HIV outline more support is needed co-progressing illness, such as diabetes or Hep C – more support on assessment and linkage	GP / 111 / Hospital access rated as much as general population (in line with HWL feedback) and in fact this community rated access slightly higher than 2022 feedback from general community	Elderly / Young and Black LGBTQIA collaborators reported isolation	HSC can be alienating – but so can sections of the LGBTQIA community
Targeted advertisements to be used for different sections of communities – don't want to be targeted / but at same time cis-normative approaches lead to lack of interest	SOGI – Sexual orientation and gender identity data – not standardised on NHS – cis-normative, and allows gaps to form over patients lifetime	Access to support services needed development – most didn't know what was available – and most were never signposted by HSC staff to other community organisations to provide support	Just over half of Collaborators felt they had be stigmatised in their health; or unheard due to their disclosure of sexual orientation when with HSC staff	
	Trans Health for general HSC as well as ongoing		YP felt asking for advice from HSC regarding	

	community / social and general public to be provided to support community		sexual experiences was dismissed as ‘and ‘would grow out of’	
			Sexual minority women (SMW) find there is a shortage of culturally affirming care	
			SMW also state more invisibility even within own communities / white British support services	

d) Thematic Summary Findings from Survey: Collaborators Denny Survey (Only)

- Awareness needed of affirming hormone therapy information for young people
- ‘Binding’ education needed for young people
- Division within those who were LGBTQIA+ - if you are part of the community it is invaluable and almost a replacement to the family; if you were not, you felt they did not represent you at all
- More needed space for anonymised feedback on health and care – digital app progression
- SOGI (Sexual Orientation Identity Information) data gathering to be reviewed
- Sexual Minority Women (SMW)felt an invisibility in general population, for healthcare exacerbated as no routes to have voice heard
- Gender identity to be seen as ‘evolving’ and not fixed, as per medical date (some forms related to being seen as ‘bi-sexual; which was stated when younger, but now changed’)
- Assumptions from health and care staff made when gender orientation disclosed

- Young people (Pakistani lady) outlined mental health services being cultural disparity in representation
- Support for Trans Gender families particularly young family members needed to increase
- Male on Male sex individuals had a larger fear of disclosing health concerns for stigmatisation
- Black (Other and British) disclosed concealment factors affecting support or accessing support

e)Interview Questions for Case Studies

DENNY ENGAGEMENT – Interview Questions and overview

- Introduction Notes Outline
- Outline of Project
  - HWL gathering feedback from 2022
  - ICB Project for Denny Review in Health Inequalities
  - HWL LGBTQIA+ - Survey specific Q's
  - Forums
  - Interviews
  - Case Studies
- Project end in December/January
- Progression work – continue into 2023
- Now going to ask questions

Questions? (Refer to internal Case Study Interview Guide for reference)

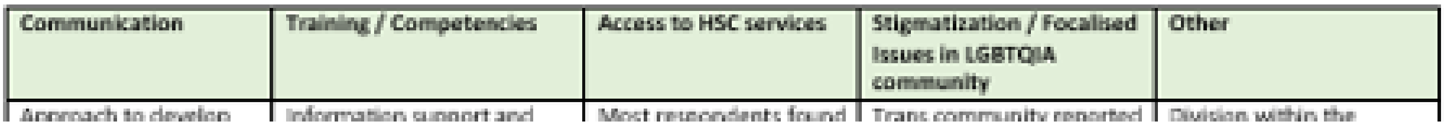
Use Interview style to ask more questions – happy to be case study? Will be thematically reported – but individualised:
Name: Or Anonymous?
CONSENT TO SHARING CONTENTS
How do you identify:
Demographics:
Age:

Overview of ICB themes (agreed by steering group and Healthwatch proposal documentation) to give context for questions:

Culture and Religion	Communication Barriers	Understanding / Knowledge of	Cultural Competencies of NHS Staff	Accessible Language about

		Health services		**health prevention**

Other finding from Denny Survey and Interviews



Communication	Training / Competencies	Access to HSC services	Stigmatization / Focalised Issues in LGBTQIA community	Other
Approach to develop	Information support and	Most respondents found	Trans community reported	Division within the

Question 1: Could you provide an overview of your experience in the health and care system: *Prompt to enquire:
- Affected by your sexual orientation / gender / sexuality / which you are happy to share:

Question 2: How did this make you feel?
Question 3: Can you outline what you think could have been improved / how it could be improved?
Question 4: Themes from ICB –

- Culture and religion aspects
- Communications
- Understanding or knowledge of health and social care services available to support you
- Staffing cultural competencies
- Accessible language
-

Question 5: Other themes to highlight

- Inclusive Language used in health and care messaging
- Staff attitudes to your sexuality / orientation / questioning / identity
- Service usage for sexual care / sexual health care
- Awareness of services for sexual health / general health
- Stigmatisation with health and care experiences
- Advice provision for newly questioning / young people support
- Digital support and interest in health and care
- Community terminology
- Anxiety and mental health
- Micro-aggressions
- Diagnostic overshadowing

- End Case Study Interview
- Round up any further queries or questions may have
  - Report to Denny
  - Ongoing work;
- Hand back to XX for further info ongoing

END REPORT

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Inequalities in Milton Keynes

Published February 2023

Contents

Image credit: Centre for Ageing Better

Introduction

Bedfordshire, Luton and Milton Keynes Integrated Care Board (ICB) and the Bedfordshire, Luton and Milton Keynes Integrated Care Partnership (ICP), known as the BLMK Health and Care Partnership hold a joint priority to tackle health inequalities.

To achieve this, both the Board and Partnership recognise that working with, and listening to communities, particularly seldom asked, and therefore seldom heard communities within Bedfordshire, Luton and Milton Keynes is essential. Only with their shared experiences can the Integrated Care System (ICS), as a whole, better understand what barriers people face in accessing health and care services.

The ICB commissioned the Reverend Lloyd Denny, from Luton, to undertake a review of health inequalities in Bedfordshire, Luton, and Milton Keynes. During a first phase of this project, the University of Sheffield was commissioned to undertake a literature review. This literature review brought together both national and local research and reports into a single report evidencing historical health inequalities in Bedfordshire, Luton, and Milton Keynes, the people within our communities who faced the greatest health inequalities, under-representation, and themes of their biggest barriers.

In August 2022, the ICS convened an Inequalities Steering Group which invited proposals from local Healthwatch and Voluntary and Community Sector partnerships to deliver a second stage of the project which included in-depth engagement and listening activities, with a focus on intersectionality, to capture experiences of health inequalities within specific groups identified within the literature review.

There is, and will continue to be, a big focus on understanding and learning more about what inequalities people experience by the BLMK ICS with the intention to address those inequalities and improve the way health and care services support people who experience greater health inequalities.

Health inequalities are not a novel topic and there has always been a strong moral and economic case for acting to address these. The government and the ICS are now even more dedicated and determined to tackle health inequalities as shown by recent policies, system overhauls and changes in societal attitudes.

Background

Healthwatch is the statutory body created to help improve local health and social care services and make sure they work for the people who use them.

Healthwatch Milton Keynes is the local independent champion for people using health and social care services in Milton Keynes. Our main statutory functions as local Healthwatch are:

- To obtain the views of people about their needs and experience of local health and social care services
- To make reports and recommendations about how those services could or should be improved
- To promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services
- To provide information and advice to the public about accessing these services and the options available.

We represent the voice of local people on various health and social care forums, including the Integrated Care Board and the Health and Care Partnership (formerly called the Health and Wellbeing Board).

We're part of a national network that reports to Healthwatch England, NHS England and The Department of Health and Social Care on national health and social care trends.

Much of our work is driven by the difficulties experienced by people as they try to navigate local health and care services. This meant we were confident in our ability to highlight specific issues to the ICS Inequalities Steering Group as part of a BLMK wide project to explore ways to reduce the inequalities that are growing for some of our residents as the health and care system comes under increased pressure.

The evidence we gathered for this report underline the themes we have highlighted in previous work and we look forward to seeing the results that the renewed interest in coproducing solutions with affected residents will bring.

Acknowledgements

Healthwatch Milton Keynes would like to acknowledge and thank the residents who contributed, with such openness and honesty, their stories in order to improve the experiences of others. Their stories highlight the impact that applying blanket processes, strictly adhering to arbitrary rules, and unconscious bias have on individuals who are often unable, for a variety of reasons, to overcome the barriers they face on a daily basis.

We would also like to thank the hardworking teams at the various community groups for their time and support, and their understanding and help to highlight the inequalities as well as the diversity and resilience within our city.

Methodology

Healthwatch Milton Keynes ran a survey and conducted interviews with residents at planned outreach events, and drop-in visits to spaces including Community Larders and local groups such as MK Snap, Carers MK and the Somali Outreach Project.

The survey asked questions drawn from both from the inequalities themes from the literature review and input from the ICS Communications and Engagement team. The questions can be found in Appendix 1. Our outreach team used a semi-structured conversation approach when meeting residents on a one-to-one basis or in groups. The conversation topics were based on the survey questions and the conversations were recorded via hand-written notes. This approach allowed people to talk freely about their experiences in their own words and give priority to what was most important to them.

Healthwatch Milton Keynes had **144** responses to our published Inequalities survey and held listening interviews with **151** people through outreach events, focus groups and our assertive outreach work.

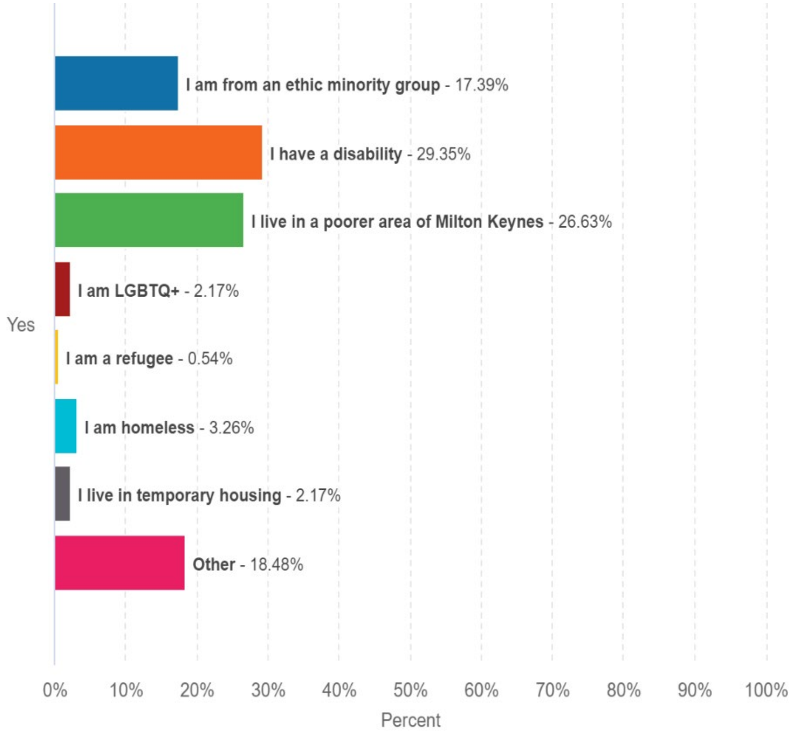
Our Outreach officer also had conversations with listening group organisers about the inequalities and themes that they were seeing, and advocating on behalf of their client groups, most often. Many of these groups have been created by, and for, members of local communities to pass on support and knowledge that they found was missing when they needed it themselves.

The personal stories we heard were added to the survey results and a selection of these stories have been included, verbatim, to provide insight into the issues being experienced by these marginalised, and often vulnerable, people when seeking care and treatment.

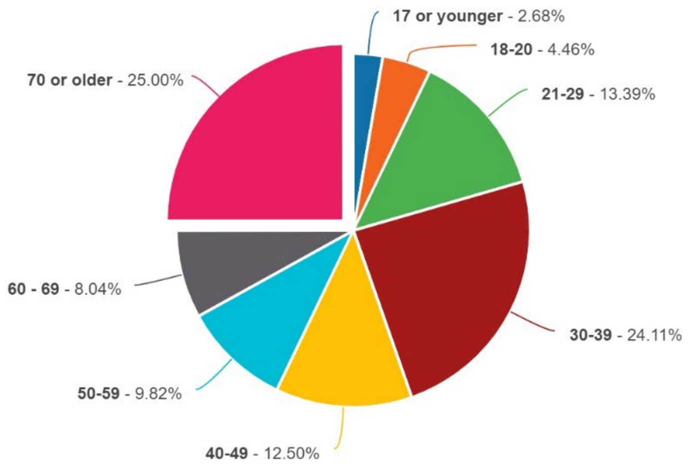
Tell us about yourself

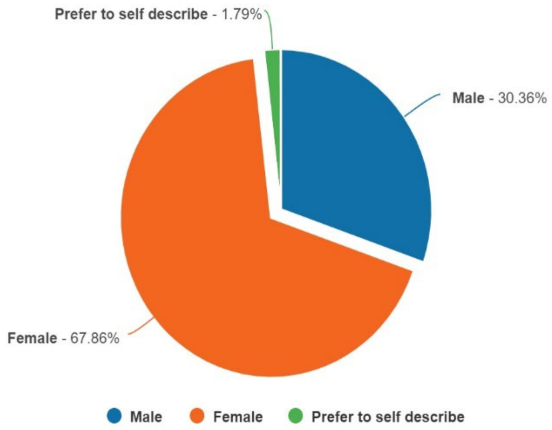
The residents we interviewed and heard from identified the following aspects of how their social and political identities combine to affect their experiences of health inequality:

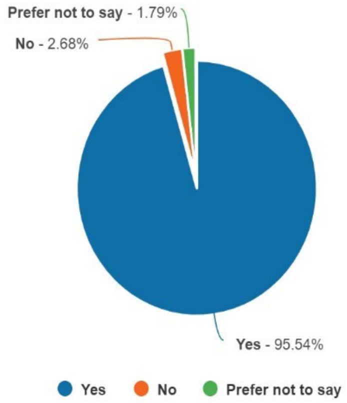
- 58% of survey respondents that didn't identify as having a disability or long-term condition attributed their health inequalities to their age, ethnicity or their gender/gender identity
- 31% survey respondents were carers
- 27% of people engaged with were from ethnic minority groups
- 18% of all people sharing their experiences identified as having a disability
- 23% of all people sharing their experiences lived in deprived areas of Milton Keynes
- 9% of all people sharing their experiences identified as LGBTQ+
- 4% of all people sharing their experiences lived in temporary accommodation
- Other intersectional inequalities trends were noted for older women across all communities, people on lower incomes, people living in council housing, and religious beliefs.
- 1% of people said whilst they were more than financially stable, their disability or carer responsibilities meant they experienced unequal access to care

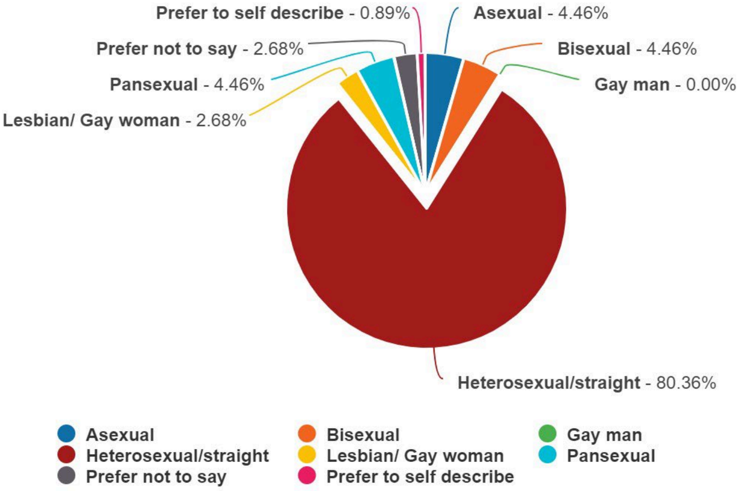


Tell us about yourself cont…



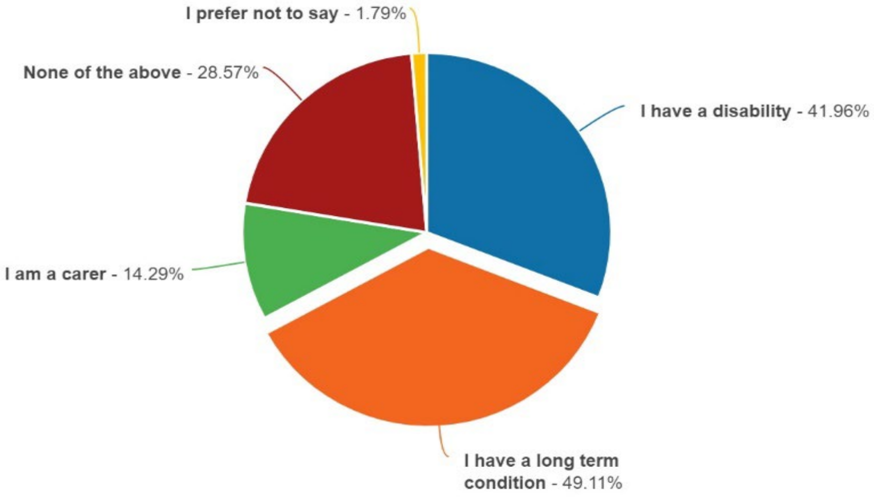

How would you describe your gender?


Is your gender identity the same as the sex you were assigned at birth?

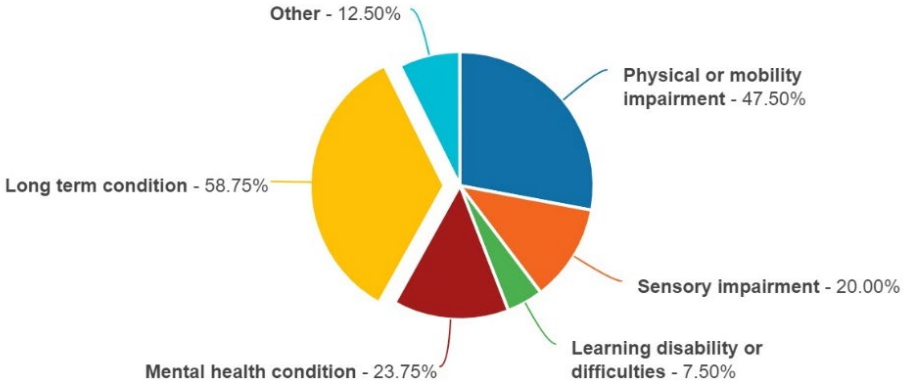

Please tell us which sexual orientation you identify with.

Tell us about yourself cont...

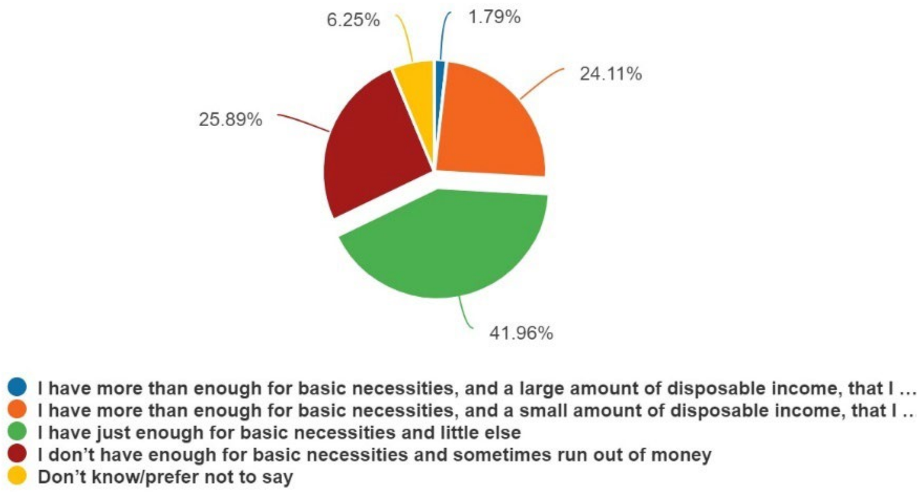
Please select any of the following that apply to you.



If you consider yourself to have a disability, how would you describe your disability?



Which of the following best describes your current financial status?



Which Services?

When we asked what health or social care services people had used in the last three years, the GP was by far the most popular answer.

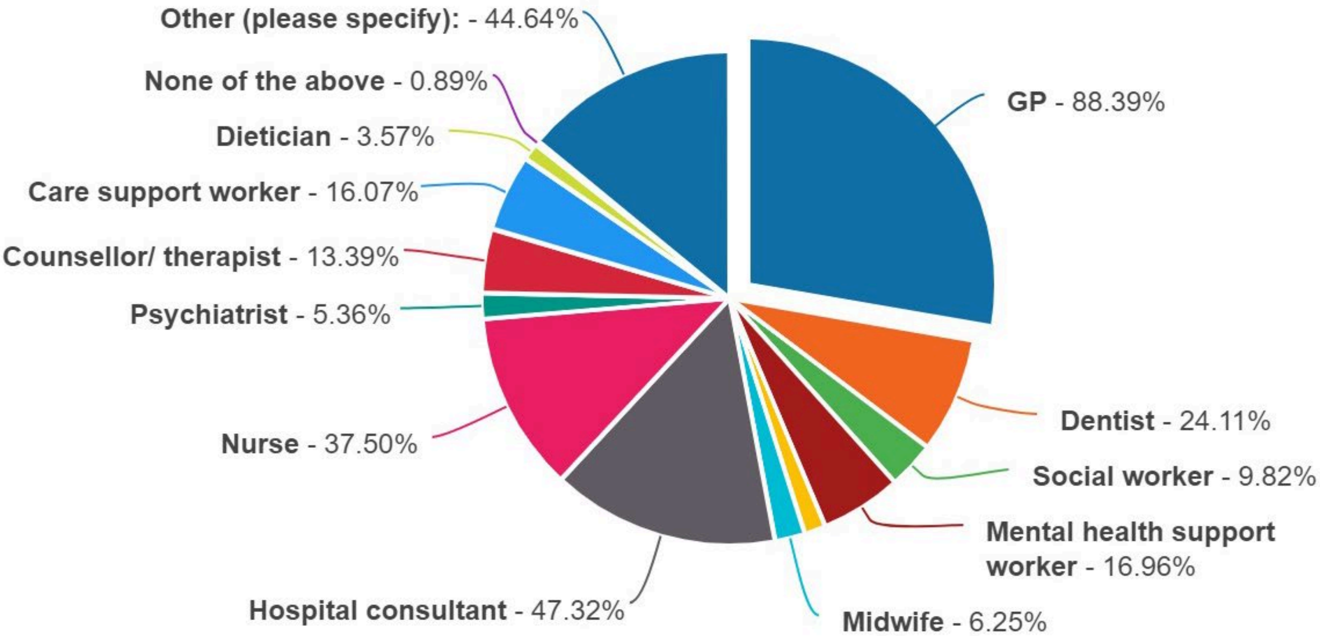
This is largely because the GP is at the centre of the health and, to an extent, social care system. There are few services that can be accessed without a referral from a GP, including assessments that fall under the social care umbrella such as the Integrated Autism Service.

There were almost 45% of people who selected 'other'. Of the people who chose to specify what service this had been, the physio, district nursing service, and pharmacists were the most mentioned. Sadly, around 1 in 5 people said that they had not been able to see a GP or be referred to the service they required, such as a midwife, as they were unable to register.

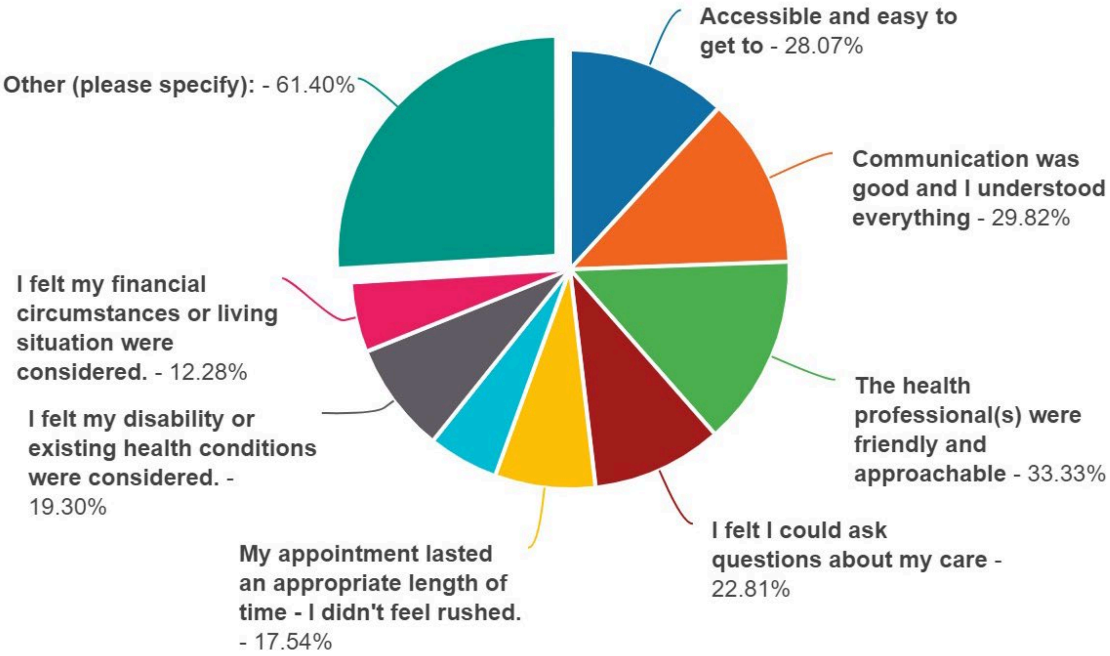
> "I really need to see a GP and a dentist but I've been told I can't see a GP because I don't have the ID. I can't afford to see the dentist. I'm in a lot of pain. I worry about my kids' teeth"

The COVID-19 pandemic also increased people's reliance on their GP practice as the vaccination programme was rolled out, and as the other support services people may have turned to were unable to accommodate the changes brought about by lockdowns and restrictions.

When added together, almost 40% of the people we spoke to had seen a mental health professional. Some of the people who selected 'other' also mentioned mental health specialist teams, MK IAPT (Improved Access to Psychological Therapies), and addiction services.



What went well?



49% of survey respondents skipped this question. The most common positive comment made by those who selected 'other' related to the support they had received by professionals who had advocated for them to get appointments, assessments, or treatment. Around 1/3 of people commented that they had not actually been able to get to see their health or care professional.

For the people who did respond to this question, health professionals being friendly and approachable was a more common experience than having their identity, disability, or living situation considered.

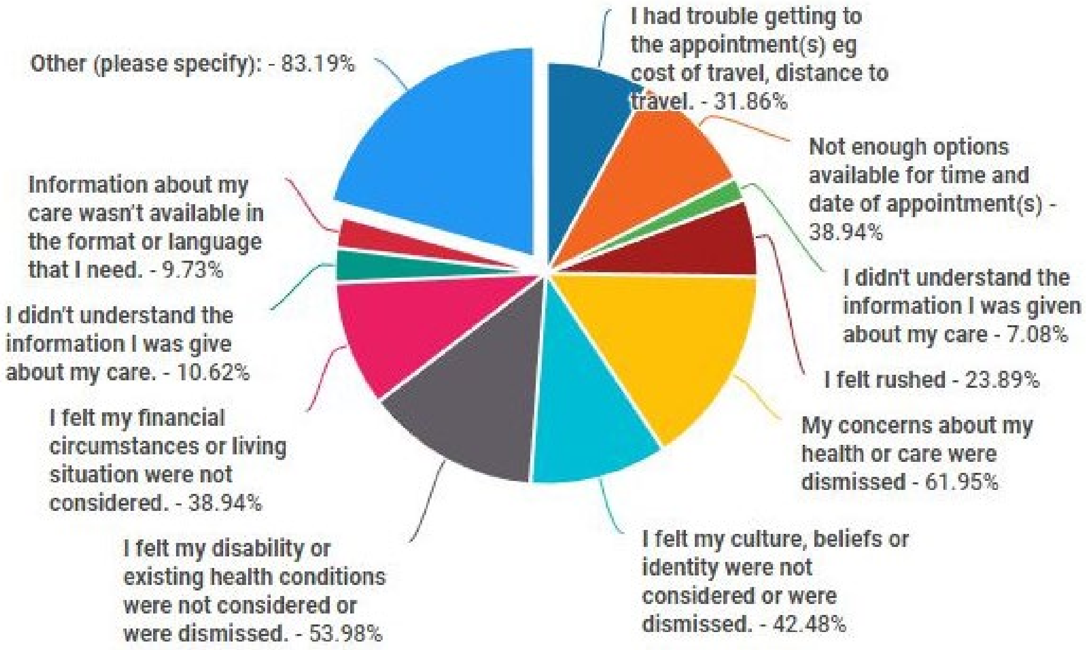
What did make a difference for people who provided comments was the times where they were seen as a person, not just a set of presenting symptoms or circumstances.

The common thread was that things went well when people were lucky enough to encounter individual professionals who worked around the system to personalise the approach, but that the overall system did not allow for individual differences or needs.

Personal stories:

" These vary from service to service, and individuals within the service, too. I am ticking every box that has ever applied to any one service or professional within it - but they don't all apply to every visit, service and health professional. … [GP] also seems to have a disconnect between my disabilities and the actual limitations they place on my life

What didn’t go so well?



When thinking of how to improve the patient experience, it is worth noting that the number of people who felt their concerns about their health or care were dismissed were almost as high as those who had difficulty in getting an appointment, or getting to it, combined. This has a negative, and sometimes fatal, impact on patient outcomes:

“My sister tried to see a GP. She had tried throughout the pandemic to get an appointment and because she kept getting told to 'call back tomorrow at 8' she gave up. By the time she ended up in A&E, she was diagnosed with terminal bowel cancer. She died last year.”

The organisations we spoke to relayed the difficulties caused for people they worked with when professionals didn’t take the time to explore personal circumstances. This was mentioned in relation to hospital discharge where people were being sent home to potentially unsafe spaces, and where people had not been given the information necessary to contact services for follow up or if their situation worsened.

“People should not be discharged into unsafe and unsuitable situations. Those being paid to look after them need to be more organised and actually care about the people they look after.”

“I assume no one asked this lady what her home was like and didn't bother to check that she would be safe”

A high number of women expressed their frustration at being patronised or dismissed. Women frequently experience diagnostic overshadowing, and a disregard towards gender appropriate support from the system. This view was held by women when connecting with almost all health services, throughout their lives, from puberty to menopause:

“Don't keep writing everything below the chest off to 'women's problems' - and because you are a woman yourself - you should understand how patronising that is”

“My practice is now down to two men in an area where there are many Muslim women. When I spoke to a receptionist about this yesterday and she commented that if they were really ill they’d see a man!”

“Because I am a woman, and my symptoms were vaguely in my pelvis, everyone just leaps to the conclusion that it is gynaecological, and just something to put up with”

“I feel there is discrimination against single older women, especially poorer women (in council housing and on state pension only). This has been evident at my GP practice. If they break a leg, for instance, they do not always/routinely get physio. Without a computer or smart phone, you have to telephone the practice on a land line (45 min wait) or go to the practice where you're often sent away to ring in or wait for a call from a Doctor. There is no recognition of additional vulnerability or need. The hospital is much better but if you need a procedure for day case surgery, you are on your own afterwards. This is high risk and scary”

Trans people told us they experienced similar attitudes from professionals who did not seem aware of the damage this could cause:

“They constantly dead name me, refer to my biological sex and this causes me enormous distress”

“Staff need to be aware of LGBTQI+ issues, it is hard enough without being outed or judged every time we need an appointment”

There were a number of comments made by hearing impaired people who continue to struggle with health and care services who insist on using telephones for communication, even after their need for email or text communication has been added to their patient record. This is incredibly frustrating when the Accessible Information Standards have been a legal requirement since 2016.

“I got a text asking me to call to make an appointment. My husband called to advise I needed text or face to face as I am deaf. They asked me to provide a letter from my GP or consultant to confirm this. I got the letter and tried to deliver it to them but could not access their premises and they have no letterbox. They told me they could not see me face to face, and that their practitioners do not have email they can use with patients. So because I am Deaf, apparently I can't access the service”

“I am deaf and severely sight impaired so information is hard to get - even online information needs to be sent in a format my screen reader can 'read’.”

The number of people who commented about not being able to register with a GP or being removed from GP Practice lists reflects the growing amount of feedback we receive about this issue. There is disbelief among patients that ‘Home Visits’ is a genuine reason for maintaining strict boundary areas as this removes the patient choice and cuts off any continuity of care they might have received. Patients have also told us that there does not seem to be any consideration given to the reasons behind the behaviours that have led to their deregistration:

“I was removed from GP register due to non-attendance of appointments. I have suffered severe trauma, struggled with depression, had a recent suicide attempt, am still in the process of being diagnosed and have previously been prescribed anti psychotics.”

“Was told that GP Practice only registered people with a MK6 postcode and that 'No Fixed Abode' is not accepted here”

“I was released from prison with a prescription that I can't get filled because I am in temporary housing, pharmacy wont fill prescription if I am not registered with GP and GP practices won't register me because I don't have the right paperwork/ ID”

People who were on low incomes felt that the difficulties this caused in getting to appointments, eating well, or getting/ maintaining a healthy home were not considered by professionals.

“They don't understand how hard it is to be in temporary accommodation and have no money for transport”

“I have run up rent arrears and am now really struggling. The council didn't tell me that Housing benefit was available to me. Addiction Services treated me as a case not a person”

Personal stories:

“ No support for my family while I was in hospital. My husband was given a warning by his employer because he had to take time off to look after our children. We earn too much for 'government' help but not enough to pay for 6 weeks of childcare.

What could be better?

96 people opted to add comments to further explain the answer selection they had made when asked what could be changed to help them feel better supported when connecting with services and professionals.

One of the themes emerging was that adhering to strict admission or referral thresholds and criteria created barriers when people were seeking support:

"Services are led by everything BUT the patient and their needs. If you can't fit into a very specific box, you've nowhere to turn"

People felt that, especially if they had been living with a long-term condition or disability, it should be acknowledged that they probably had more knowledge about their condition, its effects, and its treatment, than most General Practitioners. This was especially true when people were seeing a doctor who was new to them.

While each person's circumstance or condition was different, the overwhelming theme of all the comments was that better communication is needed. Good communication leads to people being treated with dignity, as whole human beings, and being involved and informed about what is happening with their care and treatment.

"With Black women being more likely to die during childbirth - why was my wife being ignored?"

"I never feel like my support needs were considered or available unless I went to private care, which I can't afford even with family's financial help. I also have bad anxiety over phone calls, and nowhere seems to understand that or be able to offer other arrangement"

"Trans person being asked, by GP Admin team, questions relating to sex assigned at birth and ignoring my stated gender"

What could be better cont...

There was an ask for information to be compassionately, and proactively provided by all organisations and service providers. This included the way diagnoses were given, where people could access non-clinical support, and general information to support new or changed circumstances.

“The council housing team should provide an information pack for the new area they are moving people to - and the hospital could have told me about RNIB, SARC or CiL to help me until I know whether my sight loss is permanent or not”

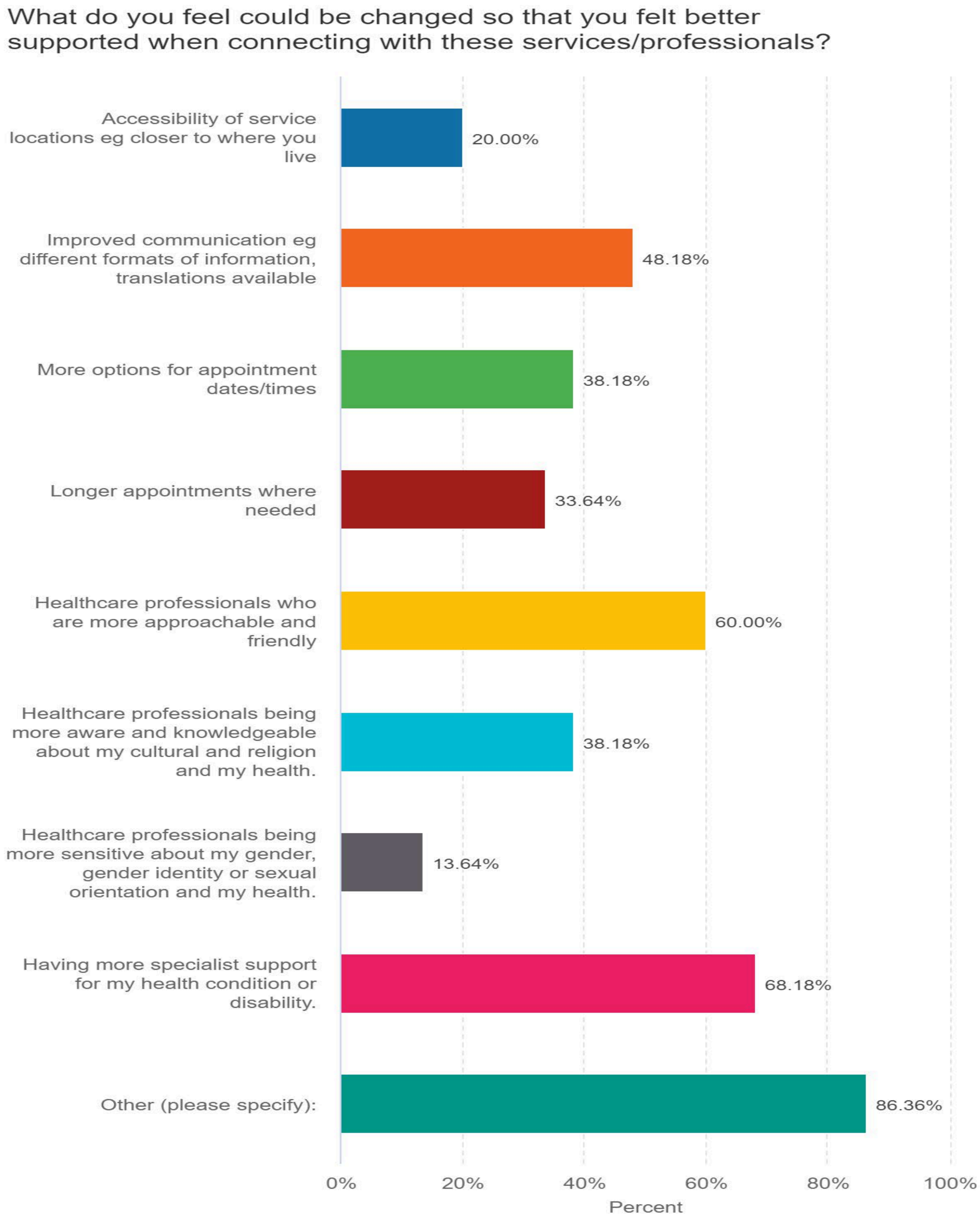
“I was alone when I received my cancer diagnosis. This was from a nurse who rushed into the room, apologised that the doctor was too busy to be there and threw some leaflets on the table. She then said I’d hear about “staging” in the next couple of weeks. That’s how I was told I had cancer”

“If the GP is going to be the gatekeeper for every treatment, the GP needs to be available and to follow up - noone can do anything without the GP referral but the GP is never there and other GPs at the practice tell me we have to see the original Dr”

Personal stories:

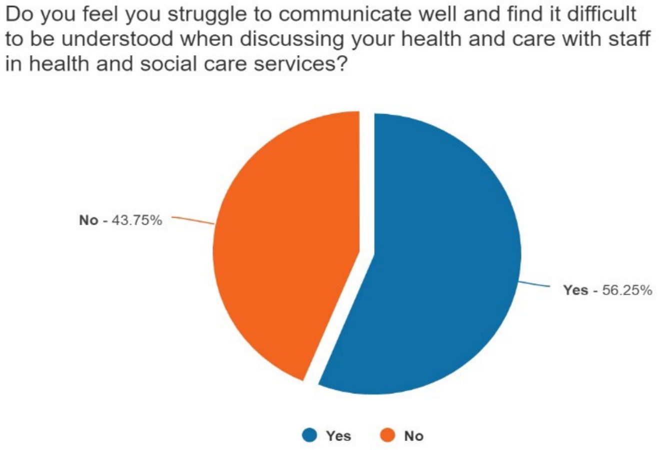
I am an atheist. Many services provided discriminate, sometimes inadvertently, against those with no religious belief by being held in religious settings or being run by religious organisations. I refer particularly to socially orientated provisions and support groups which are necessary for everyone for a healthy, happy existence, regardless of faith. I have been a single parent which also leads to discrimination because many health services cannot be accessed because of lack of childcare provision. As a single woman I am further discriminated against because my earnings are low and statistically are likely to remain low throughout my life, yet I am expected to pay the same for services as others who, because of their gender or because they are part of a couple have considerably higher earnings. This naturally affects my health because not only have I always had to worry about money at every stage of my life, inducing physical and mental ill health, I am also less able to afford treatments which are not free for example dentist, chiropodist, physiotherapist. As a single parent I also feel I have been discriminated against in terms of housing provision which has had a detrimental effect on my overall wellbeing. As a woman I feel that my health concerns have not been taken seriously leading to poorer health now in later life and a shorter life expectancy. I feel that the lack of provision of health and welfare services throughout my life (much of which has been spent in Milton Keynes) has been so extreme as to be abusive.

What could be better cont...



Communication

Improved communication in all its guises forms the recommendation that Healthwatch Milton Keynes makes most often. Appropriate communication is also a legal obligation under the Accessible Information Standards, the Equalities Act, and the Human Rights Act. Because this right to be treated with fairness, dignity, and respect and to be given information in a way that a person can easily understand, is enshrined in law, it is assumed that providers and organisations will provide it. This means that it does not tend to be included in service specifications, governance documents, or staff training. In practice, organisations and professionals, striving to deliver services with high levels of contractual requirements, budgetary, and staff restraint, often overlook this vital duty.


Do you feel you struggle to communicate well and find it difficult to be understood when discussing your health and care with staff in health and social care services?

Over half of the people we spoke to said they had difficulty communicating or being understood by staff in health and social care settings. With only 20% of respondents telling us they had a sensory impairment; this indicates that language and wider cultural differences play a large part in communication barriers.

When people expanded on the difficulties they faced a common theme was that their opinions, thoughts, and feelings were dismissed by health and care professionals:

“Our concerns are just brushed aside as if we don't understand enough, aren't smart enough, to understand what they would tell us”

“The GP doesn't listen. Has already decided what he thinks is wrong and doesn't listen”

“Because I am young, I am considered not to know what I want or need”

“They could be more helpful - I think it’s because I have an accent that they assume it means I am stupid - I am probably more educated than they are - and speak more languages for a start”

People need to trust the health or care professional when they are talking about their diagnosis, treatment or plans and having a relationship or rapport with the healthcare professional was an important aspect of this:

“I haven't managed to get an appointment yet. I want 'person to person' - not a discussion on the phone with someone I have never met and don't have any rapport with .... this is my health and my body. I am important, I am not a subjective case history!”

Communication Cont...

For people with sensory impairments or neurodiverse conditions, the move to a virtual health and care world is creating issues in communication which are having very real impacts on their health outcomes. People told us that the anxiety around online or telephone appointments is so high that they are avoiding even trying to contact their health professional.

"I find it hard to make a GP appointment when I need it because they do not give a time that they will call you. They call you at any time. My Autism means that I need routine so the uncertainty of when they will call makes me anxious all day and unable to work on anything in case they call."

"I am partially deaf now. I always feel rushed which makes me nervous and forget what I want to say. As this has been an ongoing situation throughout my life, it is now ingrained behaviour and I constantly feel of little or no importance. Long waits and impatient staff over the years also increase my nervousness and inability to approach health and care services in a relaxed manner. I have also felt on occasions that not everyone is treated with the same degree of care and respect"

People who are hearing impaired and people who are not fluent in English are in danger of being 'non-compliant' with the medical advice they are being given because they have not heard or understood it.

"I am Deaf. BSL is first language. NHS never use BSL interpreter and always call me. I can't answer phone and get taken off waiting list for mental health after baby. Say I did not reply"

"I am deaf in one ear so I often miss words and feel as though Drs get annoyed if I ask them to repeat themselves. So I don't always ask - but then I don't always know what I am supposed to do"

People who identify as LGBTQI+ told us that they don't feel they can be open with their health professional, or that they feel judged if they are open about their sexuality or their gender identity.

"...My GP appears to think a post-menopausal woman doesn't need to have a sex life, or at least if she does, it must be with one regular partner. I think the LGBTQ side of things is best kept under wraps because I think her own cultural and/or religious beliefs would make that hard for her to give me the fair treatment I deserve. And she's the best of the bunch at my surgery. On the other hand, on certain purely medical issues where there is not a link to my LGBTQ status, she has been rock solid. I do think she would benefit from equalities training because there's no way she will have had any while training to become a GP."

Trans people experienced treatment which highlights the need for further diversity and inclusion awareness and training.

GP Admin staff need to have some cultural competency training to stop stigmatising trans people

Looking after yourself

When we asked people if they felt they looked after their health well, or to the best of their ability, 85% of people felt they did. This has an interesting relationship to the 93% of people who identified as having a long-term condition or disability. In exploring this further and asking what people were most proud of when looking after their own health, people who had long-term conditions or disabilities knew what they needed to do to keep healthy whereas those who were in general 'good' health tended to respond with 'I go to the Doctor'. This group did not appear to identify that good eating habits, physical exercise, and staying engaged were part of looking after their health.

Things people told us most often that they were proud of was being educated and aware of their own health and condition, eating well, and being physically active as far as they were able. People who identified as having a mental health concern were proud of the fact that they recognised when they needed to ask for support, and that they did actually ask for that help.

We asked what people felt they could do better to look after themselves, the underlying message was that people wanted more support to live the lives they wanted:

"Have some help to get my independence back"

"Get answers to questions about genetic condition"

"My parents are more in charge of my health than I am"

"Get more support so I don't have to do everything while looking after 2 children with SEN"

"Have health professionals who respect I am the expert in my own body"

"Have more money to buy better food. to be in accommodation that helps me stay healthy"

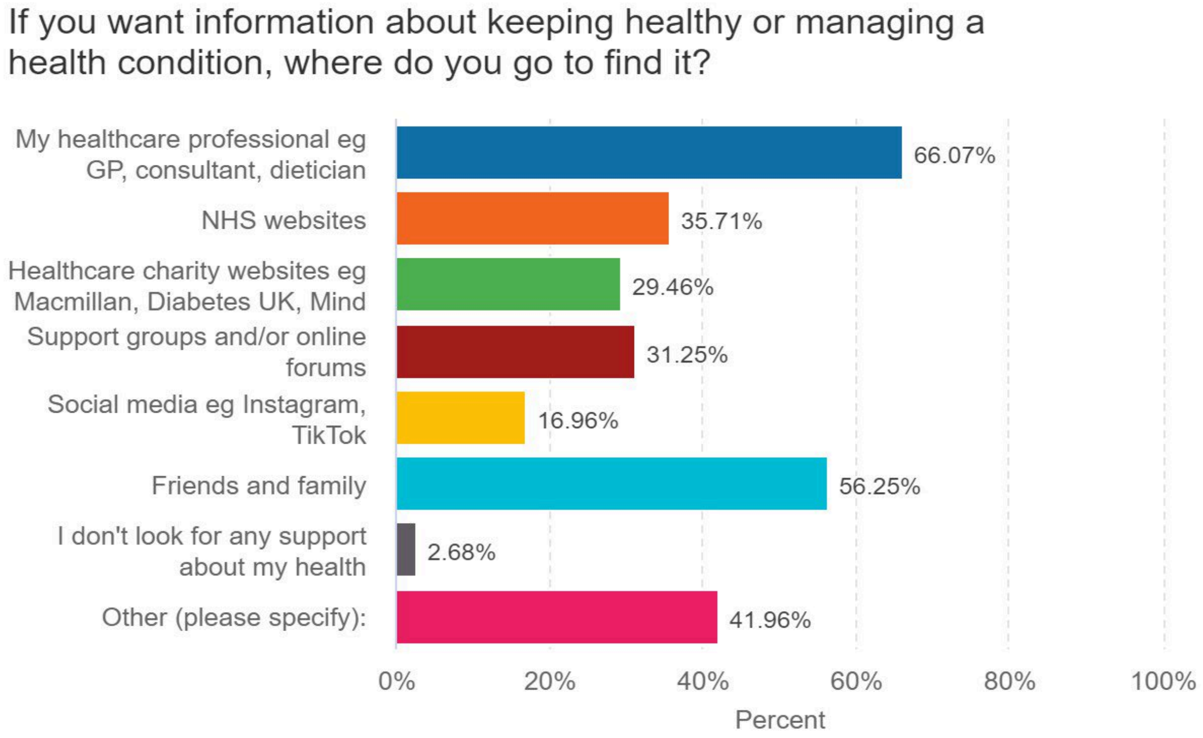
"Get registered with a GP"

"Be younger, richer, and male"

Health Information

We wanted to understand the level of people's knowledge of how to keep healthy or if they knew when to get help, as people's 'health literacy' is becoming a topic of discussion across many of the heath care and prevention meetings we attend. 70% of the people we spoke to felt they had a good level of knowledge and 25% responded with 'sometimes'.

When we asked where they got their information, the vast majority used 'official' health information sources and/ or friends and family.



A number of people selected 'other' so they could add context to their selection:

"I can find all the information I need but then the organisations don't provide the help they are meant to"

"I know when I should get help but don't always know where to get it from. Thank goodness for Healthwatch and the other charity groups who make sure I get the information I need - the professionals don't give it out!"

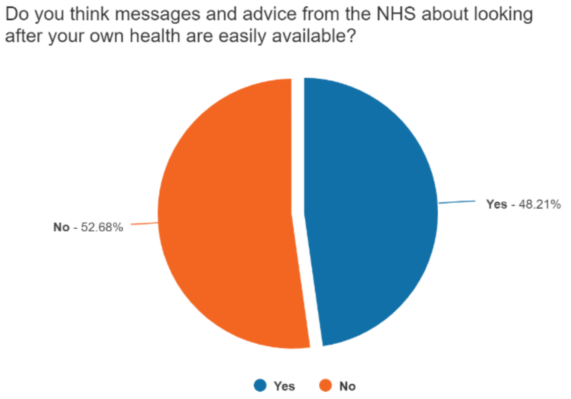
"I know when to go and get help - unfortunately, the help isn't there"

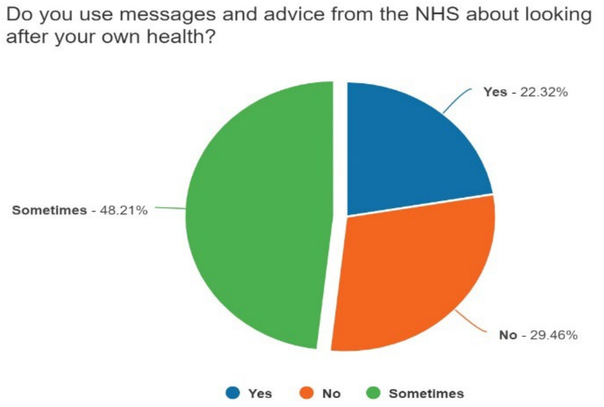
"I would say GP but they are not helpful at all - if you want information you have to go other places and then tell the GP what is wrong"

As this was a survey run by Healthwatch Milton Keynes, it is perhaps unsurprising that Healthwatch were mentioned numerous times as a safe and trusted place to get information and signposting. Children and Family Centres, P3 support workers and Parish Councils were also noted as being reliable sources of information and signposting.

NHS Messages

When asked whether the health messages from the NHS were easily available, the responses were very evenly split. The reasons given for feeling that the messages were not easily available included the disproportionate amount that were only shared digitally. People with visual impairments said that many of the messages were not compatible with screen readers, or that letters which offered different formats were in small and faint print. Language was also a barrier to access with most NHS messages not being released in an easy read format or translated into other languages for some months after the original message and none of the social media or online messages were available in these formats at all.


Do you think messages and advice from the NHS about looking after your own health are easily available?


Do you use messages and advice from the NHS about looking after your own health?

We followed these questions by asking what more people felt the NHS and other health and care services do to help them be their healthiest selves.

A common response related to the availability of the services to be able to follow the advice:

“I can't follow the advice NHS give if I can't access the services”

“When I follow the messages that the NHS give, the health organisations should facilitate this, otherwise - what is the point?”

“Make sure their staff know what the messages are as well”

The suggestions related to accessibility of the messages themselves made up, by far, the largest proportion of responses:

“make sure they use BSL interpreter”

“I'm not very computer literate and don't often go online. I need to do some training”

“have them easier to find and to understand”

“make sure things are written so people with autism can understand them - clear, concise, not vague”

“Make the messages accessible for people with sensory impairments”

“Question applies to those who have access to a computer, and are able to use one. others are left out”

NHS messages cont...

While thinking about what they needed from services to help them be their healthiest selves, the need for understanding, compassion, and cultural competency was given the greatest importance:

“Provide advice for people with physical disabilities (eating healthy, exercising when not very mobile, specific mental health support)”

“Include older people in their plans, if you don't help us stay healthy we are going to be more expensive to look after!”

“Be deaf aware so that I understand what they are telling me”

“Don’t tell me to look after myself but then make everything (food, cooking, health care) too expensive to be able to”

“Make sure people are aware that if they don't get called for a screening, they can still ask for one. Make sure people who have cancer worries are able to see a Dr!”

“Don’t treat me as a second class citizen because I have an accent”

“Treat me like a person, give me the information they have that will help me”

“Make health and care services accessible for wheelchair users”

“Be aware of cultural needs”

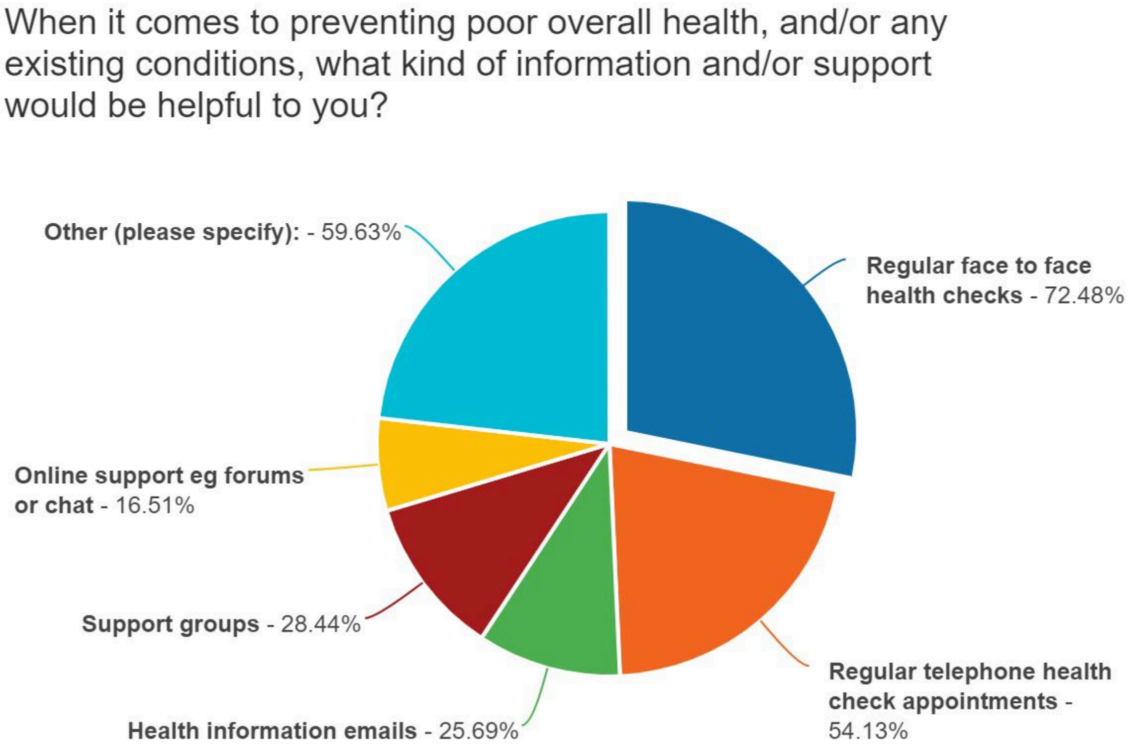
“Offer help that's available to disabled and neurodivergent and queer people with people who know and understand these and how it can affect our lives and wellbeing”

10% of people who left a comment said that being able to register with a GP would be the best way the NHS could help them.

Ten people asked for health professionals that listened to them and were able to acknowledge that other consultants, or even the patient themselves, might know more than they did about that particular condition. Some people asked that health and care professionals looked at them as a person, not just as an illness.

What information or support would help?

One of the statutory roles of a local Healthwatch is to ensure people's voices are heard and considered when health and care organisations are designing and delivering services. Any recommendations we make are drawn directly from what people tell us they need because we, as involved as we may be, cannot know what the end user of the various services are experiencing. To this end, we asked people to tell us what would help.



It will be no surprise to anyone reading this report that the 'other' information and support that people said would be helpful would be accessible for people with sensory impairments, language support, or learning disabilities. It would recognise people's cultural needs, gender identity, sexuality, age, and financial circumstance.

People asked that health and care settings were, physically and emotionally, safe spaces for them, no matter their identity or their health need.

"I want to feel like the people who looks after me, actually cares about me as a person, not a paycheque"

Recommendations

Whilst this report was commissioned to support the work of the BLMK ICB Denny Review in reducing inequalities and promoting coproduction, we feel there is benefit in the wider dissemination of the findings, and subsequent recommendations to the workstreams and teams who are currently designing services and pathways.

The following recommendations are taken from our July 2022 report, *"Perceptions of Health Inequalities in Milton Keynes'*, our 2022 report to NHS England on the Pakistani and Bangladeshi perceptions of the NHS vaccination programme, our 2019 report and 2020 review of GP registration, and the findings of our 2019 report on LGBTQ+ Health Inequalities and Access to Treatment.

We have included links to these reports in the appendices for ease of access.

- **Ensure that every patient or service user is asked about, or offered, the support they will require to be able to understand the information being given to them.**

  This is required under the Accessible Information Standards11 and the Equality Act 2020. Whilst not being able to speak English is not a 'protected characteristic' defined under the Equality Act 2010, section 13G of the National Health Service Act 2006 ("NHS Act") states that NHS England, 'in the exercise of its functions, must have regard to the need to reduce inequalities between patients with respect to:

  - Their ability to access health services; and

  - The outcomes achieved for them by the provision of health services.

  Commissioners may need to consider how these services are procured across the BLMK area, or how they are written in to service specifications to ensure they are being provided by commissioned services.

  Consider the way that a patient's need for reasonable adjustments can be shared at the point of referral or discharge. Current practice causes common inequality reported by people with hearing impairments or languages other than spoken English.

- **Consistent BLMK wide Inclusion and Diversity Awareness training should be part of the induction for all new staff, with regular refresher training to ensure that best practice is maintained.**

- **Address the issue of diagnostic overshadowing and ensure approaches to improve person-centred, holistic care is a focus for BLMK Integrated Care System leaders.**

  We would recommend further research is done locally with core groups of patients affected by diagnostic overshadowing to establish the extent and to support the system to develop a practical approach to reducing the prevalence.

Recommendations Cont...

- Healthwatch Milton Keynes recommends that GP Practices in Milton Keynes review their practice procedures to ensure that they fall in line with, and do not contradict Primary Medical Care Policy and Guidance.
- The Primary Medical Care Policy and Guidance policy highlights that patient registration is a complex issue. We recommend that Practice Managers ensure that national policy is not applied selectively in practice procedures.
- Accurate Information on GP practice websites
- Healthwatch Milton Keynes recommends that all GP practices in Milton Keynes ensure that the patient registration information on their website complies with the national policy.
- The role of the receptionist in the registration process is critical. Healthwatch Milton Keynes recommends that Practices provide further, and ongoing, training to their teams, so that they feel empowered to make reasonable exceptions based on individual circumstances.

  Healthy London Partnership produced some useful training resources, aimed at helping receptionists understand homeless peoples' experiences of accessing Primary Care, and highlighting the vital role that receptionists can play in changing this. https://www.healthylondon.org/resource/homeless-health-elearning/.

- Healthwatch Milton Keynes recommends that when Practices refuse a patient registration, they undertake the relevant record keeping and communication to the applicant, as outlined in the Primary Medical Care Policy and Guidance.

  If a practice does have reasonable grounds to decline a patient registration, then following this process will help ensure the patient understands why their application has been rejected. This record keeping should also be accurately recorded and communicated when deregistering a patient.

Appendix 1: Survey Questions

Have your say on inequalities in health and care services

Q1. Tell us about yourself. Tick all that apply to you.

I am from an ethic minority group	I have a disability	I live in a poorer area of Milton Keynes	I am LGBTQ+	I am a refugee	I am homeless	I live in temporary housing	Other

Q2. Can you tell us which health and social care services you have used in the last 3 years?

Q3. Can you tell us some of the things that went well?

Q4. Can you tell us some things that didn't go so well?

Q5. What do you feel could be changed so that you felt better supported when connecting with these services/professionals?

Q6. Do you feel you struggle to communicate well and find it difficult to be understood when discussing your health and care with staff in health and social care services?

Q7. If you answered Yes, can you tell us more about these difficulties?

Q8. Do you feel you look after your own health well, or to the best of your ability?

Q9. What do you feel most proud of when looking after your health?

Q10. What do you feel you could do better to look after yourself?

Q11. Do you feel you have good level of knowledge about being healthy and know when to get help?

Q12. If you want information about keeping healthy or managing a health condition, where do you go to find it?

Q13. Do you think messages and advice from the NHS about looking after your own health are easily available?

Q14. Do you use messages and advice from the NHS about looking after your own health?

Q15. What more could the NHS and other health care services do to help you be your healthiest self?

Q16. When it comes to preventing poor overall health, and/or any existing conditions, what kind of information and/or support would be helpful to you?

Q17. Please tell us your age.

Q18. How would you describe your gender?

Q19. Is your gender identity the same as the sex you were assigned at birth?

Q20. Please tell us which sexual orientation you identify with.

Q21. Please tell us your ethnicity.

Q1. Tell us about yourself. Tick all that apply to you.
Q22. Please select any of the following that apply to you.
Q23. If you consider yourself to have a disability, how would you describe your disability?
Q24. Which of the following best describes your current financial status?
Q25. In which area of Milton Keynes do you live?

Appendix 2: Relevant Reports

For context we have incllded links to reports with recommendations mae previously to the MK CCG and, later, to the BLMK ICB.

My Right to Healthcare: Review:

https://www.healthwatchmiltonkeynes.co.uk/report/2020-12-04/my-right-healthcare-review

LGBTQ+ Health Inequalities and Access to Treatment

https://www.healthwatchmiltonkeynes.co.uk/report/2019-06-07/lgbtq-health-inequalities-and-access-treatment

Perceptions of Health Inequalities in Milton Keynes:

https://www.healthwatchmiltonkeynes.co.uk/report/2022-05-05/perceptions-health-inequalities-milton-keynes

Exploring perceptions of the NHS England Vaccination Programme within the Pakistani and Bangladeshi communities in Milton Keynes:

https://www.healthwatchmiltonkeynes.co.uk/report/2023-01-31/exploring-perceptions-nhs-england-vaccination-programme-within-pakistani-and

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YMCA MILTON KEYNES

COMMUNITY ACTION: MK

healthwatch Milton Keynes

Inequalities in Milton Keynes: A joint summary

Contents

Introduction

Bedfordshire, Luton and Milton Keynes Integrated Care Board (ICB) and the Bedfordshire, Luton and Milton Keynes Integrated Care Partnership (ICP), known as the BLMK Health and Care Partnership hold a joint priority to tackle health inequalities.

To achieve this, both the Board and Partnership recognise that working with, and listening to communities, particularly seldom asked, and therefore seldom heard communities within Bedfordshire, Luton and Milton Keynes is essential. Only with their shared experiences can the Integrated Care System (ICS), as a whole, better understand what barriers people face in accessing health and care services.

The ICB commissioned the Reverend Lloyd Denny, from Luton, to undertake a review of health inequalities in Bedfordshire, Luton, and Milton Keynes. During a first phase of this project, the University of Sheffield was commissioned to undertake a literature review. This literature review brought together both national and local research and reports into a single report evidencing historical health inequalities in Bedfordshire, Luton, and Milton Keynes, the people within our communities who faced the greatest health inequalities, under-representation, and themes of their biggest barriers.

In August 2022, the ICS convened an Inequalities Steering Group which invited proposals from local Healthwatch and Voluntary and Community Sector partnerships to deliver a second stage of the project which included in-depth engagement and listening activities, with a focus on intersectionality, to capture experiences of health inequalities within specific groups identified within the literature review.

The specific groups and themes identified in the literature review were:

Communities	**Themes of Inequalities experiences**
Gypsy and Roma Traveller Communities	Culture and Religion
People from ethnic minorities living in deprived areas	Communication barriers that exist
People with a learning or physical disability living in deprived areas	Knowledge and understanding of the health service
Homeless people	Cultural competency of NHS staff
Migrants	Accessible language and messaging about poor health prevention
People identifying as LGBTIQ+	

Healthwatch Milton Keynes, YMCA Milton Keynes and Community Action: Milton Keynes worked in collaboration to provide insight from across all community groups and themes identified in the literature review, with the aim of providing the ICS Inequalities Steering Group with:

- Rich insight into the experiences of the Milton Keynes community – Delivered by Healthwatch Milton Keynes through a programme of assertive outreach methods, listening events and a digital survey
- A detailed picture of existing intelligence and data from the VCSE, connecting with these communities that have recently worked, or are currently asking our communities very similar questions – Delivered by Community Action: MK through a programme of insight gathering, research and listening events
- Detailed insight into the intersectional nature of inequalities with specific communities – Delivered by YMCA Milton Keynes through face-to-face and virtual interviews.

Background

Healthwatch Milton Keynes, YMCA Milton Keynes, and Community Action Milton Keynes are charity organisations who were set up to work with the people and the voluntary groups within Milton Keynes to ensure that the people who live and work here are supported to achieve the outcomes they need and want.

YMCA Milton Keynes

YMCA Milton Keynes was established in 1981 and in that time has supported over 10,000 young people aged 18-35 through emergency accommodation and supported housing. They are the largest provider of dedicated supported housing to young people in Milton Keynes. YMCA Milton Keynes work with young people who have experienced homelessness and provide them with, not only a safe place to stay, but a range of support services that empower them to belong, contribute and thrive.

Community Action: MK

Community Action: MK is the local infrastructure support charity for the Voluntary and Community Sector (VCSE) in Milton Keynes. They provide advice and guidance for VCSE groups around governance issues and funding, are the local Hub for volunteering and have run a number of Community Development projects across the City. A large focus of their work is to enable the VCSE sector to communicate the needs of their beneficiaries to policy makers and service providers, and to support the Sector to come together and collaborate through a range of networks

Healthwatch Milton Keynes

Healthwatch Milton Keynes is the local independent champion for people using health and social care services in Milton Keynes. Our main statutory functions as local Healthwatch are:

- To obtain the views of people about their needs and experience of local health and social care services
- To make reports and recommendations about how those services could or should be improved
- To promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services
- To provide information and advice to the public about accessing these services and the options available.

Methodology

In collaboration Healthwatch Milton Keynes, Community Action:MK and YMCA Milton Keynes designed a line of questioning, drawn both from the inequalities themes from the literature review and input from the ICS Communications and Engagement team. The questions can be found in Appendix 1. The collaborative agreed that the questions provided a foundation for conversations but that each community and for many individuals, different approaches to gathering insight and evidence would be required.

It was agreed that for many people, the inequalities they experienced were so much a part of their everyday lives, that they may not identify certain experiences as an inequality, and this would require flexibility in approach, time and the numbers of people engaged with. We also acknowledged that difficulties being experienced by all residents in accessing health and social care in the current environment added a layer of complexity when exploring experiences of inequalities in accessing services with those who were identified as typically experiencing even greater barriers.

The agreed line of questioning was designed to allow people to tell us, in their own words, what had worked well, what hadn't, and what they thought would improve their experience. All three organisations used these questions to guide conversations with individuals, with groups, and with representatives of the voluntary and charity groups working with Milton Keynes' residents.

Due to the interconnections of the activities between the three organisations within this project it was important to avoid duplication when engaging within our communities. Regular meetings were held to discuss any emerging themes and enabled a consistent approach to any alterations to the framework that might have needed to be made.

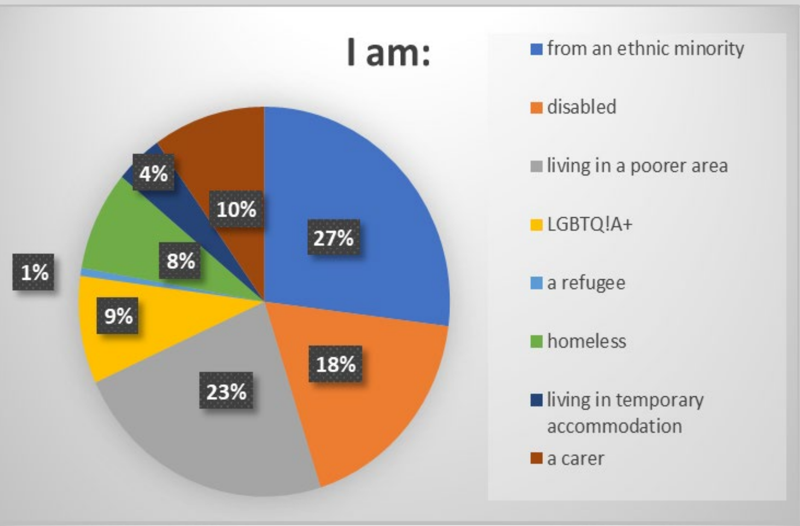
YMCA focused on engaging with younger people who have experienced homelessness. Their approach included conducting informal discussions in groups, and individually with YMCA residents.

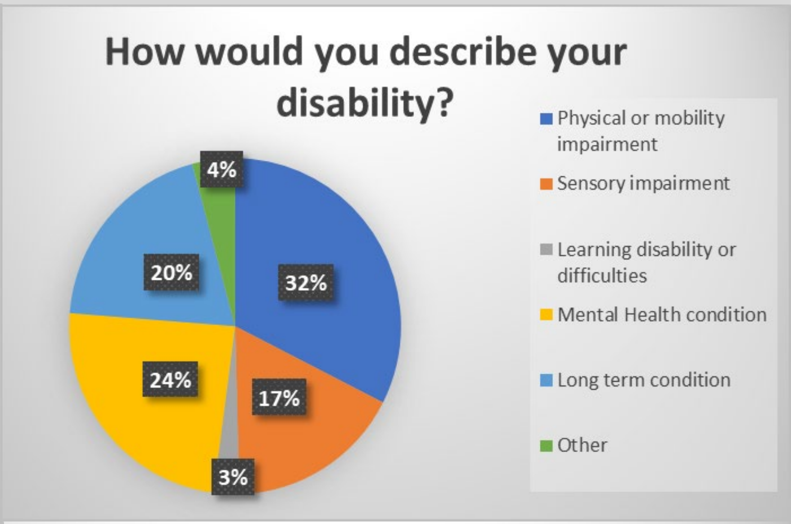
Community Action held discussions with Voluntary and Community sector groups that provide support to Milton Keynes residents and drawing on recent insight and evidence held in their Community Insights system.

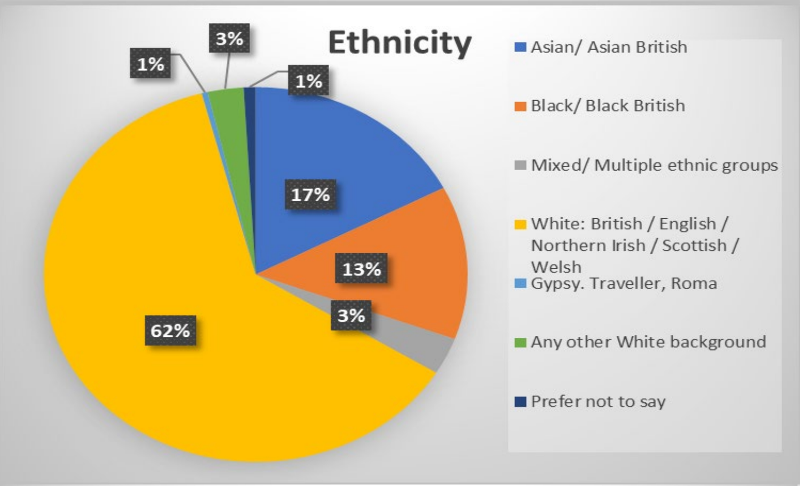
Healthwatch Milton Keynes ran a survey and conducted interviews with residents at planned outreach events, and drop-in visits to spaces including Community Larders and local groups such as MK Snap, Carers MK and the Somali Outreach Project.

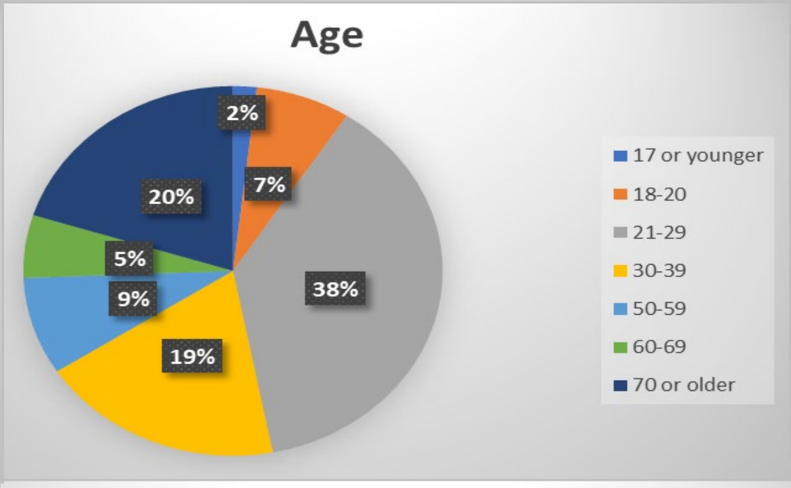
Community Action: MK and YMCA Milton Keynes, and Healthwatch Milton Keynes drew findings into three detailed reports. As part of the collaborative agreement, Healthwatch Milton Keynes then analysed data and insight across all three reports to draw out a cohesive Milton Keynes Place-Based picture of the inequalities that the identified communities and residents experience. Once this was drafted, a further meeting was held to agree the content and evidence of the summary and draw recommendations from the collected data.

Demographics


I am:


How would you describe your disability?


Ethnicity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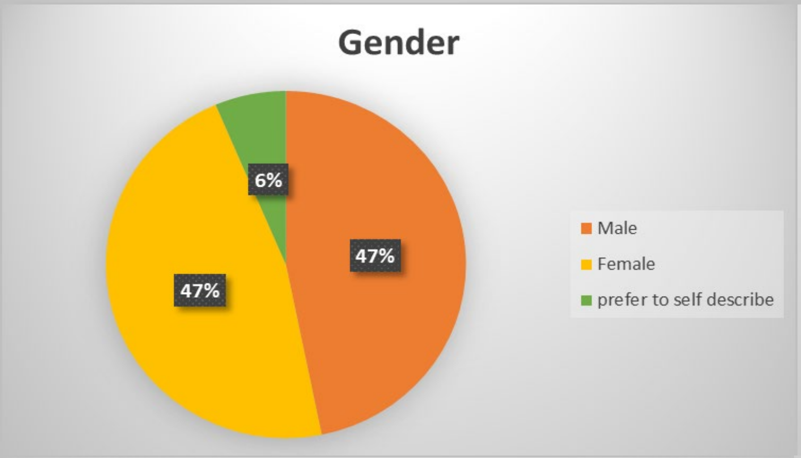
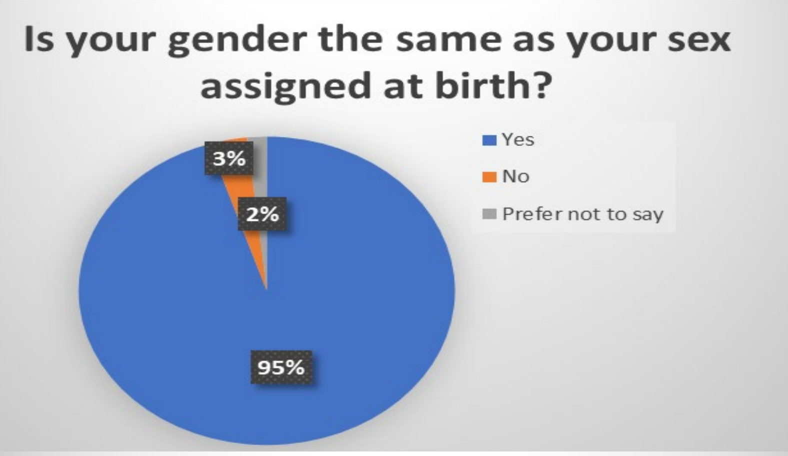
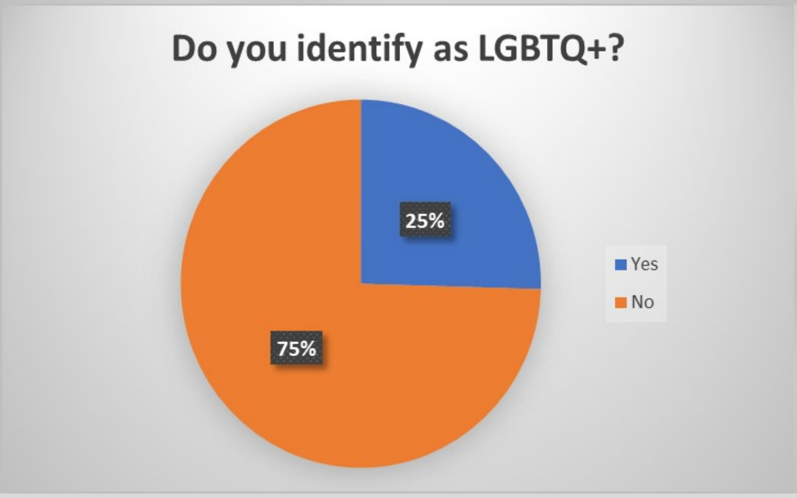
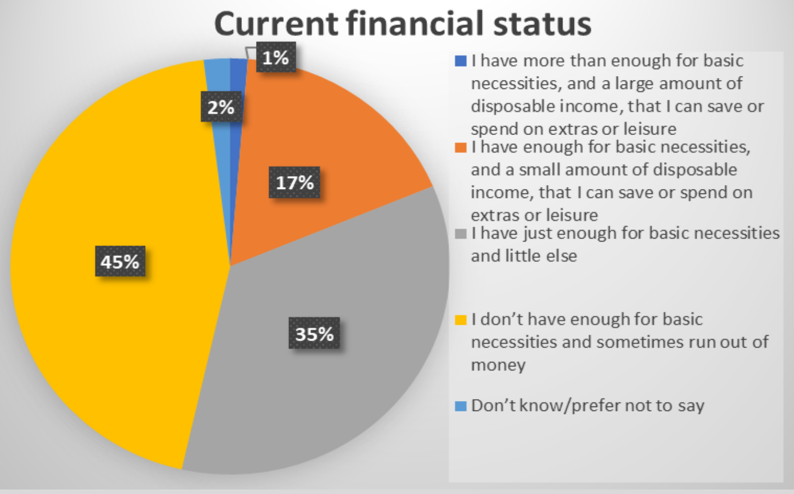

Gender


Is your gender the same as your sex assigned at birth?


Do you identify as LGBTQ+?


Current financial status

People and Intersectionality in summary

YMCA Milton Keynes

YMCA Milton Keynes spoke to **47** young people who live at YMCA Milton Keynes based in central Milton Keynes. Residents were asked to provide basic demographic information that they felt comfortable to share, recognising that half of YMCA residents have a background of significant trauma which could include growing up in the care system, or having direct experience of the criminal justice system. For young people with these experiences, they can find direct or structured questioning challenging, or can find even a basic level of interviewing as an interrogative experience. Some residents can also question the motive(s) of professionals seeking their information. Therefore, flexibility and informal approaches to listening to their experiences was essential.

All the young people interviewed felt comfortable to share their information and views with a trusted professional in a familiar setting. YMCA staff conducting listening activities clearly explained why they were collecting the information, and how the information would be used. All young people reacted positively to the idea that health and social care commissioners were interested in hearing from them directly.

The young people interviewed identified the following aspects of how their social and political identities combine to affect their experiences of health inequality:

- The residents interviewed were aged 18-35
- Young people were asked to self-identify their gender. 6% of respondents identified as other, 3 were transgender men
- Young people were asked to self-identify their ethnicity. Those responding as 'Mixed other' included Bermudan and American, Black British, and Caribbean and Jamaican and Irish
- 34% of respondents self-identified as LGBTQIA+. This included those that identify as lesbian, bisexual, pansexual, and transgender.
- 49% of respondents identified as having a disability, including mental health conditions. 13% declined to answer the question.

The interviewer noted that many young people who did not self-identify as having a disability later spoken of multiple diagnoses in their comments, including depression, anxiety, PTSD, autism and learning difficulties.

Healthwatch Milton Keynes

Healthwatch Milton Keynes had **144** responses to their published Inequalities survey and held listening interviews with **151** people through outreach events, focus groups and our assertive outreach work.

The residents we interviewed and heard from identified the following aspects of how their social and political identities combine to affect their experiences of health inequality:

- 58% of survey respondents that didn't identify as having a disability or long-term condition attributed their health inequalities to their age, ethnicity or their gender/gender identity
- 31% survey respondents were carers
- 27% of people engaged with were from ethnic minority groups
- 18% of all people sharing their experiences identified as having a disability
- 23% of all people sharing their experiences lived in deprived areas of Milton Keynes
- 9% of all people sharing their experiences identified as LGBTQ+
- 4% of all people sharing their experiences lived in temporary accommodation
- Other intersectional inequalities trends were noted for older women across all communities, people on lower incomes, people living in council housing and religious beliefs.
- 1% of people said whilst they were more than financially stable, their disability or carer responsibilities meant they experienced unequal access to care

Community Action: MK

Community Action: MK spoke to voluntary sector groups who work within Milton Keynes with the communities identified in the Literature Review, excluding those working with homelessness to avoid duplication. They carried out 13 interviews with groups / representatives, using a mixture of video calls, phone calls and in person meetings depending on the group's preference.

Q:alliance are the LGBTQ+ support charity for Milton Keynes. Each month they directly support around 50 adults and 35 young people (11-18). There is an estimated population of 10,000 LGBTQ+ in Milton Keynes and Q:alliance provide indirect support to all who identify as LGBTQ+ through awareness raising and diversity training for local groups and businesses to improve the overall awareness and understanding within the wider community.

The Ethnic Minority Achievement Team work with around 45 Gypsy, Roma and Traveller (GRT) families per year (around 200 individual adults and children). 90% of the GRT families the EMA team support are from the Irish Traveller community and 10% have English gypsy heritage.

Talent Unlimited directly supports around 40 adults fairly evenly split between males and females, 90% white British and between 18 and 50, with most under 30.

Talkback offer support with personal development skills, support in colleges and communities, and employment skills to people with Autism or Learning Disabilities.

Camphill Communities support over 70 residents who have learning difficulties, autism, and/ or mental health needs. Support is provided in small family units where individual living skills are developed and quality of life is enhanced, and where individuals are at the centre of their own care and support.

The Centre for Integrated Living supports people through a wide range of free and confidential information on any disability related issue for people with a disability, their families, and carers.

The Macmillan Cancer Support Research Project collected information from people from Black and Minority Ethnic groups to understand the barriers that prevent the uptake of MacMillan Cancer support services

The Wisdom Principle focus on mental health support for Black and Minority Ethnic communities.

Welcome MK provides support and assistance to meet the needs, both immediate and longer term, of refugees and migrants arriving in Milton Keynes.

Summary of Findings

There is strong public awareness of the current pressures both on the NHS and on Social Care, with people experiencing challenges accessing the services they need. As the nation recovers from the Covid-19 pandemic, many of us are facing long waiting lists for diagnostics and surgery, difficulty getting an appointment with a GP, accessing an NHS dentist or social care support. However, for some people and communities such challenges and barriers to health and care support preceded the pandemic and have worsened because of where they live, what they earn and who they are.

The current levels of pressure and capacity issues within health and social care and the cost-of-living crisis has not created inequalities of access, care and support in the health and care system, but it is impacting greater numbers of people, so people and communities that were already experiencing inequalities in access, care and support are even more greatly impacted.

> "I really need to see a GP and a dentist, but I've been told I can't see a GP because I don't have the ID. I can't afford to see the dentist. I'm in a lot of pain. I worry about my kids' teeth"

Healthwatch Milton Keynes, Community Action:MK and YMCA Milton Keynes have set out our individual findings in three separate reports. We then drew together the demographic data and insight from direct engagement with residents and analysed this alongside the insight provided by representative voluntary organisations and community groups. This analysis reflected a number of common themes and experiences for the people and communities we engaged with.

Accessibility – People from the communities we spoke to shared that they experienced barriers to accessing the help they needed. This could be by having to convince a receptionist they needed to see a GP, or convincing a GP that they needed a referral, convincing 111 that they weren't exaggerating, convincing consultants of their own experience of their condition, convincing a Social Worker that they had care needs. There was a strong common experience of this issue drawn out from our insight. People experiencing poorer health outcomes shared with us a sense of greater challenge with the language, capacity, or confidence needed to self-advocate when speaking with professionals.

> I always feel rushed which makes me nervous and forget what I want to say. As this has been an ongoing situation throughout my life, it is now ingrained behaviour and I constantly feel of little or no importance. Long waits and impatient staff over the years also increase my nervousness and inability to approach health and care services in a relaxed manner

Communication – Individuals from all communities shared challenges around communication. This included D/deaf people being given phone numbers to services or staff talking to them while wearing masks. For some residents, they felt that as soon as the front-line staff member heard their accent, saw their skin colour, or even the way they dressed, they began to experience barriers to the right support they needed. Unconscious biases held by professionals led to assumptions or judgements being made before the person had a chance to relay their need.

> "Giving birth as a black woman in A&E, it's... my sister died. As a black person, or anyone from a different ethnic origin, there always seems to be a bad outcome or complication somewhere"

Cultural Competency and personalisation - Many felt assumptions based on stereotypes are being made about them by professionals. This included assuming what their views about certain illnesses based on their gender, ethnicity, mental health status or religious beliefs, assuming the level of engagement, or action they would take with the professional's advice, and making assumptions about their level of understanding, which included over or underestimating a person's capacity to understand information provided.

Insight from the voluntary sector reflected many of these experiences through the demand and type of help being requested by people from these communities. Many VCSE groups, including YMCA Milton Keynes and Healthwatch Milton Keynes are seeing increasing demand from residents seeking help to advocate for their rights to access health and care.

> "CIL volunteers aren't trained advocates, but they are calling the gas company, or GP or Council on the client's behalf"

The barriers people face have a common theme - communication. This includes the professional to service user communication and inter-organisational communication that breaks down or does not happen. For people in the communities that we heard from, this translates to challenges discussing, and accessing the help they need but also struggling to access good, integrated support when moving between, or receiving care from two or more services.

No one we interviewed reported being offered an interpreter, and many people said they had to rely on either hearing friends and family, or on spouses or children to interpret for them.

> "If English isn't your first language, you may have a male family member take you to the appointment but how can you feel comfortable if the appointment was to talk about a female thing, a personal female issue?"

Conclusion

Accessibility

We heard that accessibility issues were almost equal to communication issues, when it came to barriers people said they experienced. Our findings evidenced that experiences of accessibility challenges were relatively evenly split between experiencing physical access issues to services, and accessibility to appointments, referrals, or even information about the services that were available. People with physical disabilities found that having to attend A&E or Urgent Care because they were unable to get GP appointments was particularly difficult because the long wait times could be physically impossible for them. This was also noted as an issue for people with mental ill health or neurodiverse conditions. People in the communities we spoke to told us they felt doubly penalised because they tended to avoid contacting the GP due to worries about staff attitudes towards their particular characteristic, and so their needs were more acute and complex by the time they were seen.

We also heard that trends toward access to support through digital methods is causing barriers for people with low levels of literacy, people who don't speak English very well, and people who can't afford an internet connection, or the devices needed to use the internet.

"I can't get an appointment, when I do get through on the phone, they say you have to access the online portal. When I say I can't, they hang up on me"

Improving accessibility must start with increasing the knowledge people and communities have of what services are available to help them, and how access such services. In particular, ethnic minority groups and elderly people without easy access to the internet reported this as a barrier.

While there is a wealth of support provided by VCSE groups across Milton Keynes, as well as the statutory services themselves, there is no one place to find this information with information scattered, and often in digital and inaccessible formats. GPs or Social Workers may have limited knowledge of the services themselves, and very little time within an appointment to find and provide information to support and other services that can help people.

"I know when I should get help but don't always know where to get it from. Thank goodness for Healthwatch and the other charity groups who make sure I get the information I need - the professionals don't give it out!"

Knowledge of support available for people and communities can be complicated by inconsistency and complexity of access points and poor integration in the health and care system. When people were asked whether the messages about looking after your health were easily available, almost half said the messages were, but that information about where to go or how to follow the advice was not. Clear information about access points to support, for example, whether a referral by a GP is necessary, whether self-referral is possible and information about an expected care pathway is required.

Communication

The law states that Health and Care information must be made available in a format that people can understand (The Accessible Information Standards[1] and the Equalities Act[2]) and is also pledged by the NHS Constitution:

> *"The NHS also commits to inform you about the healthcare services available to you, locally and nationally; and to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions."*

Cultural Competency and Personalisation – The people and communities we heard from told us that they need to be seen as a whole and unique person but often felt like assumptions based on their age, ethnicity, gender, disability, or symptoms created barriers to their needs as an individual.

This call out for 'cultural competency' was raised by people within the LGBTQI+ community, faith communities, ethnic minority communities, people with physical or sensory disabilities, mental ill health, neurodiverse people, as well as people living on low incomes. The theme that came through was that care, rather than being 'person centred', was centred around the set of symptoms/ condition, what worked for the professional, or what worked for the organisation. This means that there is little to no flexibility in the approach taken for the person.

People from ethnic minority groups told us that they often felt that health professionals didn't see them as a whole person, and that they had strong sense that they weren't really being cared for or cared about because the appointments were so rushed and there was no 'small talk' asking about the family or the person's day.

Religious people told us that felt that there was no place for their faith to be part of discussions around care and treatment. Whether discussions were around lifestyle or around medication, they felt that their particular belief system was seen as separate to themselves, their illness or their recovery and they felt that their beliefs should be integrated into the conversation to support more appropriate clinical care.

People with Mental ill health felt that a lot of the care or treatment they receive is done to them, not with them, and felt that they were not involved in discussions about the benefits, or side effects, of available treatments. These

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[1] https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

[2] https://www.legislation.gov.uk/ukpga/2010/15/section/149

people also told us that they had concerns about Diagnostic Overshadowing, when other issues they have were overshadowed by, or attributed to their mental health condition. They shared that they often felt 'fobbed off' with pills on the first attempt to talk about their mental health. Those who had an existing diagnosis told us that they were worried that if they talked about what they were experiencing, they would be sectioned.

> "With mental health, I didn't get any support with my schizophrenia. Other people think you are scary, so they put you to one side. I didn't get support. When I was in the Marvel House, for people with schizophrenia and serious illness, people who can't cope and that. It was [not good], you don't see no one. You're locked away. It's worse than prison. No one can visit, you can't leave. It's all security gates. They have rooms with support workers, and I know they are trying to help you but as soon as they know you have schizophrenia, they manipulate you and treat you like you have a big issue"

People who identified as LGBTQI+, shared common experiences of Primary care and told us that GPs who don't always have a good understanding of their specific needs and concerns, which influences a reluctance to access health services. For many people in the LGBTQ+ community this is resulting in many people reaching crisis in their physical and their mental health before they seek treatment.

> "I've moved homes about 4 times in the last 2 years, and I've changed GPs twice. I put Mr down on all of my forms, but they changed it to Mx. They didn't ask me, they just changed it. I think it could have been linked to my hormone injections, I think they just assumed. Mx is still misgendering me, it's not how I identify... I signed up as a Mr so why would they change that? It's super frustrating. Mistakes get copied over from previous GP's so you can't even get away from it".

Opportunities for health and care professionals to have wider discussions about an individual's life can draw out important information to provide more relevant and more person-centred care, for example, identifying financial and access challenges, understanding what pronouns an individual would like to be addressed by, how their individual beliefs could inform their care and treatment plans, or a person's caring responsibilities.

Recommendations

The recommendations made in this report are based on the findings of the three contributing organisations and have been formulated with the needs of residents experiencing inequalities as well as with ICB priorities in mind.

The authors of this report believe that focussing on the suggested groups will allow for an inequalities coproduction process to be piloted, and perfected before rolling the programme out to the wider system, particularly communities with more complex intersectional inequalities and needs. For example, the authors of this report suggest that the coproduction concept should be embedded and proven before it is broadened to the Gypsy, Roma, Traveller communities. This group experiences far higher levels of inequality than most other population groups and the system will need to tailor longer-term, sustainable approach and resources to build trust with people who have little reason to believe that their cultural needs will be considered, or their input valued.

The groups within the recommendations have been put forward because it has been demonstrated that they experience high levels of inequality, and because they have strong support from groups and organisations who will be able to aid them in a coproduction journey. It is strongly suggested that any coproduction involves least one VCSE sector organisation or group who can consult & engage with their service users or community to introduce and facilitate engagement in the coproduction of each new service or project development.

The resources produced in coproduction with these groups will provide a good foundation for developing the resources needed by many of the other people who experience similar inequality in access and communication.

Recommendation 1)

Coproducing a set of identified service gaps, and a set of reasonable adjustments to health services, physical spaces and communications to make them more appropriate and inclusive for the focus population groups

We recommend that this coproduction work begins with the following groups:

- People with learning disabilities
- Young people affected by mental ill health, including Autism Spectrum Conditions

Recommendation 2)

Coproduction to design training and resources for health providers that would support them to increase their awareness of cultures, needs and conditions relating to the focus population groups

- LGBTQ+

Healthwatch Milton Keynes

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YMCA MILTON KEYNES

The Denny Review

Health Inequalities Report

About YMCA Milton Keynes

YMCA Milton Keynes has been established since 1981 and in that time has supported over 10,000 young people aged 18-35 through emergency accommodation and supported housing. We are the largest provider of dedicated supported housing to young people in Milton Keynes. We work with young people who have experienced homelessness and provide them with, not only a safe place to stay, but a range of support services that empower them to belong, contribute and thrive.

YMCA Milton Keynes £18.5 million development in central Milton Keynes

Our Resident Community

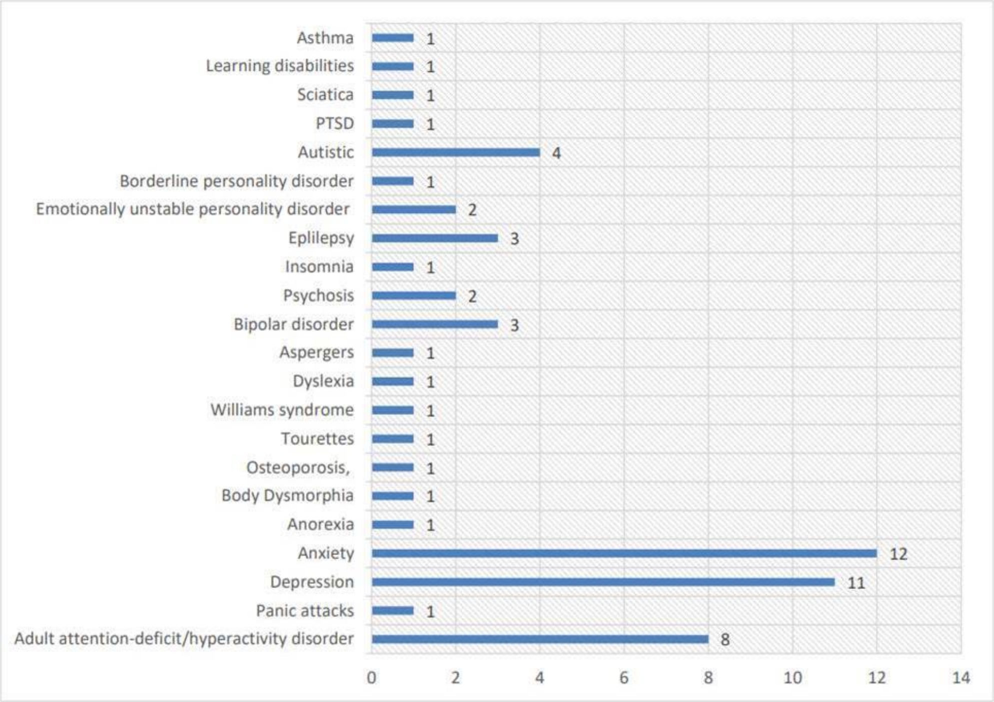
The University of Northampton independently reviewed YMCA Milton Keynes & its services and produced the following data. These statistics are constantly in flux because we have a transient resident community of up to 242 young people but will give a general overview of the level of needs our services meet:

- 66% of residents were homeless before coming to the YMCA
- 27% of our residents are Black & Minority Ethnic (BAME)
- 13% of our residents are LGBTQIA+ (a total of 27 young people currently) of which 3% identify as transgender
- 60% of our resident’s class themselves as having a disability, predominately due to mental health issues
- 50% of our residents report a background of trauma
- 54% of our residents have been victims of domestic abuse
- 45% of our residents have been involved with the criminal justice system
- From our own data, we know that in the last 12 months 8 male residents and 6 female residents have attempted suicide

Many of our residents have multiple complex needs which are a unique combination of the varied experiences highlighted above.

Below is a table of the different conditions declared when residents were asked about their disabilities:

Figure 3. Distribution of the disabilities N=29 (%).



Staff feel the numbers are much higher in reality, but the range of conditions highlighted here is an accurate representation of the diverse support needs present in our resident community.

Our Demographics

As demonstrated above, our resident community includes many of the groups listed within the Denny Review:

- Ethnic minority communities living in deprived areas
- Disabled people living in deprived areas
- Homeless people
- LGBTQIA+ communities

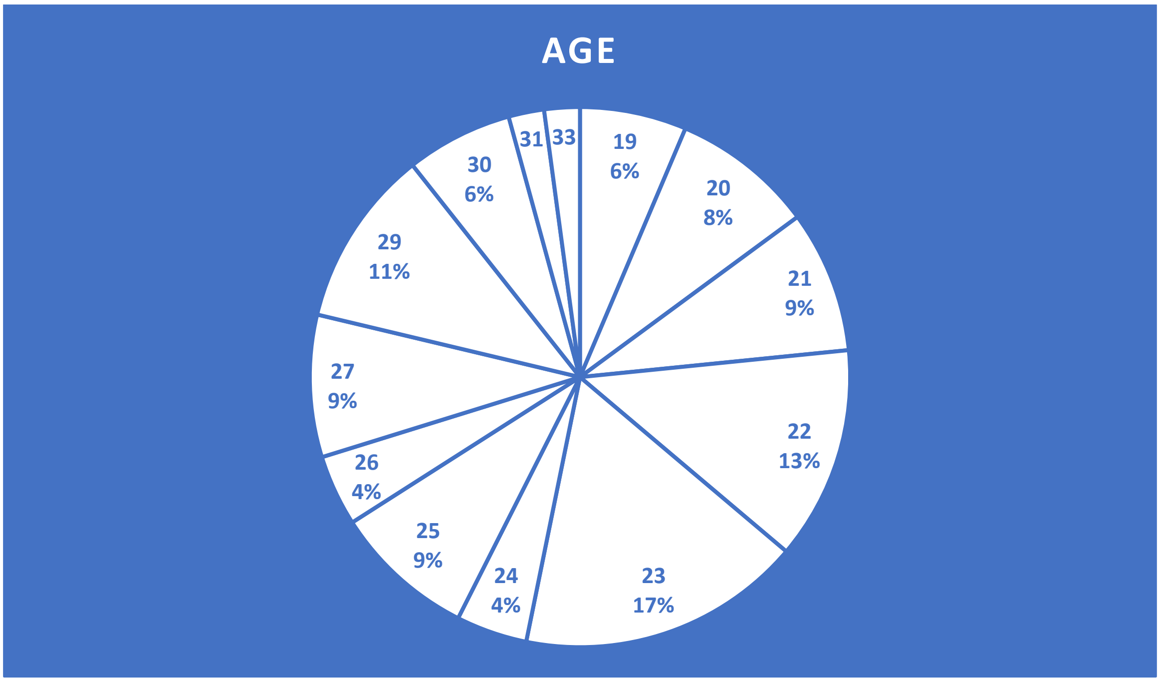
For this report, we spoke to 47 young people who live at YMCA Milton Keynes based in central Milton Keynes. We collected some basic demographic information that young people felt comfortable to voluntarily share, recognising that half of our residents have a background of significant trauma which could include growing up in the care system or direct experience of the criminal justice system. This means that they may find direct questions challenging or can experience even a basic level of interviewing as an interrogation. Some residents can also question the motive(s) of professionals seeking their information.

That being said, all young people felt comfortable to share their information and views with a trusted professional in a familiar setting. We clearly explained why we were collecting the information, and how the information would be used. All young people reacted positively to the idea that health and social care commissioners were interested in hearing from them directly.

Below is the demographic data we collected during the consultation period:

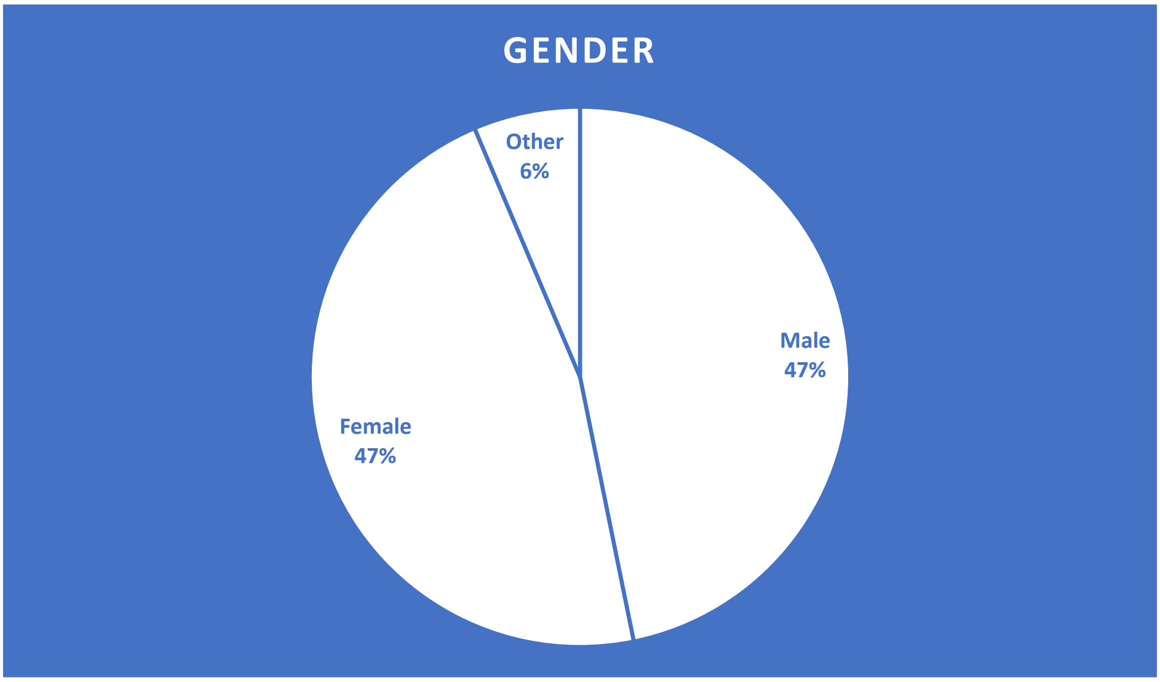
Age

YMCA Milton Keynes residents are aged 18-35, with the age breakdown of those consulted outlined below:



Gender

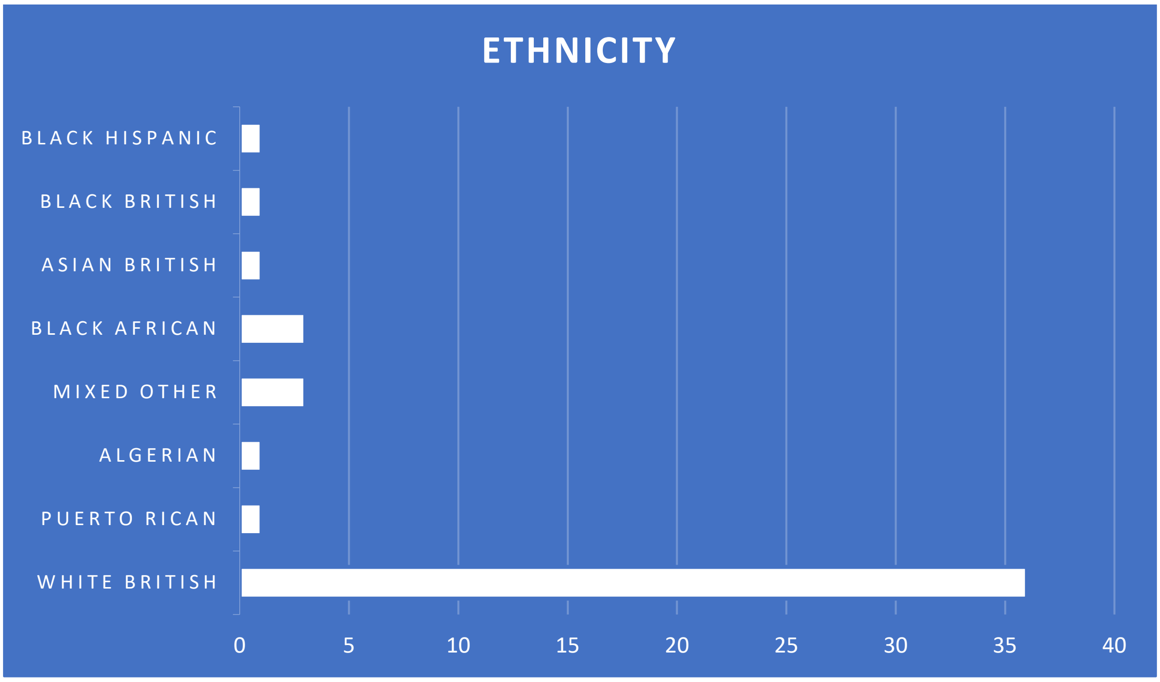
Young people were asked to self-identify their gender:



‘Other’ includes three transgender men.

Ethnicity

Young people were asked to self-identify their ethnicity:



Mixed Other includes three young people who identify as both Bermudan and American, both Black British and Caribbean and both Jamaican and Irish.

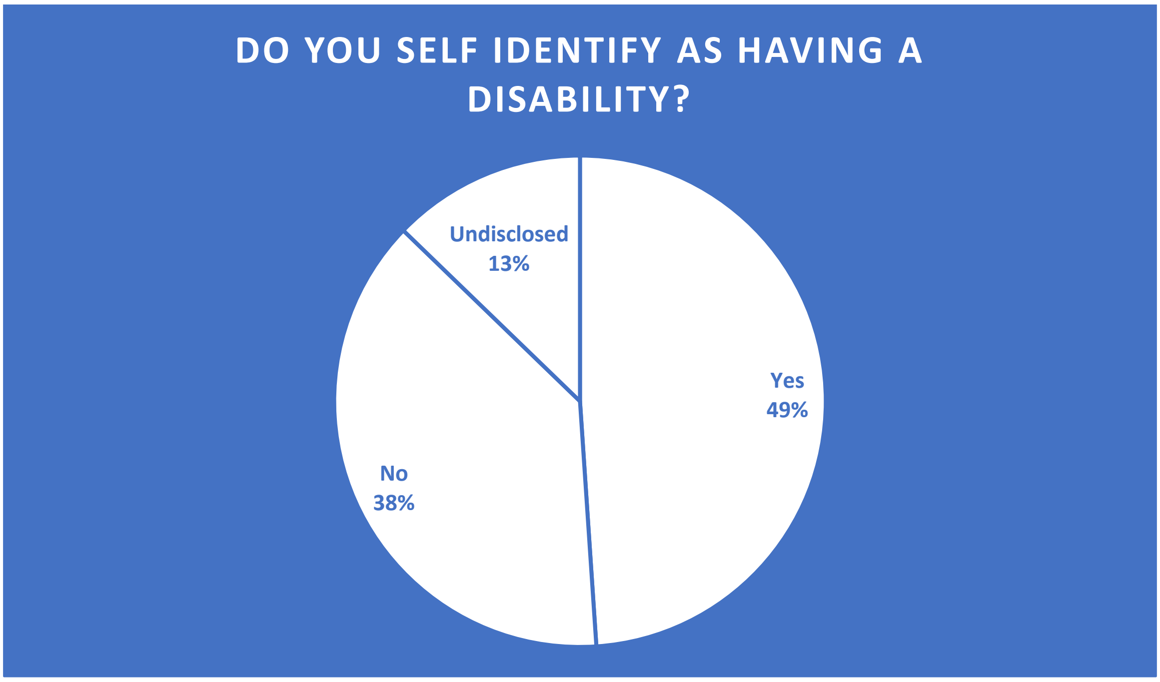
LGBTQIA+

Young people were asked if they self-identified as LGBTQIA+:

Those who answered 'yes' included those that identify as lesbian, bisexual, pansexual, and transgender.

Disability

Young people were asked if they self-identified as having a disability, including mental health conditions:

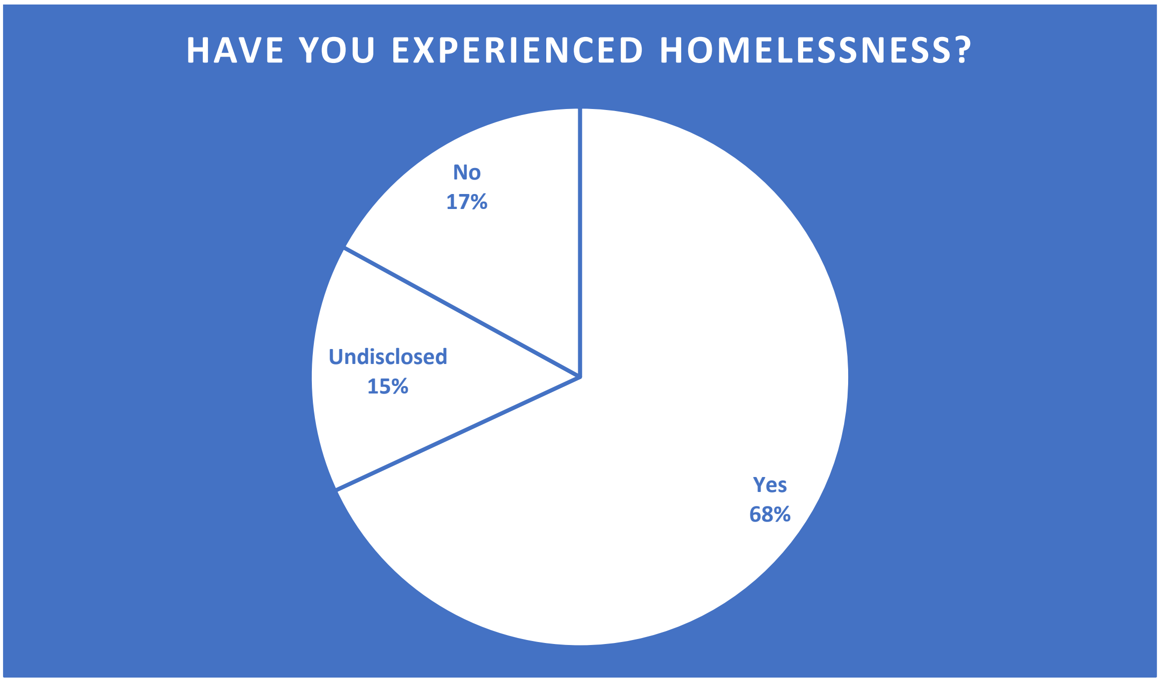


Some young people declined to answer and are marked as 'undisclosed'.

NOTE: The interviewer noted that many young people who did not self-identify as having a disability later spoke of multiple diagnoses in their comments including depression, anxiety, PTSD, autism, learning difficulties etc. There is a potential therefore that the graph above significantly underplays the disabilities present in the group of young people interviewed. It also suggests that young people may not understand what having a disability means beyond traditional notions of physical disability.

Experience of Homelessness

Young people were asked if they have experienced homelessness:



Some young people declined to answer and are marked as 'undisclosed'.

Our Methodology

For maximum success, we utilised a variety of resident engagement techniques including informal face to face conversations and group sessions. We engaged with 47 residents in total across all three stages of our housing pathway including Supported Living, Shared Living, and Independent Living.

47 residents were engaged informally in person at YMCA MK either individually or in small groups of up to 6. These direct comments from residents form the main body of text. The interviewer has experience in both youth work and community engagement and used physical prompts and open questions to encourage dialogue. Comments have been written as they were said to the interviewer in their full form although expletives have been edited or excluded in some circumstances.

We asked participants to self-identify in the following categories only: age, gender, LGBTQIA+ status, ethnicity, disability status, and experience of homelessness. This methodology promoted engagement and protected young people's anonymity and therefore the integrity of the comments given.

Topic Index

Our Findings

Below are the young people's comments written as they were said to the interviewer grouped loosely by topic or theme:

Accessing GP Surgeries

'The GP now feels really accessible to me. Before, I had to go in. Now, they have an app so I can send photos and book a telephone call and they can make an assessment that way. I don't work in MK [Milton Keynes] and I can't always get to weekday appointments so it's the best way for me currently', Female aged 25.

'I prefer when I can phone to get an appointment. At my new GP, you have to book online at 8am and I don't like it. When I phone, they tell me I'm not allowed. I have learning difficulties so I can't use the website. When I call, I can talk to a person and explain what I need. The website is too confusing for me', Female aged 23.

'I moved to Whitehouse GP now as my GP at CMK [Central Milton Keynes] stopped my referrals that I had from a previous area from consultants. This GP was my named GP so I asked to change GP's, but they wouldn't let me, so I changed surgeries instead. The process wasn't beneficial for my mental health. I find it really difficult to book online for 8am, with my needs I find it hard to get up and remember appointments often. At Whitehouse, they have a dedicated Mental Health Nurse. You can phone at any time, and they will help', Male aged 30.

'I know the receptionist at my GP so she always gets me in, that helps!', Male aged 33.

'Accessing the GP is stressful, then you have to wait months for an appointment, you don't get a kind response. Sometimes I'm on the phone for 10 minutes waiting, sometimes I don't call, sometimes the help isn't worth it. I've been waiting for a psychiatrist referral for 2 months. They don't update you; they should give you a holding letter', Male aged 24.

'I think all health services are crap. My keyworker has to support me to get appointments, I get anxiety talking on the phone. I do it, but I don't like it', Male aged 30.

'GP's never answer the phone and when they do, they just prolong the situation and don't take you seriously – you have to be literally dying, or they just refer everything to COVID. You can wake up with a headache and they just say COVID, everything's COVID. Doctors don't doctor anymore. Everything is an answerphone, or not even a person, or a person not a doctor – they try and triage you over the phone & they assume things. Assume it's COVID!', Male aged 30.

'GP is kind of long, they don't answer your calls. They have me on hold for an hour, and then answer and tell me to call back Monday. It takes three weeks to book an appointment', Female aged 20.

‘Anyone can call, but it’s hard to get seen in a reasonable time. Last time I called, they said it would be two months to get an appointment. It took me one and a half hours of waiting before they told me it would be two months to see someone. In that time, the illness would resolve or I’d be dead!’, Male aged 26.

‘I don’t go to the GP often. I was registered but it was in Whaddon which is a trek. [My keyworker] is trying to help me move GP’s now. They are easy, but you do have to make an effort to access them’, Male, aged 21.

‘I think the GPs are rude. I know they’re stretched but it’s not helping me’, Female aged 22.

‘I find it really hard to get an appointment with my GP, they don’t get to the bottom of the problem. You get referred on, but it’s not to the right department. Or you are referred, but the appointment is for a years’ time. I can never see appointments on the online system for the next day, I try to call them but it’s impossible to do that – it doesn’t put me on a waiting list, it just ends the call’, Female aged 22.

‘I don’t go to the doctor, I only get help if I have a medical emergency – I just call 999’, Female aged 23.

‘I’ve tried signing up to the Bradwell Common GPs. I’ve called 3 times, been in twice. I’ve put in two registration forms but they just keep saying it’s not coming up on the system. I don’t feel like they are taking it seriously. I really need support at the moment for my mental health and I think they need to take more responsibility for their side of things’, Female aged 19.

‘It depends on the day, depends on the time of the call. If you call in the morning, it’s not that long, but if you call at like 1pm then it’s half an hour [waiting] at least’, Male aged 21.

‘I’ve been waiting for 8 weeks to talk about my mental health with a doctor on the phone. They told me I’d speak to someone within a month’, Female aged 29.

‘Doctors have forgotten to send prescriptions before, so I’ve withdrawn from a really strong dose of anti-depressants which made me feel suicidal and emotionally distressed - it’s really dangerous to do that’, Female aged 29.

‘You have to declare your personal business to a receptionist and beg for something that should be available to you regardless’, Female aged 29.

‘GPs are just crap. I can’t get an appointment, when I do get through on the phone, they say you have to access the online portal. When I say I can’t, they hang up on me’, Male aged 27.

‘I can never get an appointment. They are fully booked, and I have to wait months to see anyone. Some people just walk to their doctors and get seen straight away, I don’t get it’, Female aged 29.

‘I needed a blood test for anaemia, they said they’d call me for an appointment but they never called. Since then, I haven’t bothered. I don’t see the point in going’, Female aged 21.

‘GPs are hit and miss, I think. It should be the same across the board’, Female aged 29.

‘I don’t want to change doctors when I move. I have a GP I really like in Fenny Stratford, but I now live in CMK. I think there should be special circumstances where they allow you to stay. [Why do you like your GP?] I like him because he listens and takes the time, goes over the five minutes he’s allowed with me. He gives me options and lets me ask questions. He lets me choose. That’s why I will only talk to that doctor’, Female aged 29.

‘Phone consultations only give doctors five minutes to deal with you. I was trying to explain my codeine and anti-depressants cancel each other out, and then he suggested an anti-inflammatory which gave me bad side effects before. He asked what side effects and I said constipation and back pain so he prescribed me laxatives as well. I said I work, I’m at college, I can’t take them. It’s a really good example of my voice not being heard. I also asked to change my anti-depressant which he forgot, and I withdrew from badly, it’s a good example that five minutes isn’t enough time to deal with a patient’, Female aged 29.

‘GPs should be able to discuss more than one issue in the appointment. If they could cover multiple issues then less appointments would need to be made. Sometimes it can be quickly resolved’, Male aged 27.

‘I’d like to receive GP appointments at the YMCA, I think it would really help. And eye tests too, all of it here’, Male aged 27.

Accessing Walk-In Clinics and Emergency Services

‘I think A&E is great, every time I’ve been I’ve never had a problem. I’m epileptic so I’m rushed into hospital once a month, I spend a lot of time in there!’, Male aged 27.

‘They’ve saved my life a few times actually [in A&E]. They saved me when I got stabbed. They saved me when I had a heart attack, I’ve had two now. The staff are polite… and flirtatious, the nurses!’, Male aged 33.

‘Twice in a week I was losing consciousness and I waited for hours [at A&E] but I’m ok with that, I got sent home with nothing. The problem has continued but I don’t go to A&E anymore, no point. I might go to a walk-in centre instead’, Male aged 24.

‘It’s like, some [people] are seen twice before you are seen once. It feels understaffed. It feels like you have to prove you are in an emergency’, Female aged 24.

‘A&E… I can’t fault them. I always get seen straight away. I do wait, four hours, but I take my crochet or my iPad to watch a film, keep myself busy. They do their job, I don’t mind it’, Female aged 29.

‘I don’t understand why those who are more injured have to wait longer at A&E? I don’t feel staff take us seriously because we are younger’, Female aged 24.

‘A&E is so confusing, there are like 8 entrances. It’s so hard to get around’, Male aged 23.

‘I was stabbed in my spine; I went to A&E, and I was leaking blood. I didn’t get seen for a couple of hours. I was in a huge amount of pain. They said it wasn’t life threatening. I had to have crutches and physio to learn how to walk again, it was very blasé – no one was actively supporting me. I was 15 then, but now I wouldn’t go into a hospital. I don’t feel comfortable when I go there, I just get a bad vibe from it. They could make it more comfortable, but they choose not to’, Male aged 23.

‘I wouldn’t access A&E alone; I can’t go alone. I was allowed to take a friend which meant I did go, but I wouldn’t have stayed if this wasn’t the case. The environment is very busy, noisy, too much going on – it makes my anxiety worse’, Male aged 30.

‘I think A&E is slow as f***. I broke my finger and I was in loads of pain. I called prior to going to arrange a time to be seen, I was still sat there for two and a half hours. Then I got sent away, and then they put me in an arm cast for a broken finger’, Female, aged 23.

‘I find the staff quite cold normally [in A&E], they seem stressed’, Female, aged 23.

‘I’ve been to A&E quite a lot actually… [When entering in an] ambulance A&E is perfect, they see you so quickly. It makes sense. I’ve arrived at A&E at night, & I wasn’t seen until 10am the next morning when the doctors came in. I recently had a broken foot from work, and I wasn’t seen for 11 hours. They told me I needed to rest it for 2 weeks, I can’t do that – I need to work’, Female aged 22.

‘You do get seen faster if you go in in an ambulance, I do intentionally try to get an ambulance as I know I will be seen quicker. I think lots of young people do it, it’s the only way we get taken seriously’, Male aged 23.

‘[A&E is a] hostile environment’, Male aged 22.

‘The walk-in centre has to triage you, so those who are worst get seen first. Last time I went, I waited for five hours. I don’t know what other people had but my throat was closing up and I was struggling to breathe or eat – it was the most painful experience I’ve ever had’, Male aged 26.

‘[A&E is] horrible’, Male aged 30.

‘Children get seen quickly in A&E, and older people get seen, but young people don’t get seen. I feel like receptionist’s stare at you and don’t think you should be there; they can be really rude, and I don’t need it really. The nurses and actual medical staff are always really nice, it’s just the people behind the desk’, Female aged 22.

‘[Your experience in A&E] depends on what you go for. Every time I’ve gone for something visible, it gets taken seriously. If it’s something they can’t see, it feels like it doesn’t matter. The other day I had a fever and I felt like I was high. I went to the walk-in centre; they said I had epiglottitis which could be fatal if left untreated. They took me straight to A&E, the walk-in staff handed me over, but the A&E nurse said, “you are able to get around so you’ve probably got a sore throat”. They did tests and it turned out I did have it, and another infection too, but because they couldn’t see it, they didn’t believe it until the tests came back. [How did it feel?] It feels like shit. I felt so unwell, I had a fever, I couldn’t focus and I just wanted some help’, Male aged 23.

‘[Doctors] only see blood results as proof that there is something wrong’, Female aged 24.

‘I only go to A&E when I need too. The people behind the desk at A&E are condescending, they always say I need to go to the walk-in centre’, Male aged 23.

‘One time I had COVID, I didn’t know it yet, but I felt like I was going to die. I called an ambulance as I couldn’t even walk, and they told me I wasn’t a priority. It took seven hours for the ambulance to come. When I asked them why it had taken so long for them to arrive, [the paramedic] said “some people exaggerate their symptoms”. I reported that he’d said that to me, but no one ever got back to me’, Female aged 25.

‘The walk-in centre wait time is longer than A&E, and they always send you to A&E anyway, so you have to wait again. It’s just so hard to get seen’, Female aged 22.

‘The [A&E] staff will say come back to A&E in a week, but I go back, and they send you to the walk-in clinic’, Female aged 22.

‘An ambulance crew forced me to come down to the [YMCA] foyer from my bedroom, and I was vomiting at the time. They refused to take me in, as my vomiting had briefly stopped, and they said I was having a panic attack. I wasn’t. In the end, my mum took me down to the hospital and they admitted me straight away, and the ambulance people saw me in my bed and looked so shocked. I think that they think we are lying just to get admitted to hospital’, Female aged 22.

‘My experiences with A&E have not been great. One time I fell down the stairs and I had numbness down the back of my legs. I had to wait 12 hours for an MRI, and they discharged me twice without even looking for me in the building. Another time, they left a catheter [cannula] in my arm for 6 hours which I didn’t need as they were giving me pills by mouth. I had to take it out myself in the end, it really hurt’, Female aged 29.

Accessing Mental Health Services

‘Last year, I had a mental breakdown and I was really unwell. I was planning to take an overdose, I told them “I want to take an overdose, I want to die”. The [A&E] nurses said, “you look really on edge, here is some medication so go home & take it and we will call in an hour”. An hour later, I was back in A&E as

I’d taken all of the medication and more, and they just shouted at me’, Male aged 22.

‘Mental health [support] is few and far between. Mind and GPs, the NHS, don’t interact and I find it frustrating. [Mind] are all the way over in Bletchley so they aren’t that accessible. I struggled to find it. I find the travel expensive, they do have a support line’, Male aged 30.

‘There is not enough support and resources to help people, in general, but especially with mental health’, Female aged 29.

‘I think mental health [services] should be a lot more. I think we need people to talk to… activities… support really’, Male aged 29.

‘I think mental health is misunderstood. Most people I’ve met in [mental health] services don’t care about the person experiencing mental health. I’ve needed help since I was 13, and I didn’t get anything [in terms of support] until I demanded it. I still had to wait three months even then. I feel like they just pity you – have a bath, have a cup of tea’, Female aged 21.

‘[Mental health services] haven’t always taken me seriously, no fast response, they just fob me off’, Female aged 19.

‘I went to the hospital for mental health support. I felt like they didn’t care, they were judgmental and came to their own conclusions without listening to me. They referred me for alcohol support but I didn’t need that, I took alcohol with an overdose – that wasn’t an alcohol problem, it was a suicide mental health problem. I just felt like the mental health nurses didn’t want to be there. Why do that job if you don’t want to listen? If you don’t want to help?’, Female aged 25.

‘I had to wait for three years for diagnosis as they kept handing me around and my GP didn’t take me seriously and said my anxiety and depression was ‘normal’ for my age even though I was self-harming at 13. I was in care, and once my mum took us back, I didn’t get any support or therapy, and I’m still experiencing the effects from it now. I suffer with CPTSD, I struggle to work, can’t do everyday activities alone and daily tasks are a struggle. I eventually got medication, but they caused physical issues like I got anxious ticks so now I can’t drive. My CPTSD will never go away, and I will suffer from panic attacks, depressive episodes, and manic episodes for the rest of my life. [How does it make you feel?] I feel angry, let down and upset. If I got the help I needed sooner, I could have been fine’, Female aged 20.

‘I think for some people therapy is more important, medication can work in the short term, but you need therapy. Some people don’t know how to manage their own care’, Male aged 22.

‘Mental health support is really poor. I’ve gone to A&E several times because I wanted to un-alive myself and I’ve just had a conversation. They gave me a leaflet with services on it and that was it. I could have gone home and… yeah’, Female aged 25.

‘Mental health is a double-edged sword, I’ve been accessing services since I was 10. The main issue is the wait times, I waited a year for group therapy and went once, realised it didn’t work for me and so now I’m on a waiting list again. There is no support or services in between whilst you are waiting, you are left alone to deal with your stuff’, Female aged 29.

‘Mental health support just want to send you to group therapy all the time. I don’t want to share my issues with 10 other people. I feel their stories could trigger me, and vice versa’, Female aged 22.

‘No one really helps you that much with your mental health, you have to figure it out for yourself. I was directed to the Mind app but it wasn’t helpful for me, it might work for others but it’s all relax, chill out, and I need something stronger than that. I think you’ve got to build your own mental fortitude, a lot of what’s out there is for a stereotype [of a person with mental health issues] rather than what I personally need’, Male, aged 21.

‘I think people think [mental health issues] is an easy way to get out of work, but it’s not. I work. They always want to give you anti-depressants and say it’s anxiety and depression when it’s actually ADHD or something else’, Female aged 22.

‘It takes ages to get mental health support, you have to be on the waiting list for ages’, Female aged 19.

‘I don’t think CBT works. With the mental health team, I think they need staff with lived experience. I don’t want to be on medication that makes me feel like a zombie or go to group therapy. I think someone with lived experience would make better choices to give better care. Midwives often have babies, so they know what it’s like, it’s why they choose to do it’, Female aged 22.

‘I’m really enjoying talking therapies for my trauma. The GP referred me to an agency. I think I waited 3-4 months, I was surprised as I thought it was going to be at least a year’, Female aged 27.

‘I’ve been referred to talking therapies but it’s online, but I would rather it be in person. I want to be in front of someone and speak to someone in person, I don’t find being in my own surroundings helpful. I made it clear about that from the start, but it wasn’t under I met the therapist online who agreed that it wasn’t the right fit for me that they took it seriously. They didn’t believe me, but they believed a professional. This is what I mean when I say they don’t listen to us. Now I’m back on another waiting list waiting for support, they didn’t listen so the time has started again’, Female aged 19.

‘Mental health support is woefully unhelpful. They ask you questions & regardless of how I answer they give me twelve pieces of paper of other people to call. I think what’s the point? Why are you here? My friends and I have all experienced the same thing, our severity didn’t seem to impact it – from suicidal thoughts to mild anxiety, same thing’, Male aged 26.

‘I have PTSD, anxiety, separation anxiety, depression and I was diagnosed with bipolar when I was younger. Counselling didn’t work, tablets didn’t work, so I’m going day to day without anything. I need someone to actually listen, to actually be there. I'd like something to distract me. When I was young, I went to the local family centre and they were great, I got asked how I felt on a scale of 1-10 and it helped me to share how I felt. I feel like professionals judge too much, they just tell me to get over it', Female aged 26.

'[Mental health support] is about having someone to talk to when I need it. I speak to my keyworker but I wouldn't talk to them about some things. I see [my keyworker] once a week, and they really help me, but it would be good to have someone else to discuss this stuff with – once a week isn't enough', Female aged 26.

'When you are sectioned, they say they want to help you but it doesn't help you at all. They are really cold towards you, and everything feels very black and white. It was really scary. And once I was out, they only saw me one more time after', Female, aged 23.

'[As someone with autism] mental health doesn't work for me. It triggers me, it makes me worse. I accept and love myself, but when I access mental health services it just doesn't work for me. I feel I'm very self-aware… [when I do access mental health services] I feel triggered, I feel uncomfortable and I feel really anxious. I did counselling in school but my brain thinks it's when I have to share details. I carry so much trauma, there is too much, and I was taught not to share my emotions so I find counselling really hard. Breathing exercises just don't work for me, it doesn't feel good in my body. I can't imagine what good health services for me would look like. I hope that there will be a service that meets my needs in time', Male aged 19.

'I think the more I've learned to advocate for myself, the better [support] I've had. In my early 20's, it was hard to open up and tell [health] services how I'm feeling. When I opened up, I was able to access the right services', Female aged 27.

'My epilepsy meds cause depression. I've found it affects me as a guy. Men in this culture can't show their feelings, it's seen as weak. I have found my mental health support [quality] depends on whether it's a man or a woman. You can get relatable therapists, but I think most are there for the high need's patients because that's where the money is. There's no help for guys, its all "you'll be ok"', Male aged 33.

On Mental Health Stigma

'I think personality disorders are really stigmatised, most psychiatrists just want to give you pills and tell you to go away', Female aged 21.

'With mental health, I didn't get any support with my schizophrenia. Other people think you are scary so they put you to one side. I didn't get support. When I was in the Marvel House, for people with schizophrenia and serious illness, people who can't cope and that. It was shit, you don't see no one. You're locked away. It's worse than prison. No one can visit, you can't leave. It's all security gates. They have rooms with support workers and I know they are trying to help you but as soon as they know you have schizophrenia, they manipulate you and treat you like you have a big issue', Female aged 29.

'[Mental health] has lots of stigma, I know the help is there, but I don't know what the help will be. I don't always want to call a stranger. Sometimes I'm too ill to get the mental health support, or I forget an appointment and I'm penalised for it', Male aged 24.

On Reaching Crisis Before Gaining Support

'I have been with mental health services for a long time. If you want to be seen, you have to release, let it all go, then I get arrested. I've been arrested three times now for this. Then when you are in the cells… they have to see you on the edge... no past the edge. You have to try to kill yourself to get help', Male, aged 25.

'When you try to kill yourself, they just section you. For me, I think they treated me differently, I don't know why… they took time to think that I shouldn't be in with people much more serious than me… with personality disorders and stuff… but I went to A&E and they saw me… I'd taken an overdose so they made me drink charcoal and I was sick for like five hours. After that, the crisis team saw me every two days for a month. It was my fault that happened, I got a job and I stopped taking my medication. I had a big dip, and yeah, you know the rest. The support isn't there [prior to crisis], it's only there when you do it', Male, aged 22.

On Getting Stuck in the System

'You wait for ages, and then at the end of the wait, they say there's nothing they can do. It's the same across all the services. They make referrals to seem like they're doing something and it never goes anywhere', Male aged 19.

'I struggled for ages to register with my GP. Then I got signed up, but they didn't have any appointments – even emergency appointments – until the next month. I couldn't wait that long so I went to the walk-in clinic who gave me medication and said I'd need a follow up with the GP in a week's time. The GP couldn't get in me until the end of the month so I had to go with no meds again. I was waiting longer and longer as it went on, I think others would just give up. I had to put in a lot of effort and really chase them. If someone's struggling, they wouldn't be able to do all of this', Female aged 19.

'I don't have a GP. I don't have any ID so I can't join. We tried to register at Bradwell Common. It means if I have any health issues, I have to go to A&E. I need a fit note from the GP for my universal credit, but I can't get it as I'm not signed up to the GP', Female aged 22.

'Because I had to wait so long to move in [to the YMCA] and for CBT [Cognitive Behavioural Therapy], in between all that I think I started wanting to leave my house. I got so frustrated that everything was taking so long, I felt disheartened, like I deserved to be stuck where I was [with unsafe family members]. I mean I was born there, I couldn’t do anything about [my circumstances]’, Female aged 20.

‘I’m diabetic but I haven’t been tested properly, I had DexCom 1 fitted but when I moved to YMCA, I had to move GP’s and some of my records have been lost. Now my new GP are saying they only have the DexCom 1 sensor on my records and not the transmitter so they are saying they can’t re-prescribe it. I am constantly being hospitalised with high blood sugar, but I can’t even get a pin prick set to manage it for myself. I was with paramedics for four hours in an ambulance the other night and my blood sugar went from 2.9 and spiked to 4.3 and dropped again and then went to over 11 all in less than 15 minutes. When I share this with my new GP, they tell me it’s normal. I just don’t know what to do or where to go. It’s really affecting my day-to-day life’, Female aged 21.

‘When I was made homeless, I got referred to the council, but I never heard anything from them. When I called, the woman laughed and said I wasn’t a priority. I’m a young woman with disabilities and poor mental health’, Female aged 29.

‘I went to the walk-in, I was sat there in pain. When I saw someone, they referred me back to my GP so it was pointless. I was sat for 3-4 hours waiting to be seen. It was out of hours on a weekend so I couldn’t see my GP. I called 111, they advised me to go there, and then I just got referred back to my GP’, Female aged 25.

‘Sometimes I have to stay up overnight just to be awake to get an 8am slot [for a GP appointment]. I work nights so it doesn’t really work for me. I can get seen at the hospital, but then they refer me back to the GP, and I can’t see them! It feels like I’m being pushed from pillar to post. There are so many steps to follow and it feels overwhelming. I’ve been forced to go private before, but then I fall behind on my rent’, Female aged 24.

‘I haven’t had a period for a year and feel like nobodies listening. They make me feel guilty for calling. I feel stuck in a loop. I can’t afford to take time off work’, Female aged 24.

‘I often get caught in a loop between the walk-in clinic and A&E. The walk-in clinic say you’re too serious for them, but A&E say you aren’t serious enough’, Female aged 22.

On A Medication First Approach

‘[Mental health support] depends on your GP. My previous GP wasn’t helpful, just gave me medication and didn’t get down to the root of my issue. My new GP took time to understand what was going on for me, they also gave me medication but one better catered to my needs – it helps with my sleep and appetite, not just diminishing my emotions’, Female aged 25.

‘GP doesn’t listen to me; he just palms me off with anti-depressants. The anti-depressants mean I can’t work, they make me lose all motivation and I can’t sleep. I don’t take them; I need to work. I need to keep my mind busy. If I’m busy, I feel better’, Male aged 25.

‘Mental health assessments just make people relive their experiences only to just give them a pill, instead of trying to find the problem they say this is the symptoms for this, so they give me a pill. It’s not listening to or helping me with my feelings. They assume, they don’t listen properly and then prescribe any drugs – the wrong drugs – and it will make them worse. Some anti-depressants are downers or uppers, they need to know. They turn me into a druggie’, Male aged 30.

‘It’s so easy to give out pills, but they should try other things like go to the gym’, Male aged 30.

‘[GPs] just stick you on tablets, they just want to go for the easy thing. It’s quick, they can get you in and out and on to the next patient’, Female aged 26.

‘The GPs don’t seem to listen; I’d like them to listen more. I went to the GP for mental health support, they just threw medication at me. It just made me worse. They suggested talking therapy, but I’m still waiting to hear from them two years later’, Male aged 29.

‘I think they [GPs] push pharmaceuticals if I’m honest, instead of trying to solve the situation. My epilepsy meds give me anorexia, they melt your teeth. I think the meds I’d like to be on are only available privately, I shouldn’t have to destroy my body because I’m on the NHS’, Male aged 33.

On Sharing Side Effects

‘I don’t feel like [the NHS] share the side effects of [mental health] medication properly. I had some medication for suicidal thoughts but in the first week, I wanted to kill myself even more. They didn’t tell me that until the most recent time. Luckily, I could manage those thoughts but some people might not’, Male aged 22.

‘I went on anti-depressants but I wasn’t warned about the side effects. Honestly, the doctors are rubbish to me anyway so I don’t bother’, Female aged 24.

On Accessing the Appropriate Service

‘We need to know when to call 999, lots of people call 999 when they shouldn’t I think’, Female aged 23.

‘I think people go for ridiculous reasons [to A&E], or no reason actually. They might be trying to get drugs out of it. I think people go, not all people but some, but they block the waiting list’, Female aged 21.

On Receiving a Diagnosis

‘Diagnosis is important to me, so I know what’s going on in my head. If I know what it is, I can fix it. I don’t know, a diagnosis makes it feel easier to cope. With a diagnosis, you can manage your condition for yourself. I can go to my keyworker, and we can be like: This is what’s up, and this is how we sort it’, Female aged 26.

‘You need a diagnosis to access the support you need’, Male aged 25.

‘I spent ten years undiagnosed not understanding who I am or what’s going on for me. I didn’t know where to go or what to do, or how to access help. Having a diagnosis means I can research and learn about my conditions. Since I’ve been diagnosed, I don’t overthink or worry about what’s wrong with me or why I am the way I am – it makes sense to me now’, Female aged 29.

‘I’ve been waiting for [an Autism & ADHD] diagnosis but no luck. It takes years. It’s not seen as a priority but it means so much to me for closure and clarity. [Without it, it] makes me revert to feeling like a child… make me feels vulnerable’, Female aged 24.

Accessing Drug and Alcohol Services

‘I was engaging with ARC, but I just didn’t turn up to meetings. I was either too drunk, or on drugs, or not in the [YMCA] building. It’s just not the right time, so I wouldn’t access the service however it was delivered. I think I need to be in the right place to access it’, Female aged 22.

‘I’ve called up for alcohol support before, they took all my details and then they never got back to me. I think I called AA? I’m not sure. They were absolutely useless’, Male aged 26.

‘I do have a problem with alcohol and cocaine. When you are homeless, time drags. You are tired all the time so you take it [cocaine] to stay awake. Then you get a come down, but I don’t want to feel that, so I take a Zanex. When I take Zanex, I lose time. I took 5 Zanex and ended up in A&E but I didn’t know where I was. I only knew I’d been to A&E the next morning because I had a hospital ID tag, the ones they put on your wrist, on my bike. I was like, did I go to A&E or did my bike?! I’m not addicted to Zanex though’, Male aged 29.

‘The main issue for me is substance misuse, that’s my biggest problem. I don’t have many excuses now not to take drugs, I have a roof over my head… but I’m a realist, it’s going to take me years to get off drugs. I have to want to do it’, Male aged 29.

‘One of the only ways to get by on the streets is to do crack or sell crack, you have to do one or the other. You hit rock bottom, and people are waiting to take advantage of you. I wonder, what’s it like for a female or someone with mental health issues [on the streets]? You wake up sometimes and people you trust have taken your stuff. I wonder… sometimes I wonder about the choice… you find yourself in poisonous situations, it's tragic. Is it coercion? Who is responsible? There are so many reasons people take drugs', Male aged 29.

'I went to rehab for alcohol addiction, and it felt like home. It was a local place, and I miss it to be honest. I had so many friends in there. I didn't have any responsibilities and I had loads of support. I don't have a big family and I was all alone [outside of it], so it felt like home. Still feels that way, but the YMCA keep me going. I still would like to make more friends', Female aged 22.

'Drug and alcohol services are really good. I've been a recovering weed addict for the past 3 years. I didn't have to wait for referrals, there were services I could just walk into and receive help. A good example is Compass [now ARC], they gave me one to one support and group therapy which I got access to straight away', Female aged 29.

'Only problem with Compass [now ARC], it that it wasn't based in a very nice area so I had people offering me drugs on the way in – it really didn't help!', Female aged 29.

'I did have a drug and alcohol problem, but they just gave me a booklet to work through. I want to talk to someone, not do a booklet and then book another appointment. By that point, I'd helped myself', Female aged 21.

'I smoke weed to manage my epilepsy. It's similar to what I'd get if I could afford to go private, CBD it's called', Male aged 33.

'I don't know why alcohol is legal honestly. I think it costs the system a fortune, and there is a double standard. It's OK to go out and drink beer with your mates in the pub, but you can't smoke weed in your own home. Doesn't make sense to me', Male aged 33.

Accessing Social Services

'I think the system makes me dependent and then it blocks my chance to learn to do things for myself… [social services] say they will remind you to do something, and then they don't. I could have set an alarm for myself', Male aged 24.

'I don't like the social services. They tell me I can see my daughter once a month. I can video call, but it's not enough. It pisses me off because her dad can see her more than I can. I don't always have a tablet or phone to Facetime from', Female aged 22.

'[Social services] don't listen to the male party when it comes to children. I feel they've heard her side of the story and acted on it but haven't heard my side. I need to be heard too', Male aged 25.

'I'm with Luton social services and they are on and off, ask anyone. Support wise it depends on the social worker. My current one is quite good, she bought me lots of stuff to help me settle in at YMCA. Most social workers are shit, but mine’s good. Some just do it for the money, but there are those that do it because they like their job – that’s better’, Female aged 21.

‘[Social services] tried to take me away, they tried to put me in care. I was going to lose my family. I did in the end anyway, but…’, Male aged 21.

‘I had a social worker when I was living in hostels aged 14 to 18. I saw my social worker once in four years, it was supposed to be once a month’, Male aged 27.

‘At the age of five to now, I’ve been with social services. They’ve been shit. I’ve been in and out of foster homes… I was sexually abused there; I feel they need to do more to protect us… They do try, but they give children to n****’s [paedophiles] who abuse them for a long time’, Female aged 29.

‘I’m not sure about them [social workers]. When I was younger, I wasn’t sure if I had one or not. I had a social worker who took me out sometimes but she pushed me to say things about my mother – it put a lot of pressure on me as a kid. Later on, my siblings had a different social worker. I felt I could confide in her but I felt she used the information I shared with her against my family so they could take my siblings into care. I just wanted some help, but it made the situation worse. There was… tension you know, because of what I shared. Now my younger sibling is in care, they keep me updated and include me in his care plan. They do support me now with housing letters and things for my job. It’s really varied’, Female aged 25.

‘It’s been eighteen months since I’ve been involved with my kids. I was deemed unfit because of my mental health. The social worker asked my partner questions about my mental health but they never asked me. I feel I was written off because of it and I’ve been completely pushed out the picture. No effort to speak to me or to try and help me with my kids so I can have a relationship with them’, Male aged 31.

Black and Minority Ethnic Experiences

‘Giving birth as a black woman in A&E, it’s… my sister died. As a black person, or anyone from a different ethnic origin, there always seems to be a bad outcome or complication somewhere’, Puerto Rican Male aged 23.

‘I went to the NHS and got put through to a psychologist. She’d say I was coming back with a new thing each week; I had a lot going on in my life at the time, and she asked me why I kept coming with different things – her words were, “I’m not your therapist, I’m here to manage your issues only”. I asked for someone not Asian, and they gave an Asian psychologist anyway who then accused me of internal racism for requesting a non-Asian doctor. That is exactly why I didn’t want someone like that. She made comments about my religion, my dress sense – she said, “You’re quite Western, aren’t you?” – and couldn’t get the name of my hijab right even though I’d told her multiple times’, Asian British Female aged 25.

‘I’ve experienced a lot of racism [accessing the NHS]. One time, I said I had food poisoning and the paramedic said, “have you eaten chicken curry?”. I think to myself, why is that? Is it because I’m Asian? He then asked me if I eat ham and I thought why are you asking me this [the paramedic], he wouldn’t do anything related to my food. I could sort that with other staff later’, Asian British Female aged 25.

‘Somali is my first language and English is my second. I speak in English at the YMCA but Somali everywhere else. [Would you like anything translated?] Nah, I prefer reading documents in English’, Male aged 20.

Transgender and Non-Binary Experiences

‘I have transitioned from female to male, the GP and hospital still call me by my birth name, and it really impacts my mental health. I avoid anywhere or anyone who won’t correctly use my pronouns. I followed a process to get my name changed by deed poll and now my GP is using my correct name, but it’s been a long process. I just think if they used my correct name [from the start], it would be much easier, it's not that hard. It’s basic courtesy and respect’, Male aged 30.

‘I’ve moved homes about 4 times in the last 2 years, and I’ve changed GPs twice. I put Mr down on all of my forms, but they changed it to Mx. They didn’t ask me, they just changed it. I think it could have been linked to my hormone injections, I think they just assumed? Mx is still misgendering me, it’s not how I identify... I signed up as a Mr so why would they change that? It’s super frustrating. Mistakes get copied over from previous GP’s so you can’t even get away from it’, Male aged 23.

‘When you are waiting to be seen in the GP surgery, your name and title comes up on the screen. If it’s the wrong gender, it’s really hard. I have been a victim of hate crime quite a few times, that’s why I moved to the YMCA, so getting my title and gender wrong could actually be endangering to me’, Male aged 23.

‘I would like to see more funding for trans services, the gender clinics are so backed up. I’ve missed my last two hormone injections. They have been rescheduled by my GP a lot, then your hormone schedule gets messed up, and I can’t talk to anyone [at the gender clinic] about what to do so I’m just going without’, Male aged 23.

‘I knew I was trans when I was 11. My GP refused to let me access an under-18 clinic. I had to wait until I was 18 to refer myself and had to wait on the waiting list for two years to be seen. Also, you don’t get given help straight away – they make you wait to check that it’s definitely what you want. I’ve heard you have to wait six years in some parts of the UK now, I feel for young trans people coming up’, Male aged 23.

‘It was really hard to not kill myself [whilst waiting to access the gender clinic]. I think 40%, or 60%, of trans people kill themselves. Can you fact check that for me? Maybe if they put more funding in [to trans services] that number wouldn’t be so high. It’s not just the hormones or surgery that we need, it’s the [specialist] therapy as well’, Male aged 23.

‘Accessing therapy is a risk for transgender people. If you go through IAPT, you don’t know if you’ll get someone who understands trans issues – it’s a bit of a gamble. I did get a really good therapist actually, but I know some people don’t’, Male aged 23.

On Autism and ADHD

‘I’ve just been accepted for a full autism assessment. I’ve been waiting ages; the waiting list is 24 months currently. It really matters to me, but I’m willing to wait for it. The wait might mean I struggle to find work, it takes me a long time to process things and I feel really drained. I find bright places draining, I wear headphones and sunglasses to manage it. With a diagnosis I could get additional support and I’d really like support whilst I’m working and to have someone I can talk too if I need support. I hope a diagnosis will explain to employers and managers why I am the way I am’, Male aged 19.

‘I’ve been waiting a year and a half for autism and ADHD testing, I think I’d live a better quality of life with a diagnosis’, Female aged 29.

‘My autism and ADHD mean I clash with work. I can’t handle the stress. I don’t feel like doctors listen or accommodate me’, Female aged 24.

On Consent

‘They find it hard to find my veins, they poke me a lot. I have scars on my arms from where they’ve done this. I get faint because they dig the needle around. I said I wanted them to stop, they said they’d “take it easy” and then continued’, Female aged 25.

On Being Signed Off

‘Doctors don’t give me sick notes [anymore] – I have to call 111 but that just leaves me feeling angry’, Female aged 24.

‘The GP will sign me off for a month, but I just feel fobbed off. They don’t offer you any support in that time off. A friend told me that she had a three-hour call with a doctor when she was signed off, I had nothing. It’s really inconsistent’, Female aged 24.

On Fatphobia

‘I went to the GP last night and they should think about the way they say things. They said I was obese; it came out of nowhere and it really hurt me. The [health] issue was nothing to do with my weight, I’m on the pill as well which makes it much harder to lose weight’, Female aged 23.

‘I think weight is always mentioned [by GPs]. My friends who are a bit chubbier than me, they just always say you need to lose weight. I am slimmer so they treat the issue, but with my friends it’s weight first. They don’t even tell you how to lose weight, just that you need to’, Male aged 22.

On Being Surveyed

‘I wouldn’t want to be asked these questions by someone I don’t know, it’s personal you know. Those questions [listed in a survey], it’s too much’, Male aged 30.

On Sexual Health

‘With the sexual health clinic, why is it only for certain ages? I wanted to access Brook, but I couldn’t because I’m 29. Why can’t anyone just walk in? Everyone has sex, it’s natural’, Female aged 29.

‘I think you should be able to get appointments with gynaecologists directly, not having to go to the GP to ask them to refer you. Why can’t you just go direct to specialists?’, Female aged 24.

Do You Feel Healthy?

‘During the day I do, but at night I can’t sleep, and I have things running through my head’, Female aged 23.

On Students Being Present

‘I’ve had students in with the doctor before, and I don’t like it. I think they do it with younger people because we won’t say we don’t feel comfortable. I wasn’t given an option. Now I’d say I’m not comfortable with a student being present, but I didn’t feel confident when I was younger’, Female aged 27.

On NHS Staff Development, Pay & Working Conditions

‘Why don’t they give [future/potential] NHS staff free degrees and training to make it more accessible to poorer people? I don’t think people are encouraged enough to become nurses and doctors, it’s not an appealing job’, Male aged 27.

‘I don’t think NHS staff are paid enough; it should be a lot more. I understand receptionists must get a lot of abuse, but it needs to be professional. It should be kind and respectful to all’, Male aged 23.

‘Doctors get paid well everywhere else around the world, but here, they get shit pay. All of the NHS staff are underpaid’, Male aged 30.

‘A&E staff are understaffed & underpaid’, Female aged 21.

‘I do feel sorry for the doctors and nurses as it’s so understaffed, but that doesn’t mean they can treat you like shit’, Male aged 23.

‘GPs are ridiculous. They are so understaffed. They aren’t paid enough. They are so underpaid it’s not motivating them to help’, Female aged 21.

‘I think GPs are doing the best they can. They are overworked and underpaid… you are only going to get the quality of service you pay for’, Male aged 33.

‘They should employ more staff to decrease the waiting times, it’s unlikely’, Female aged 23.

On Taking Medicine

‘When I have to take something every day, I struggle to remember and follow routines. They say take it the same hour and this makes it even more difficult for me’, Female aged 20.

On Receiving Letters

‘Why do they send us letters? Like, it’s not very young people friendly is it? We like texts and emails, not letters. I don’t open them’, Male aged 27.

On Sexism

‘I’ve found accessing the GPs extremely difficult. I feel very dismissed by the GPs, they say “avoid that GP, he’s a bit of a misogynist” [Who said that?] The other NHS staff. I’ve found communicating with male GPs very difficult, I feel like I’m not trusted to speak accurately about what is going on with MY body. I feel like it’s dismissed as ‘women’s problems’’, Female aged 23.

On Feeling Unimportant

‘[The] lack of access, the lack of care… it… makes you feel like you don’t matter’, Female aged 29.

‘I’ve been let down by all of them, the whole system. I’ve had no support – I did it all by myself’, Female aged 29.

‘I feel like… babies and kids, a priority… elderly, a priority… adults 20-40, NOT a priority. I feel like we are slipping through the net’, Male aged 27.

‘I’ve done it myself; I’ve done it better myself. I’ve been sorting [my health issues] alone for the past 16 years’, Female aged 21.

Contact Information

If you'd like to request any further information about the contents of this report please contact Kat Newman, Head of Youth and Community, at YMCA Milton Keynes - kat.newman@mkymca.com / www.mkymca.com / 01908 295 600