

BLMK System Insight Network

Community and Mental Health Services



**Communications and Engagement Team
August 2025**

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1. Introduction

On 6 May 2025, we held the second System Insight Network (SIN) in Bedfordshire, Luton and Milton Keynes (BLMK), bringing together residents and partners from across our area to take part in a discussion about mental health and community health services.

The System Insights Network was established to ensure that people, experiences and ideas from our partners and communities inform and shape health and care services in our area, helping with our mission to improve healthy life expectancy and reduce health inequalities in our communities.

The meeting focused on gathering insights and lived experiences from attendees to inform the Case for Change. This report brings together the ideas and experiences discussed, capturing the essence of what we heard. These experiences are helping the Integrated Care Board (ICB), and its partners re-imagine community and mental health services that are fit for the future. The goal is to deliver services that meet the needs of our whole population, ensuring access to care within the available resources.

More than 200 people attended the two events including, people with lived experiences (service users and carers) and residents; staff from the current providers - East London Foundation Trust (ELFT), Central and North West London (CNWL) Foundation Trust and Cambridgeshire Community Services (CCS) Trust; health and care providers who refer patients to these services, such as social prescribers, GPs, clinical nurses and mental health practitioners from Primary Care Networks (PCNs) in BLMK; as well as social workers, family centre managers, local Healthwatch and representatives from various VCSE organisations, faith leaders, elected councillors, a hospital governor, the fire service and youth councillors from Central Bedfordshire, Luton and Milton Keynes youth councils, and staff leading the work from BLMK ICB (see attendee list in appendix 1).

Following a short presentation (see appendix 2) attendees were invited to join two facilitated discussions focused on four themes. The groups were arranged to ensure there was an even split of lived experiences across all discussion groups to encourage a robust, lively and balanced discussion. The themes and questions included:

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| <p>1. Access - We have already heard the things that make accessing services a challenge such as not knowing who to contact, communication with teams whilst waiting for or in between treatments.</p> <ul style="list-style-type: none">- <i>What do you think could make it easier?</i> |
| <p>2. Staying healthy</p> <ul style="list-style-type: none">- <i>How can we help residents to look after themselves and their families better?</i>- <i>Are there other things we could do differently?</i> |
| <p>3. Crisis support - We've heard that people sometimes go to A&E during a crisis, even though it might not be the best place for that kind of help.</p> <ul style="list-style-type: none">- <i>Where would be a better place or what could support look like for someone in a crisis?</i>- <i>What would help people feel safe and cared for?</i> |
| <p>4. Communication to enable integrated working - The government is introducing a new 'neighbourhood working' approach, which aims to bring services closer to where people live and connect health, social care, and community support more closely.</p> <ul style="list-style-type: none">- <i>What does this idea mean to you, and how do you think it could help you or others in your community?</i> |

We conducted nine appreciative inquiry interviews with service users and carers following the event, to build on what we had heard, enhance our understanding and consider their future needs beyond the current contract. While some of these interviews were initially set up to focus on either mental health or community services, the conversations naturally crossed over, offering valuable insights into both areas. This approach allowed us to further explore some of the emerging themes. The questions we used are detailed in appendix 3.

2. Summary of insights

Workforce, stakeholders and residents shared a wide range of views and experiences about accessing and using community and mental health services. The event created an environment in which all participants could openly share their views and reflections, acknowledging some of the challenges. While conversations often focused more on areas for improvement rather than what was working well, there was a strong sense of hope in the room. Attendees said they want things to change, and they believe it can happen, as long as the right actions are taken. Several cross-cutting themes that applied across both mental health and community health services came through clearly in both the group discussions and one-to-one interviews.

Communication - Clear and consistent communication is essential to build trust and ensure everyone is informed and engaged. Improved communication between services, and with the public, can help people navigate the system more confidently and reduce confusion.

Access to information – Better access to up-to-date information about NHS and VCSE services, tools, and resources is crucial. Locally maintained directories can support quicker and easier connections to the right help at the right time.

Coordination, integration and collaboration - Stronger coordination and integration between services are vital. A single point of access, multidisciplinary teams (MDTs) wrapping care around a person and their family, and shared IT systems would help reduce duplication and stop people from having to repeat their stories or be passed between teams unnecessarily.

Digital integration – Shared digital systems are a key enabler for seamless care. Integrated records and communication platforms can support smoother handovers between services. Digital tools, including Artificial Intelligence (AI) enabled systems, could also help with tasks like assessments, signposting to self-help, and managing appointments.

Equity and cultural sensitivity - Services must work for everyone, including seldom heard groups such as neurodivergent individuals, people who don't speak English as a first language, and those from culturally diverse communities. Access to services should not depend on your postcode or GP surgery. Culturally appropriate services and language and interpretation support are critical to delivering fair and equal access.

Community involvement - Residents and carers should be seen and treated as equal partners. Delivering services in trusted, familiar settings helps build relationships and ensures services are responsive to the needs of the community.

Personalisation - How people are treated makes a big difference. Several spoke about feeling judged, dismissed, or not understood by professionals, which discouraged them from seeking further help. Services need to recognise individual needs and treat all users with empathy, respect, and dignity.

Education and tackling stigma - Public education can help reduce stigma and encourage people to seek support. Community-based events, especially those involving professionals and people with lived experience, were seen as a powerful way to normalise conversations about mental health.

Staying well - Prevention and early support help people stay healthy and avoid reaching crisis point. People want tools and information to manage their health, as well as

community-based support like exercise spaces, cultural groups, and healthy food access. Supporting people to "wait well" when on referral lists is also important.

Crisis support - Crisis services need to be more responsive, better connected, and rooted in the community. People want immediate access to crisis support in the community to prevent visits to A&E and to access support in places they feel comfortable, such as their home, crisis cafés, or via crisis lines. Services like virtual wards, 365-day crisis cafes, and community teams which have a wide range of skills were seen as key to effective crisis care.

3. What we heard at the System Insight Network meeting

In this report we have pulled out a series of quotes from attendees that were shared at the meeting to bring to life the experiences and priorities that were voiced.

3.1. Access

From the discussions about access, the following themes emerged

- Communication and awareness
- Coordination and integration
- Digital integration
- Education and stigma
- Access to information
- Equity and inclusivity

Improving communication and awareness was seen as a foundation for better access to mental health and community services. Attendees consistently noted that services could be promoted more widely and effectively. Attendees stressed the need for better communication and promotion of services, particularly through GPs and Primary Care Networks (PCNs). With frequent GP locum turnover, it was acknowledged that maintaining up-to-date knowledge on service pathways and referral routes is a challenge.

“Need to constantly communicate with GPs to keep them up to date. Locums move around, is there a better way to make sure GPs are up to date?”

Building on insights from the Denny Review, addressing language barriers through real-time translation services and the consideration of literacy levels is essential. Participants noted a reliance on family members for translation and interpretation in many cases, due to a lack of formally arranged interpreters which is poor practice, unfair on the patient and potentially unsafe. The length of appointments for those with additional needs was also flagged as an area for development with longer time needed for those accessing therapy through online signing apps. Meeting individuals in places where they already feel comfortable, and supporting trusted local organisations, was recognised as an effective way to boost engagement, make the individual more comfortable and facilitate better access.

“Dropout rate for Talking Therapies is about 10-20%, but for patients who require interpretation it’s 60-70%.”

There was a strong sense of alignment across workforce, VCSE organisations and residents on the importance of improving coordination and integration of services to improve access. Multidisciplinary and blended teams were consistently seen as key enablers of more holistic and responsive support. Attendees also highlighted the need for clearer roles, standardised referral processes, and improved data sharing as necessary to help ensure people are not lost in the system when moving between services.

Attendees spoke in favour of single points of access, integrated IT systems, and a 'no wrong door' approach. Patients strongly argued they should not have to repeat traumatic stories at each stage of their care.

Positive views were expressed about multidisciplinary teams (MDTs) and blended teams possessing a range of skills to provide comprehensive support.

“Self-referral is a key to access – there should never be a ‘wrong’ door when people are trying to find their way into services.”

Digital tools were both welcomed and critiqued. Staff described some current IT equipment as outdated and cumbersome, often requiring them to move between devices and locations to make secure notes. Attendees welcomed the potential for AI-driven tools to streamline access and offer diagnostic support and self-help techniques. However, concerns were raised about the digital services for older adults, highlighting the need for alternative formats for people who can't access digital services. They also suggested that while AI can be helpful, it is not always the most appropriate tool - some participants noted that it can occasionally misinterpret symptoms, leading to unnecessary worry or suggesting more serious conditions than are present.

“It's important that there is a human element... a ‘bot’ might be quite frustrating.”

Tackling stigma and education remained a recurring issue and was seen as crucial for enhancing mental health support. Participants supported early education about mental health to reduce stigma, with calls for more support within schools to prevent poor health. Involving people with lived experience and health professionals at community events were suggested as ways to normalise and de-medicalise conversations.

“Stigma of using the word ‘crisis’ - consider ‘recovery support’ or something less stressful sounding.”

Access to information was identified as another key factor. Attendees recommended a local directory of services, tools, and resources accessible to both health professionals and residents. Increasing awareness of voluntary sector services was seen as vital to ensuring people receive the support they need.

“As a young person, it can feel that people are bombarded with information on pathways, it needs to be simpler and easier to access.”

A shared concern was the inconsistent access to support depending on where the person lived or their GP practice, saying as a system, we need a more consistent approach. We were told that the discontinuation of the MK Recovery College and Primary Care Plus has increased demand on remaining services, contributing to long waiting lists and referral rejections. This can sometimes result in patients turning up in A&E, which may not be the most appropriate setting for their care.

Finally, equity and inclusivity were seen as essential. There were specific calls for improved support for neurodiverse individuals, same-day services for autistic people and better communication from professional (e.g. advance notifications before calls).

Attendees also recommended working with local authorities so that children and young people could gain access to educational support in primary and secondary school, without the need for a formal ADHD/ASD diagnosis.

“Some people are waiting 2 years for an ADHD assessment... treating early will be less expensive and provide better care for patients.”

The key message from the discussions was that improving access is not just about adding more services, it is more about making the system coherent, inclusive and transparent. Attendees urged for better awareness, seamless collaboration, and a more flexible, person-centred system that meets people where they are.

3.2. Staying healthy

From the discussions about staying healthy, the following themes emerged

- Preventive measures and early intervention
- Empowerment and education
- Social and environmental factors
- Cultural sensitivity and inclusivity
- Digital integration and communication
- Collaboration and funding

Preventive measures and early intervention were repeatedly highlighted as key to helping residents manage their health more effectively. Across the discussions, there was encouragement for improved tracking of referrals and communications with patients about their appointment status. Both residents and workforce participants emphasised the value of providing timely information to support self-management while individuals await treatment. The use of digital tools to clarify referral pathways and offer timely updates was seen as a cost-effective and accurate approach.

“Keep in regular contact with patients, make efforts to understand why someone is not engaging with services, what barriers they have and what would support them to engage.”

The concept of ‘waiting well’ was raised frequently. There was strong support for drop-in services and link workers to support individuals while they wait for treatment, alongside clear signposting to local services. A consistent theme was that residents felt that insufficient community-based support has led to an overreliance on acute services and that resources needed to be divided better.

“We need support for people with long-term conditions and those who have recently been diagnosed – they need wrap-around mental health support.”

Empowerment through education was a strong theme. Participants supported encouraging residents to self-manage through initiatives like the ‘5 Ways to Wellbeing,’ which help prevent minor issues from becoming more serious. Early education around mental health in schools to reduce stigma and build resilience was also encouraged.

“... lifestyles and healthy living to be shared with young people in PHSE.”

Concerns were raised about inconsistent health messaging, with attendees emphasising the need for information to be clearer, more accessible, culturally sensitive, and tailored to

local areas. One person highlighted the lack of awareness around conditions like hypertension, describing it as an “invisible disease” that many people do not realise they should be tested for.

A broader understanding of health was suggested, encompassing social and environmental factors. More needs to be done to encourage better nutrition and physical activity. It was suggested that inspiration should come from Blue Zone countries – regions such as Sardinia (Italy) and Okinawa (Japan) where people live longer and healthier lives. These communities are known for strong social communities, regular physical activities and a deep connection to nature. Improving local infrastructure and creating programs suited to different communities was recommended, including partnerships with supermarkets to understand local eating habits and promote healthier eating. There was also an emphasis on using social spaces to reduce loneliness, especially for neurodivergent people.

“Lots of need in mental health services is social and not clinical – issues with housing etc. exacerbate poor mental health.”

Cultural sensitivity and inclusivity were identified as essential for making services more approachable and effective. Attendees stressed the value of community advocates in improving cultural understanding and helping people feel safe enough to engage with services. Suggestions included creating welcoming social spaces, health and wellbeing clubs, and promoting youth and women’s groups, particularly in areas like Luton, to help foster inclusion and encourage participation.

“Life expectancy of people with learning difficulties and autism is low. If you can get the systems and processes to work for the ‘hardest to reach’ populations, the systems would work for other populations too.”

Attendees stressed the importance of early health education to build lifelong healthy habits and reduce future reliance on medical services. Concerns were raised about inconsistent mental health and PSHE support, especially during the transition from primary to secondary school where personalised care tends to diminish.

Suggestions included earlier intervention, noting that some young people only receive help in crisis. Engaging Multi-Academy Trust CEOs and schools early was recommended to strengthen collaboration and ensure consistent support that helps young people.

Digital integration was again a central theme. Apps for self-management and health tracking were welcomed, with the NHS App suggested as a potential one-stop platform. Concerns were however raised about digital exclusion, and the need to provide safe spaces for private conversations for those who may lack privacy at home.

“Look at challenges facing different age groups and target the messages / services accordingly.”

Participants also urged for a change in tone - moving away from messaging that focuses on negative outcomes, towards a strengths-focused approach that could help build trust and encourage greater engagement.

Instead of saying ‘If you don’t do this, this will happen,’ say ‘Why don’t you try this, this may help you?’

Finally, sustainable collaboration and funding were seen as essential to deliver long-term change. Some attendees reported that some public health outreach teams no longer in place, attendees called for consistent funding for VCSE services and greater integration across services to maintain trusted connections with local communities.

“Looking at health as a whole rather than giving it a label, teams to work together to support a person’s health and wellbeing.”

The over-arching message from the discussions is that if we support people to stay well, we will reduce long-term pressures on hospital and crisis services and therefore improve quality of life overall.

3.3. Crisis support

From the discussions about crisis support, the following themes emerged:

- Rapid response and crisis management
- Community-based support
- Preventative measures
- Crisis cafes and alternative settings
- Digital integration and communication
- Training and awareness
- Holistic approach
- Support for carers

The need for effective rapid response and crisis management services was a recurring theme throughout the discussions.

Across the discussions attendees agreed that hospital accident and emergency departments (A&E) are inappropriate places to deal with mental health crises. The setting is hectic and stressful, which is not conducive for people in crisis who need peace and calm.

Attendees emphasised the importance of providing alternative sites for those in crisis. Community-based services such as crisis cafes, crisis houses and virtual wards were suggested as better alternatives for assisting individuals within their own homes or neighbourhoods. While crisis cafés and houses were seen as vital for those experiencing mental health emergencies, virtual wards were highlighted as a valuable resource for people facing urgent health issues related to long term physical health conditions. Delegates advised that the crisis café, such as the one in Bletchley, which is in a central location and open 365 days per year, has reduced A&E attendance considerably and is a spend-to-save initiative. However, for Central Bedfordshire, attendees were concerned that residents often face difficulties travelling to the two crisis cafes depending on where they live.

“A&E is the worst place to go for a person experiencing a mental health crisis – it can be a triggering environment for mental health patients. It’s noisy/loud, busy...”

It was acknowledged that mental health and community health crisis support lines are available, but that they are not sufficiently advertised, and more needs to be done to promote these to residents.

Preventive measures are necessary to avert crises at an earlier stage. Currently, not all services can refer to crisis teams; referrals must go through GP surgeries. Attendees suggested introducing a new layer or team below the Crisis Care Team, someone who would listen without judgment and validates experiences. This role might be fulfilled by social prescribers or community connectors, ideally individuals with lived experience.

“While our crisis teams are functional, current operations involve either calling 111 or attending A&E. It is essential to implement preventive measures to avert crises at an earlier stage.”

Digital integration and effective communication are crucial for crisis support. It was acknowledged that providers use different IT systems, which is a problem for health and social care workers. There is also a need to raise awareness of the extended services that are available outside of normal operating hours, such as the urgent care centres and NHS111 option 2. Suggestions were received for the NHS111 service to be linked to a texting service and for call responses to be speeded up for NHS111.

“It would be better to use WhatsApp in some situations. An application like WhatsApp is used effectively in CYP services / CAMHS.”

Training and awareness are important for crisis support. Attendees emphasised that professionals need to be well-informed about the patients’ notes, family dynamics, and basic details like medications and date of birth. Incorrect handling can lead to withdrawal from the patient. Compassion, care, and respect are crucial qualities that professionals must exhibit.

“If GPs, social care, and health were all on the same system, it would help enormously”

Attendees emphasised the need for a holistic approach to crisis support, agreeing that it is vital to consider the entire family unit. Many participants stressed the importance of understanding the challenges faced by individuals in crisis, their carers, and their families. It was widely acknowledged that carers play a crucial role, with several attendees noting that professionals often depend on them to support family members with mental health needs. However, concerns were raised about the lack of adequate support for carers in return. Suggestions were made to ensure that carers receive meaningful assistance, recognising that strengthening their support network improves overall care.

“As a second-generation carer, I support my daughter who has mental health issues and grandson. I’m responsible for managing the aftermath of her emotions and actions and picking up the pieces. Its mum can you do this; mum, can you do that. If I want to go on holiday it takes extensive planning to ensure that my daughter and grandson will be okay while I’m away”

Community-based support was discussed and attendees agreed crucial for crisis management. There was agreement that community-based personnel, such as Police Community Support Officers should work more with mental health teams, receive training on mental health, and know about the services and referral routes.

Some attendees praised a previous staffing model, *The Mix*, for its effectiveness. The approach brought together a social worker, housing officer, peer support worker, mental health professional, other relevant staff and volunteers to respond in crisis houses. The group suggested that initiatives like this should be reinstated.

These themes highlight the importance of providing an effective crisis service; however, it is equally important to focus on preventive measures to reduce the occurrence of crisis.

3.4. Communication to enable integrated working

From the discussions about communication to enable integrated working, the following themes emerged

- Effective communication and system integration
- Community involvement and outreach
- Digital integration and information sharing
- Simplifying access to services
- Cultural competency and inclusivity
- Education and awareness
- Collaboration and trust
- Tackling stigma

Attendees strongly acknowledged that effective communication is the backbone of integrated health and social care. There was clear consensus on the need for full integration, particularly through shared care records and a joined-up funding approach, where a single budget supports both health and social care services. It was widely recognised that current structures still operate in silos, with differing pay scales and employment terms creating barriers to true collaboration. Tackling these disparities was viewed as essential for delivering a seamless, person-centred experience and improving outcomes for residents and experience for staff.

“Lack of resource drives the tick list approach. People need time, and there isn’t time, because there isn’t enough money.”

It was recognised that community engagement plays a pivotal role in successful integration. Attendees from the workforce spoke positively about the roles of community connectors, social prescribers and VCSE organisations - individuals who are embedded within communities and trusted by local people. Their presence was seen as a bridge between formal services and the everyday lives of residents. There was agreement that outreach should be proactive, meeting people where they are rather than relying on them to seek out support in centralised locations. Suggestions included expanding the use of community hubs, local groups, and clubs to create welcoming and accessible touchpoints.

“We were able to make progress with local VCSE groups, utilising population health data. They were able to reach out to people who might not usually engage with services, and this can transform their relationship with the public sector. It requires effort, resources and the right mindset for working in partnership.”

The importance of digital integration was a recurring theme throughout the discussions. Attendees widely agreed that effective, joined-up care is impossible without systems that can communicate with each other. There was frustration that, from a resident’s perspective, it remains unclear why different services do not have access to the same information.

“Having to repeat your story to inform assessments over and over again to different professionals in different teams is exhausting.... There is a lot of duplication which is frustrating, tiring, can be a headache and wastes everyone’s time. People don’t want to tell their story more than once.”

Attendees called for the development of a central digital platform, a single source of truth, where people can easily find the right services and receive coordinated care. Improved digital infrastructure was seen as key to enhancing access and communication between providers.

“MIDOS is supposed to offer information on different services which are available but is not always up to date. Some services are still listed as being available, but they have been decommissioned.”

There was strong support for simplifying the pathways into care. Attendees embraced the idea of a single point of access, whether through a central hub or an integrated contact system as a practical way to streamline services. This would reduce the burden on individuals, who often must repeat their stories multiple times, and would support quicker and more accurate referrals. While attendees recognised that implementing such a model would be a complex and a large-scale undertaking, there was general agreement on its value and potential.

Throughout the discussions, attendees echoed the importance of trust and collaboration between different services and organisations, particularly VCSE organisations. It was acknowledged that understanding each other’s roles and aligning priorities can help make the most of limited resources. There was a shared call to move away from competition and towards a model of partnership, where collective effort and shared responsibility would lead to better care delivery.

“Include more people in the neighbourhood to support people to prevent them from needing acute mental health support. Re-connect people and support within the community. Bring the right people into the neighbourhood.”

Attendees agreed that truly integrated care – where teams of people from different parts of the system working together at neighbourhood level - must be inclusive and culturally competent in order to achieve the outcomes for all residents. There was recognition of the need for readily available translation services, including British Sign Language (BSL), and that providers should not rely on family members, and that adequate time should be allocated for people using services where translation/interpretation is required. It was emphasised that services should be welcoming and responsive to the diverse needs of all residents, ensuring that language, culture, or disability do not become barriers to accessing care. A shared understanding emerged that services must be approachable, empathetic, and representative of the communities they serve.

“A group of professional counsellors sitting in a room together is really unapproachable, you don’t feel you can just pop in for a chat.”

The group recognised that public awareness and education are key to integrated care. There was strong support for using social media to communicate available services and to tackle stigma. Attendees highlighted the role of schools in fostering early understanding and resilience, noting that education can help normalise seeking help and therefore make support more accessible. Empowering residents with knowledge was seen as a vital step toward more effective use of services.

Attendees agreed that reducing stigma, particularly around mental health, remains a key challenge. There was emphasis on the need to engage not only residents but also parents, those in schools, and community leaders in open conversations. Small group discussions, community events, and inclusive outreach were all cited as ways to create safer spaces for dialogue and reduce the fear of judgement that can prevent people from seeking help.

4. What we heard during appreciative inquiry interviews

4.1. Key themes across interviews:

During the interviews with people who had lived experiences of community health and mental health services, the following themes emerged

- Multidisciplined teams, continuity and consistency of care
- Respect and validation
- Inclusive family-centred approach
- Timely crisis support
- Flexible, needs-based support
- Training and awareness
- Hope for change

Service users and carers told us that services across BLMK need to work better together. They want joined-up support from health, education, and social care professionals who understand their full history, so they don't have to keep repeating their stories. We heard that when care breaks down or changes because of a move or life event, it can be really damaging and isolating. They said they want teams that stay with them – a group of professionals who know them, work together, and provide ongoing, consistent care.

We were told that feeling judged or not taken seriously by professionals makes things worse. When people don't feel heard or respected, it can push them away from getting the help they need. Interviewees spoke about wanting to be treated with kindness, empathy, and a real understanding of what they and their families are going through.

Carers felt strongly that care should consider the whole family, not just the individual who is unwell. We were told that carers often take on huge responsibilities, helping to hold everything together and making sure their loved ones are safe. People called for carers to be listened to, supported in their own right and included in decisions about care – especially in crisis or when there is complexity.

We heard that urgent help isn't always there when it is needed most. They told us that in a crisis, they were sometimes met with doubt or had their concerns brushed off, particularly when it came to mental health or neurodivergent traits. They said that quick, appropriate crisis support is essential but still too hard to access.

Interviewees reflected on the check box approach currently used to assess need and felt that they had to exaggerate their symptoms to access help or to be taken seriously. Others spoke about the skills they had developed to 'throw people off' - allowing them to deceive services and attempt to take their own life.

“I knew what to say to get them off my back so I could carry out my plan to take my own life. If they'd read my notes, they would have spotted some red flags, and maybe asked more questions, but they were missed.”

Services were described as too rigid and too focused on short-term fixes. They said that support should be based on what people need, not on fixed time limits or strict rules. There were clear calls for services to be more flexible – to listen, to be understanding, and not to withdraw support if someone misses an appointment or does not meet a set criterion.

“I wanted to come off my medication for anxiety and my doctor encouraged me to try talking therapies. While waiting for a referral, I had a set-back, and my doctor

increased my medication as a temporary measure. When I finally got an appointment, they refused me. They said I did not meet the criteria because my anxiety was being managed through medication. I now have two choices – come off the medication and try to manage alone, or accept I'll be on medication for the rest of my life. It's soul destroying".

We heard from several people with lived experiences that some professionals need more training to provide them with a better understanding of autism, trauma, addiction, and how these issues overlap is needed if care is going to be helpful and not harmful.

Even though most said they felt tired and disheartened, there was still a shared sense of hope. We were told that they want change and believe it's possible if the right action is taken.

4.2. Case studies

Please note that all names in the case studies have been changed.

Case study 1 Lindsey's story

Lindsey is a dedicated carer for both her daughter, Sarah, who has a mental health condition, and her 10-year-old grandson, recently diagnosed with autism and functional disconnection syndrome (FDA).

Sarah's struggles began at age 12, but despite Lindsey's repeated pleas for help, professionals dismissed her concerns. It was only when Sarah became pregnant a decade later that support finally arrived.

"I want her to feel validated and listened to"

Lindsey says that clear, compassionate communication is key. Medical professionals often use jargon or speak too fast, making it hard for families to process vital information. When her grandson was diagnosed, his letter was filled with technical terms, so Lindsey simplified it for Sarah—something no professional had thought to do.

Sarah tries hard to be a good mother while managing her own challenges, but services often fail to notice when she needs help.

Simple steps, like sending a text before a call, could reduce anxiety and improve engagement. Having consistent care providers would also help gain trust.

"Don't just discharge someone with mental health if they don't engage, there might be a reason, get the carer involved."

Lindsey has found support through a buddy system, offering her a space to talk about herself—not just her caring role. She hopes her story will inspire services to truly listen and recognise that helping families means supporting carers too.

Case study 2 Bill's story

Bill retired in late 2019, he had struggled to adjust to his new lifestyle, which led to depression. The pandemic made things worse, and after being diagnosed with prostate cancer, he attempted suicide in June 2020. He survived but lost his left leg and suffered a brain injury.

The day before his suicide attempt, the Crisis Team had spoken to him, but because he gave measured responses, they downgraded him to low risk and didn't follow up. After spending seven months in hospital, Bill returned home in early 2021. Adjusting was tough, but immediate support from community services made a difference - physiotherapists and occupational therapists helped him settle, while daily carers supported his transition.

A brain injury psychologist explained the cognitive effects of his injury, giving Bill a sense of control. He appreciated being included in care planning, but gaps in communication between hospital and GP services left him feeling lost.

From his experience as both a patient and a retired healthcare professional, Bill sees the value of a joined-up approach.

When services worked together and truly listened, he felt safe. He believes care should focus on the patient - not just ticking boxes or saving money, but saving lives.

“NHS has served me well – 96% of good stuff – but it's the bad stuff you remember. My Physios, Drs and OTs – all were brilliant”

Case study 3

Peter's story

Peter has lived with osteoarthritis in his spine since his late 20s, managing daily pain and mobility challenges. Now in his 50s, he uses crutches or a wheelchair, while also coping with COPD, emphysema, and diabetes. Despite his health conditions, he retrained and now works from home, delivering mental health training.

Peter's experiences with NHS care have been mostly positive. His GP is supportive and refers him quickly, but long waits and a lack of continuity in care create challenges. He often sees different doctors, forcing him to repeatedly explain his health history. Managing his pain medication is frustrating, as regular reviews delay prescriptions, leaving him worried about running out.

After surgery was ruled out, Peter was referred to a pain clinic - a process that took 18 months, with no communication in between. Physiotherapy and acupuncture didn't help, but HydroHealth was transformative. Moving in water relieved pain and boosted his mental health, he was given 12-weeks access leaving him questioning why some patients received longer support.

Peter praises occupational health for swiftly adapting his home after a move but highlights gaps in diabetes care, where a promised referral never materialised. He believes simple changes, like better communication, reducing wait times, and ensuring proper follow-ups, would make services more effective. He believes the care is there - it just needs to be better connected.

5. How will we use the insights provided?

The insights provided as part of the System Insight Network and follow-up appreciative inquiry interviews have been brought together into a detailed report and shared with both the Community and Mental Health Transformation Team and BLMK Quality and Performance Committee for consideration.

They will inform the development of a Case for Change document, which will be published in October 2025. This document will reflect the voices of residents, staff, service users and carers – ensuring their lived experiences are not only heard but actively embedded in the future design of services.

As part of this ongoing engagement, a series of emerging transformation priorities have been identified. Throughout August and September, the ICB and partners will continue to engage to test, challenge and refine these priorities.

The feedback from this document, and further engagement will be used to help shape how community and mental health services will be delivered across Bedfordshire, Luton and Milton Keynes in the next 10-15 years.

Ends.

Appendix 1

Delegates who attended the afternoon or evening session (details from registration form).

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Abbey Hill	Dr	Milton Keynes
Abbey Hill		Milton Keynes
Addiction Recovery Community (ARC) - MK	Sector Manager	Milton Keynes
Addiction Recovery Community (ARC) MK Central & North West London Foundation Trust	Service Manager	Milton Keynes
Age UK Milton Keynes	Director of Community Services	Milton Keynes
Be Active Bedfordshire	Senior Relationships Manager- Health & Inequalities	Bedford Borough Central Bedfordshire Luton
Be Active Bedfordshire	Health & Inequalities Officer	Bedford Borough Central Bedfordshire Luton
Be Active Bedfordshire		Bedford Borough Central Bedfordshire
Bedford Borough Council	Elected councillor	Bedford Borough
Bedford Borough Council Family Hubs	Family Hub coordinator	Bedford Borough
Bedfordshire and Luton Community Services	Co-Production Specialist	Milton Keynes
Bedfordshire CAMHS	Clinical Team Lead	Bedford Borough
Bedfordshire Community Health Services	Assistant Practitioner in OT	Bedford Borough Central Bedfordshire Milton Keynes
Bedfordshire Community Health Services	Pharmacy Technician	Bedford Borough
Bedfordshire Community Health Services (East London Foundation Trust)	Associate Director BCHS & Lead Nurse	Bedford Borough Central Bedfordshire
Bedfordshire Community Health Services, East London Foundation Trust	Therapy Team Lead, South	Central Bedfordshire
Bedfordshire Council of Faiths		Bedford Borough
Bedfordshire Council of Faiths		Bedford Borough
Bedfordshire older adults.	Discharge lead practitioner / Social worker	Bedford Borough Central Bedfordshire Luton
Bedfordshire Talking Therapies	Operations Lead	Bedford Borough Central Bedfordshire
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Engagement Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Integrated Neighbourhood Manager	Bedford Borough
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Bedford Place Team	Bedford Borough
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Partnership Governance Lead	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Engagement and Coproduction coordinator	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Place Transformation Manager	Central Bedfordshire
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transforming Care Manager	Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Associate Director of Strategy, Planning (Performance BI and PHM)	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior Contracts Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Quality Improvement Manger	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior Place Transformation Manager	Central Bedfordshire
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Associate Director for Continuing Healthcare	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior Transformation Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Innovation	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transformation Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transformation Support Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Deputy Chief Operating Officer / Director of Contracting	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Programme Director Community and Mental Health Services Transformation Programme	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Central Bedfordshire Place Team	Central Bedfordshire
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior Commissioner Mental Health	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Assistant Director Mental Health and Learning Disabilities	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Non-Executive Member and Chair of System Insights Network	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Deputy Chief Executive & Chief of Strategy & Assurance	Bedford Borough Central Bedfordshire Luton Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Mental Health Programme Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Corporate Governance	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Associate Director Communication, Engagement and Insights	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Mental Health and Learning Disability	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Strategic Advisor for Community and Mental Health Programme	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Transformation Mental Health and Learning Disability	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transformation Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Head of Quality	Central Bedfordshire
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior System Engagement Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Sustainability and Growth Programme Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Senior Communications Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Strategic Advisor for Community and Mental Health Programme	
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transformation Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bedfordshire, Luton and Milton Keynes Integrated Care Board	Transformation Manager	Milton Keynes
BLMK Post Covid Fatigue Service / Beds Chronic Fatigue Service	Principal Clinical Psychologist & Service Lead	Bedford Borough Central Bedfordshire Luton Milton Keynes
Bloom Health	Director of Operations	Milton Keynes
Bloom Health	Project Coordinator	Milton Keynes
British Red Cross	Health operations manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
C2C Social Action		Milton Keynes
C2C Social Action		Milton Keynes
Cambridgeshire Community Services (Cambridgeshire Community Services)	Chief Nurse	Bedford Borough Central Bedfordshire Luton Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Cambridgeshire Community Services (Cambridgeshire Community Services)	Deputy CEO	Bedford Borough Central Bedfordshire Luton Milton Keynes
Cambridgeshire Community Services (Cambridgeshire Community Services)	Service Director, Bedfordshire and Luton Adult Services	Bedford Borough Central Bedfordshire Luton
Cambridgeshire Community Services (Cambridgeshire Community Services)	Cambridgeshire Community Services	Bedford Borough Central Bedfordshire Luton
Caraline Eating Disorder Service	Clinical Lead	Luton
Caraline Eating Disorder Service	CEO	Bedford Borough Central Bedfordshire Luton Milton Keynes
Carer	Carer	Milton Keynes
Central & North West London Foundation Trust	Senior People Participation Lead	Milton Keynes
Central and North West London NHS Foundation Trust	Chief Strategy Officer	Milton Keynes
Central and North West London NHS Foundation Trust		Milton Keynes
Central and North West London NHS Foundation Trust	Deputy Service Director	Milton Keynes
Central and North West London NHS Foundation Trust	AD Business, Strategy & Partnerships	Milton Keynes
Central and North West London NHS Foundation Trust	Director of Community Services	Milton Keynes
Central and North West London NHS Foundation Trust	Area Manager, Addictions	Bedford Borough Central Bedfordshire Luton Milton Keynes
Central and North West London NHS Foundation Trust	Head of finance, performance and improvement for Milton Keynes services	Milton Keynes
Central and North West London NHS Foundation Trust	Team Manager	Milton Keynes
Central and North West London NHS Foundation Trust	Medical director Diggory division Central & North West London Foundation Trust	Milton Keynes
Central and North West London NHS Foundation Trust	Director, MH	Milton Keynes
Central and North West London NHS Foundation Trust	Head of Clinical Transformation	Milton Keynes
Central and North West London NHS Foundation Trust	Patient, Carer & Community Engagement	Milton Keynes
Central and North West London NHS Foundation Trust	Service Manager Community Mental Health	Milton Keynes
Central and North West London NHS Foundation Trust	Deputy Director of Nursing	Milton Keynes
Central and North West London NHS Foundation Trust	Head of Contracts, Partnerships and Business Development	Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Central Bedfordshire Council	Head of Strategic Commissioning	Central Bedfordshire
Central Bedfordshire Council	Head of Service	Central Bedfordshire
Central Bedfordshire Council	Councillor	Central Bedfordshire
Central Bedfordshire Youth Parliament	Member of Youth Parliament	Central Bedfordshire
Central Bedfordshire Youth Parliament	Youth Council Support	Central Bedfordshire
Central Bedfordshire Youth Parliament	Member of Youth Parliament	Central Bedfordshire
Central Bedfordshire Youth Parliament	Member of Youth Parliament	Central Bedfordshire
Central Bedfordshire Youth Parliament	Member of Youth Parliament	Central Bedfordshire
Centre for Youth and Community Development	Project Manager	Luton
Communitas Clinics	Head of Service Development	Milton Keynes
Community Action: MK	Integrated Discharge Hub VCSE Coordinator	Milton Keynes
Community Action: MK	CEO	Milton Keynes
Community Beds Team (discharge to assess)	Clinical Community Bed Manager	Bedford Borough Central Bedfordshire Luton
Community Occupational Therapy	Occupational Therapist	Central Bedfordshire
CYCD - Centre for youth and community development	Director	Luton
DAFS (Drug and Alcohol Family Support)	Volunteer	Milton Keynes
DAFS (Drug and Alcohol Family Support)	Volunteer	Milton Keynes
East London Foundation Trust	Community Engagement Manager	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	CNS in MS	Bedford Borough Central Bedfordshire
East London Foundation Trust	Director of Children & Specialist Services	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust		Bedford Borough Central Bedfordshire Luton
East London Foundation Trust		Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Director	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Community Nursing Team Lead	Bedford Borough Central Bedfordshire Luton Milton Keynes
East London Foundation Trust	Lead Pharmacy Technician	Bedford Borough
East London Foundation Trust	Chief Medical Officer	Bedford Borough Central Bedfordshire Luton

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
East London Foundation Trust		Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Specialist Lead Nurse	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Senior Continence Advisor	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Service Director – Bedfordshire Community Health Services	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Corporate Governance Manager	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Head of People Participation	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	People Participation Lead for S117 Aftercare programme	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Head Occupational Therapist	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust - CAMHS	Psychological Therapies Lead	Central Bedfordshire Luton
East London Foundation Trust - CAMHS	Associate Director CAMHS in Beds and Luton	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust (also work substantively for Central & North West London Foundation Trust)	Dept Director Integrated Care	Bedford Borough Central Bedfordshire Luton Milton Keynes
East London Foundation Trust BCHS Physical Health Psychology	Lead for Clinical Health Psychology Service, & Consultant Clin Psychologist Cancer and Palliative Care. BCHS East London Foundation Trust	Bedford Borough Central Bedfordshire Luton Milton Keynes
East London Foundation Trust People Participation	Public Governor	Central Bedfordshire
East London Foundation Trust-Bedfordshire Community Therapy Services	Therapies Clinical Service Manager	Central Bedfordshire
East MK PCN	Social Prescriber	Milton Keynes
East MK PCN	Social Prescriber	Milton Keynes
East: MK PCN		Milton Keynes
EAST:MK Primary Care Network	Operations Manager	Milton Keynes
GP, Whaddon Healthcare and Deputy Director of PC Alliance MK		GP
Harry's Rainbow	CEO	MK, and surrounding areas which can reach Bedford, Luton and other areas.
Headway Bedford	Service Development Manager	Bedford Borough Central Bedfordshire

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Healthwatch Bedford Borough	Community outreach officer and volunteer lead	Bedford Borough
Healthwatch Bedford Borough	H&SC student on placement	Bedford Borough
Healthwatch Luton	CEO	Luton
Healthwatch Luton	Chair	Luton
Healthwatch Milton Keynes	Deputy Chief Executive Officer	Milton Keynes
Healthwatch Milton Keynes	Chief Executive	Milton Keynes
Leighton Buzzard Health Matters	PPG member	Central Bedfordshire
Leighton Buzzard Voluntary Patient Transport (LBVPT)	Leighton Buzzard Voluntary Patient Transport (LBVPT)	Central Bedfordshire
Luton All Women's Centre	Domestic Abuse & Trauma Specific Support Service Coordinator	Bedford Borough Central Bedfordshire Luton
Luton All Women's Centre	Services Manager	Luton
Luton Borough Council	Head of MH LD and Autism	Luton
Luton Borough Council	Acting Director of Public Health	Luton
Luton Borough Council	Youth Support Team	Luton
Luton Council - Special Educational Needs	Autism Advisory Teacher	Luton
Luton Youth Council	Youth Councillor	Luton
Luton Youth Council	Youth Councillor	Luton
Milton Keynes City Council	Family Centres Manager	Milton Keynes
Milton Keynes City Council	City Councillor	Milton Keynes
Milton Keynes City Council	Partnership Lead for Children and Young People's Mental Health Services	Milton Keynes
Milton Keynes City Council	Deputy Family Centres Manager	Milton Keynes
Milton Keynes City Council	Elected councillor	Milton Keynes
Milton Keynes City Council		Milton Keynes
Milton Keynes City Council	Milton Keynes Youth Council	Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Milton Keynes City Council	Community Partnership Engagement Manager	Milton Keynes
Milton Keynes City Council ASC Mental health and Complex Needs Team	Team Manager	Milton Keynes
Milton Keynes University Hospital	Governor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Democratic Participation officer	Milton Keynes
Milton Keynes Youth Council	Milton Keynes Youth Council	Milton Keynes
Milton Keynes Youth Council	Milton Keynes Youth Council	Milton Keynes
Mind BLMK	Operational Services Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK	Recovery Lounge Worker	Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK	CEO	Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK	I&P Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK		Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK	Lived Experience Operations Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Mind BLMK	Crisis Operations Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Nexus PCN	Clinical Nurse Specialist	Milton Keynes
Nexus PCN	Pharmacy Technician	Milton Keynes
Nexus PCN	Social Prescriber	Milton Keynes
NHS	Clinical Lead, Talking Therapies	Bedford Borough Central Bedfordshire
Penrose- Social interest group	Service Manager	Luton
Primary Care Plus - MK	Senior Mental Health Practitioner & Non-Medical Prescriber	Milton Keynes

Attended: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Resident	Service user	Milton Keynes
Resident		Milton Keynes
Resident	Resident	
Resident / mother of neurodivergent young person with mental health issues.	Secondary Inclusion Officer	Central Bedfordshire Luton
Service user & member of Bedford Borough Central Bedfordshire Luton Milton Keynes People Participation Group	Service user	Milton Keynes
Service User & Peer Leader	Service user	Milton Keynes
Service User MHLDA Committee Member	N/A	Central Bedfordshire
Talkback (learning disability and autism charity)	Senior Manager	Central Bedfordshire Luton Milton Keynes
The Spectrum Place - Neurodiversity children young people and carers	Charity founders	Milton Keynes
The Spectrum Place - Neurodiversity children young people and carers	Project Manager	Milton Keynes
Voiceability	Team leader	Central Bedfordshire
Voiceability	Qualified advocate	Central Bedfordshire
Watling Street Practice	Social Prescriber	Milton Keynes
YMCA MK	Youth and Community Manager	Milton Keynes
Yoga for Health Alliance & Yoga State of Mind	Committee Chair & Founder	Milton Keynes

Delegates who registered but were unable to attend on the day

Apologies: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Bedford Borough Parent Carer Forum	N/A	Bedford Borough
Bedfordshire Community Health services	Pharmacy Technician	Bedford Borough Central Bedfordshire
Bedfordshire Community Health Services	Pharmacy Technician	
Bedfordshire Community Health Services (Wheelchair Service)	Clinical Service Lead / OT	Bedford Borough Central Bedfordshire Luton
Bedfordshire Hospital Trusts	Deputy Head of Nursing Emergency and Acute Medicine	Bedford Borough
Bedfordshire Rural Communities Charity	Head of Community & Wellbeing	Bedford Borough Central Bedfordshire
Bedfordshire Rural Communities Charity - Social Prescribing	Community & Wellbeing Manager - Social Prescribing	Bedford Borough Central Bedfordshire
Beds Rural Community Charity	Social Prescriber	Bedford Borough
Beyond Food - part of the Food Bank	Budget Coach	Milton Keynes
Beyond Food - part of the Food Bank	Project Coordinator	Milton Keynes
BLMK ICB	Transformation Manager, STT	Bedford Borough Central Bedfordshire Luton Milton Keynes
BLMK ICB	Head of Milton Keynes Improvement Action Team	Milton Keynes
BLMK ICB	Chief Medical Officer	Bedford Borough Central Bedfordshire Luton Milton Keynes
BLMK ICB	Non Executive Board Member- Chair MHLDA Collaborative	Bedford Borough Central Bedfordshire Luton Milton Keynes
BLMK working together group	N/A	Bedford Borough
Bloom Health	Doctor	Milton Keynes
British Red Cross	Senior Business development manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Carers MK	Adult Carer Service Manager	Milton Keynes
Central & North West London Foundation Trust	Children in Care Primary Mental Health Practitioner	Milton Keynes
Central & North West London Foundation Trust	Clinical Director	Milton Keynes

Apologies: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Central & North West London Foundation Trust	Service Manager -Specialist Childrens Manager	Milton Keynes
Central & North West London Foundation Trust (Milton Keynes)	CAMHS TRANSITIONING LEAD/Senior MH Nurse Practitioner	Milton Keynes
Central & North West London Foundation Trust NHS community mental health	Community nurse	Milton Keynes
Central and North West London NHS Foundation Trust	CAMHS TRANSITIONING LEAD/Senior MH Nurse Practitioner	Milton Keynes
Central Bedfordshire Council	Senior Strategic Commissioner	Central Bedfordshire
Central Bedfordshire Council	Commissioning Officer	Central Bedfordshire
Central North West London Foundation Trust	Director of Finance	Milton Keynes
Chiltern Hills PCN	Health well-being coach	Central Bedfordshire
Community Action: MK / Bedford Borough Central Bedfordshire Luton Milton Keynes VCSE Strategy Group	VCSE Development Officer: Bedford Borough Central Bedfordshire Luton Milton Keynes	Bedford Borough Central Bedfordshire Luton Milton Keynes
Deaf Access Bedfordshire	Manager	Bedford Borough Central Bedfordshire Luton Milton Keynes
Deaf Access Bedfordshire	BSL Tutor	Bedford Borough Central Bedfordshire Luton Milton Keynes
East London Foundation Trust	Team lead community nurse	Central Bedfordshire
East London Foundation Trust	Therapy Team Lead - Mid Bedfordshire	Central Bedfordshire
East London Foundation Trust	Deputy Lead Nurse - Unplanned Care	Bedford Borough Central Bedfordshire
East London Foundation Trust	Deputy Director	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust	Chief Nurse	Luton
East London Foundation Trust and Central & North West London Foundation Trust	Dept Director Integrated Care	Bedford Borough Central Bedfordshire Luton Milton Keynes
East London Foundation Trust - Podiatry	Operational Lead for Podiatry	Bedford Borough Central Bedfordshire Luton
East London Foundation Trust NHS	Podiatry Professional Development Lead	Bedford Borough Central Bedfordshire Luton
East London NHS Foundation Trust	Public Governor	Luton
EAST:MK Primary Care Network	Operations Manager	Milton Keynes
Great Barford Parish Council / East London Foundation Trust	Operations Manager with East London NHS Foundation Trust (Bedford CAMHS)	Bedford Borough

Apologies: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Healthwatch Bedford Borough	CEO	Bedford Borough
Healthwatch Bedford Borough	Student	Bedford Borough
HMP Bedford	Mental Health Practitioner	Bedford Borough
HUC	Relationship Business Partner	Bedford Borough Central Bedfordshire Luton
Luton Borough Council	Area Project & Involvement Officer	
Luton Borough Council	Specialist Clinician for Looked after Children	Luton
Luton Borough Council	Public Health Manager - Mental Health	Luton
Luton Youth Council	Campaign Lead for Mental Health (Youth Cllr)	Luton
Milton Keynes City Council	Cabinet Member for Adult Services, Health and Communities	Milton Keynes
Milton Keynes City Council	Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Milton Keynes Youth Council	Youth Councillor	Milton Keynes
Mind BLMK	Recovery lounge worker	Luton
Mind BLMK	Recovery lounge worker	Luton
Newport Pagnell Medical Centre/ The Bridge PCN	Social Prescribing Link Worker	Milton Keynes
Nexus Oakridge Park	Health and wellbeing coach	Milton Keynes
Nexus PCN Milton Keynes	Occupational Therapist	Milton Keynes
Nexus PCN Milton Keynes	PCN Manager	Milton Keynes
Nexus PCN Milton Keynes	PCN Dietician	Milton Keynes
Nexus PCN Milton Keynes	Primary care mental health nurse	Milton Keynes
Nexus PCN Milton Keynes	Care Coordinator	Milton Keynes
Penrose Luton Synergy	Deputy Manager	Luton
Penrose Luton Synergy	Deputy Manager	Luton
Pulloxhill Parish Council	Chair	Central Bedfordshire
Resident		Milton Keynes

Apologies: Organisation / Group/ Community being represented	Job title / role	Place(s) service provided or live (if attending as a resident or group representative)
Resident	East London Foundation Trust Elected Public Governor for Central Bedfordshire	Central Bedfordshire
Service user		Luton
Service user on Working Together Group		Milton Keynes
Special Educational Needs Service, Luton Council	Senior Advisory Teacher	Luton
Speech and language therapy	Speech and language therapist	Bedford Borough Central Bedfordshire
Stony Stratford Town Council		Milton Keynes
Stony Stratford Town Council	Councillor	Milton Keynes
Supporting MP for Buckingham and Bletchley	Constituency Support Manager	Milton Keynes
The Bridge PCN	Social Prescribing Link Worker	Milton Keynes
The Bridge PCN	Social Prescribing Link Worker	Milton Keynes
Watling PCN	Occupational therapist	Milton Keynes

Appendix 2

Bedfordshire, Luton
and Milton Keynes
Health and Care Partnership

Welcome to the System Insight Network

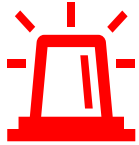
Community and Mental Health Services

#BLMKSystemInsights

Wi-fi Password: Featherst0ne

Lorraine Mattis
Chair
System Insight Network

Housekeeping



There are no fire alarms planned today, so if you hear the alarm sound, please use the exits and make your way to the car park at the rear of the building.



Toilets are next to reception area and there are accessible facilities on both floors.



Tea and coffee is available, so please help yourself.



Photographs will be taken, so please let us know if you do not want to be included.



There is a quiet room for anyone who needs a break throughout the meeting. The room is upstairs and is signposted. If you need some support, just indicate to your facilitator.

Agenda

Time	Area for discussion	Led by
2pm / 6:30pm	Welcome	Lorriane Mattis, Chair, Insights Network
2:05pm / 6:35pm	Designing a service fit for the future	Kathy Nelson, Programme Director / Penny Harris, Strategic Consultant
2:30pm / 7pm	Workshop: Help us to co-design the future of community and mental health services <ul style="list-style-type: none">• Access• Staying healthy• Crisis Support• Communication to enable integrated working	All
3:40pm / 8:10pm	Feedback and closing remarks	Lorriane Mattis, Chair
4pm / 8:30pm	Close	

The purpose of our Network discussion is to...

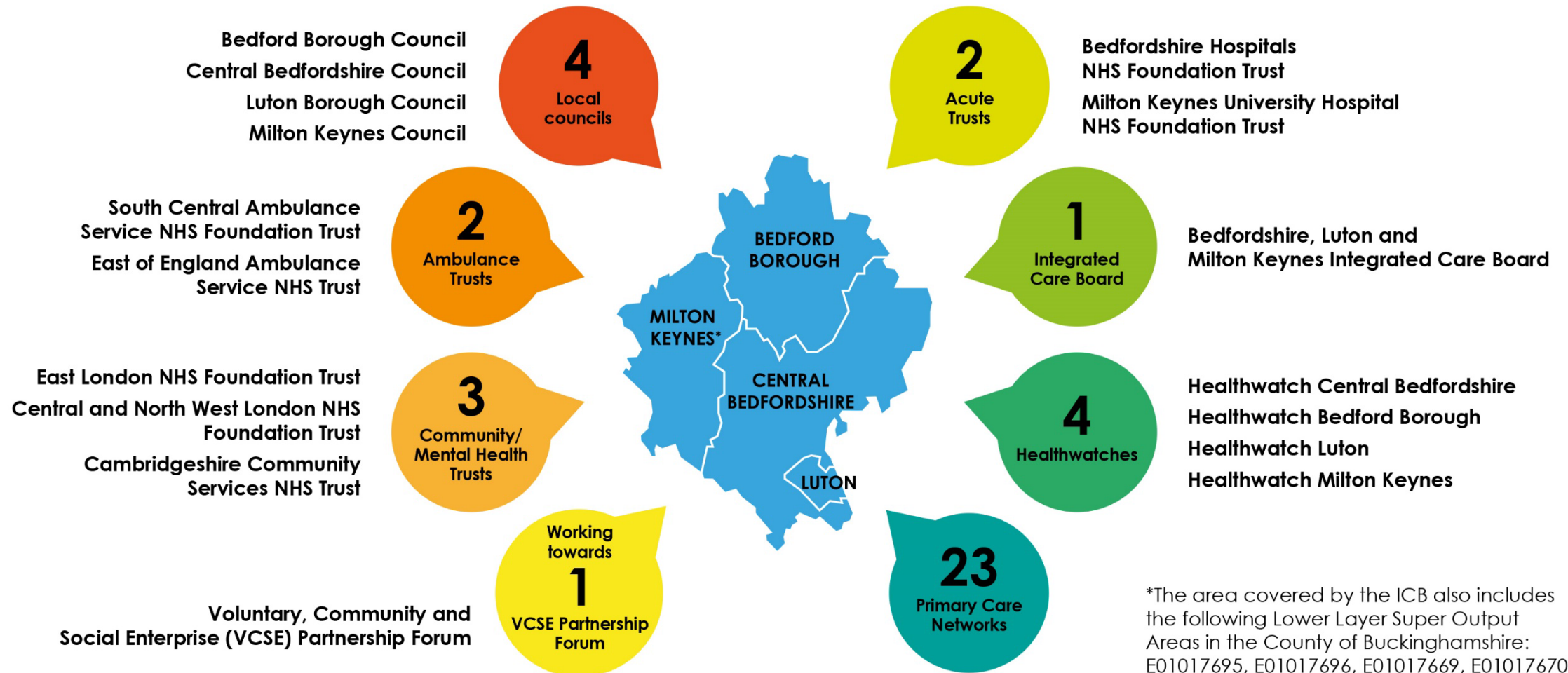
...listen to your lived experiences,
ideas and insights ...

And recommend ways to improve
health and care services nationally,
and across BLMK.

First, an introduction to us and why we're leading this discussion...



Proud to be working together for better, more integrated services in Bedfordshire, Luton and Milton Keynes Integrated Care System



*The area covered by the ICB also includes the following Lower Layer Super Output Areas in the County of Buckinghamshire: E01017695, E01017696, E01017669, E01017670



Afternoon:

Kathy Nelson

Programme Director

Community and Mental Health Services



Evening:

Penny Harris

Strategic Consultant

Community and Mental Health Services

How you can help us...


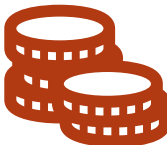



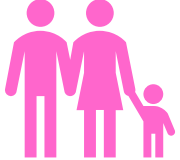


Our local population

BLMK shares many of the same challenges as other areas of the UK.



- Demand for mental and community health services are growing.
- We want to give everyone access to great care.
- Help us re-think the services we provide.
- We want to find new ways of delivering what you need, within the resources available.
- We are ambitious.
- This project will take two years to complete – but it will deliver lasting change.

Before we begin, some key facts to think about...

	<p>The Denny Review highlighted significant health disparities across BLMK. Some communities face greater challenges in accessing and benefiting from mental health services.</p>		<p>The ICB spends over £270 million per year on Community and Mental Health services in BLMK</p>
	<p>Estimates show more than 40,000 people in BLMK not getting treated for high blood pressure (hypertension)</p>		<p>BLMK has amongst the highest levels of mental health need in the region, and significant growth - 8,000 adults registered with serious mental illness</p>
	<p>Community and Mental Health Services have more than 1.2 million contacts with patients each year</p>		<p>12,000+ referrals to CAMHS (>200% increase since 2018/19)</p>
	<p>District Nursing Service has nearly 200,000 contacts a year across BLMK (approx. 17% of all contacts)</p>		<p>Community Crisis Response and Intermediate Care Service has nearly 240,000 contacts a year (21% of all contacts)</p>

This is a huge area of work, with lots of different people involved...



OcularOutcomes

ClearEarDr



Luton MSK and Intermediate Care



AJMHealthcare



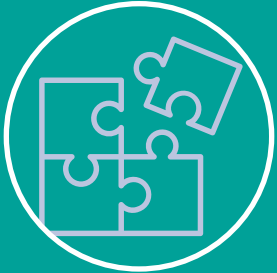
Whaddon Healthcare



Primary care (GP+, Dentistry, Pharmacy)



So, what do we want to do?



Reduce the variation in service provision across our places and by provider



Spend our money differently to address workforce and performance challenges



Reduce impact on other service such as A&E



Reducing inequalities and improving patient outcomes and driving prevention agenda



And most of all, we want to stop people getting sick in the first place...

We'll do this by creating healthy communities and respond to direction set out by Government to make three changes:

Move from hospital to community – providing better care close to or in people's own homes

from treatment to prevention – supporting people early on, to prevent people becoming unwell

from analogue to digital – using digital technology to improve care

We're listening...

Discussion Area	Questions
Access	We have heard that some things act as a barrier to access – but what do you think could make accessing services easier?
Staying Healthy	How can we help people to look after themselves? What can we do differently?
Crisis Support	We know that A&E isn't always the best place for people to get help when they are in a crisis. How can we support people in times of crisis? What would help people feel safe and cared for?
Communication to enable Integrated Working	We are working with partners in neighbourhoods to bring services closer to where you live. What does this idea mean to you, and how do you think it could help you or others in your community?

And our facilitators will help you make your voice heard...



There are no silly questions

Please ask if you are not sure about something. Feel safe to share your thoughts.



We'll respect each other's views

Not everyone here will think the same thing. Please disagree agreeably and be respectful.



There will be time to speak

While we will finish on time and cover everything we want to talk about, facilitators may move the conversation on to give everyone time to talk and share their views.

Feedback session

Summary and next steps

How we will use your feedback

- Feedback from today will be written up into a report and shared with attendees and published on the ICB website.
- The insights and experiences shared will be incorporated into our case for change document, which will shape community and mental health services in our area.

Appendix 3

Appreciative Enquiry for Mental and Community Health Services

Purpose: To understand and learn from lived experiences to inform more compassionate, effective, and responsive mental and community health services in Bedfordshire, Luton and Milton Keynes.

Interview Section	Suggested Questions
1. Introduction	<ul style="list-style-type: none">• Could you tell me a little about yourself and your experience?• What's something in your life right now that you feel proud of or grateful for?• When you think about your journey with mental/community health services, what words come to mind?
2. Discovery <i>"What's Working?"</i>	<ul style="list-style-type: none">• Can you tell us about your experience with community/mental health services? And specifically think about:• The very beginning of your journey and when you were referred into services. What was your experience of the GP – was it helpful? Are there lessons we can learn from this?• When you accessed the service – did they give you care in the way that worked best for you?• Did you ask for care to be delivered in a specific way and what was their approach?• What did the service do that made a positive difference for you?• Were there specific people, approaches, or moments that stood out as especially helpful?• What strengths or qualities did you notice in yourself during that time?
3. Dream <i>"What Could Be?"</i>	<ul style="list-style-type: none">• Imagine the best possible mental/community health service.• What would it look and feel like?• What would your ideal experience of care and support include?• How would staff interact with people accessing the service?• How would you know you were being heard, valued, and respected?
4. Design <i>"What Should Be?"</i>	<ul style="list-style-type: none">• Based on your experiences, what changes would make services better for people like you?• What practices, if adopted more widely, would lead to more positive experiences?• What role could people with lived experience play in shaping or delivering services?• How could the system better support your recovery or wellbeing journey?
5. Destiny/Delivery <i>"What Will Be?"</i>	<ul style="list-style-type: none">• What do you think could help improve services?

Appendix 3

	<ul style="list-style-type: none">• Would you be interested in contributing to change (e.g., co-design, peer support)?• What support or encouragement would you need to stay involved in shaping services?• What gives you optimism about the future of mental and community health?
6. Closing and Reflection	<ul style="list-style-type: none">• What's one thing you want service providers or decision-makers to understand about your experience?• What message would you give to someone going through a similar journey?• Is there anything else you'd like to share that we haven't asked?