1. Community group or individual(s) engaged with and number of people in attendance:

14 members of ReConnect – an ongoing mental health mutual support group, from Slough and RBWM – plus two facilitators from ABB (Emel Soylu: Psychologist and David Sparrow: Arts Lead) attended a two-hour session. Five group members were unable to attend the discussion on the day, but submitted their responses by mail.

We started by explaining the background and purpose of the conversations and Frimley Health Care's intention to shape a meaningful future together with the community. We highlighted the health care system's need for deeper understanding of community needs. We mentioned reports such as the Darzi review and Grenfell recommendations, both stressing that social factors such as housing, education, income, and social networks have profound effects on health outcomes. We displayed the starting points, and split into three groups for discussion. Then we came back together to discuss our group's thoughts and further insights.

6. What was most important to participants about their health, care, and wellbeing? (Summarise main themes, e.g., housing, access to care, environmental factors)

Repeating themes were Mental Wellbeing, Good housing, Autonomy, Quality of Care, Access to Care

Feeling heard, being listened to, being taken seriously
Being listened to is most important for me. It gives me enough reassurance.

Housing causing illness(mental and physical)
Unsuitable housing for my disability - hard to get on list, mould, no safe access
A damp house - Asthma is rife in damp housing. My children suffer from asthma.
Damp leads to chest illness. Lack of knowledge can lead to asthma.
Need a safe house - Free of asbestos, in safe neighbourhood, with repairs done

Need for autonomy, help to live your best life
Having confidence to ask for help …manage a good enough life with assistance where needed … for daily living and safety both physically and mentally (they are interconnected)

Compassion and empathy
We need to speak with persons, not machines

Having a supportive and permanent/fixed GP;
So I can build a rapport and discuss all aspects of my mental health, illness/disorders and complex nature; especially if my mental health is declining; and they check my risk of harm and safety.
Have my medications reviewed regularly.

I have a very good GP - she has surprised me in how much transparency and consideration she gives me. It has helped me thrive and also take time out when I need to and feel independent and not stuck in a mental health service user "bubble" of needing to be supported by the CMHT!

Safe Community - Feeling safe, being safe in the area where I live
I love being outdoors, enjoying nature, walking. Helps my mental health and wellbeing.

7. Top priorities identified for health and care in the community (list any specific priorities raised by participants)

Prompt access to top-quality GP and CMHT services when required
Supportive GPs with sufficient time and support services for patient needs, face-to-face.
CMHT to listen better to patients, and take issues seriously.
Symptoms and behaviour may seem repetitive etc, but this is due to my illness.

Tackling isolation and safety
My Social surroundings are unsafe. I feel isolated
There is lack of care in community (floating support).
Isolation during grief – there was no sign of my mental health support or the GP
With the closure of cinema and library, there are no spaces for social interaction

Improve/rethink Social Prescribing
Good in theory – but Not working
Not all GPs are signed up to it.
Social prescribers seem not to be fully trained to understand the patients' needs.
They see so many people and there aren't enough of them, so they rush things

Better services for neurodiversity
Training for neurodiversity should be mandatory, not a choice
More education on what a person needs or goes through at crisis point
Connections between services – Talking Therapies to connect better with/refer to services

Not having to "fight" the system
I have had a mixed experience with the local Slough CMHT. Half the time as a service user was very helpful or mostly then not so much and "pulling rank" and some awful members of staff impacted on me when extremely unwell and suffering with CPTSD. Having to "fight" the system when severely unwell is unacceptable but happened to me and looking back I'm amazed at how I dealt with them. I am grateful to no longer be a service user and I hope to remain that way as much as possible. They have initiatives such as Hope College etc but there is a lot more they could be doing 'behind the scenes'. It should not be about power playing. That is what I have witnessed and experienced.

8. What barriers did participants highlight? (e.g., access to services, financial concerns, transportation)

Waiting lists and times
ADHD, ADD, Autism tests - 2/3 years wait for me to be eligible for the appropriate help
Too long a waiting list to get doctor's appointment and then you only get a phone consultation
GP apart very difficult to get on phone and face to face.
Waiting times are crazy across NHS
Only being able to access treatment if I have other diagnosis

Transport
Community groups can be difficult to get to, some are costly - public transport is not always accesible/near or times clash
It took me six hours round trip to visit my mum in Wexham park by buses on weekends (from Maidenhead)
Travel costs to certain hospitals and difficulty in bus routes to access appointment

Costs of Healthy living suggestions
Healthy eating is expensive - I need to feed my family. Cannot afford fresh fruit and veg.
Cheaper to feed unhealthy food to keep us full for longer
Costs of gas, electricity and water too high for my benefits to cover effectively, benefits don't rise when the bills go up - You need money for good food
Swimming sessions suggested by GP for my mental and physical health is too expensive - £8.50 per hour! - on benefits I cannot afford this including travel to pool.

Access to medical records
I need to access my records, but don't know how.
I accessed my medical records and realised that I was diagnosed (during my hospitalisation) with things that I was not aware of. I knew of my main diagnosis but not the severity of it and extra diagnosis.
I want to own my own diagnosis and lead my own health journey – but I need to understand my diagnosis fully

Hot Potato
Getting passed around by GP to NHS to GP to NHS and so on. The issue is never sorted. Online requests can be misread.
There is never enough staff and the staff employed are not trained in answering different
Population is too big for the cost given to health providers to treat patients effectively and respectfully

9. What improvements did participants feel would have the biggest impact? (Capture specific suggestions or ideas shared)

Better information/communication

Adult social services/council have connections to social community groups but they are not advertised enough. Not everyone knows who or how to find information
Not everyone can use internet
Procedures not being explained properly
Dr unsure who is in charge of my meds, GP or CMHT?
eConsult is considered less than helpful/rubbish

Better empathy and understanding from professionals
When help needed, response was apathetic, non-plussed or uncommitted
Help was not readily available at crisis times
There is always a rush – short time for consultations
We are a person - don't want to be treated as a diagnosis (mental or physical)
Don't make assumptions – caused me a 4 year wait for correct diagnosis
Remember we are human beings
My pain levels are not the same as others, this is not being taken into account

Speaking to a person, not a machine
Too many 'press 1 for…' When in need/crisis, a person is not alert to be able to go through all those automatic stages, not alert enough for this process
Sending the photo of your ailment is not good enough for diagnosis
Impersonal interactions with health professionals doesn't work for me

Better follow up, particularly for mental health medication
Medication makes me lethargic, not enough time to discuss with GP.
Psychiatric lack of follow through. Ie prescribes drugs but not given for months

Community Support
Smaller emergency hubs - rooms scattered around the towns
Day centres would be good for service users (mental health)
General support in the community is needed
Blood tests at GPs please, not in hospitals
Cooking and shopping are good medicine

Independent advocates
If I ever needed to be referred to CMHT again, I would want to be seriously, heard and seen by them this time. Having a support person independent of the CMHT to me help me 'get back on my feet'

Addressing the Postcode Lottery for some treatments

10. Your reflections - Key Takeaway(s) and next steps (Briefly summarise the most impactful insights and any actions or commitments you'll make based on the conversation)

There were of course many issues and frustrations expressed during the session. However, there was also appreciation for people working for the NHS generally, and understanding that money and resources are short – which is in itself a frustration.

One of the biggest issues was – I want to be listened to and heard! Not to be patronised, or made to feel at fault for being ill. To be a real part of the process, with agency over my own health and wellbeing. This was underlined by the positive stories of being heard - what a difference it makes to the recovery journey.

Communication was also a hot topic – not just between professional and patient, although that featured strongly. A pattern emerged that better communication between agencies (council, adult social care, CMHT, support organisations, GPs, Social prescribers etc …) and a focus on community-based care (local hubs, community support, third sector) could provide a much more joined-up and supportive structure for mental health patients at each stage of the journey.

From the point-of-view of Art Beyond Belief as a charity working in the area of mental health: a few years back we were one of the lead organisations which took part in the pilot programme on Social Prescribing in Slough. Despite the successes of the pilot, Social Prescribing does not seem to have realised the benefits for patients, or enabled providers such as ourselves to offer services for them effectively. We still believe the model is a good one, and would welcome the opportunity to be involved in any future reshaping or updating.

In addition to the topics the group was asked to focus on, other topics were discussed, Comments on these, plus specific positive experiences from participants, and the plea for Independent Advocates (mentioned above) – see below

- **Attached images** ABB01_07feb25 and ABB02_07feb25 : The Art Beyond Belief ReConnect Group *Participants have given their permission to be photographed here*

- **Other topics of discussion – hospital/urgent care – external factors impacting mental health**

Palliative Care
Had to fight for palliative care for dying mother for 2 weeks. When finally granted, it took 4 days to implement. Then it was fabulous. Palliative care should not be a secret, it should be available to anyone who needs it.
When our mother was dying, we could not get a room for her, she died in a ward at midnight, with other patients around her. All the nurses did was to pull the curtain. I dread to think the state of mind of the other three patients (one was a teenager) hearing mother dying and we being asked to collect her belongings after she died. We needed respect, she needed respect.

Hospital/Urgent Cares
More beds are desperately needed
Ambulance waiting times are too long

Cost of hospital parking for visitors
hospitals should be free to park, not everyone is able to pay or public transport is too way out - Who gets that parking money?
Parking is too expensive and most of the times there is no parking at Wexham. When mother is in hospital, everyday we paid enormous amounts of money - when we were able to find spaces. Despite being disabled, we could not use her disabled badge as she was not in the car with us.

Benefits:
Relying on benefits due to illness can take a toll when you hear about the cuts the government want to do for people with long term health problems on benefits.
I recently had to migrate over from ESA to Universal Credit and it was very stressful especially as I was very depressed when I got the first letter and then had to try to go through the UC application and communicate with the DWP. I was so fearful of losing my benefits. Fortunately the migration over to UC was okay and my illness was still accounted for.
Correct information and ease of doing benefits between DIS, UC etc - too confusing.

Housing – also bullying
Previous housing difficulties with renting and landlords behaviour impacting on my mental health was very traumatising but I did my best to stand up to it and that is hard anyway. Being gaslighted and bullied by a landlord took a big toll on my daily living. Fortunately that landlord is no longer my landlord anymore and a community advocate supported me in trying to deal with him. In past, I also experienced a nasty neighbour who was trying to prey on me and at my most vulnerable. This took a lot of strength to deal with and stand up to.
Cost of care
Cost of care in hospices, nursing homes etc is too high.
Cost of a letter from Dr for proof of diagnosis and meds - who gets that money?

Wrong treatment
Traumatised over two weeks' infection due to caesarean stitch – what could I do?

- **Positive experiences and feedback**

When I had cancer scare, I was seen promptly. Mammograms were efficient, smear tests were smooth.

Ambulance staff were excellent, when they arrived, they treated me well.

Sent a complaint to my GP surgery, was responded to promptly and explained the process and reasons.

Respect - I had a recent health scare, my GP, ambulance service and hospital specialist health with me respectfully. They treated my problem professionally and adequately, easy to understand what was being done and explained the next steps.

Social prescribing - Kind, compassionate with promises, (but not followed up, just messages with links. They are just a service for sign-posting).

My surgery has always been thorough with me, once I've managed to get to see Doctor

Urgent Care were much more cooperative and took any complaints or awful treatment by a minority of their staff seriously when I was in a utter breakdown. It took me an enormous amount of courage and strength to raise any concerns and upset as a mental health sufferer to them when treated awfully when already suffering with CPTSD. I was really heard, apologised to and proactively kept in the loop. A lot of their workers are also very good at what they do especially when you are in such an awful breakdown and struggling daily with extreme panic attacks and survival from morning to night for months/years.

Excellent GP
Having a supportive GP who treats me with respect and takes my complex mental health disorders and difficulties seriously and with care. That I'm taken at face value in how my illness presents itself. Which she and the other staff do. I am a patient at Farnham Road Practice for over a decade.

- **A plea from one of the group for Independent advocates**

If I ever needed to be referred to CMHT again, I would want to be seriously, heard and seen by them this time. Having a support person independent of the CMHT to me help me 'get back on my feet' instead of being fobbed off and probably be banished to insanity indefinitely. Which would have happened without an amazing community advocate who went the extra mile with me purely out of kindness and due to seeing my honest suffering in not being taken seriously by people who are meant to be supportive professionals. She helped me turn my life around and helped me believe in myself again and to accept my MH illness struggles and work on my recovery and see myself as worthy again.

Unfortunately due to time and cost restraints people with mental health illness and disorders don't always get the adequate support they need. We are put in "boxes" by professionals to help them label and treat us. Independent support workers and advocates could really help shape and improve some patients/ people's lives to help them believe in themselves again, build trust in professionals again and see a better future and have the courage to speak out and challenge professionals who are mistreating them or just not listening to them.

I know it's not as simple as that and might be too idealistic but I am an example of how the above support via a community advocate, has helped me recover to some extent from awful traumatic experiences and some of those at the hands of service users and MH professionals. She has helped me to become more independent in leading my life.