

# **The Big Conversation**

## **Insights from Resident Engagement 2023**

# Tips for navigating this online document

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## 1. Background

During the summer and autumn of 2023 Bedfordshire Luton and Milton Keynes Integrated Care Board (BLMK ICB) undertook a programme of engagement with residents across Bedfordshire, Luton, Milton Keynes called 'The Big Conversation'. This gave residents an opportunity to share their lived experiences of health and care services, tell us what was important to them, and what could be done to help local people to stay healthy and live longer.

This period of engagement followed on from the [Denny Review](#), where we commissioned our local Healthwatch organisations and other VCSE organisations, to listen in depth to communities often described as 'seldom heard'. This included people from ethnic minorities, people with physical and learning disabilities, LGBTQ+ people, and those living in areas of deprivation.

Working with our system partners we attended a range of community events and existing group meetings, listening to communities to understand their views and aspirations for health and care services.

The aim of the Big Conversation was to give our residents the opportunity to share their latest views on health and care.

## 2. Methodology

From June to November 2023 we attended over 50 events across Bedfordshire, Luton and Milton Keynes and captured insights from over 450 residents. This included:

- Large scale weekend community events attracting thousands of residents including Luton Health Fest, the African Diaspora Festival in Milton Keynes and MK Foodbanks' Guinness World Record - MK Can
- Smaller events such as the launch of the Queens Parks Family Hub in Bedford and Cheering for Volunteering celebrations in Central Bedfordshire
- Roadshows including the Healthwatch Central Bedfordshire's Just Ask, Luton Council's See the Ability and various community safety events across Bedford Borough, Central Bedfordshire, Luton and Milton Keynes
- Exhibitions including the Aging Well Exhibition, Festival for Older People and Ukraine Flag raising event.
- Health and Wellbeing events in places of worship
- Various coffee mornings and drop-ins including children centre family sessions, stroke survivors' groups, coffee mornings run by groups of GP practices (called primary care networks) and Food Bank sessions.

A list of the events can be found in Appendix 1.

To avoid duplication and prevent 'engagement fatigue' we engaged with residents, groups and communities that were not included in the Denny Review or that had recently been engaged with.

We wanted to understand what patients thought about local health and care services, and find out what their experience had been.

We asked two questions;

*Do you have any experiences of health or care services that you would like to share with us?’*

*‘What is the one thing we could do to help people in Bedfordshire, Luton and Milton Keynes stay healthy and live longer?’*

To enable people to talk freely and to not restrict the flow of the conversation, the conversations were recorded via hand-written notes. In addition to capturing the hand-written notes, residents were also given the opportunity to provide their response to the second question digitally, by scanning a QR code to enter their response via a mobile phone or other smart device. The responses can be found in section 5 of this report.

The content of this report are experiences explained to us by residents from across Bedfordshire, Luton and Milton Keynes. It is important to highlight that the experiences are what residents wanted to tell us, rather than us asking specific questions. This approach will enable us to draw out what is important to our local community as opposed to what we think is important.

### 3. Summary of Findings

The conversations covered a whole range of health and care services in addition to other factors that had an impact on their health and wellbeing. The feedback has been summarised and grouped by service area in the ‘findings’ section of this report (see section 4) with the full range of responses and experiences included in **Appendix 2**.

#### 3.1. Service summaries

##### **GP Practices** (see section 4.1)

The most common service that residents fed back on was GP Practices, and the difficulties often faced with either getting an appointment or making appointment. Many felt that the experience could be improved by implementing new telephone systems or online booking systems. There was a divide regarding digital services, many favoured the ability to be able to access information or contact the surgery when it suited them, whilst for some the use of digital services and reliance of information and services being online was a barrier to them accessing services.

Throughout the conversations, it was clear that patients valued their GP surgeries, residents wanted the service in their neighbourhood and had clear expectations of what they would like to see provided. The recent roll-out of new telephone system was commented on as a positive improvement in several experiences as were some of the great services being delivered.

##### **Hospital Services** (see section 4.2)

A large proportion of the feedback received was regarding long waiting lists and communication.

Residents recounted their experience of having to wait over a year to be seen by a specialist, during which time their life was ‘put on hold’ due to severe discomfort or major life-changing events like having to give up work. They wanted waiting times to be reduced

and to receive information and/or advice to support them to manage their condition in the interim.

Once in the system, many said they were often confused or unsure what the next stage of their treatment or pathway was. They suggested that they should be given a fact sheet which included contact information, detailed the patient pathways and whether they should contact the service or vice versa. They wanted the different services and/or providers to talk and update each other, many shared examples of their results or tests not being shared and appointments or time wasted due to information not being shared. Patients wanted to receive confirmation that their referral had been received and to know how long they would have to wait to be seen.

### **Maternity** (see section 4.3)

Of the experiences received, many were regarding the referrals and waiting lists to see paediatricians, we heard stories from families who were so worried about their baby's health that they went private.

The need to be listened to was a regular theme, with several families telling us that they did not feel that they were being listened to, or their concerns taken seriously. This resulted in them seeking professional advice or support from another source, resulting in two appointments for the same issue.

### **Cancer** (see section 4.4)

A few experiences were gathered regarding cancer services, with several people commenting on excellent services. One person expressed concern regarding the take-up of breast screening within the Bangladeshi community, advising that more needed to be done to increase awareness and education regarding screening programmes in communities.

### **Stroke** (see section 4.5)

From the experiences shared, one of the main concerns from people who have survived a stroke, is the referral process and pathway. They provided examples of being discharged from care homes or hospital and then having to wait six or more weeks for the next level of support to kick-in, they recommended that the providers plan and to make the referral prior to discharge. They also suggested that the approval process for social services funding be improved.

Patients shared frustrations that the services were inflexible, often being given a standard number of weeks of rehabilitation, they asked if the service could be more personalised and flexed to meet their needs.

### **Musculoskeletal (MSK) Services** (see section 4.6)

A consistent theme regarding Musculoskeletal services was waiting times.

### **Mental Health** (see section 4.7)

Residents expressed difficulties navigating the system and accessing mental healthcare services, including a lack of 'Out of Hours' support in Milton Keynes and the increased need for mental health services, especially among younger people.

Overall, there is a need for more mental health awareness and information on the available support for residents.

### **Dentists** (see section 4.8)

Access to a dentist was a theme, with several people telling us about the problems they had finding NHS dentists for adults and children, resulting in them not getting their teeth checked or delaying treatment that is needed. A few people gave examples of travelling overseas to get treatment or registering with a London NHS dentist for their family check-up.

### **Childrens and Young People's Services** (see section 4.10)

Several parents expressed concerns about the lack of mental health support during school holidays and waiting lists for hospital appointments, providing examples of children waiting in a lot of discomfort for diagnosis which impacted their mental health. Some parents had trouble finding an NHS dentist for their children.

Some parents believed that schools should do more to pick up on signs that their children had a need for extra support, such as needing glasses or having dyslexia.

Foster carers reported that when their children moved between local authority areas, they often had to rejoin waiting lists for treatment, which delayed access to care.

Young people expressed frustration with adults communicating with them and avoiding certain phrases, such as "suicide prevention." They wanted to be invited to be part of the discussions about them. Young people also suggested that more engaging after-school activities, such as cookery clubs and street art displays, should be available. They felt that they spend too much time on electronic devices and need more activities to keep them active. Finally, there were suggestions that primary schools should offer cooking classes to teach children and their parents how to cook healthy food on a budget.

### **Pharmacies and Medicines** (see section 4.11)

Two examples were given where residents advised they had either been issued the wrong drug or wrong dosage. In both cases the errors were picked up by the patient or pharmacist and rectified before any medication was taken.

### **Wellbeing** (see section 4.12)

Residents acknowledged that access to high-quality health and care services is crucial, but the provision of services and environment to support maintain an active lifestyle, a well-balanced diet, safe housing, social inclusion opportunities, and gainful employment are also vital for overall well-being.

- a) **Exercise** - People acknowledged the positive effects that regular exercise has on their general health and mental wellbeing, with some asking for physical activity classes that improve balance and reduce falls for older people. Many advised gym costs and childcare issues prevented them from attending classes, and requests were made to provide cheaper or free exercise options, such as subsidising gym fees or providing credit to use at sports facilities.

People with disabilities reported a lack of provision and appropriate equipment. Wheelchair users specifically requested more activity options and funding to set up wheelchair tennis classes/teams.

- b) **Diet and nutrition** - The feedback indicated that while most people know the importance of having a healthy diet, some might be unaware of their unhealthy eating habits. Convenience foods and takeaways were cited as easier options. Suggestions included educating children and offering after-school cookery classes

to promote healthy eating. Recommendations were made to diversify school menus to include more culturally appropriate dishes, promote healthy eating in a fun way, and make healthy food options more affordable.

- c) **Employment** – Some residents expressed a need for more local job opportunities to help improve their self-worth and promote stable employment. They told us about the challenges they faced in acquiring experience to obtain jobs (despite acquiring the required skills and qualifications), creating a vicious circle.

We were told that job centres cause anxiety and depression for some individuals, and they suggested that the staff should provide programs to enhance self-confidence to help with job searches and to be more proactive and supportive in helping individuals find jobs.

- d) **Housing** - Several individuals expressed issues with finding suitable accommodation or experiencing delays in receiving benefits.
- e) **Safe green spaces** - Having access to green open spaces and being able to enjoy them whilst feeling safe was mentioned by several people, with a few commenting that they felt very lucky to be living in Milton Keynes.
- f) **Transport and local activities** - Several individuals highlighted the importance of attending social activities to reduce social exclusion; however, many face challenges in getting there, particularly if they don't drive or have a disability. They suggested having better transport links and more social activities for the elderly, with support to attend them.
- g) **Information and advice** – Residents suggested having more public events providing information and advice. They also suggested including services like the Stop Smoking service. Additionally, they recommended holding free education and information events with easy parking.

### **Rough Sleepers** (see section 4.13)

The experiences of rough sleepers accessing health and care services were explored through conversations with individuals attending drop-in sessions and Food Banks. Challenges included difficulties in making phone calls, lack of a stable address for correspondence, and limited access to needed support services. These narratives highlighted the amplified challenges faced by rough sleepers, including barriers to appointments, communication, and mental health support.

## **3.2. Cross-cutting themes**

### **Appointments**

A common thread across the experiences of the individuals is the challenge in securing timely appointments for health and care services. Whether it's the long waiting times to scheduling appointments, coupled with the frustration of waiting for calls to be answered, difficulties in getting health and care professionals to return calls, or the complexities surrounding booking systems and notification of appointments. This cross-cutting issue underscores the urgent need for improvements in service delivery.

### **Involving patients in their care**

Several people told us that nobody really pays attention to what they say, they feel like nobody is really listening or understanding them.



This highlights how important it is to make sure we talk and listen well to each other. For healthcare professionals and patients to work together, they need to understand and respect each other's expertise. Patients are experts in their own experiences, knowing about their bodies, feelings, and what outcomes they want and healthcare professionals bring their clinical knowledge to the partnership.

### **Information and advice**

Making sure that information and advice are easy to find and understand is really important for everyone to be able to use local health and care services. People like to get information in different ways, so it's important to share it not just online but in other ways too. We should make things like websites easy to use for everyone, and share information in different ways so that everyone can understand it. When we do this, it helps everyone get the information they need to make good choices about their health, making sure that everyone has the same chance to get the support they need.

### **Patient Pathways**

It was evident across the various healthcare services that the service pathways are often complicated, leading to a sense of confusion and uncertainty for the patient.

It is important that we address this issue by simplifying the patient journey where possible and enhancing communication about what to expect in terms of services and treatments. Sharing clear and accessible information with patients could alleviate some of the challenges associated with navigating the system.

### **Waiting Lists**

The challenge of waiting lists extends across various services within the local system. The longest waiting lists were for medical procedures and consultations at the local hospitals, often leaving patients in a state of anticipation for essential care. Residents also commented on waiting lists for community services, such as MSK or rehabilitation services for stroke survivors. Furthermore, the approval process for funding by social services introduced another layer of waiting, impacting individuals' ability to access services in a timely manner.

Reduction of waiting times and information on how to best manage a condition or what to do if symptoms or condition change, together with clarity on waiting times could be shared with patients to support them whilst waiting for the care would help patients.

### **Communication between providers**

Many residents highlighted the lack of communication between GP Practices, hospitals and community services, which presented a difficulties or delays to them receiving the care or service they needed.

They asked that we introduce more cohesive and connected systems so that services communicated seamlessly with each other and shared test results. This more co-ordinated approach would enhance service efficiency and also contribute towards a more holistic and patient-centred healthcare experience.

## 4. Key findings from conversations

### 4.1. GP Practices

#### Appointment Process

One of the most common issues people raised was the difficulty contacting the surgery and arranging appointments, in particular:

- Booking appointments by phone and the long queues waiting for the telephone call to be answered.
- The telephone systems used by practices, lengthy recorded messages and confusion knowing which option to select.
- The ‘triaging’ of patients, many did not feel comfortable explaining their condition to a receptionist, they were also concerned that the receptionists were not listening to them or did not have the medical knowledge to decide whether they ‘eligible’ to have an appointment with a GP.
- The availability of appointments and there being no appointments available when ringing the practice at 8am or being advised by their GP to book an appointment and no appointments being available.
- Not having a named GP and having to repeat their medical history.
- Appointments not being long enough and only being able to discuss one condition at a time.

Several people fed back that due to issues getting through to their surgery or lack of appointments, they preferred to either contact NHS111 or visit the walk-in centre where they knew they will be seen.

A few suggested that it would be easier if they could book an appointment online, at a time that was convenient to them and not waiting for a long telephone queue.

- *GP services need to be improved - we need more GP appointments, shorter waiting lists, and be able to ring at 8:45 for any type of appointment.*
- *I wish it was easier to make an appointment to see my GP – I’m at xxx and can’t get an appointment despite ringing at 8am.*
- *Access to GP Services is very difficult and needs to be improved, it can be very difficult to get an appointment. I was unwell and was not able to get an appointment, so I attended the Walk-in service in Milton Keynes, I had to wait for 3hrs to be seen but the service I received was very good.*
- *Patient has fibromyalgia and would like to be able to see the same GP for this long-term condition. It would improve treatment for all those with long term health conditions to have a regular named GP who knows them and their condition. This will stop the patient having to repeat their medical history each time and will enable to GP to see in changes in the patient.*
- *I have 3 children, it’s very difficult to get an appointment for them to be seen by a GP... It’s a viscous circle trying to get an appointment. I usually contact NHS111 if we need to be seen an urgently and NHS 111 arrange for this me.*

It should be noted that although most of the feedback was negative, positive feedback was received, with a few residents commenting that it was easier to book appointments following the implementation of new telephone systems.

- *The GP surgery in Flitwick is amazing – the electronic triage system that it uses is so much better than the phone system. The receptionists are very good and usually respond to queries within 10 minutes.*
- *I do like the new telephone system they have at the doctors. You ring them, and they then ring you back.... No need to be on hold for hours waiting in a queue.*

## Communication

A few people commented on different aspects of 'Communication'

**Whilst in the surgery** - One couple commented that they'd asked their GP to repeat himself several times and despite repeating several times still couldn't understand him, so left and made an appointment to see another GP, resulting in two appointments for the same purpose. Another said as they couldn't see the electronic patient board in the waiting room that informed them to go the treatment, they nearly missed their appointment.

**Letters and texts** – The general census was that it would be good if patients were able to choose how the practice communicated with them, for example some liked to receive text messages for reminder appointments, invitations to book a flu or covid vaccination, however, there were a few who commented they would like to be able to opt out of certain types of texts which are not valid.

**Language** – a support worker from the Citizens Advice Bureau commented that many of the people they meet don't speak English and are unaware that they can request a translator for their medical appointments. They suggested that posters and flyers are provided that they could hand out to residents.

- *We both find it very difficult to understand the doctor as he has a very strong foreign accent. We kept asking him to repeat himself but still couldn't understand what he was saying. In the end we just left and made an appointment to see a different doctor.*
- *I like to receive letters in the post with information about my appointments, and much prefer seeing someone face to face than speaking on the telephone.*
- *Patient with major sight impairment and with guide dog attended GP Practice for appointment. Patients name came up on the board but patient not aware and another patient alerted him. Patient then asked to go to consultation room 4. Receptionist never thought of helping and directing patient to his appointment.*

## Digital services

Feedback regarding the use of digital services was mixed. The ability to use digital services was favoured by some, however, there were some resident groups who struggled using digital services, especially the elderly and people with disabilities.

**NHS App** – A few residents commented that the process of ordering prescriptions was relatively straight-forward on the NHS App, but found it irritating having to log onto a record

via the main website in for other family members (children or elderly relatives) to access their record. Many did not realise that the records of family members (profiles) could be linked to an account.

A few commented that they found the app useful for viewing their medical record and in doing so felt more 'prepared' for their appointment. There were a few instances where patients with access to the app, were unable to view their record, so we suggested they contact their surgery to request access.

**Online forms** – Feedback was mixed with some people finding it easy to use the e-consult forms or forms to request an appointment whilst others struggled due to them not feeling well as the time and not having the energy to complete a form, struggles to use the platform and in numerous cases not having access to a computer or a smartphone.

Many older people relied on family or friends, to complete the forms for them.

**Virtual (video) appointments** – There was a general feeling that services are getting 'back to normal' and residents in most cases can choose between an online appointment or face-to-face appointment. From the feedback attached, some people who need to be seen face-to-face due to difficulties communicating, for example someone who had had a stroke and who relies on body language, and those who prefer to be seen face to face regardless of the reason for the appointment, and who feel more assured that they're being given the correct advice, or diagnosis if in the same room.

- *The couple [aged 80+] go to their GP once a year for their flu and covid jabs. They don't use any on-line service. Their neighbour gets a message from the surgery when it's time for flu jab and when clinics are running. The neighbour then tells the couple who go to the surgery to book themselves in.*
- *Doesn't use NHS App, is not IT literate, finding it more and more challenging as processes become more digital. Person is registered at xxx Surgery and finds it difficult to get help when in need. The receptionists need customer services training, very aggressive.*
- *Face to Face appointments with my GP would be much better, since my stroke I have Aphasia and having telephone consultations is difficult and I need my husband to help me, I would be more confident if I were talking face to face with the GP. for example I sometimes say yes instead of no which could be detrimental to a consultation. When I am in front of someone, they would be able to pick up on this better through my body language.*

## Experience

- *I don't feel that the GPs are that interested in me or my condition. I don't bother, as my GP doesn't bother.*
- *You ring the doctor to make an appointment and the receptionist makes you feel like a nuisance.*
- *The behaviour of the receptionist in my practice was very bad - they lacked manners and etiquette. They kept calling out the wrong name of the patient, when they realised they'd been calling the wrong name they took it out on the patient and didn't even give an apology.*

## Positive Feedback

- *My GP surgery is very good – they're proactive (which we really appreciate). They contact me when he [husband] is due a vaccination or a blood test and make arrangements for these to be done at our home. They even issue my vaccines at the same time. A really good surgery*
- *Patient advised that she finds it much easier to get appointments since the new provider and delighted that she sees the same GP on a regular basis.*
- *I have a great GP and have a fixed appointment every 5 weeks to check how I am progressing following my stroke.*

## Leighton Buzzard Health Facility

We joined Healthwatch Central Bedfordshire at their 'Just Ask' events including an event in Leighton Buzzard, the themes from our conversations included:

- Exasperation on the length of time that residents have been waiting for a new health facility and a loss of confidence with the NHS.
- The content of the feasibility study which was less detailed than they had been anticipating and just a primary care focus.
- The growing population and that the need for a hub or medical centre
- The location of the health centre was key, and needed to be served by local transport links, with bus services and parking provision.
- That a hub should host a range of services including urgent services, blood test, GPs and dentists.

- *Can't the land at the back of the Swan pub all the way to the post office be used for the proposed new hub, rather than on the outskirts of Leighton Buzzard? It's inaccessible there and needs to be in the centre of town for those without cars, which is the majority of senior residents and low-income families. There's no point in building on the outskirts as there are no transport systems in place and we need a well-established one for it to be utilised properly'.*
- *Dentists, doctors, and other facilities are needed to be built and should all be free of charge. We lost the idea of cottage hospitals many years ago. Planning is an issue, but estates should only be built if they can include all these services. I've been a Leighton Buzzard resident for 34 years and all types of services have been lost – police, ambulance, justice. The facilities in town are worse than they used to be.*
- *Lacks any strategic direction and practical solutions and a seeming will to make things happen - just more paper. No urgency in providing much needed medical premises and both GP and hospital services in the community.*

## 4.2. Hospital Services

### Pathways and Waiting Lists

Feedback regarding long waiting lists was a common theme. Residents shared narratives of enduring waiting periods exceeding 18 months after being referred to a service. Many expressed feeling stuck in a state of limbo during this time, with some experiencing a loss of independence. Instances were recounted where residents had to cease working, relocate to live with family members, or give up driving while awaiting diagnosis or treatment. Additionally, some mentioned the challenge of being ineligible for disability benefits due to the ongoing wait for a confirmed diagnosis. Further examples highlighted situations where individuals required hospitalization or emergency treatment as their conditions reached critical points.

- I'm waiting for an ENT appointment... the waiting list is very long. When my GP referred me, he asked whether I wanted to be referred as an NHS patient or pay privately. I'm still waiting for my appointment and will then have to wait for surgery.*
- My wife has a severe gastro problem. She's been seen her by GP (De Parys) who has referred her to the hospital. Her appointment is in 2024 – it's ridiculous that she has to wait over 8 months to be seen. In the meantime she's in agony and has had to give up work.*
- Female had a liquid cyst and was waiting for surgery to have it removed (7 months wait). It burst whilst she was waiting for the surgery and had to be admitted to hospital. She would like to see waiting times reduced.*

*I kept getting headaches, had blurred vision, was dizzy, confused, disorientated and very forgetful. My GP said it was a common problem after having a baby and was not concerned.*

*In November 2022 I collapsed and was 'paralysed' from the head down, my family called for an ambulance but was told there was a 90-minute wait. My family drove me to the hospital where I was checked over and told I had a urine infection.*

*A few weeks later I still had a painful head and was very clumsy.*

*In March 23, I was paralysed again and had to call an ambulance - the doctor who saw me said that it was quite common for mums to get lazy and suggested I join a gym. He also asked whether I'd seen a psychiatrist – he assumed that I was suffering from depression but hadn't asked me (just assumed)!*

*I was told I had M.E.*

*I'm waiting to see a neurologist – the appointment is for January 2025 (that's more than 18 months away!)*

*I also have an appointment to be seen in cardiology in 2024.*

*I keep having episodes so have moved back home to live with my parents and have had to stop working. I have good days and bad days – I can't drive any more, am tired and get very weak.*

*I've now changed my GP. My new GP arranged for me to have genetic testing and has told me that I shouldn't have been diagnosed with ME.*

*I keep asking for GP for stronger pain relief, he says he can't give it to me, and I need to be seen by the neurologist before he's able to prescribe.*

*I don't like my child seeing me like this, I feel awful, I feel like I neglect him. I'm very lucky that I have my family to provide support – but what about people who don't have family?  
I'm not entitled to Universal Credit as I've not had a diagnosis yet.  
I fear every day whether I'm going to be ok or whether I'm going to have a paralysis.*

## Communication

A few people commented on different aspects of 'Communication'

**Post and Pre-appointment** – Several spoke about their concerns whilst waiting for an appointment, some advised that it had been so long since they'd received any communication about an appointment that they thought they may have fallen off the list or 'be lost' in the system. A few suggested that it would be useful to receive written information as to where they were in the patient pathway, the name of the service they were being referred on to and how long it would be before they would be seen and/or contacted.

Several people advised that they had problems receiving letters about appointments, anecdotes were received from people who had had moved house, had informed the hospital about the move and letters were still being sent to an old address.

Residents with no fixed abode also told us of the problems they have receiving letters, with letters being sent to a shelter, but not reaching them.

A suggestion was made to have care coordinators at the hospital, who patients could meet with following their diagnosis or appointment to talk through the information, check that they understood what they had been told and to talk answer any queries they had.

Several residents suggested that it would be useful to receive advice whilst they were waiting for treatment or diagnosis to support them to manage or control their condition.

- I've been waiting over 6 months to be seen by the gynae clinic at Hospital (referred in March). I kept ringing the clinic and leaving messages asking them to call me back – but no one did.  
  
In the end I contacted PALS at the hospital. I spoke to someone, and they said that they'd look into for me. They (PALS) rang me back and offered an appointment the next day, unfortunately I couldn't go to it. They said that the gynae team would arrange a different appointment – I still haven't heard back from them.*
- It would be useful for patients to be informed / receive updates of where they are on the patient pathway. The patient pathway can be confusing and patients have to wait several months between referrals, appointments and/or communication.*
- The hospital uses an App for informing / scheduling my appointments (oncology services). I thought the App would be easy to use, however you really need to be on the ball and check the App regularly. I'd find it much less stressful if I was notified about my appointments by email, letter or text.*
- It would be useful to have people in health teams who are dedicated co-ordinators, able to review a patient's history and spend the time with them going through what the advice they've been given, explaining the next stage of the*

*process or referring them to the provider (rather than putting the onus on the patient to make contact). This would save resources and speed up pathways.*

A common frustration for residents was the lack of communication between the many providers, sharing of information and test results between hospital trusts which often resulted in delayed treatment or the patient having to update the clinician on what had happened at the other health setting.

- Patient with osteoporosis - Under the rheumatology department at the L&D who have provided a great service, experienced pain in her pelvis so had to see her GP, who referred her to have an x-ray at MKUH. MKUH sent the x-rays to her GP which took a long time to come through and they were not shared with the rheumatology department who were already providing her care. This happened a second time when she experienced pain in her shoulder. If the systems were more joined up it would improve the service and waiting times for patients.*
- Lack of communication between all the hospital that control my wife's care – stroke, heart problems. The individual Doctors & GPs seem to be in silos and unable to talk to each other and to the patient. Also waiting lists are far too long and the patient suffers.*
- I wish the hospitals kept each other up to date with test and scan results – I have to attend appointments at Milton Keynes and Oxford hospitals, they don't seem to communicate at all. It would be much better if they shared all my results with each other.*

## **Accident and Emergency**

During the exercise we only heard a few experiences about A&E, with some praising the service they had received, and others who had poor experiences, including one person who was discharged in the middle of night and told to make their own way home.

One person explained to us that if someone needs to be seen urgently in the Ukraine, you just call an ambulance. They found it very strange that in the UK, you had to make your own way to the hospital or urgent treatment centre and wait for treatment.

### **Positive Experience**

- I was admitted to Bedford Hospital as an emergency patient. I'd been to see my GP as I was feeling very ill, they told me to go and have a blood test immediately. I had the blood test and the next day my GP rang me; they told me to go to A&E straight away. I went to A&E and within 20 minutes I was taken to a treatment room. I had my first treatment (blood transfusion) within 2 hours and was then discharged from hospital 2 days later.*

*I was very ill, and the NHS worked.*

### **Negative Experience**

- A&E at Bedford hospital is a nightmare, I was in the waiting room for 6 and a half hours waiting to be seen. The person sat next me was coughing, spluttering and then vomiting. The whole area felt extremely contagious – people on drips,*



*people spitting into bedpans and another vomiting. The area should be split into different sections.*

- I had a suspected heart attack just after midnight and was taken to the L&D by ambulance. I was seen by a Deputy GP, given some pills and sent home. It was 3am, I was wearing just my nightie and slippers so asked how I should go home. 'I don't know, you should walk' was the reply from the staff. I had no shoes, no coat, no underwear and no money. A kind stranger gave me the money to go home in Dunstable.*

### **4.3. Maternity**

We visited several play sessions at local children's centres with the intention of talking about health and care services in general, however the conversations often gravitated towards very recent experiences of maternity and postnatal services.

#### **Labour and pre-health checks**

- I was pregnant was an ovarian cyst – at 40 weeks I did not have a birth plan! No one was able to commit/confirm what I could have. I was eventually called in to an appointment to produce my birthing plan - the person I saw had no idea! We got there in the end... I had my baby my caesarean.*

#### **Postnatal services**

Several parents told us that their babies had trouble feeding, swallowing or allergies and that the waiting times for services including paediatric or perinatal mental health were long. A few reached out to other parents on social media asking for advice whilst others paid to be seen by private health providers.

- My baby has reflex problems and allergies. I don't feel I got the support I needed. My baby was not feeding, and I wasn't sleeping, I felt that I was being fobbed off and no one was taking me seriously. I felt so alone. I eventually got the support by paying to go private – I put out a plea on Facebook as I was at the end of my tether, [friend] read my post and she contacted me as she had gone through similar.*
- This is my fourth child, so I know when something isn't right. My baby had severe reflux and feeding issues, so we referred to a paediatrician in January, but our appointment wasn't until May. My baby was so poorly my husband and I would take turns sleeping. We were frightened of going to A&E in case we caught something. We ended up going private so we got help straight away – it cost us £450, but was worth it. We were lucky that we could find the money to pay privately.*
- I gave birth to my second baby at home ... it hadn't been planned that way! I was haemorrhaging badly so was taken into hospital. The whole birth was horrific, and I suffered from panic attacks and anxiety. The waiting lists were so long for support I went for private therapy and counselling.*

- *My twin babies were born 3-months premature, one of them died. I wanted to find support / meet other families who were going through or had gone through the same as me. I've not been able to find the support I'd like.*

Several people provided examples of how they were expecting to be contacted by the hospital or health care professional, but that no one had contacted them, resulting in a delay to receiving treatment.

- *We got 'lost' in the system. When I was discharged from the hospital, I was told my baby would have leg/hip braces fitted at 4 weeks. We heard nothing and contacted the GP and also the hospital several times but still nothing happened. I ended up complaining to PALS at the L&D, who got things sorted. She eventually got her braces fitted at 16 weeks (if they'd been fitted at the right time, they wouldn't have needed them for this long time).*
- *I had to contact the health centre and ask for my child's vaccinations. It was their first set of vaccinations (which they should have had when they were 2 weeks old). I thought the GP practice / health visitor would have contacted me to arrange. As no one contacted me I contacted the health visitor to arrange. It would be helpful if the health nurses were more proactive and contacted parents about getting the various vaccinations as some parents don't know.*

## Communication

Verbal communication - Several women said they felt alone and wanted feedback and reassurance from the professionals so they knew whether they were doing things right especially in the first few days after the mother and baby were home.

For some, the need to be listened to and for their concerns to be taken seriously were a key issue, several parents told us that they did not feel confident with the advice they were given and often sought advice and/or professional opinion elsewhere.

- *I don't feel that the breast-feeding service listened to me. They kept telling me I was doing Ok, but I wasn't.*
- *I had a very traumatic birth; I was in labour for 4 days (under observation). I kept telling the team I was in a lot of pain, but they didn't really listen to me.*
- *Giving birth at the Lister hospital was the best day of my life. The labour ward staff were incredible. I was then transferred to the L&D, I wanted reassurance that I was doing things right, I didn't get any and felt very alone. It would be better if the midwifery teams did 'first visits' like they do at Lister to make sure everything is ok and to also check that the home environment is safe.*

## General positive feedback

- *The health visitors were really lovely – I felt they listened to me, they were very reassuring and helped with feeding.*
- *I have a 6-month baby, I'm really happy with all the services that have been provided. We've had all the help and care we need.*

- *I had a wonderful experience at the L&D having my baby.*

#### 4.4. Cancer

A few experiences were gathered regarding cancer services, with several people commenting on excellent experiences.

A support worker was particularly concerned about the women from the Bangladeshi community not attending breast screening appointments or accessing services too late.

- *Screening for Bowel Cancer and abdominal aortic aneurysm (AAA) is excellent, why is there no national screening programme for prostate cancer.*
- *"My mum has had a mastectomy (Prior to moving to UK). She needs to get some new bras. How do get these? [resident did not know that these were available to purchase from stores such as M&S]."*
- *Recent research - Women from the Bangladeshi community are not attending breast screening appointments and are accessing services too late. Need more awareness and education regarding screening programmes. Many of the women can't read or write and therefore don't understand the letters. [Details forwarded to commissioners who have made contact]"*
- *The L&D have been brilliant, I had a section of my bowel cut out in in November 2021 as I had bowel cancer. They are proactive and have called back in for follow-up checks. Anyone who says the service is bad is an\*\*\*\*.*

#### 4.5. Stroke Services

The insights gathered are from the conversations talking to people attending stroke support coffee mornings. We visited the groups with the intention of talking about health and care services in general, however the conversations with two of the groups naturally gravitated towards their experiences of stroke services.

It was very apparent from the conversations that people's experiences and outcome following a stroke differed immensely and is often dependent on their route into the service.

#### Referrals and Pathways

For many the referral process and pathway can be improved. Various insights were given where people have said they felt they were in a state of limbo or deserted at home after being discharged from hospital or a care home following a stroke diagnosis and waiting for the next stage of care to start or for funding to be agreed to continue rehabilitation.

- *Female experienced initial stroke symptoms in March 2022, it took until July 2023 to get an initial referral. Has been waiting for over 1yr for Neurology scans.*

## Rehabilitation

A worker from the Stroke Association told us that reducing the waiting times for physiotherapy (currently around 12 weeks) would be a huge improvement. They advised that local care and residential homes often refer the patient for physiotherapy services when the individual is being discharged from care, however if they could be referred to the service sooner, they would be able to access physiotherapy as soon as they are discharged.

We heard how one person had received 'care' in hospital and at two different resident care home but had never been offered physiotherapy.

*He was home alone for some time before he was found by a relative, he was then taken to Bedford Hospital. He was discharged to a residential nursing home in Dunstable because he lived alone and no who could care for him.*

*He was offered no re-hab at the home. Following another hospital stay in Bedford he was discharged to another residential nursing home in Biggleswade. Again no re-hab and no encouragement to be active etc.*

*Why did rehab not follow the patient to the residential home?*

Stroke survivors and their carers feel that the 'rehabilitation pathway' is too fixed and that it should be personalised according to an individuals need; some feel they do not get enough support and others suggest there should be more flexibility regarding the type and level of support given.

- *It would be better if stroke services were more personalised, the person currently receives 6 weeks of this service then 6 weeks of a different support. Some people need more or less support, so it would be better if tailored according to need.*
- *It feels like the early intervention stroke teams, just do the bare minimum to get you off of their books. There was no pushing, no motivating, targets for physical movement were not monitored - so what is the point of them?*

*Stronger early intervention would improve the lives of those who have had the stroke and reduce the long-term impact on the system. The first 3 months is the most important following the stroke and intensive support at this stage will improve outcomes and save the system money in the long run.*

## Information and advice

Stroke survivors and their carers said that they often feel over-loaded with information and advice at the start of their 'journey' and not able to process the information or don't feel ready to access the support that is being offered or recommended. They suggested that it would be useful to have a factsheet providing information about the service, contact details and route to the service (whether the service will contact you or you should contact the service).

- *The system is so difficult to navigate – we had the tenacity to find and access the support we needed (such as speech therapy from UCL), but not everyone has the drive or knowledge of how to do this. It would be useful to have a diagram showing what support was available and how and when to access it.*
- *There are many parts to stroke services, with acute care followed by initial rehabilitation and various support services for longer term support. It should not be down to the patient to try to navigate all of these services to find the right support. It should be incumbent on the services to work together and have a clear pathway so that patients do not fall through the gaps and not know what support and services they can access. There seems to be a grey area in between end of early discharge and what's offered by social care/ community services.*

## Positive feedback

- *Speech Therapy has been very good after my second stroke.*
- *The district nurses visited me twice a week to sort out my catheter – they were very accommodating when I wanted to change the date and time of my appointment (so I could come to stroke club meetings).*
- *Had an excellent response to stroke symptoms - was taken straight to the L&D by Ambulance Crew, the consultant was ready at the hospital when he arrived (Sunday Morning). He was told afterwards that from door to needle (a blood clot buster) was 22 minutes.*

*The gentleman (aged 50) had a stroke in November 2021, he was initially taken to L&D and then transferred to the ICU at Addenbrookes. During his time at Addenbrookes he contracted pneumonia and sepsis.*

*He was discharged back home but with no support as such; a district nurse visited him 4 times a day, but he did not receive any physio or other support.*

*In January 2022 he went into residential care for 6 weeks – during this time he had physiotherapy, psychiatry and CBT / coping strategies.*

*His home was adapted to meet his needs, after this he was 'left to it'.*

*The Stroke Association suggested he get support from the Luton Wellbeing Service, he contacted them, they gave him lots of advice and offered gym membership.*

*He uses a 'rollator' to help walk and would like to be able to walk unaided or with a less obtrusive walking aid. He's been signposted to Headway who have confirmed they're able to support him and provide physio. However, the funding for this needs to be approved by Luton Council. Headway confirmed that they've sent the paperwork to Adult Services, but it usually takes several months for funding to be approved.*

## 4.6. Musculoskeletal (MSK) Services

A consistent theme regarding Musculoskeletal services was waiting times with residents commenting that they have had to wait more than 6 months for an appointment, and during that time were in pain and struggling to carry out everyday activities. This waiting time had resulted in them accessing private care.

In regard to the services provides, feedback included:

- option to attend group physiotherapy sessions, so they could see others exercising and know they were doing the exercise correctly
- Unanswered voicemails messages
- Referral between clinicians once in the system

- *The waiting list for treatment [MSK] are so long I paid privately to get my knees and back fixed.*
- *My doctor referred me for treatment for my hand, I had to wait 6 months for treatment. Luckily my daughter was able to help me cook and clean. I wish I could have been seen sooner so I didn't have to rely on my family.*
- *After I gave birth, I had severe back pain, my doctor referred to be the physio and I was given exercises to do. When it didn't get any better I went back to my GP who told me to persevere with the exercises and take pain killers. I went on holiday to Pakistan and my back was so bad I arranged to have scans and x-rays whilst I was there. When I returned [to England] I showed the scans / x-rays to my GP and they referred to an orthopaedic/MSK services. I'm now on a waiting list to be seen – it's at least a 12 week wait. I've now be in pain for over 2 years – I have difficulty cleaning, bending, standing and lifting (which is very hard when you have a young child).*

## 4.7. Mental Health

During the 5 months talking to residents about their experiences of health and care services, only a few insights were received regarding mental health services. The feedback included:

- Lack of 'Out of Hours' support in Milton Keynes and that it should be levelled up across the area.
- A request for mental health awareness and information about the support available.
- Difficulties finding the services available and navigating the system and being able to receive support as many of the sessions were online.
- Following covid, there are more young people with mental health needs and anxiety issues, with a request being made for information about the support available to be issued to all households.
- A representative from the fire service advised that he has raised concerns on numerous occasions with system partners and feels that they have not been addressed, he is concerned whether people known to service providers as 'hoarders' have the capacity to understand and evaluate risk. The concern stems from responses from social workers stating that they were unable to

conduct a home assessment as the dwelling was unsafe. The argument being how do they know that the person has capacity to be able to calculate risk.

In addition to the points above, residents provided some positive feedback about the service they had received and recommended that that system be improved so that social workers responded to voicemail messages.

- *I wouldn't be here today if it wasn't for the Path 2 Recovery Programme – they've been a real lifesaver. I have a keyworker called - she's an angel and really supports me. I'm now supporting the program by setting up a patient participation group.*
- *The Milton Keynes mental health team have been there for me, with a good crisis team at the end of the phone.*
- *I've just been discharged from Onyx Ward (inpatient mental health) as I'd overdosed. Am back home but the social workers are a bit hit and miss, you ring them, leave a voice message asking them to ring you and they don't.*

#### **4.8. Dentists (Adults)**

A consistent theme was residents' experiences of trying to find an NHS dentist, saying that there were not enough dentists in the area.

Several commented that they had or were considering seeing a private dentist.

- *I've been on a waiting list for 18 months trying to see a dentist. I contacted NHS 111 and was then given an appointment to be seen 3 months later. I ended up flying to Poland to have my treatment as it was taking so long.*
- *I've not been able to find a dentist – it's going to cost me £800 to get my teeth sorted.*

#### **4.9. Older Persons Services**

An elderly lady was concerned that many lose their independence when discharged from hospital to a care home for respite care. See story below.

*I was living with my sister in a bungalow. I was admitted to hospital earlier in the year and then discharged to xxx care home for respite.*

*The care I received in the home wasn't good – the care workers didn't administer the medication at the right times / intervals (following cataracts operation).*

*I'm 92 and an active person, I regularly go out and about and into town to do my shopping. When I was at the home I wasn't 'allowed' to go out when I wanted – in the 3 weeks I was there, I was only allowed to leave the home twice.*

*I became immobile like everyone else at the home. I'm a strong-willed and very independent – I wanted to get my strength back, so have been able to. But if I*

*wasn't so determined, I could have become weaker and lost my independence altogether and ended up having to live in residential care.*

*I now live in sheltered accommodation and have my independence back with care workers visiting me each evening (at the right time).*

## 4.10. Childrens and Young People's Services

**CAMHS** – Several parents told us that they were concerned about the lack of mental health support during school holidays, saying it would be better if there was more support available. They also commented on waiting lists.

**Looked after children** – foster carers advised when moving between local authority areas, the child often had to rejoin a waiting list, thus delaying access to treatment or missing out on routine checks such as rudimentary eye tests.

**Waiting lists** – parents expressed concerns regarding waiting times, examples were given where a young person was waiting more than 6 months for a hospital appointment.

**Dentists** – several parents commented on difficulties finding an NHS dentist.

**Schools** – several parents felt that schools should have picked up signs that their child had a need, for example that a child needed glasses or had dyslexia, and that these needs had not been picked up by the school.

- *My teenage daughter is on the waiting list to receive some mental health support. I find it so frustrating and worrying – it's a 6-month wait. During the school holidays it feels as though there's no safety-net – social services tell me to take her to A&E. I'd like waiting times to be reduced and for there to be better support available during the school holidays.*
- *There's a lack of continuation of care for foster children – the child we were looking after was really struggling at school and could not read. It turned out that they needed glasses, and this hadn't been picked up.*
- *I tried to find a dentist for my two daughters but couldn't find anywhere nearby. We eventually found a free dentist in London which my daughters go to (it's the only NHS dentist we could find).*

Colleagues who work with children and young people suggested that an easy improvement would be the way that staff and organisations interact and communicate with young people.

- *Young people are fed up of being lied to. Avoiding certain phrases like 'suicide prevention' just adds to the stigma. Young people should be invited to be part of conversations about them – it's about them and their everyday life. Don't underestimate young people.*



## Wellbeing

A common observation was the excessive inactive behaviour among young people, often spent watching television or playing on electronic devices. The feedback emphasised the need for more stimulating and adventurous activities to be offered in after-school clubs and youth groups.

Concerning healthy eating, recommendations included the establishment of after-school cookery clubs with the added suggestion of inviting parents to participate in these classes.

- *Children should be taught more in school. They have 'life studies' classes every week, they could be taught about being healthy (healthy eating and moving) and the risks about smoking, vaping, being inactive, and also first aid – signs and symptoms of a stroke, what to do if someone is having a heart attack.*
- *Need to provide more activities for young people – when I was young there were regular discos we could go to (it was something we looked forward to going to them). We need to provide enticing activities for young people – maybe something like graffiti boards or street art displays?*
- *There should be schemes to get children into low-cost activities. For example they could have they could provide cooking classes in primary school (after school clubs) showing children and their parents how to cook healthy food on a budget.*

## 4.11. Pharmacies and Medicines

A few examples were given by patients who advised that they had been either issued the wrong drug or wrong dosage. In both cases the errors were picked up by the patient or pharmacist and rectified before any medication was taken.

- *"I keep being issued the wrong medication by my pharmacy at xxxx Surgery. I'm prescribed eye-drops for glaucoma but am allergic to one of the brands. It states on my prescription (the print-out that's issued with the medicine) that I'm allergic to the brand and should not have been issued them – however the pharmacy regularly dispenses them.  
  
It's such a waste as I've had to return the incorrect dispensed drops and they're then disposed of by the pharmacy – it's a waste of money.  
  
I now always checks what's in the bag before I leave the pharmacy - I'd like the pharmacy to take more notice of what they're doing!"*
- *My child was on a controlled drug, the GP prescribed the wrong dosage for my child. Fortunately the pharmacist realised that the wrong dosage had been prescribed and corrected the mistake.*
- *There is a big issue with patients hoarding and stockpiling medicines, this is bad for the patient and is a waste of medicine and resources.*
- *The pharmacist 'Kays' in Bedford is fantastic – he is unbelievable and helps me with my medication.*

## 4.12. Wellbeing

Access to high quality health and care services is very important, however, keeping active, having a balanced diet, decent housing, social inclusion opportunities and being in paid employment have an important part to play.

### 4.12.1 Exercise

Consistent feedback was that people knew that exercise was good for them, and that regular exercise supported both their general health and their mental wellbeing. Whilst part of the population is not interested in increasing their physical activities, there are some who would if barriers were overcome.

Many suggested that if gym fees were subsidised, they would be more likely to join as they found the fees too expensive for both membership and one-off classes. Several people also commented that they struggled to attend due to childcare or creche provision.

Some older people asked for physical activity classes to help improve their balance and reduce falls.

- It would be better if gyms and exercise classes were cheaper. I know it's cheaper to pay a monthly fee, but at my age (82) I'm not always well enough to go, so it's a waste of money. I can't afford to pay the one-off costs, so I end up not going to any sessions or classes.*
- Keeping exercising keeps you mentally well. I used to go the gym 5 times a week and then my mum died, I lost my job and I now have no money. It's hard...if gyms were free, I'd go. I know it would make me feel so much better.*
- I used to live in Ipswich. They had good scheme called the [iCard Ipswich Fit](#). It was recognised by local businesses (sport facilities) and issued by social workers as a prepayment /credit to go swimming, use the gym. I know that exercise is good for me – it helps with my anxiety and depression, I wish there was something in similar. I'm on benefits and can't afford to go to the gym.*
- I'm a wheelchair user, my doctor told me I was fat and needed to do some exercise. Active Luton told me I needed to go swimming. It's so expensive – it would be better if there was funding / it was cheaper.*
- It would be useful if there was some kind of provision to look after children whilst parents exercised. I can't exercise as I have young children that I have look after it would be too expensive paying for childcare and gym classes for myself.*
- I'd like more activities to be made available in local community centres and for these to be free. I'm getting food from the foodbank – I can't afford to send them [children] to clubs.*

A few commented that there was a lack of provision for people with disabilities, and where there was some provision, there may not always be the correct equipment to use.

- Sport and physical activity are my happy place. When I became disabled, I soon realised that there were few activities for wheelchair users to take part in.*
- I'd love there to be other sport activities for wheelchair users available in Luton – I've been working with [xxx] from Luton Council who is supporting me to apply*

*for funding to set up a wheel-chair tennis class / team. It's expensive as need different sized wheelchairs, clothing etc.*

#### 4.12.2 Diet and nutrition

Consistent feedback was that most of the population know they should have a healthy diet, but that some might be unaware that their diet was unhealthy. It's often easier to eat ready-prepared food or takeaways was a common response; many suggested that educating children and providing after school cookery classes would be a good way of getting families to eat healthier.

- There are not enough menu / food choices for school meals – they should be more ethnic and culturally appropriate dishes and recipes.*
- The best way to help people to live healthier lives is to get them to eat healthily. Start by teaching them how to cook properly, real cooking – using non-processed foods and fresh vegetables.*
- It would help if healthy eating was promoted in a fun way and that cheaper healthy food options were made available.*

#### 4.12.3 Employment

Several commented on the struggles they were having obtaining paid employment and the mental stress this caused them; and whilst they were supported to gain the right skills or qualifications, without experience many still failed to get paid or voluntary work.

- I wish the job centre would be more supportive and pro-active to help me to find a job. They arranged for me to be get a fork-lift drivers licence – but I still can't get a job, no one will take me on as everywhere wants someone who has experience. I can't even volunteer as I have no experience and companies don't want to spend time doing the in-house training.*
- When I go to the jobs hub I get filled with anxiety and feel depressed. I know I'll feel much better about myself (better mental health) if I have the job, but going to the hub always makes me feel worse. The staff should be more creative with their thinking and support – it would be useful if they could provide a programme to help build self-confidence, if I'm more self-confident it'll help me to look for and apply for jobs.*
- Make the workplace a stress-free place – educate people on how to be less stressful, how to manage stress and how to navigate the systems available.*

#### 4.12.4 Housing

A few people commented on problems they were having to find suitable accommodation or delays in benefits and then time it was taking for issues to be resolved.

- My son has cerebral palsy and autism, he goes to a special school. I've been waiting for the OT team at the council to sort out our housing for ages. He's now*

5, we have one bedroom - he has to sleep, eat and live all in one room (our lounge). When the OT team visits, they tell me we don't have the right furniture in the room. I feel that they don't think we're good parents, we try our best and it's difficult. I just want to get my housing sorted. [person was signposted to LBC colleague who took actions to contact the OT team]

- I've recently moved to Bedford and me and my wife receive support from the Charter House housing team. When we moved to Bedford, Luton Council stopped all our benefits - we then had to apply for benefits in Bedford. It would have been better if we'd received some benefits as we received no money for a while. The Charter House housing team have been fantastic – they helped us to reapply for all of our benefits and register with a GP – they knew I was on regular medication, so made sure I had enough medication to see me through. Knowing that I can ring the Housing Team if I have any kind of problem is very reassuring and a great help.
- There should be better housing for people with mobility scooters, with space to park your scooter. I've spoken to both the council and Housing Association and there's nowhere available in the town centre.

#### **Positive**

I was contacted by a social worker (Central Beds Council) when my wife died, they wanted to check how I was. The team were very good and arranged for me to be rehoused from All Saints View. I love it there!

#### **4.12.5 Safe green spaces**

Having access to green open spaces and being able to enjoy them whilst feeling safe was mentioned by several people, with a few commenting that they felt very lucky to be living in Milton Keynes.

- Trying to walk to work in MK is very difficult, there are plenty of places to walk for exercise, but I would like to walk to work to build a healthy routine into my day and the way the city is designed I have to walk through multiple housing estates. To walk a short distance can take an hour because there are no direct routes. Also the underpasses do not feel safe in the winter, so I will not walk through them in the winter although I would do in the Summer. There needs to be some road level walkways to make those walking feel safer.
- I recently moved to Milton Keynes – it's a totally positive experience for me and my family. There's so much diversity with people from many ethnic backgrounds. We feel part of the community and no longer outsiders.  
  
There are so many open-spaces and lots of activities going on. I'm so glad we moved here.

#### **4.12.6 Transport and local activities**

Several people stated that being able to attend social activities and reducing social exclusion was important. Many commented on the desire to attend different activities or classes, but either struggled to attend or couldn't attend due to transport issues – examples

were provided where wheelchair users or people with guide dogs are charged a premium rate for taxis and older people requiring a lift from their homes.

- *It would be better if there were better transport links – it can be tricky attending events and activities if you don't drive.*
- *Disability transport is an issue, particularly in Central Bedfordshire. Some companies will do hospital and outpatient runs only. Patients need transport to social events to avoid social isolation post stroke. Private taxi companies charge more for wheelchairs or guide dogs – pricing unregulated.*
- *There should be more social activities for people locally, with support to get elderly people to them. My dad has dementia and lives in Ampthill, there's not much he can get to from his home and I work full time so I can't take him to different places. The day-care centres were really good, and nothing has replaced them since they were shut down.*
- *We found today's presentations really useful, it would be very useful if there were more events or presentations on different subjects about how to keep healthy and well. The elderly are very fixed in their ways – it would be useful to have someone lead (or show us how to lead) different exercise classes for the elderly (such as chair-based exercises).*

#### 4.12.7 Information and Advice

- *You should have more events like today (See the ability, not the disability – St Georges Square, Luton), providing information and advice. Include services like the 'Stop Smoking' service.*
- *Hold education and information events – provide them free of charge and with easy parking.*

#### 4.13. Rough Sleepers

We spoke to several rough sleepers attending drop-in sessions and Food Banks. Their experiences of accessing health and care services were similar to those who had with fixed accommodation, however, the issues were magnified due to their homelessness, as they had issues making telephone calls (paying for calls or keeping phones charged), having an address for letters to be sent (and post going missing).

From the conversations, it appeared that many were not accessing or unable to access the services that they needed to support their health.

- *Registered with xxx. It's difficult getting an appointment and when he does get one, the doctor never rings back. He can't get seen face to face. He would sooner go to A&E to be seen as he knows he can walk in and get to see someone if he is ill. He has many health conditions as he had a heroin and crack addiction that has messed up his lungs. He'd like to give up smoking now but has no idea how to access support.*

*He has mental health issues as well as other health concerns, but the doctor won't talk about more than one issue at a time as they have a short appointment with him.*

- xxx is 35 and has lived in a hostel for a few months. He's unhappy there as there are people who have mental health issues, and he does not feel safe. He asked for support in accessing housing from the council, but no one called him back. No one from local support organisation helped him find accommodation, he managed to find the current shelter himself. He reports that he asks for help and people just don't reply. He is registered at xxx but it's not all that easy getting an appointment. He has MSK issues from sleeping on a park bench – but doctor just prescribes pills that make him drowsy. He is worried about being drowsy as he needs to be alert to care for himself. He is keen to find work – even volunteering or peer work but does not know where to go or how to start. He is a Polish speaker and has offered to help with translation where needed, but Noah can't help him with that. No one calls him back. He has stopped asking for help from health and care professionals. He feels no one cares and so he has stopped caring about himself.*
- xxx is Polish and has been sleeping rough for 5 weeks. He is keen to find work but does not have legal paperwork to reside. He spends his days at the library trying to find work in Europe where he can travel. He was helped to access a shelter for two nights after his visit to Noah. He is currently fit and healthy but says that he will visit A&E if he is sick.*
- xxx lost his home after his wife died in 2019 and he has been sleeping in his car on Tesco car park since. Some friends take him to Scotland for a month each year, but the Salvation Army, Noah and xxx helped him to find a shelter in Luton to stay. He has been there for the last few months. He has Type 2 Diabetes and is registered at Castle Street surgery, who he says continue to look after him. He is booked to have an eye scan at the L&D tomorrow (8/6) and recently had an eye test at Specsavers. That all went well. He struggles to access a GP appointment because of how busy people are and he needs to be careful with how he uses his phone. He mostly uses his bus pass to get into town to put in his prescription for diabetes pills. That process is easy but talking to someone isn't – because of the waits on the phone. He has problems getting appointments because the hospital sends things out by post, but because he has no address and post goes missing at the shelter, he doesn't always get letters. The practice now email him but he has to keep his phone up, so he can get access to information / appointments. He is struggling with grief and anxiety and has not been signposted to grief counselling / talking therapies support. He didn't know he was able to access those services or talk about that with a professional. He worries about his accommodation and how long he'll be able to keep it for if he spends time with his friends in Scotland this summer – but feels he needs to get away to be with his wife's friends as they help him with his grief.*

*No one is helping him with that at the moment. He asks for help and there's no guarantees which is affecting his mental health.*

- *An Irish man who wasn't happy to engage too much. Asked where he went if he was poorly – he replied nowhere. Asked if he ever rang a doctor, he responded 'Christ no, those boys are too busy for me'.*
- *It's a joke, I'm homeless. I was visited by xxx in the summer when it's warm, but in winter when it's cold and wet no one comes to visit me.*

## 5. What is the one thing we could do to help people in Bedfordshire, Luton and Milton Keynes stay healthy and live longer?

116 residents responded to the question above, their suggestions have been grouped by theme. The top 5 suggestions made by residents to help them stay healthy and to live longer are to:

### 1. Provide information to support people to live healthier lives and make healthier life choices (21%)

Residents suggested targeting at-risk populations through events and campaigns and continuous education and information sharing with community groups and at community events.

Several expressed concerns about the number of licenses for fast food outlets, emphasising the importance of cooking and eating healthily. Suggesting that more information about healthy eating be taught at school and culturally appropriate recipes be made available.

### 2. Provide more opportunities or make it easier for people to take part in physical activities (13%)

Residents suggested various ways to increase exercise opportunities and promote overall well-being. Ideas include introducing buggy-fit classes, encouraging outdoor activities, and offering free or affordable options especially for those with financial constraints, through free or subsidised classes and creche facilities.

### 3. Make it easier for people to access GP services (9%)

Residents suggested providing more GPs appointments and improving the booking systems.

### 4. Communication, Information and advice (9%)

Residents asked that we recognise the diverse communication needs, including spoken and written English, and use of digital devices and platforms, and provided training to residents on how to use the Apps and platforms.

Suggestions were made to promote enhanced access appointments and the availability of translators for health and care appointments, recommending that posters be displayed in community settings.

One person suggested improving communication between providers and patients by avoiding redundant letters and emails to the same person, advocating for a single reminder and correspondence per address to save resources.

**5. Make it easier for people to access dentists (6%)**

Residents asked that we provide more NHS dentists in BLMK.

The full list of responses, including other themes can be found in Appendix 3.

## **6. Next Steps**

This engagement report will be published online and shared with the groups and organisations who facilitated our conversations with local residents.

The insights will be shared with commissioners and providers, so they have a better understanding of what is important to local people and can ensure that the services provided locally meet the needs of local communities.



# Appendix 1

Events and groups visited as part of the Big Conversation.

Date	Event Name	Organiser / Group	Audience	Place
09/05/2023	Recovery Toolkit - focus group	Milton Keynes Council – Domestic Abuse Team	Victims of abuse	Milton Keynes
14/05/2023	Cancer Awareness at Guru Nanak Gurdwara, Dallow Road	Medics Primary Care Network	Residents from Sikh community	Luton
16/05/2023	Just Ask - Biggleswade	Healthwatch Central Bedfordshire	Residents and patients	Central Bedfordshire
17/05/2023	Women's Refuge	MK-Act (Domestic Abuse Intervention Services)	Victims of abuse	Milton Keynes
23/05/2023	Just Ask - Leighton Buzzard	Healthwatch Central Bedfordshire	Residents and patients	Central Bedfordshire
07/06/2023	Cheering for Volunteers	Central Bedfordshire Council and CVS	Volunteers	Central Bedfordshire
07/06/2023	Drop-in at NOAH	NOAH	Homeless and rough sleepers	Luton
15/06/2023	Dunstable South Children's Centre	CBC Children's Centre	Young families	Central Bedfordshire
21/06/2023	Picnic in the Park	Luton Council and the Early Years Alliance	Families	Luton
23/06/2023	Health Promotion Event	Titan PCN	Residents/patient Houghton Regis	Central Bedfordshire
24/06/2023	Pride in Luton*		LGBTQ in Luton	
24/06/2023	India Day MK	IDMK	Residents from Indian communities	Milton Keynes
26/06/2023	Staff Wellbeing / EDI event	Central Bedfordshire Council	CBC staff	Central Bedfordshire
27/06/2023	Better health and financial wellbeing this summer	Public Health - Central Bedfordshire Council	Residents and patients	Central Bedfordshire
28/06/2023	Refugee Networking and Community Event	Community Action MK	Refugee communities in Milton Keynes	Milton Keynes
30/06/2023	Salvation Army Bedford - Food Bank	Food Bank	Residents from Bedford	Bedford Borough
01/07/2023	Luton Health Fest	Community Interest Luton	Residents and patients in Luton	Luton
01/07/2023	African diaspora Festival		Residents and members of African communities	Milton Keynes
04/07/2023	See the ability not the disability	Luton Council	Luton residents - focus on physical disabilities	Luton
05/07/2023	BLMK Community Fayre	ELFT	Residents, staff and governors	Central Bedfordshire
07/07/2023	Just Ask - Houghton Regis	Healthwatch Central Bedfordshire	Residents and patients	Central Bedfordshire
08/07/2023	Park run for the NHS	Park Run	Residents from Bedford	Bedford Borough

<b>Date</b>	<b>Event Name</b>	<b>Organiser / Group</b>	<b>Audience</b>	<b>Place</b>
12/07/2023	See the ability not the disability	Luton Council	Luton residents - focus on sensory	Luton
13/07/2023	Celebrating 10 years of Healthwatch Luton and AGM	Healthwatch Luton	Residents and patients	Luton
20/07/2023	Drop-in / stand at Bedfordshire Hospital Trust	Bedford Hospital	Patients, Carers, staff	Bedford Borough
20/07/2023	See the ability not the disability	Luton Council	Luton residents - focus on neuro and hidden disabilities	Luton
28/07/2023	Health and Wellbeing Activity Day' on the Lakes Estate.	Lakes Estate Renewal Forum and Locals of the Lakes Residents Association	Residents from Lakeside	Milton Keynes
28/07/2023	See the ability not the disability	Luton Council	Luton residents - focus on neuro and hidden disabilities	Luton
28/07/2023	Toddington Action Day	Safer Communities and Partnership Team	Residents and patients	Central Bedfordshire
03/08/2023	Community Drop-in Coffee Morning	East Bedford PCN	Residents and patients	Bedford Borough
10/08/2023	Scott Hall - Food Bank	Food Bank		Bedford Borough
18/08/2023	Gurdwara in MK	South Central Ambulance Service	Sikh community in MK	Milton Keynes
21/08/2023	Central Beds Stroke Survivors	Central Bedfordshire Stroke Survivors	Patients / Stroke survivors (Central Bedfordshire)	Central Bedfordshire
23/08/2023	Ukraine Flag Raising Day	Rufus Centre	Ukrainian guests and hosts	Central Bedfordshire
01/09/2023	Just Ask Flitwick	Healthwatch Central Bedfordshire	Residents and patients	Central Bedfordshire
02/09/2023 & 03/09/23	Desifest*	join eQuality PCNs stand	Community Event in Luton - would	Residents / Patients in Luton (multi-cultural event)
09/09/2023	MK Pride*	VIA - Healthwatch Milton Keynes	LGBTQ community MK and residents	Milton Keynes
09/09/2023	Launch of Queens Park Family Hub	Bedford Borough Council	Families - Queens Park	Bedford Borough
13/09/2023	Play and Learn (Toddlers) Goldington	Early Childhood Partnership, Bedford	Families in Goldington	Bedford Borough
13/09/2023	Play and Learn (Toddlers) Kingsbrook	Early Childhood Partnership, Bedford	Families in Goldington	Bedford Borough
19/09/2023	Open Day - Cauldwell Medical Centre	ELFT	Patients / Residents Cauldwell	Bedford Borough
23/09/2023	Milton Keynes Murugan Temple Open Day	Milton Keynes Murugan Temple	MK residents attending temple open day	Milton Keynes
06/10/223	Festival for Older People	Healthwatch Central Bedfordshire	Older People	Central Bedfordshire

<b>Date</b>	<b>Event Name</b>	<b>Organiser / Group</b>	<b>Audience</b>	<b>Place</b>
11/10/2023	Ageing Well Exhibition	Age UK Bedfordshire	Older People	Bedford Borough
16/10/2023	MK Can	MK Food Bank	Residents	Milton Keynes
24/10/2023	Young People's Conference	Healthwatch Central Bedfordshire	Young People	Central Bedfordshire
26/10/2023	Luton Stroke Survivors	Different Strokes for Different Folks	Patients / Stroke survivors (Bedfordshire)	Bedfordshire and Luton
27/10/2023	Dunstable Food Bank	Dunstable Food Bank	Residents in Luton	Central Bedfordshire
03/11/2023	Bedford Stroke Survivors	Bedford Stroke Survivors	Patients / Stroke survivors (Bedfordshire)	Bedford Borough

\*Partner organisations encouraged attendees to respond to the online question

## Appendix 2

Insights and feedback have been summarised and grouped by service area.

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## GP Practices

- 1) Councillor requested a handful of the 'your guide' leaflets to display in the town council. Also had a conversation about xxx and the hope for a better service with the new provider. Explained that we were keen for the current providers to 'leave well' and had a marketing plan post June as the new providers took over.
- 2) Resident asked about the new providers as he said he had heard that there were bad reviews on Google. We had a good conversation about believing all you read online, and whether people leave reviews if they are happy with the service they received and again, encouraged them to give the new providers a chance as they take over.
- 3) Resident asked about the new providers and suggested that online booking should be re-instated and also the opportunity to pre-book appointments.
- 4) Issue of access to GP services, long wait to get to see a GP and not able to see the same GP.
- 5) xxx currently lives in a hostel. He has been there for 6 months after his relationship broke down with his family.  
His experience of accessing health and care has been a challenge as while he is registered with GP he can't get an appointment easily. He has got to be careful with his mobile phone as he can't afford to wait in line and pay. His experience is that GPs rush people through – they're too busy to listen.
- 6) xxx said that he has several ailments he wants to discuss with the doctor, and he's told one thing per appointment as there's no time, so he now feels like there's no point. No one cares. They just prescribe pills.
- 7) I have 3 children, it's very difficult to get an appointment for them to be seen by a GP... It's a vicious circle trying to get an appointment. I usually contact NHS111 if we need to be seen urgently and NHS 111 arrange for this me.
- 8) It's a nightmare trying to get a GP appointment – please make it better
- 9) Patient at xxx surgery, the health services provided are good, it is a supply and demand issue. The new housing estates such as Clipstone Brook are creating too much demand for the services to cope with. We need a new facility to cope with demand.
- 10) Believes we should have more admin staff at GP practices to allow people to get through to the receptionist team straight away. This will allow for a constructive conversation with the receptionist team to allow them to sign-post and book the most appropriate appointment for the patient. Currently patients waiting 1 hr to get through, when they do have the conversation, it is negative from the start with the patient just wanting the next available appointment, they are not in the frame of mind to have a constructive conversation. Increasing admin support would be more cost effective and quicker to implement than additional clinical roles.
- 11) It would be good if patients were able to opt out of texts and letters from GP practices that aren't applicable to them – for example invitations / notifications for the covid vaccination
- 12) Person just moved from Toddington to Bedford. They advised that when you rang the practice patients were given different advice depending on who they spoke to. This can be confusing for patients and patients not confident that they're receiving the right information.
- 13) A patient was very surprised by an off-hand unprofessional comment made by their GP. The GP had a strong accent and patient found it difficult to understand them – the GP told the patient to 'wash-out' their ears.
- 14) I don't like the way the GPs work now – I go to xxx. I used to be able to talk to my GP, but there's not enough time to do this anymore
- 15) I wish it was easier to make an appointment to see my GP – I'm at xxx and can't get an appointment despite ringing at 8am
- 16) I like to receive letters in the post with information about my appointments, and much prefer seeing someone face to face than speaking on the telephone.

- 17) GP services need to be improved - we need more GP appointments, shorter waiting lists, and be able to ring at 8:45 for any type of appointment
- 18) I was 'on hold' for 2 hours at xxxx Surgery.
- 19) Person was unaware that they could use their NHS App for other members of the family (link to different profiles)
- 20) Access to GP's is a real issue, it's so difficult to get appointments. Has fibromyalgia and would like to be able to see the same GP for this long-term condition. It would improve treatment for all those with long term health conditions to have a regular named GP who knows them and their condition. This will stop the patient having to repeat their medical history each time and will enable to GP to see in changes in the patient.
- 21) Worried about the closure of Wenlock Street and the access for her friend who has Mental Health issues and is not physically mobile. Generally access to practices for older people is difficult, often if there is parking available it is too far from the building and older people are not able to stand for long periods waiting in queues.
- 22) Really long waiting lists for accessing GP services and no ability to get an appointment
- 23) Access to GPs a problem. Young people being affected a lot – affecting their lives/missing schools
- 24) Really long waiting lists for accessing GP services and no ability to get an appointment
- 25) There is intermittent access to GP appointments at xxx Surgery and elderly residents are expected to fill in online forms to try and get an appointment, which they do not feel able to do so will give up trying to get an appointment.
- 26) I've got no money and can't afford to buy food this week. xxx the social prescriber at London Road Surgery arranged for me to have a food voucher – that's why I'm here today.
- 27) I've been really happy with all the help I get from my doctors, I'm diabetic and have had cancer.
- 28) The GPs surgery in Flitwick is amazing – the electronic triage system that it uses is so much better than the phone system. The receptionists are very good and usually respond to queries within 10 mins
- 29) We both find it very difficult to understand the doctor as he has a very strong foreign accent. We kept asking him to repeat himself but still couldn't understand what he was saying. In the end we just left and made an appointment to see a different doctor.
- 30) I do like the new telephone system they have at the doctors. You ring them, and they then ring you back.... No need to be on hold for hours waiting in a queue
- 31) It's very difficult getting an appointment to see my GP
- 32) I'm registered with the De Parys Surgery – they've been good. I'm able to book appointment, they've referred me to local services – I've been with them for 3 years, so far so good.
- 33) It's very difficult getting a GP appointment, if I need to see a GP I tend to go to the walk-in-centre or use 111
- 34) Need more GP Appointments - patient's personal experience was he tried to book an appointment today (19th Sept) and couldn't get in until October although the GP had asked him to book in sooner.
- 35) When I speak to my doctor, they are very good and speak the same language as I do, but it is difficult to get an appointment in the first place.
- 36) It can be very difficult to get an appointment, having to ring at 8am and then when you finally get through being told that there are no appointments left and to ring back the next day. I also don't like all appointments being over the phone, it's much easier to talk to the doctor face to face to explain problems, I do not feel comfortable doing this over the phone.
- 37) Access to GP Services is very difficult and needs to be improved, it can be very difficult to get an appointment. I was unwell and was not able to get an appointment, so I attended the Walk-in service in Milton Keynes, I had to wait for 3hrs to be seen but the service I received was very good.
- 38) Doesn't use NHS App, is not IT literate, finding it more and more challenging as processes become more digital.
- 39) Registered at \*\*\*Surgery and finding it difficult to get help when in need

- 40) Receptionists need customer services training, very aggressive
- 41) Finding things becoming more discriminatory against older people. People having to use devices to register, offers of telephone and online consultations, feeling of being left behind
- 42) Access to GP if you have severe health problems.
- 43) \*\*\* Surgery – Lots of delays in receiving results e.g. bloods
- 44) When he rings surgery always gets a machine but nobody to explain health concern
- 45) \*\*\* surgery - Patient with major sight impairment and with guide dog attended GP Practice for appointment. Patients name came up on the board but patient not aware and another patient alerted him. Patient then asked to go to consultation room 4. Receptionist never thought of helping and directing patient to his appointment. "it's the little things that help"
- 46) xxx Surgery – GP Appointments difficult to get
- 47) xxx Surgery - Appointments difficult to get
- 48) Shefford HC – Patient advised that get a fab service and uses online tools to book appointments with GP & Hospital
- 49) xxx - 2 x Patients – struggle getting GP appointments at their surgery.
- 50) xxx surgery – 2 x patients advised of difficulty in getting appointments
- 51) xxx surgery – patient finding difficult to get appointment for shingles
- 52) Houghton – Good GP, plenty of appoints and direct links to pharmacy
- 53) 2 x patients 87 & 88, go to the GP once a year for their flu, Covid jabs. Don't use anything online, their neighbour gets messaging from GP Surgery when it's time for flu jab and when clinics are running, he then tells these patients then they go to the surgery to book themselves in.
- 54) xxx surgery – patient struggling to a GP Appointment
- 55) Ivel Medical Centre – Patient advised that she finds it much easier to get appointments since the new provider and delighted that she sees the same GP on a regular basis
- 56) 2 x Patient advised that they use the NHS App and find it easy to use. They use it for ordering their prescription and their health details are up to date
- 57) 3 x feedback, challenging to use online services, don't use NHS App
- 58) Patient looking for literature that may be available for pre-diabetic patients, taken telephone number and will link up with commissioner
- 59) Looking for service to get Covid Jab not contain polyaniline. xxx took telephone number to see where this may be available.
- 60) Houghton Close – patient advised challenges at times to get a GP appointment.
- 61) Flitwick Surgery – patient advised challenges at times to get a GP appointment.
- 62) Patient – Dyslexic – struggling with all the services offering online services, form filling online, need to keep provision for patients who cannot access information online
- 63) From her clientele: Getting a GP appt difficult.
- 64) Personally feels that long triage process through receptionist at GP surgery.
- 65) Sundon Park surgery are great. Thanks
- 66) Difficulty getting through for appointments with GP
- 67) Booking an appointment is difficult – it's booking online only. Need to have some as telephone booking.
- 68) Difficulty getting through for appointments with GP.
- 69) Long triage process through receptionist whilst making an appointment.
- 70) In general happy with services. Note that for routine appointments with the GP, you don't see the same GP (your registered GP) each time.
- 71) For more minor things, e.g. has had physio in the past for back pain. Has found it better to go private with a short wait time.
- 72) Registration should be quick. Register people with practices more quickly – allows seniors to complete their processes and see people.
- 73) Issues with getting appointments at xxx when calling takes over 100 tries to get through.

- 74) My GP surgery is very good – they're proactive (which we really appreciate). They contact me when he's due a vaccination or a blood test and make arrangements for these to be done at our home. They even issue my vaccines at the same time. A really good surgery
- 75) As a working person I find e-consult very useful
- 76) The voicemail messaging system for xxx is very long – it's extremely annoying as it covers both more than one practice. [we rang the number - the welcome and advice element of the message was 1 minute 10 secs, the recording then started to list numerous options and buttons to press, this went to 1 min 50 secs]
- 77) Man in his 80s and registered with Kirby Road practice, the practice contacts him when he's due for his different check-ups which he finds reassuring. The telephone system has is much better than it used to be. If he needs to make an appointment, he rings the surgery and gets a call back.
- 78) Issue with cross-boundary services for one practice – with some services funded by Luton Council and others by Central Bedfordshire Council. Complaint raised with practice over 4 years ago and still ongoing – PPG chair having to do all the chasing, he wanted to know when issue is likely to be resolved [referred to primary care team].
- 79) I don't feel that the GPs are that interested in me or my condition. I don't bother, as my GP doesn't bother.
- 80) It's very frustrating using digital services like e-consult, my brain and fingers just don't work.
- 81) I'd like to have a telephone call with my own named GP once a month to talk through any concerns I have. Treat me as a person rather than a number.
- 82) The behaviour of the receptionist in my practice was very bad - they lacked manners and etiquette. They kept calling out the wrong name of the patient, when they realised they'd been calling the wrong name they took it out on the patient and didn't even give an apology.
- 83) You ring the doctor to make an appointment and the receptionist makes you feel like a nuisance.
- 84) We need more urgent services in Milton Keynes, especially with the Broughton Centre closing. Milton Keynes is growing so much – people who need to be seen at the weekend are having to wait 7 to 8 days.
- 85) My grandmother was able to get an appointment and received the necessary treatment
- 86) I'm registered with Stony Stratford surgery. I can always get an appointment. It's a brilliant service
- 87) I don't have an issue getting appointments at Telford Surgery (Stony Stratford) – but the practice do prefer people to do everything online rather than calling reception which is often much easier for patients
- 88) At Oakridge Park Surgery I'm able to get appointments when needed
- 89) I can't see the logic of having the GP surgery at 8am each morning for a non-urgent appointment. Then having to call back every day. There's no option to book an appointment for a few weeks' time, which means I'm adding to the long telephone queue unnecessarily. GPs need to the pressure of our hospitals
- 90) Resident asked for clarity on the plans for Ivel Medical Centre. Confirmed with them that they had received the latest patient letter and reiterated the content. Explained that the new providers need time to bed in and encouraged them to give them a chance.

### **Insights about Leighton Buzzard**

- 91) Growth in housing and no equivalent growth in medical services, feel disgusted that Leighton Buzzard has been left behind.
- 92) Growing population, lack of facilities. Mentioned the survey of 5,000 residents - but questions how it will all match up moving forward. Need to push the ICB to get results - as the feasibility study doesn't talk about secondary care at all - only primary care. GP access is terrible and there is disjointed care for LB residents, Need a minor injuries unit. Why did Dunstable get a hub when right next to the



- hospital? Pathways for patients don't always work well - need more work on making sure patients go to the right place at the right time and have linked up services.
- 93) Fed up with not having extra provision. Lived in Leighton Buzzard for 52 years - promised a cottage hospital way back then and all this time later we are still waiting for something.
  - 94) Referrals onwards, are spread too wide across the county, with transport accessibility. Leighton Buzzard needs a walk-in centre so can be triaged there rather than having to wait so long for GP appointments. The NHS feels so disjointed in Central Bedfordshire. There needs to be more public health messaging on how to access services.
  - 95) Dentists, doctors, and other facilities are needed to be built and should all be free of charge. We lost the idea of cottage hospitals many years ago. Planning is an issue, but estates should only be built if they can include all these services. I've been a Leighton Buzzard resident for 34 years and all types of services have been lost – police, ambulance, justice. The facilities in town are worse than they used to be.
  - 96) Will it ever even be built or is this just another delay tactic?
  - 97) Can't the land at the back of the Swan pub all the way to the post office be used for the proposed new hub, rather than on the outskirts of Leighton Buzzard? It's inaccessible there and needs to be in the centre of town for those without cars, which is the majority of senior residents and low-income families. There's no point in building on the outskirts as there are no transport systems in place and we need a well-established one for it to be utilised properly.
  - 98) This is a good start on something that should have been done more than 40 years ago. Speed is of the essence and any NHS waffle and buck-passing should be exposed, shamed and sanctioned. I understand yours is a fairly new team - this is your chance to show that you care, are competent, and are worth your large personnel salaries. I have come from a town where, twenty years ago, the NHS authorities were equally limp and sometimes hostile to "the public". The community fought back, retained its much loved and needed facilities, and, when asked, raised £2 million to support them. It was slightly galling that those same authorities took the credit when the improved health care became an international success story, but, hey-ho, we got what was needed. I think the same level of anger is now present in the Leighton Buzzard population. Please don't ignore us or fob us off.
  - 99) What does "future proof" mean? I cannot forget that the ICB Chief Executive compared Leighton Buzzard to a rabbit hole. I do not have confidence in the ICB and their judgement. What about very poor transport from Leighton Buzzard to distant venues?
  - 100) Disappointing as not a comprehensive or particularly useful study -e.g., only mentions two hospitals to which patients from the town need to travel to and with very optimistic suggested car travel times, but no mention at all of public transport which is very difficult for all who use it and particularly for the more vulnerable.
  - 101) Lacks any strategic direction and practical solutions and a seeming will to make things happen - just more paper. No urgency in providing much needed medical premises and both GP and hospital services in the community.
  - 102) A more detailed and useful study 'Strategic Outline Case 2019' was much more helpful in going forward but was halted and then became non-obtainable from Central Bedfordshire Council or the ICB.
  - 103) Leighton Buzzard was historically the forgotten town and sadly this did not change with all the new housing developments we now have with absolutely no additional health provision. Many residents believed that health provision would be made, but the patient participation groups (PPG) are having to campaign hard for that and prioritising what we must get initially and those 5000+ residents who completed the recent Patient Survey helped with that by providing their views and anecdotal evidence - thank you.
  - 104) Feasibility Study - Leighton Buzzard - Far less detailed study than the one commissioned - Arcadis (Strategic Outline Case 2019) which no action has been taken on. Very disappointing that no

mention is made of secondary care. For the size of Leighton Buzzard and the huge developments that have and are taking place in the town, an Urgent Treatment Centre/Minor Injuries Unit, Outpatients Clinics and extra GP surgery are desperately needed.

105) A new health facility in Leighton Buzzard should contain:

- Outpatient referral clinics for all three of the hospitals – Milton Keynes Hospital, Stoke Mandeville and Luton and Dunstable
- Bus services to the L&D stopped so now have to change in Dunstable, there is bus to MK but does not stop very close to the hospital so makes it tricky for those relying on public transport
- The limitations on public transport, mean that those who rely on it have a limited window in which they can have hospital appointments.

106) A fourth surgery or hub is needed in Leighton Buzzard. It should be a mini hospital with basic x-ray facilities to allow for diagnostics including urine infections, contraception, to reduce the pressure on the GP practices.

## Hospital Services

- 1) So much new housing and no more medical facilities to keep up with demand. Quite a distance from an acute hospital and often have to travel to the hospital for simple procedures such as blood tests.
- 2) I kept getting headaches, had blurred vision, was dizzy, confused, disorientated and very forgetful. My GP said it was a common problem after having a baby and was not concerned. In November 2022 I collapsed and was 'paralysed' from the head down, my family called for an ambulance but was told there was a 90-minute wait. My family drove me to the hospital where I was checked over and told I had a urine infection. A few weeks later I still had a painful head and was very clumsy. In March 23, I was paralysed again and had to call an ambulance - the doctor who saw me said that it was quite common for mums to get lazy and suggested I join a gym. He also asked whether I'd seen a psychiatrist – he assumed that I was suffering from depression but hadn't asked me (just assumed)! I was told I had M.E. I'm waiting to see a neurologist – the appointment is for January 2025 (that's more than 18 months away!) I also have an appointment to be seen in cardiology in 2024. I keep having episodes, so have moved back home to live with my parents and have had to stop working. I have good days and bad days – I can't drive any more, am tired and get very weak. I've now changed my GP. My new GP arranged for me to have genetic testing and has told me that I shouldn't have been diagnosed with ME. I keep asking for GP for stronger pain relief, he says he can't give it to me, and I need to be seen by the neurologist before he's able to prescribe. I don't like my child seeing me like this, I feel awful, I feel like I neglect him. I'm very lucky that I have my family to provide support – but what about people who don't have family? I'm not entitled to Universal Credit as I've not had a diagnosis yet. I fear every day whether I'm going to be ok or whether I'm going to have a paralysis.
- 3) The Luton and Dunstable hospital expect everyone to have a mobile /smart phone and be able to make appointments, attend online consultations etc with their phones. I don't have a computer or a smart phone and find it very difficult to make an appointment or access the information they want me to.
- 4) It would be useful for patients to be informed / receive updates of where they are on the patient pathway. The patient pathway can be confusing, and patients have to wait several months between referrals, appointments and/or communication.
- 5) Patient with osteoporosis - Under the rheumatology department at the L&D who have provided a great service, experienced pain in her pelvis so had to see her GP, who referred her to have an Xray at MKUH. MKUH sent the x-rays to her GP which took a long time to come through and they were not shared with the rheumatology department who were already providing her care. This happened a second time when she experienced pain in her shoulder. If the systems were more joined up it would improve the service and waiting times for patients.
- 6) I had heart failure in 2019. I was at the L&D in intensive care – and had a very good support team. During covid I fell off their system. I've now moved address and live in Bedford; the L&D hospital are still monitoring me regularly. They send letters to my old address even though I've informed them that I've moved and have given them my new address. I prefer to receive letters than emails.
- 7) A&E at Bedford hospital is a nightmare, I was in the waiting room for 6 and a half hours waiting to be seen. The person sat next me was coughing, spluttering and then vomiting. The whole area felt extremely contagious – people on drips, people spitting into bedpans and another vomiting. The area should be split into different sections.
- 8) I was admitted to the cardiology ward – they were amazing!!

- 9) I'm waiting for an ENT appointment... the waiting list is very long. When my GP referred me, he asked whether I wanted to be referred as an NHS patient or pay privately. I'm still waiting for my appointment and will then have to wait for surgery.
- 10) The hospital uses an App for informing / scheduling my appointments (oncology services). I thought the App would be easy to use, however you really need to be on the ball and check the App regularly. I'd find it much less stressful if I was notified about my appointments by email, letter or text.
- 11) I wish the hospitals kept each other up to date with test and scan results – I have to attend appointments at Milton Keynes and Oxford hospitals, they don't seem to communicate at all. It would be much better if they shared all my results with each other.
- 12) I'm a student nurse – I think some of the wards at MKUH are brilliant, whilst others are not.
- 13) I've been on a waiting list for treatment for over 2 ½ years. In the end I was seen privately – what a waste of public money!
- 14) I'd like to see a variety of different foods available to patients in hospitals – it would be good to see some African options on the menu.
- 15) I'm not confident that the staff at the Luton and Dunstable know what they're doing. I've been seeing the same specialist doctor in London for years and much rather be seen by them. If I go to the L&D, the staff just hook me up to a machine
- 16) I was admitted to the L&D for emergency care. The L&D did not send my notes to my consultant at Harefield, I had to keep chasing the L&D to send them.
- 17) I was discharged from Harefield hospital and sent back home, but there was no one at home to provide support I needed, as my wife had been admitted to the L&D.
- 18) You wait for a long time for an appointment. It would be better if you be sent for tests, so doctors and consultants have your test results when you eventually have your appointment
- 19) I go to the eye clinic at the L&D. There's a yellow line that they ask patients to stand / queue behind. The line is very faint and it's difficult for a visually impaired person to see. When visiting the hospital the staff knew that I would have difficulty completing the forms, so they arranged for someone from PALS to help me complete the form.
- 20) The L&D sends a map with instructions on where to go for your appointment – this is very difficult to see if you have a visual impairment, it would be useful for this to be available in electronic format, or even better would be a written description - Catch the number x bus, go to x entrance this is on...
- 21) It would be useful to have people in health teams who are dedicated co-ordinators, able to review a patients history and spend the time with them going through what the advice they've been given, explaining the next stage of the process or referring them to the provider (rather than putting the onus on the patient to make contact). This would save resources and speed up pathways.
- 22) The hospital staff at BHT do not know how to care and support people with progressive MS. After a 3-week stay, people can be discharged from hospital with their condition significantly worse.
- 23) I'd like to work with the ICB to review the pathway, I made contact in January, but nothing materialised. [Reconnected with commissioner]
- 24) The service I've received at Bedford Hospital has been fabulous.
- 25) Observation whilst stood outside Swannery Restaurant - Person was in a wheelchair self-propelling themselves down the corridor. Hospital porter was coming in the opposite direction wheeling a patient in a bed. Porter could see the person struggling to get the wheelchair up the slope of the corridor so stopped to give them a push – kind and considerate, (he wasn't asked, but could clearly see person was having difficulties)
- 26) Treatment at L&D under consultant for Neurology has been excellent.
- 27) Waited at A&E for 7 hrs with elderly resident after they had hit and cut their head, had to queue up outside to wait to be triaged with relative who had a heavily bleeding wound.

- 28) My wife has a severe gastro problem. She's been seen her by GP (De Parys) who has referred her to the hospital. Her appointment is in 2024 – it's ridiculous that she has to wait over 8 months to be seen. In the meantime she's in agony and has had to give up work.
- 29) The hospital arranged for me to have an interpreter.
- 30) I had an abyss in my throat, I kept ringing my GP at 8am to try and get an appointment but couldn't get one. It was getting worse, so I rang 111 and had a virtual appointment. I sent them a photo of my throat / the abyss and they said it was ok and prescribed some medication.  
I was in so much pain that I couldn't cope, so I went to the hospital on the Friday night. They admitted me and I had surgery on the Saturday. I was in hospital for 3 days. If I had been seen by a person, they would have seen how bad I was it wouldn't have got as bad as it did.
- 31) In the Ukraine if you think you need to be seen urgently, you just call an ambulance. It's very different here in the UK – my son had tonsillitis and we had to wait 6 hours for him to be seen at the hospital.
- 32) It would be better if people were seen by health professionals sooner and waiting lists for treatment weren't as long.
- 33) I was admitted to Bedford Hospital as an emergency patient. I'd been to see my GP as I was feeling very ill, they told me to go and have a blood test immediately. I had the blood test and the next day my GP rang me; they told me to go to A&E straight away. I went to A&E and within 20 minutes I was taken to a treatment room. I had my first treatment (blood transfusion) within 2 hours and was then discharged from hospital 2 days later.
- 34) I was very ill, and the NHS worked
- 35) I have angina, my symptoms rapidly got worse, so I saw my GP. Within 2 weeks I'd been tested at the hospital and had a stent fitted. I can't fault the system.
- 36) My 96-year-old uncle spent 8 hours in an ambulance outside the L&D then moved to a trolley before being admitted and died the following day.
- 37) Patient waiting on hospital appointment, always delays, need more doctors, when eventually appointment arranged it gets cancelled
- 38) Patient needed help following operation. Patient transported from hospital to home by ambulance but did not have any help once home, no wrap around support and struggled until back on her feet
- 39) Bedford hospital transport from Langford nr Biggleswade not available. Had 8 x physio appointments at hospital post stroke. Hospital transport not available. Had to pay for private transfer - £40 each way, it was very expensive and same happened on discharge.
- 40) Long waiting time for tertiary care appointment (Guys & St Thomas)
- 41) Believes that health service for acute issues 'bigger things' is good. (e.g. hip fracture)
- 42) I had a suspected heart attack just after midnight and taken to the L&D by ambulance. I was seen by a Deputy GP, given some pills and sent home. It was 3am, I was wearing just my nightie and slippers so asked how I should go home. 'I don't know, you should walk' was the reply from the staff.  
I had no shoes, no coat, no underwear and no money.  
A kind stranger gave me the money to go home to Dunstable.
- 43) Female had a liquid cyst and was waiting for surgery to have it removed (7 months wait). It burst whilst she was waiting for the surgery and had to be admitted to hospital. She would like to see waiting times reduced.
- 44) There's a lack of communication - it's an at all-time low. The hospitals don't communicate with the GPs, the GPs don't communicate with the pharmacists. Information gets lost in the system.
- 45) Waiting times are so long - it would be good to have some reassurance that you've not fallen off the list. The hospital should let people know when they're likely to be seen and give some advice what they can do to support themselves whilst they're waiting to be seen.
- 46) I've been waiting over 6 months to be seen by the gynae clinic at Bedford Hospital (referred in March). I kept ringing the clinic and leaving messages asking them to call me back – but no one did. In the end I contacted PALS at the hospital. I spoke to someone, and they said that they'd look into for me. They (PALS) rang me back and offered an appointment the next day, unfortunately I couldn't

- go to it. They said that the gynae team would arrange a different appointment – I still haven't heard back from them.
- 47) I've got endometriosis and need to get a polyp removed – it's a 47 week wait. I'd like to see waiting times reduced.
- 48) Lack of communication between all the hospital that control my wife's care – stroke, heart problems. The individual doctors and GPs seem to be in silos and unable to talk to each other and to the patient. Also waiting lists are fa too long and the patient suffers
- 49) I wish that the disabled parking at the L&D could be improved – it's very difficult to park
- 50) I've received a very good service from the L&D – I've just been discharged from them. I had the operation, then a follow up.
- 51) My Mother-in-law (lives in Stondon) had to attend an appointment at Addenbrookes to have some special eyedrops. She was told that she wasn't allowed to use public transport and had to arrange her own transport to get home. My husband had to take a day off work to give her a lift (he's self-employed so lost a day's earnings). It would be better if transport was available (even if you have to pay for it)
- 52) My daughter has autism, when she stayed at Milton Keynes hospital she found it very distressing with all the lights and noises.

## Maternity Services

- 1) Giving birth at the Lister hospital was the best day of my life. The labour ward staff were incredible.. I was then transferred to the L&D, I wanted reassurance that I was doing things right, I didn't get any and felt very alone. It would be better if the midwifery teams did 'first visits' like they do at Lister to make sure everything is ok and to also check that the home environment is safe.
- 2) My baby has reflux problems and allergies. I don't feel I got the support I needed. My baby was not feeding, and I wasn't sleeping, I felt that I was being fobbed off and no one was taking me seriously. I felt so alone. I eventually got the support by paying to go private – I put out a plea on Facebook as I was at the end of my tether, XXX read my post as she contacted me as she had gone through similar.
- 3) This is my fourth child, so I know when something isn't right. My baby had severe reflex and feeding issues, so we referred to a paediatrician in January, but our appointment wasn't until May. My baby was so poorly, my husband and I would take turns sleeping. We were frightened of going to A&E in case we caught something. We ended up going private, so we got help straight away – it cost us £450 but was worth it. We were lucky that we could find the money to pay privately.
- 4) We got 'lost' in the system. When I was discharged from the hospital, I was told my baby would have leg/hip braces fitted at 4 weeks. We heard nothing and contacted the GP and also the hospital several times but still nothing happened. I ended up complaining to PALS at the L&D, who got things sorted. She eventually got her braces fitted at 16 weeks (if they'd been fitted at the right time, they wouldn't have needed them for this long time)
- 5) I was pregnant was an ovarian cyst – at 40 weeks I did not have a birth plan! No one was able to commit/confirm what I could have. I was eventually called in to an appointment to produce my birthing plan - the person I saw had no idea! We got there in the end... I had my baby my caesarean
- 6) I had a C-section and was expected to travel to the Children's Centre for my appointment. I think I should have been able to be seen at home
- 7) I was in labour for 3 days (staying at the hospital) – I ended up having an emergency caesarean. At no time during my painful labour did the hospital pick-up that my baby's legs were dislocated at the hip and facing towards their head.  
I also had to keep repeating myself - there was 'synchronising' of information between doctors and nurses
- 8) I worry about children that get 'missed' – if it's someone's second or third child, they often don't see health professionals / health visiting teams so often.
- 9) Maternity services at the L&D were brilliant
- 10) It would be better if we were sent texts about appointments rather than letters.
- 11) I gave birth 3 weeks before lock-down. I didn't have any breast-feeding support and it was very painful to sit down. I tried to contact a health visitor, but no one would see me. After several infections (and finally getting someone to see me), I found out that I'd been stitched up too tight.
- 12) My twin babies were born 3-months premature, one of them died. I wanted to find support / meet other families who were going through or had gone through the same as me. I've not been able to find the support I'd like.
- 13) I have a 6-month baby, I'm really happy with all the services that have been provided. We've had all the help and care.
- 14) I had a wonderful experience at the L&D having my baby
- 15) My pregnancy and birth all went really smoothly
- 16) I had a very traumatic birth; I was in labour for 4 days (under observation). I kept telling the team I was in a lot of pain, but they didn't really listen to me.  
The health visitors were really lovely – I felt they listened to me, they were very reassuring and helped with feeding.

- 17) I had to contact the health centre and ask for my child's vaccinations. It was their first set of vaccinations (which they should have had when they were 2 weeks old). I thought the GP practice / health visitor would have contacted me to arrange. As no one contacted me I contacted the health visitor to arrange. It would be helpful if the health nurses were more proactive and contacted parents about getting the various vaccinations as some parents don't know.
- 18) Specialist services need to be made available to those who need them – I don't feel that I the breast-feeding service listened to me. They kept telling me I was doing Ok, but I wasn't.
- 19) I gave birth to my second baby at home ... it hadn't been planned that way! I was haemorrhaging badly so was taken into hospital. The whole birth was horrific, and I suffered from panic attacks and anxiety. The waiting lists were so long for support I went for private therapy and counselling.
- 20) There should be more support for new parents (peer to peer support would be beneficial) and family sessions too
- 21) I feel that it's very intrusive that health visitors and midwives come into your own home. We usually go to Milton Keynes or Cambridge for all our family care – we go there because it's better than Bedford.



## Cancer Services

- 1) Screening for Bowel Cancer and abdominal aortic aneurysm (AAA) is excellent, why is there no national screening programme for prostate cancer?
- 2) My mum has had a mastectomy (prior to moving to UK). She needs to get some new bras. How do get these? [resident did not know that these were available to purchase from stores such as M&S].
- 3) Recent research - Women from the Bangladeshi community are not attending breast screening appointments are accessing services too late. Need more awareness and education regarding screening programmes. Many of the women can't read or write and therefore don't understand the letters. [contact details shared with cancer lead as would like to support ICB]
- 4) The L&D have been brilliant, I had a section of my bowel cut out in in November 2021 as I has bowel cancer. They are proactive and have called in back in for follow-up checks. Anyone who says the service is bad is an \*\*\*\*\*

## Stroke Services

- 1) Should have hospital transport for post stroke care.
- 2) Experienced initial stroke symptoms in March 2022, it took until July 2023 to get an initial referral. Has been waiting for over 1yr for Neurology scans.
- 3) Speech therapy is only offered for 6 weeks, the NHS should be honest about the services available and what can be achieved in the amount of time funded by the NHS.
- 4) Face to Face appointments with my GP would be much better, since my stroke I have Aphasia and having telephone consultations is difficult and I need my husband to help me. I would be more confident if I were talking face to face with the GP, for example I sometimes say yes instead of no which could be detrimental to a consultation. When I am in front of someone, they would be able to pick up on this better through my body language.
- 5) I have a great GP and have a fixed appointment every 5 weeks to check how I am progressing following my stroke.
- 6) Speech Therapy has been very good after my second stroke
- 7) Information is difficult to access following a stroke, there is plenty of information available online but following a stroke, survivors often have cognitive issues and fatigue so lots on information online can feel over whelming and not accessible. In-person physical contact is needed to really support those dealing with the effects of stroke.
- 8) It feels like the early intervention stroke teams, just do the bare minimum to get you off of their books. There was no pushing, no motivating and targets for physical movement were not monitored - so what is the point of them. Stronger early intervention would improve the lives of those who have had the stroke and reduce the long-term impact on the system. The first 3 months is the most important following the stroke and intensive support at this stage will improve outcomes and save the system money in the long run.
- 9) Waiting times to see a specialist are so long. I'm waiting to see a heart consultant. I saw my GP 4 months ago (June 2023) and I've had a letter to tell me my hospital appointment is August 2024.
- 10) Person has 'Castleman's disease' – they are able to contact the hospital team direct for any issues
- 11) The gentleman had a stroke in November 2021, he was initially taken to L&D and then transferred to the ICU at Addenbrookes. During his time at Addenbrookes he contracted pneumonia and sepsis. He was discharged back home but with no support as such – a district nurse visited him 4 times a day, but he did not receive any physio or other support.  
In January 2022 he went into residential care for 6 weeks – during this time he had physiotherapy, psychiatry and CBT / coping strategies  
His home was adapted to meet his needs – he was then more or less 'left to it.'  
The Stroke Association suggested he get support from the Luton Wellbeing Service; they were good and offered gym membership  
He uses a 'rollator' to help walk and would like to be able to walk unaided or with a less obtrusive walking aid. He's been signposted to Headway who have confirmed they're able to support him and provide physio. However, the funding for this needs to be approved by Luton Council. Headway confirmed that they've sent to the paperwork to Adult Services, but it usually takes several months for funding to be approved
- 12) It would be very useful to be given a factsheet of services and numbers, providing information of what services are available and how to contact them (and/or whether they contact you).
- 13) The district nurses visited me twice a week to sort out my catheter – they were very accommodating when I wanted to change the date and time of my appointment (so I could come to stroke club meetings)
- 14) I'd like to receive the advice I need more quickly – I'd also like my own GP.
- 15) Top issues:

- Long waiting lists for community physiotherapy. Waiting times are often over 12 weeks.
  - Would recommend that care and residential homes make the referral for physiotherapy before the person is discharged / leaves the homes. The Difficulty ringing GPs and getting a GP appointment.
- 16) It would be better if stroke services were more personalised, the person currently receives 6 weeks of this service then 6 weeks of a different support. Some people need more or less support, so it would be better if tailored according to need.
  - 17) The system is so difficult to navigate – we had the tenacity to find and access the support we needed (such as speech therapy from University College Hospital London), but not everyone has the drive or knowledge how to do this. It would be useful to have a diagram showing what support was available and how and when to access it
  - 18) Had an excellent response to stroke symptoms - was taken straight to the L&D by Ambulance Crew, the consultant was ready at the hospital when he arrived (Sunday Morning). He was told afterwards that from door to needle (a blood clot buster) was 22 minutes.
  - 19) Has had a great experience of the stroke re-hab services, received 8 re-hab visits within the first 6 weeks. Was set targets for physical mobility improvements which were monitored - he is very pleased with the recovery he has made and has been discharged by the re-hab team.
  - 20) Following a stroke xxx was home alone for some time before he was found by a relative - was taken to Bedford Hospital. Following discharge from hospital, because he lived alone, was discharged to a residential nursing home in Dunstable. He was offered no re-hab at the home. Following another hospital stay in Bedford he was discharged to another residential nursing home in Biggleswade. Again no re-hab and no encouragement to be active etc. Why did rehab not follow the patient to the residential home?
  - 21) When taken to hospital was put on the hospital list, discharged to care home was put on the care home GP list, when discharged home was not put back on their own GP list and had difficulty registering again.
  - 22) There are many parts to stroke services, with acute care following by initial re-hab and various support services for longer term support. It should not be down to the patient to try to navigate all of these services to find the right support. It should be incumbent on the services to work together and have a clear pathway so that patients do not fall through the gaps and not know what support and services they can access. There seems to be a grey area in between end of early discharge and what's offered by social care/ community services.
  - 23) The gap between services is often bridged by the charity sector.
  - 24) Following discharge from early rehab team he has been referred to the Stroke Gym (but they are full at the moment) (this is Fusion Gym funded by BBC). He has also received a letter from the Stroke Association and has an 8-week follow-up appointment with consultant.
  - 25) Had a stroke 10yrs ago, had a really bad experience. Due to lack of muscle mass in his arms, blood needs to be taken from his feet, the nurse taking the blood was not experienced and caused him a lot of pain. He was given 4 aspirin and told that the scan unit was closed until Monday morning and sent home. He was told that he would receive a phone call from the stroke unit. After waiting for the call and it not coming through, he called the unit who had no record of him and was asked to go into the unit. He saw the consultant who was very dismissive of his symptoms, commenting that he had not had a stroke, but would scan him anyway. After the scans he was sent home and told to wait for a letter which took 7 weeks to arrive. The letter confirmed a minor stroke. He had good support from his occupational health team at work who signed him off from work, not wanting him to drive. When he contacted his GP to get a letter to sign him off, his GP said it was the first he had heard of it. His experience left him feeling very let down by the stroke services, at this time there was no peer support available, and only recently has he met other people that are stroke survivors. He has lived for many years in fear of whether he will have another stroke.

- 26) Had a stroke whilst on holiday in Nigeria and received initial treatment there. Whilst in Nigeria his wife made contact with the Stroke Association to find out what needed to happen in the UK. The Stroke Association made contact with the stroke recovery team in Bedford. They had issues with getting medication back in the UK as the same medications were not available. Although the consultant from Nigeria sent all of the files/ tests/ results over all of the tests had to be redone in the UK but they were quoted a 38 week wait for the MRI scan or blood tests, so chose to get the tests done privately, who sent the results on to his GP. If he had the stroke in the UK, the MRI / scans would all be part of the provision by the acute hospital and done immediately as an in-patient. Was offered physio by CCS in Bedford, including speech and language therapy and physio.
- 27) There is no follow-up from the GP practice to check that patients are getting the support and access to services they need. There is a poor community connection from GP's
- 28) Appointment with GP 1 month after the stroke, GP looked up the medication that was required but why is a similar link not made to the social support that patients need. Why can't the GP have a list of local support services that they can direct the patients to at the same time as giving them their medication.
- 29) One of the hardest things is having the courage to ask for help
- 30) We need to be responsible for our own health
- 31) It would be useful if people knew about the mental health support available.

## Musculoskeletal (MSK) Services

- 1) MSK services – It was very difficult to contact them, I kept leaving voicemails and no one returned the call. I've now been referred to xxx for physiotherapy and 2 of my 6 appointments were cancelled at short notice.
- 2) I had physio as part of my rehab. I was just given a sheet of exercises to follow... I don't think I'm doing them right. I'd much prefer a group session, so I can see other people doing the exercise and know that I'm doing them correctly
- 3) The waiting list for treatment [MSK] are so long I paid privately to get my knees and back fixed.
- 4) My doctor referred me for treatment for my hand, I had to wait 6 months for treatment. Luckily my daughter was able to help me cook and clean. I wish I could have been seen sooner so I didn't have to rely on my family.
- 5) A saw the physiotherapist at Flitwick – they listened to and were attentive to my needs
- 6) Physiotherapist at Circle MSK – considering hosting educational/ preventative sessions in community centres (Action taken – linked in with MSK leads)
- 7) Being able to self-refer for MSK services worked well – but the waiting list to receive services is very long
- 8) After I gave birth, I had severe back pain, my doctor referred to be the physio and I was given exercises to do. When it didn't get any better, I went back to my GP who told me to persevere with the exercises and take pain killers
- 9) I went on holiday to Pakistan and my back was so bad I arranged to have scans and x-rays whilst I was there. When I returned, I showed the scans / x-rays to my GP, and they referred to an orthopaedic/MSK services  
I'm now on a waiting list to be seen – it's at least a 12 week wait. I've now be in pain for over 2 years – I have difficulty cleaning, bending, standing and lifting (which is very hard when you have a young child).
- 10) It would be good to reduce waiting lists – I've been on a waiting list for MSK for over months

## Mental Health

- 1) Resident asked if we had any information on bereavement for her mother, as their father had recently died.
- 2) Person with mental health needs - has had no support or access to the right level of services since leaving care 20 years ago.  
On two incidences has attended A&E in crisis, on one occasion was discharged with no support despite the fact that he was in crisis.  
Feels that NHS institutions need to change to deliver holistic care for people with hidden disabilities. Rather than just being given medication, care needs to be holistic, and medication is just part of that. Too many mental health patients not provided with care and are left with no support which leads to high levels of suicide.  
Support for mental health users should be considered palliative - lifelong support is needed - there is no quick fix and move on - ongoing support is required.
- 3) I wouldn't be here today if it wasn't for the Path 2 Recovery Programme – they've been a real lifesaver. I have a keyworker called XXX - she's an angel and really supports me. I'm now supporting the program by setting up a patient participation group.
- 4) The Milton Keynes mental health team have been there for me, with a good crisis team at the end of the phone.
- 5) There's a lack of 'out of hours' support (telephone services) in Milton Keynes for mental health services and dental nurse services in Milton Keynes. They have out of hours services in Bedford and we should have the same in Milton Keynes.
- 6) Lots of mental health and anxiety in young people because of Covid. Need to do more education around this to support people on the doorsteps about this.
- 7) Central Beds patient looking for contact information for MH services - Finding it difficult to navigate across services. Is being offered online sessions but not IT literate and being offered service across Bedfordshire with no mode of transport or money to get transport
- 8) I've just been discharged from Onyx Ward (inpatient mental health) as I'd over-dosed. Am back home but the social workers are a bit hit and miss, you ring them, leave a voice message asking them to ring you and they don't.
- 9) There are a number of people known to service providers who are 'hoarders. They've been told by social workers that the dwelling is not safe for them to conduct a home assessment. They're concerned that the individuals may not have the capacity to calculate risk, and risk of fire etc

## Dentists (Adults)

- 1) Dental access a problem within community
- 2) I've not been able to find a dentist – it's going to cost me £800 to get my teeth sorted.
- 3) It's very difficult to find a dentist – we need to have more dentists available
- 4) It's very difficult finding a dentist (Flitwick)
- 5) Patient struggling to get GP & Dental appointments
- 6) Luton have the worst teeth ever – it's so difficult trying to find a dentist.
- 7) I've been on a waiting list for 18 months trying to see a dentist. I contacted NHS 111 and was then given an appointment to be seen 3 months later. I ended up flying to Poland to have my treatment as it was taking so long
- 8) I tried to find a dentist for my two daughters but couldn't find anywhere nearby. We eventually found a free dentist in London which my daughters go to (it's the only NHS dentist we could find)

## Older Persons Services

- 1) I was living with my sister in a bungalow. I was admitted to hospital earlier in the year and then discharged to xxx care home for respite.  
The care I received in the home wasn't good – the care workers didn't administer the medication at the right times / intervals (following cataracts operation).  
I'm 92 and an active person, I regularly go out and about and into town to do my shopping. When I was at the home I wasn't 'allowed' to go out when I wanted – in the 3 weeks I was there, I was only allowed to leave the home twice.  
I became immobile like everyone else at xxx. I'm strong-willed and very independent – I wanted to get my strength back, so have been able to. But if I wasn't so determined, I could have become weaker and lost my independence altogether and ended up having to live in residential care.  
I now live in sheltered accommodation and have my independence back with care workers visiting me each evening (at the right time).
- 2) Would be good to provide more advice, support and classes for older people on how to keep your balance (in order to reduce the number of falls)
- 3) Dementia service – You get lots of information when you first receive the diagnosis - it's too much to take in at the time. Would prefer useful information to be talked about / discussed at appointments and then repeated again at a later date so you can absorb the information and don't feel completely overwhelmed.
- 4) The palliative service needs to cater for people from ethnic minorities - there's often an assumption made by health care professionals that families will look after family members
- 5) I was contacted by a social worker (Central Beds Council) when my wife died, they wanted to check how I was. The team were very good and arranged for me to be rehoused from All Saints View. I love it there!
- 6) There needed to be more social activities for older people and transport to get them there. My mum's in her 90's and lives in Flitwick – she can't get to the local groups as she needs transport. It would be good to have a befriending service where someone could pop in and say hello to her.
- 7) Patient wanting help with simple things, lives alone, family don't live near, needs help with small things, getting older, not as agile e.g. changing light bulbs, doesn't want to ask neighbours.
- 8) The elderly are very fixed in their ways – it would be useful to have someone lead (or show us how to lead) different exercise classes for the elderly (such as chair-based exercises). We know lots of people are told to do different physio exercises – it would be better if it could be made more fun, so people did their exercises. We could get everyone doing their exercises together here at the Gurdwara



## Childrens and Young People's Services

- 1) Foster parents – they found it difficult navigating the system and long waiting lists. The child has had to join a new waiting list for treatment when as they moved from Bedford to Milton Keynes. They also can't find a dentist in Milton Keynes, so continue to see their NHS dentist which is based in Bedford.
- 2) My teenage daughter is on the waiting list to receive some mental health support. I find it so frustrating and worrying – it's a 6-month wait. During the school holidays it feels as though there's no safety-net – social services tell me to take her to A&E. I'd like waiting times to be reduced and for there to be better support available during the school holidays
- 3) There's a lack of continuation of care for foster children – the child we were looking was really struggling at school and could not read. It turned out that they needed to have reading glasses, and this hadn't been picked up
- 4) My 11-year-old has stomach pains (digestive issues) - we went to see our doctor who arranged for a sample of poo to be tested. When the results came back our doctor told us she needed to be checked out by the hospital. She has an appointment to be seen in 2024 – it's a long time to wait. She's in a lot of discomfort.
- 5) There should be schemes to get children into low-cost activities. For example they could provide cooking classes in primary school (after school clubs) showing children and their parents how to cook healthy food on a budget
- 6) Exercise and diet go hand-in-hand – need to get the messages across when people are young by providing fun and interactive sessions
- 7) Young people spend so much time on their phones, there should be more affordable after school activities
- 8) Young people are fed up with being lied to. Avoiding certain phrases like 'suicide prevention' just adds to the stigma. Young people should be invited to be part of conversations about them – it's about them and their everyday life. Don't under estimate young people.
- 9) There should be free facilities for children and young people. We often recommend swimming as part of rehabilitation – this should be free.
- 10) Paediatrician at hospital - As part of a one person's rehab, we recommended that they go swimming. The only pool that we were linked in with was being refurbished, so the young person just couldn't go and just gave up
- 11) Children are waiting for up to five terms at school to have a hearing test
- 12) Youth clubs – more things for young people that are affordable to people in Luton
- 13) Need to provide more activities for young people – when I was young there were regular discos we could go to (it was something we looked forward to going to them). We need to provide enticing activities for young people – maybe something like graffiti boards or street art displays?
- 14) Children should be taught more in school. They have 'life studies' classes every week, they could be taught about being healthy (healthy eating and moving) and the risks about smoking, vaping, being inactive, and also first aid – signs and symptoms of a stroke, what to do if someone is having a heart attack.
- 15) I tried to find a dentist for my two daughters but couldn't find anywhere nearby. We eventually found a free dentist in London which my daughters go to (it's the only NHS dentist we could find)
- 16) My daughter has dyslexia - this wasn't picked up by the school. There also needs to be more mental health services for young people
- 17) Need to provide more dental services for children and young people
- 18) There needs to be more 'talking therapies' to support people who suffering from grief or loss
- 19) It would be great if the Healthy Start scheme was available for older children
- 20) It would be good if the children's centres provided information or educational sessions on healthy eating.

## Pharmacies and Medicines

- 1) There is a big issue with patients hoarding and stockpiling medicines, this is bad for the patient and is a waste of medicine and resources.
- 2) The pharmacist 'Kays' in Bedford is fantastic – he is unbelievable and helps me with my medication.
- 3) I keep being issued the wrong medication by my pharmacy at \*\*\* Surgery. I'm prescribed eye-drops for glaucoma but am allergic to one of the brands. It states on my prescription (the print-out that's issued with the medicine) that I'm allergic to the brand and should not have been issued them – however the pharmacy regularly dispenses them.
- 4) It's such a waste as I've had to return the incorrect dispensed drops and they're then disposed of by the pharmacy – it's a waste of money.
- 5) I now always checks what's in the bag before I leave the pharmacy - I'd like the pharmacy to take more notice of what they're doing!
- 6) My child was on a controlled drug, the GP prescribed the wrong dosage for my child. Fortunately the pharmacist realised that the wrong dosage had been prescribed and corrected the mistake.

## Wellbeing

### Exercise

- 1) It would be better if gyms and exercise classes were cheaper. I know it's cheaper to pay a monthly fee, but at my age (82) I'm not always well enough to go, so it's a waste of money. I can't afford to pay the one-off costs, so I end up not going to any sessions or classes
- 2) I'm a wheelchair user, my doctor told me I was fat and needed to do some exercise. Active Luton told me I needed to go swimming. It's so expensive – it would be better if there was funding / it was cheaper
- 3) Sport and physical activity is my happy place, when I became disabled, I soon realised that there were few activities for wheelchair users to take part in.
- 4) I'd love there to be other sport activities for wheelchair users available in Luton – I've been working with xxx from Luton Council who is supporting me to apply for funding to set up a wheel-chair tennis class / team. It's expensive as need different sized wheelchairs, clothing etc.
- 5) Get the younger people to encourage the older generations to be more active
- 6) I'd like to see cheaper gym and exercise options. It would also be beneficial to have creche facilities or fun activities for children to take part in whilst parents exercise
- 7) Encourage people to take care of themselves and to practice yoga and breathing techniques. Help people realise how great they are and how great they can feel
- 8) Gyms should be subsidised / more affordable. If they're easier to access and/or afford, more people are likely to use them. Make it easier for people with families to attend – so they start exercising at an earlier age, and are fitter when they're older
- 9) Encourage more people to exercise as part of their daily routine – make it easier for people to cycle to work
- 10) Provide cheaper gyms
- 11) It would be useful if there was some kind of provision to look after children whilst parents exercised. I can't exercise as I have young children that I have look after it would be too expensive paying for childcare and gym classes for myself
- 12) Exercise keeps your mind healthy, when I was working, I could afford to go to the gym. I'm not working, have more time on my hands and can't afford to exercise. It's not good for my physical or mental health.
- 13) Keeping exercising keeps you mentally well. I used to go the gym 5 times a week and then my mum died, I lost my job and I now have no money. It's hard! If gyms were free, I'd go. I know it would make me feel so much better.
- 14) I used to live in Ipswich. They had good scheme called the [Ipswich Fit iCard](#). It was recognised by local businesses (sport facilities) and issued by social workers as a prepayment /credit to go swimming, use the gym. I know that exercise is good for me – it helps with my anxiety and depression, I wish there was something in similar. I'm on benefit and can't afford to go to the gym.
- 15) Gyms are so expensive – I would go if it was cheaper to join. As it is, I don't do anything.
- 16) I'd like to be able to buy a swim pass – you can get gym passes (which include access to pool), but I don't want to go to the gym. Swimming needs to be cheaper and more accessible
- 17) It would be useful if there were crèche facilities provided at gyms
- 18) I'd like to go to Pilates classes - but £8 for a class is so expensive
- 19) It would be good if there were free creches in gyms, also cheap membership for those who struggle to pay
- 20) Not many people can afford gym membership – the councils should provide activities and exercise classes for free

## Diet and nutrition

- 21) It would help if healthy eating was promoted in a fun way and that cheaper healthy food options were made available
- 22) People should be encouraged to use natural remedies – ginger to thin blood.
- 23) The best way to help people to live healthier lives is to get them to eat healthily. Start by teaching them how to cook properly, real cooking – using non-processed foods and fresh vegetables.
- 24) There are not enough menu / food choices for school meals – they should be more ethnic and culturally appropriate dishes and recipes
- 25) I see so many bad habits forming, seeing parents having unhealthy relationships between their work and their lifestyle. Maintaining a healthy lifestyle is more difficult than ever before and parents should be supported to break those habits.
- 26) Teach children and young people about diet and healthy food choices, teach them how to cook as part of Person Social Health and Economic (PSHE) classes at school. If you get the kids when they're young, they'll hassle their parents
- 27) Provide nutrition workshops in communities, shopping centres and in food shops
- 28) Provide advice on healthy eating – ensure it's culturally appropriate
- 29) Making healthy foods more accessible; more promotion of healthy eating. If people eat healthier they will have better health and therefore use the NHS less
- 30) Make fresh fruits and vegetables more accessible
- 31) If healthy food like fruit and veg was cheaper it would be easier to eat more healthier foods
- 32) Provide cookery classes in after school clubs – start teaching about healthy foods at early age. Young children will then pester parents to buy/cook these foods. Include healthy Polish foods.
- 33) Good, healthy cooking skills/classes etc needed.
- 34) More healthy dietary advice
- 35) There is a disconnect in advertising (fast food ad followed by starving animals appeal). Take away prime-time advertising on fast food. More preventative services should be made available.
- 36) I have high cholesterol so am on statins and eating sensibly – lots of food substitutes/food swaps. It would be good to be able to test my cholesterol more regularly – can you provide us with home-testing kits that are reliable to use?

## Employment

- 37) Being in paid work or volunteering gives people a sense of purpose and is good for their mental health. It would be good if local businesses engaged with the job centres at an early stage so we can provide training / support to potential candidates to help prepare them for employment and interviews
- 38) We need more local jobs (it makes people feel their worth). It's a vicious circle I don't have the experience. So I can't get a job. The job centre helped me to get a fork-lift driving licence – however no firms will employ me as I don't have any experience.
- 39) There should be more opportunities for business start-ups
- 40) Make the workplace a stress-free place – educate people on how to be less stressful, how to manage stress and how to navigate the systems available
- 41) Workplaces should encourage more 'down-time' for their employees, enabling them to do what they enjoy doing.
- 42) The cost-of-living crisis is causing stress for everyone, which is affecting people's health. There is stress on individuals and stress on services. Individuals have to be so careful about what they spend their money on. Stress on services mean that you can't get an appointment with a GP for weeks.
- 43) Man with narco-epilepsy – would like more opportunities for employment. 'As soon as my employers learnt about my condition' they got rid of me. I used to work for a private ambulance company, we were TUPE'd over to the NHS and they said I was 'unreliable'.
- 44) I'd like employers to have a better understanding and perception of different health conditions."

- 45) When I go to the jobs hub I get filled with anxiety and feel depressed. I know I'll feel much better about myself (better mental health) if I have the job, but going to the hub always makes me feel worse. The staff should be more creative with their thinking and support – it would be useful if they could provide a programme to help build self-confidence, if I'm more self-confident it'll help me to look for and apply for jobs.
- 46) I wish the job centre would be more supportive and pro-active to help me to find a job. They arranged for me to be get a fork-lift drivers licence – but I still can't get a job, no one will take me on as everywhere wants someone who has experience. I can't even volunteer as I have no experience and companies don't want to spend time doing the in-house training

## Housing

- 47) I had a brain injury in November 2021. When I had the brain injury, I had to give up my flat in Luton (where I was happy). I've now got a social worker; she works in Luton. She arranged for me re-housed in supported living – I really don't like it. I now live with sex-offenders and alcoholics. I smoke a lot of weed to 'try and block everything out'. I want to stop smoking weed but need the space to do that (and living here doesn't help). I'm waiting for xxx to sort me out some better accommodation. I go to church to pray and hope that things will improve
- 48) I've recently moved to Bedford and me and my wife receive support the Charter House housing team. When we moved to Bedford Luton Council stopped all our benefits - we then had to apply for benefits in Bedford. It would have been better if we'd received some benefits as we received no money for a while. The Charter House housing team have been fantastic – they helped us to reapply for all of our benefits and register with a GP – they knew I was on regular medication, so made sure I had enough medication to see me through. Knowing that I can ring the Housing Team if I have any kind of problem is very reassuring and a great help.
- 49) There should be better housing for people with mobility scooters, with space to park your scooter. I've spoken to both the council and Housing Association and there's nowhere available in the town centre.
- 50) My son has cerebral palsy and autism, he goes to a special school. I've been waiting for the Council's OT team at the council to sort out our housing for ages. He's now 5, we have one bedroom - he has to sleep, eat and live all in one room (our lounge). When the OT team visits, they tell me we don't have the right furniture in the room. I feel that they don't think we're good parents, we try our best and it's difficult. I just want to get my housing sorted. [person was signposted to LBC colleague who took actions to contact the OT team]
- 51) It would be useful to have a list of 'trusted' landlords and a register of all the properties available to rent.
- 52) I was told by the housing association that my house would be ready by the end of August. It's October and I'm still waiting to move in. I wish they'd work faster so I can move in.

## Safe green spaces

- 53) Trying to walk to work in Milton Keynes is very difficult, there are plenty of place to walk for exercise, but I would like to walk to work to build a healthy routine into my day and the way the city is designed I have to walk through multiple housing estates. To walk a short distance can take an hour because there are no direct routes. Also the underpasses do not feel safe in the winter, so I will not walk through them in the winter although I would do in the Summer. There needs to be some road level walkways to make those walking feel safer.
- 54) I recently moved to Milton Keynes – it's a totally positive experience for me and my family. There's so much diversity with people from many ethnic backgrounds. We feel part of the community and no

longer outsiders. There are so many open-spaces and lots of activities going on. I'm so glad we moved here.

- 55) The councils should make sure our green spaces aren't lost – they're good for both your physical and mental health.

## **Transport and local activities**

- 56) More should be done to encourage people to be 'socially active' – we'd love to get more people interested in volunteering (Bedford Hospital)
- 57) There should be more social activities for people locally, with support to get elderly people to them. My dad has dementia and lives in Ampthill, there's not much he can get to from his home and I work full time so I can't take him to different places. The day-care centres were really good, and nothing has replaced them since they were shut down.
- 58) It would be better if there were better transport links – it can be tricky attending events and activities if you don't drive
- 59) There needed to be more social activities for older people and transport to get them there. My mum's in her 90's and lives in Flitwick – she can't get to the local groups as she needs transport. It would be good to have a befriending service where someone could pop in and say hello to her.
- 60) I use a mobility scooter – a lot of the local building aren't accessible so I can't go in them. I can't even get into my local church
- 61) Everyone needs a helping hand - in Pakistan everyone helps one another, families and neighbours all rally together to help. Bringing up a family in Pakistan is so much easier than bringing up a family in the UK. Living in the UK is therefore more stressful, and as I'm stressed I over-eat – which is not good.
- 62) 93 and she lost her husband one month ago, she enjoys social interaction and all her life has been sporty, she takes part in dancing, singing and walking clubs and enjoys attending Healthwatch events and meeting new people
- 63) Patient wanting help with simple things, lives alone, family don't live near, needs help with small things, getting older, not as agile e.g. changing light bulbs, doesn't want to ask neighbours.
- 64) Disability transport is an issue, particularly in Central Beds. Some companies will do hospital and outpatient runs only. Patients need transport to social events to avoid social isolation post stroke. Private taxi companies charge more for wheelchair or guide dog – pricing unregulated.
- 65) I'd like more activities to be made available in local community centres and for these to be free. I'm getting food from the food bank – I can't afford to send them [children] to clubs.

## **Information and Advice**

- 66) Need to provide education and advice and make it accessible, visit community groups and deliver sessions on key issues such as Mental Health, Bowel Screening and Dementia.
- 67) If people want to be healthy, they can be. Education can only be taken so far. There's lots of information out there, people just need to be more responsible
- 68) You should have more events like today (See the ability, not the disability – St Georges Square, Luton), providing information and advice. Include services like the 'Stop Smoking' service
- 69) We should do more to promote healthy eating and exercise. This could be done with radio adverts and interviews. It often helps if people are told the reasons why they should do this and understand what the risks are if they don't do it
- 70) These sort of events where you are giving out information are really good. You should find ways of providing more public information – like putting information for people to see in the park and in shopping centres
- 71) Have more leaflets about different services (especially the lifestyle hub) in community places
- 72) Hold education and information events – provide them free of charge and with easy parking

- 73) We found today's presentations really useful, it would be very useful if there were more events or presentations on different subjects about how to keep healthy and well. The elderly are very fixed in their ways – it would be useful to have someone lead (or show us how to lead) different exercise classes for the elderly (such as chair-based exercises). We know lots of people are told to do different physio exercises – it would be better if it could be made more fun so people did their exercises. We could get everyone doing their exercises together? [South Central Ambulance Service Health and Wellbeing event at Gurdwara Baba Zorawar Singh Ji Baba Fateh Singh Ji - talks on cardiac arrests and heart attacks, major trauma and sepsis, plus CPR demonstrations, defibrillator awareness and a tour of an ambulance].
- 74) I'm a female gypsy – we live in a good community and people are very kind. People are non-judgemental – help is available to those who want it, you just need to ask

## **Volunteering**

- 75) Invest in infrastructure to support more front-line staff and volunteers (so we can bring care closer to home and, in the community,). Need more local decision which has a focus on prevention
- 76) Make it easier to volunteer, so there's less hoops you need to jump through

## Rough Sleepers

- 1) Registered with xxx. It's difficult getting an appointment and when he does get one, the doctor never rings back. He can't get seen face to face. He would sooner go to A&E to be seen as he knows he can walk in and get to see someone if he is ill.  
He has many health conditions as he had a heroin and crack addiction that has messed up his lungs. He'd like to give up smoking now but has no idea how or support to help.  
He has mental health issues as well as other health concerns, but the doctor won't talk about more than one issue at a time as they have a short appointment with him.
- 2) XXX is 35 and has lived in a hostel for a few months. He's unhappy there as there are people who have mental health issues, and he does not feel safe.  
He asked for support in accessing housing from the council, but no one called him back. No one at homeless organisation helped him find accommodation, he managed to find the current shelter himself. He reports that he asks for help and people just don't reply.  
He is registered at xxx but it's not all that easy getting an appointment.  
He has MSK issues from sleeping on a park bench – but doctor just prescribes pills that make him drowsy. He is worried about being drowsy as he needs to be alert to care for himself.  
He is keen to find work – even volunteering or peer work but does not know where to go or how to start.  
He is a Polish speaker and has offered to help with translation where needed, but homeless charity can't help him with that. No one calls him back.  
He has stopped asking for help from health and care professionals. He feels no one cares and so he has stopped caring about himself.
- 3) xxx is Polish and has been sleeping rough for 5 weeks. He is keen to find work but does not have legal paperwork to reside. He spends his days at the library trying to find work in Europe where he can travel.  
He was helped to access a shelter for two nights after his visit to Noah. He is currently fit and healthy but says that he will visit A&E if he is sick.
- 4) xxx lost his home after his wife died in 2019 and he had been sleeping in his car on Tesco car park since. Some friends take him to Scotland for a month each year, but the Salvation Army, NOAH and xxx helped him to find a shelter in Luton to stay. He has been there for the last few months.  
He has Type 2 Diabetes and is registered at xxx surgery, who he says continue to look after him.  
He is booked to have an eye scan at the L&D tomorrow (8/6) and recently had an eye test at Specsavers. That all went well.  
He struggles to access a GP appointment because of how busy people are and he needs to be careful with how he uses his phone.  
He mostly uses his bus pass to get into town to put in his prescription for diabetes pills. That process is easy but talking to someone isn't – because of the waits on the phone.  
He has problems getting appointments because the hospital sends things out by post, but because he has no address and post goes missing at the shelter, he doesn't always get letters.  
The practice now emails him, but he has to keep his phone up, so he can get access to information / appointments.  
He is struggling with grief and anxiety and has not been signposted to grief counselling / talking therapies support. He didn't know he was able to access those services or talk about that with a professional.  
He worries about his accommodation and how long he'll be able to keep it for if he spends time with his friends in Scotland this summer – but feels he needs to get away to be with his wife's friends as they help him with his grief.  
No one is helping him with that at the moment. He asks for help and there's no guarantees which is affecting his mental health.
- 5) An Irish man who wasn't happy to engage too much.  
Asked where he went if he was poorly – he replied nowhere.



Asked if he ever rang a doctor, he responded 'Christ no, those boys are too busy for me'. It's a joke, I'm homeless.

- 6) I was visited by xxx from homeless charity in the summer when it's warm, but in winter when it's cold and wet no one comes to visit me.

## Other Feedback and Insights

### Diabetes

- 1) I'd really like to go to a diabetes support group/class – most of the groups meet on weekdays, it would be good to have a weekend group.

### Opticians

- 2) Person has been waiting/wanting to have their cataracts removed for over a year. They didn't know that an optician could refer them for surgery, they would have seen an optician had they known. Suggestion for opticians to advertise their services more (that's it's not just glasses), and that they can refer people to eye clinics etc

### LGBTQ+

- 3) Resident was disappointed that there does not seem to be many support groups for LGBTQ+ residents in central Bedfordshire, details taken, and contact details of local support groups were shared via email.

### Communications and Messaging

- 4) Providing facts and figure about how much things cost make it more of a reality for some people
  - Smoking 20 fags a day costs around £420 a month, £5,000 per year
  - The cost of a blood test is £ x
  - The cost of a GP appointment is x
- 5) Make services easier to access and navigate
- 6) Ensure that all the providers across the system are working closely together
- 7) I like getting texts and reminders about my appointments – I find it very useful. There have been a couple of appointments I've have missed if I hadn't had the reminder.

### Self-referrals

- 8) People should be able to self-refer for more none life threatening conditions

### General service feedback

- 9) Everyone tries to be critical - I can't find anything to be critical of
- 10) I am very grateful to the NHS staff for my own care as I have a lot of health problems.
- 11) Great service from NHS – thanks.
- 12) There's a lack of personal contact, you're a number not a person

### National

- 13) It grates me when people moan – they don't seem to realise that we get it for free!
- 14) Need free prescriptions, better pay for NHS staff and more, readily available GP appointments.
- 15) Would like a stop to all the strikes
- 16) Ex Forces officer – would like more governance and changes to law re vaping, drugs, world changing and nobody cares.

## Appendix 3

### What is the one thing we could do to help people in Bedfordshire, Luton and Milton Keynes stay healthy and live longer?

We asked the question 'What is the one thing we could do to help people in Bedfordshire, Luton and Milton Keynes stay healthy and live longer?' the responses received are shown below. The responses have grouped by emerging theme, with some responses covering more than one theme.

#### 1. Provide information to support people to live healthier lives and make healthier life choices

- 1) Free school meals for primary school children. Food poverty affects your health in the future.
- 2) Health checks at public events
- 3) More events, which are well advertised
- 4) Be out in public areas. Provide more health checks in public.
- 5) Continually educate and provide information to different community groups (like you're doing today at Gurdwara Baba Zorawar Singh Ji Baba Fateh Singh Ji)
- 6) Attend more events like this and give out information on how to be healthy and healthy eating. It would be useful if you visited and shared information with local community groups to live healthier lives – provide more information health education
- 7) Need more information on what types of exercise can be undertaken by older people (chair exercises etc) and it would be helpful if this information was shared at places where people naturally congregate (i.e. the gurdwara)
- 8) More information on healthy eating and active lifestyles
- 9) Target at risk populations via multiple events and campaigns
- 10) Give up smoking
- 11) Have more healthier options, healthy food should not be expensive, marketing for unhealthy food should be reduced
- 12) Improve diet, encourage people to have breakfast and walk. Communicate with family members.
- 13) Provide more information about healthy eating. Recipes taught in school should be culturally appropriate (African recipes would be good!)
- 14) For midwives, health workers and schools to provide more information and advice about healthy living
- 15) Healthy eating advice - provide information on easy snack replacements, healthy food alternatives (provide them so they're culturally appropriate)
- 16) Provide more information - I'm very conscious about my health and would attend an online meeting
- 17) For the Council not to issue so many licences for junk food and take aways - there are so many takeaways in Luton. People get into bad habits, living off takeaways and forget / don't learn how to cook properly
- 18) Educate people on how to stay healthy - make sure everyone knows the damage that smoking does
- 19) More opportunities for healthy eating
- 20) More information about healthy eating and lifestyles.
- 21) More influence on healthy foods
- 22) Make it easy for people to choose and cook healthy options, it's too easy to default to unhealthy convenience food. Create meal packs in supermarkets like 'hello fresh' kits which show people what ingredients they need to make healthy meals and group the ingredients together in the shop to make it convenient.
- 23) Obesity is a real issue, there needs to be education and practical support to help people make better choices in food

- 24) Provide advice on how to eat healthily - easy food swaps
- 25) Provide education on good food

## **2. Provide more opportunities or make it easier for people to take part in physical activities**

- 26) Set up some buggy-fit classes, it will get me out of the house, keep me active and help my mental health
- 27) Make them go out and about
- 28) Offer some sort of physical exercise and holistic health free promoting health and wellness
- 29) Offer free or financially assisted help towards holistic therapies and pt coaches
- 30) Help people to stay healthy - host more exercise classes and community activities
- 31) Provide cheaper or subsidised activities for people on low incomes / large families - free swimming sessions, tumble-tots
- 32) Provide exercise classes closer to home - much easier to go to local community centre than a gym
- 33) Make exercise classes cheaper - Inspire is very expensive
- 34) Help people stay active - provide more exercise opportunities - would be good to have classes you can bring your baby along to (and have my baby a mat next to me)
- 35) More exercise and better diet
- 36) More opportunities for exercising... reduced or free classes for large families or low-income families. Easy exercise options for people who are not fit or don't like traditional exercise
- 37) Access to fitness and exercise and youth training schemes to reduce issues with the younger people not having anything to do (which often leads to anti-social behaviour)
- 38) Fitness and exercise
- 39) Help people improve their fitness with improved access to exercise
- 40) Free leisure facilities i.e. swimming/gym
- 41) Free exercise sessions
- 42) Exercise - fun – dance
- 43) Help and support people so they're not socially isolated - we lost the room we used to have at Houghton Regis Community Centre. We had regular craft and coffee sessions that people would come to - now we have nothing!
- 44) Provide young families / new mums information on how to play with their children and get babies minds stimulated and developing

## **3. Make it easier for people to access GP services**

- 45) Quick and simple access to a GP.
- 46) More GP
- 47) Better appointments with GPs
- 48) Can't access surgery because of a spinal injury, when we call we can't get through and there are no follow ups.
- 49) Let me see my own GP rather than locums
- 50) Make more available appointments
- 51) More doctors
- 52) Easier access to GP
- 53) Improve appointment system - people can't see their GPs. If you ring at 8:30, all the appointments have gone!
- 54) Provide more GP appointments and improve the appointment system
- 55) Create easier access to health services - I put off trying to get an appointment as know it will be a hassle and then the condition will get worse and be harder to treat

56) Let me have an appointment to see my doctor

#### **4. Communication, Information and advice**

- 57) Save money by not sending letters and emails to the same person. One reminder is sufficient. Also one letter per address is enough. This would save a lot of paper, time and postage. E.g. We both received an email about the flu jab, then another about the COVID jab. So we booked them. Then we got individual letters asking to book for the vaccinations!
- 58) Ensure people know about the services available to them - GP practices should promote enhanced access appointments
- 59) Let people know they can ask for an interpreter - have posters/flyers saying this in community settings such as food banks and food stores where people.
- 60) Provide computer training so people know how to use the NHS app and other health apps (like the MSK physio exercise app) - provide the training locally and in the daytime
- 61) Provide information in different ways - not everyone has a smart phone!
- 62) Provide translators at GP appointments - make sure people know they can request one
- 63) Help people to access the support they need - people need support to fill in forms
- 64) Provide information in different languages - people need to know they can access interpreters
- 65) More info / education on do's and don'ts to share with communities
- 66) More awareness how to access health care services
- 67) More social prescribers
- 68) Provide safe places for us to go and talk to someone

#### **5. Make it easier for people to access dentists**

- 69) Provide more dentists - v difficult to find one
- 70) Provide more dentists
- 71) Have more tooth doctors - I need to see one and can't afford to pay
- 72) Have more pop-up dental clinics
- 73) Provide more dentists - been on a waiting list for over a year to see an NHS Dentist
- 74) Provide more NHS dentists - it's an absolute nightmare trying to get one. Having painful teeth really has a knock-on effect on my health (it sounds daft - but it affects my sleep, and I can't eat properly either
- 75) Provide more advice re the damage that sugary drinks can do to children's teeth

#### **6. Parks and outside areas**

- 76) Stop building on parks
- 77) Use the open spaces in Milton Keynes more - they are such a valuable space. I moved to Milton Keynes from an area where there were not so many spaces - make the most of what we have
- 78) More public uplifting events.... very good for mental health
- 79) Access to lovely green open space
- 80) Children and Young People
- 81) Provide more mental health support in schools - more peer led support
- 82) Provide more outside activities for young teenagers - many live in flats
- 83) Provide cleaner environments - there's so much rubbish around Ashburnham Road, it attracts lots of flies which is not good!

## **7. Cancer**

- 84) Prostate cancer awareness, there is not enough information given to men. I am over the age of 50 and have not had a prostate exam. I do not know where or how to go about this and have not been given any information - there is no local awareness for this.
- 85) Introduce more health screening for issues like diabetes cancer (prostate etc)
- 86) Make prostate cancer screening routine like it is for breast, bowel and cervical cancer.

## **8. Medication Reviews**

- 87) Provide more medication checks - older people don't question the medication they're taking, and just keep taking more and more which could be bad for them.

## **9. Mental Health**

- 88) Provide mental health services day services for 6 days, for children and elderly. Cut down waiting times provide more services that recruit people from local towns. Need more travel provision for 3am. Many don't know that social workers will pay for taxis. Come and talk to us. Need to be mindful who you are providing a service for and be honest. Crisis service need to respond in the evening when the crisis is happening.
- 89) Just going out for a walk can improve your mental health - promote walking and encourage more community-based walking groups (less social isolation too) - it's a win win!
- 90) More emphasis on mental health... people need good mental health
- 91) Offering better mental health help for everyone
- 92) Mental health
- 93) Communicate with family members and encourage more family time
- 94) Provide safe places for us to go and talk to someone

## **10. Learning Disabilities / Autism**

- 95) Improve health services and access for people with autism.

## **11. Services**

- 96) For services to be more integrated
- 97) Extend the times for blood donation - would like to give blood after work (after 7pm)
- 98) Extend the times of day that people can donate blood - I'd like to blood in the evenings but there's no provision
- 99) Provide more face-to-face appointments - my leg problem took a long time to diagnose as no one would see me - just kept telling me to do exercises which were no good for my leg.

## **12. Transport**

- 100) Additional public transport to the gurdwara (Milton Keynes) - local community transport doesn't reach
- 101) There just isn't enough to go around. I live in a village and all the services are in Luton. I can't afford to travel all the time. The NHS says it cares but it doesn't.
- 102) Better transport - so we can go and visit places, attend groups and appointments

### **13. Waiting lists**

- 103) Remove delays for hospital appointments
- 104) Offered a diabetes prevention programme where I get shakes and substitute meals but been waiting for 6 months and no progress. Doctors need to deliver if they tell someone they're going to help.
- 105) Reduce waiting lists - my daughter (age 11) has stomach issues. Did a poo test and when results came back GP referred to hospital. Received letter in January 2023 that appointment will be in January 2024 - she is in pain!
- 106) Reduce waiting lists for Eyes, Nose and Throat services
- 107) So frustrating not being able to see a doctor. I've not seen a doctor for two years
- 108) Mainly good experiences, asthmatic don't have too long to wait when I have a referral. Saw the cardiologist for an echocardiogram but haven't had anything back for months. My GP has a system online that I can chat and say I have a problem and they can text and then get a phone referral which can be irritating.

### **14. Homeless**

- 109) More health buses and accessibility for homeless people. Breaking down the taboo. A lot of people need the health service but don't come forward to use it.

### **15. Support for all**

- 110) Remember to support single men - women and families get more support and help than single men - yes, they may need support, but we do too!

### **16. Quality of Services**

- 111) Actually give the patient real appointments and not just a tick box appointment
- 112) Provide better healthcare

### **17. National Policy**

- 113) Provide all medication free of charge
- 114) Reduce the cost of living - provide more support