It's my medication

Mental Health and Homelessness in Manchester

Inspiring Change Manchester
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How to use this report

This report isn't just about sharing findings from our peer-led research about medication, mental ill health and homelessness.

We want you to feel inspired to use these findings to make changes to systems and services — so we've included some prompts for action and left space for you to add your own notes ●

Look out for stars – they are the prompts for action

Look out for arrows showing space for your notes

Foreword

By Dr Colm Gallagher, Clinical Psychologist / Clinical Lead Homelessness

Colm is part of the Mental Health and Homelessness Team

People experiencing homelessness often experience severe and multiple disadvantage; have experienced psychological trauma and have unmet physical and mental health needs. The consequence of this is that people experiencing homelessness have poor health outcomes and have an average age of death around 30 years lower than the general population.

The social determinants of health, mental health, substance misuse and homelessness are intertwined. Whilst the societal responses to these issues are structured separately in siloed services.

The MHAG 2019 *Cause and Consequence* report highlighted the need for system change and was successful in bringing multiple agencies together to develop closer working relationships, co-production and practical changes to support those who are homeless in Manchester.

This current piece of research is a timely reminder that there is much more to do. It highlights the importance of continued dialogue across providers of services, experts by experience, commissioners and government. The onus is on all of us to ensure that the learnings from this research and its recommendations are listened to, acknowledged and actioned.

We are all learning on an individual basis as well as within and between services to think systemically, to reflect on what we do, why we do it and how we can develop.

This research provides an impetus for us to improve the culture of our organisations and systems to ensure safe, humane and compassionate leadership. It links in with the principals of the NICE guidelines into *Integrating Health and Social Care for People Experiencing Homelessness* (1) and Dame Carol Blacks report on the future of substance misuse services (2) which highlight the great need for trauma-informed working.

I hope this research along with the MHAG will connect with and challenge the work taking place across Manchester and beyond ●

References
1. https://www.nice.org.uk/guidance/ng214
2. https://www.gov.uk/government/publications/review-of-drugs-phase-two-report

Contents

Introduction

The Mental Health Action Group (MHAG) has been trying to break the cycle between mental ill-health and homelessness.

MHAG is part of Manchester's Homelessness Charter which aims to end homelessness in our city. The group brings together individuals with lived experience (past and present), with professionals representing organisations which deliver (or can influence) system change, or service delivery.

The group focus is on influencing and implementing change, specifically around mental health and homelessness.

This 'It's my medication' research extends from our 'Cause & Consequence' peer-led research which identified what's broken in systems and services for those experiencing mental ill-health and homelessnes. We looked at how we can work together to fix it.

It is thanks to individuals sharing learnings from their lived experiences as part of 'Cause & Consequence' that we started to see just how complicated the mental health medication journey can be — especially when circumstances are changing quickly

Here then, we share our 'It's my medication' journey and the insights which have emerged ●


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Cause & Consequence
Mental Health and Homelessness in Manchester

‘It’s my medication’ peer-led research

What we did and how we did it

The Mental Health Action Group (MHAG) wanted to put a spotlight on medication for mental health and homelessness.

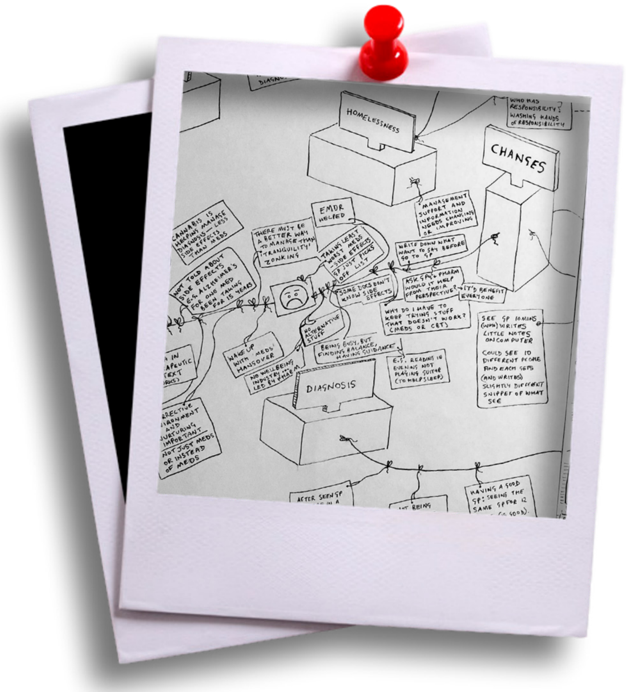
We aimed to find out what changes must happen for each individual to get the support they need, when they need it.

As part of this we wanted to think about every aspect of medication – diagnosis; getting prescriptions and medication; taking, managing and changing medication; and getting the support needed.

As a group we collected our experiences and ideas, and worked with Carmen Byrne, a creative researcher (1) to help us decide what questions we want to ask and what research to run.

We decided to use model-building and questionnaires using lots of images. This gave individuals different ways to get involved in having their say.

References
1. Dr Carmen Byrne use arts-based, narrative and creative research methods https://carmenbyrne.co.uk



About our model-making research

We ran five research meet-ups in different places across Greater Manchester for individuals with personal experience of medication for mental health and homelessness.

At each research meet-up we asked individuals to work with us to build a model to show:

> missed opportunities
> things that worked well
> what needs to happen to make systems and services around meds and mental health work better for others.

By using model-building it meant there was a lot of flexibility for individuals to share their opinions about all the different stages of the medication journey.

Each model was then drawn-up so we could look at themes.

5

meet-ups for model building

14

individuals took part in model-making

HAVE YOUR SAY

ABOUT MEDS FOR MENTAL HEALTH

PERSONAL EXPERIENCE QUESTIONNAIRE

Please complete this questionnaire if you have personal experience of homelessness and taking meds for your mental health.

Look out for questions asking how COVID-19 has changed things

The Mental Health Action Group (part of Manchester's Homelessness Partnership) is putting a spotlight on meds for mental health and homelessness, so we can find out what changes must happen for each individual to get what they need, when they need it.

We want to look at every part of this journey, for example: getting diagnosed; getting prescriptions and meds; managing meds; changing meds; having a dual diagnosis; changing circumstances and stopping meds.

By homelessness we mean all types of homelessness including rough sleeping, sofa surfing, staying in night shelters, hostels, or other temporary accommodation.

This questionnaire is divided into two sections:

ABOUT YOU	YOUR INSIGHT
In this section, we'd like to learn a bit about you.	In this section, we'd like to hear about your experiences and ideas for change linked to all aspects of the meds for mental health journey.

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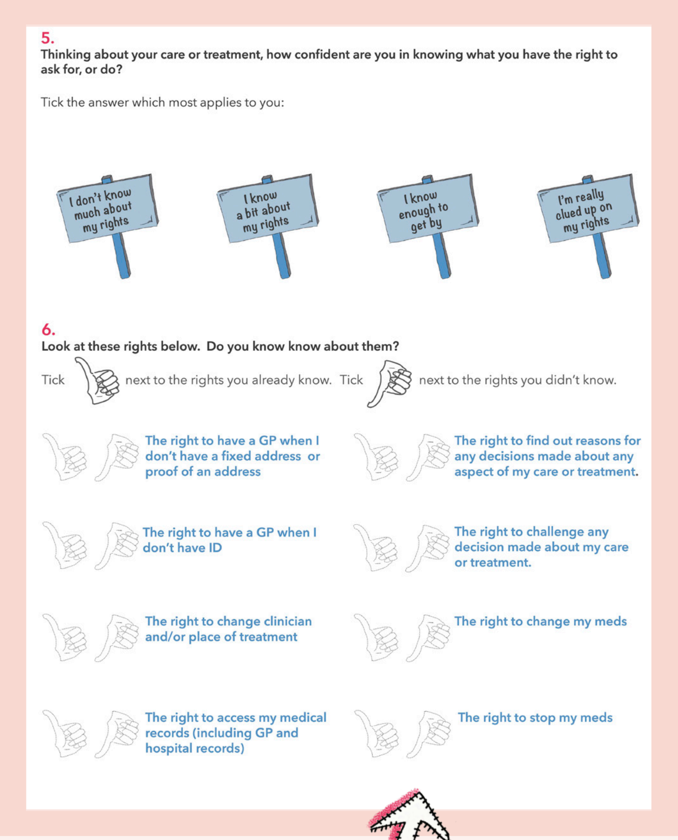


5.
Thinking about your care or treatment, how confident are you in knowing what you have the right to ask for, or do?

Tick the answer which most applies to you:

- I don't know much about my rights
- I know a bit about my rights
- I know enough to get by
- I'm really clued up on my rights

6.
Look at these rights below. Do you know know about them?

Tick 👍 next to the rights you already know. Tick 👎 next to the rights you didn't know.

- 👍 👎 The right to have a GP when I don't have a fixed address or proof of an address
- 👍 👎 The right to have a GP when I don't have ID
- 👍 👎 The right to change clinician and/or place of treatment
- 👍 👎 The right to access my medical records (including GP and hospital records)
- 👍 👎 The right to find out reasons for any decisions made about any aspect of my care or treatment.
- 👍 👎 The right to challenge any decision made about my care or treatment.
- 👍 👎 The right to change my meds
- 👍 👎 The right to stop my meds

Some examples of what the questionnaires looked like

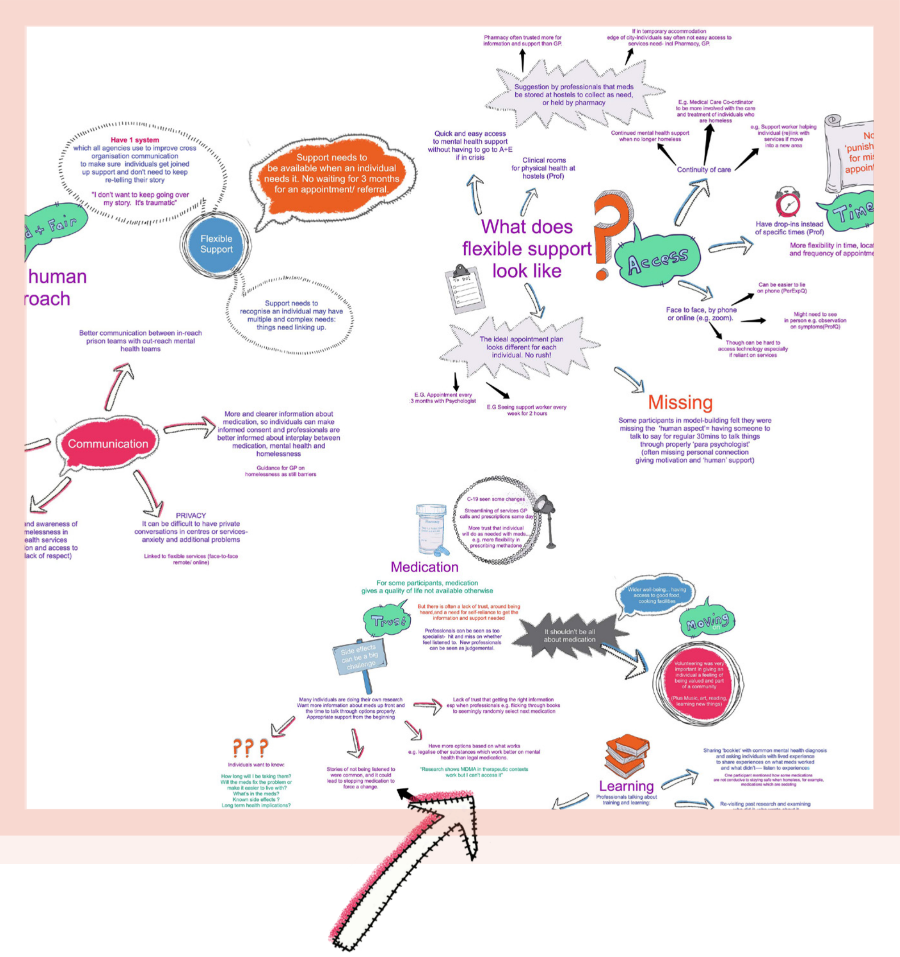
Questionnaires

Two questionnaires were created – one for those with personal experience and one for those with professional experience.

The questionnaires gave us chance to ask specific questions about medication for mental health and homelessness.

COVID-19 arrived as we were finishing preparations for the questionnaires, so we added in a few extra questions to learn about any changes to experiences.

We visited a few different drop-in places to reach individuals with lived experiences.



In the Manchester Mental Health Community of Practice group we used findings to start talking about what could happen next

Extra Insights

After bringing together all the insights from the model-building and questionnaires, we wanted to talk to some individuals with professional experience.

We thought this would give us more information about the systems and services linked to medication, mental health, and/ or homelessness.

We shared our findings with the Manchester Homelessness Mental Health Community of Practice group and had several good discussions about what action could happen from our findings ●

2

questionnaires – one for lived experience and one for professional experience

21

individuals took part in questionnaires

2

digital meet-ups with the Manchester Mental Health Community of Practice group

Our findings

Themes

Six themes became clear from looking at the finding from the model-making and questionnaires:

- Kind and fair
- Access
- Time
- Trust
- Responsibility
- Moving on

There are some links between the themes.

Over the next few pages we will share some details about each theme, and give you some prompts to start thinking about how you can use these insights.

There's also some space for you to add your own ideas for making changes.

> “... want a kind and fair approach. With being kind formalised and systems changed.”

Our kind and fair theme looks at the overall approach to system and services connected to medication, mental health and homelessness.

At the heart of this, is the need for there to be a person-centred trauma-informed approach. This should include flexible support being available when an individual needs it — for as long as they need it, in the format which best suits each individual. Findings included calls for increasing funding for specialist services.

Key priorities:

Having a self-statement

Individuals should have opportunity to have a self-written statement attached to any notes/records (e.g. at G.P, Psychiatrist or service). This should be updated as and when an individual wants to (by self or by an advocate) and may include details, such as thoughts on diagnosis, medication and how prefer to be supported.

Sharing one system

For all agencies connected to an individual to access, update and check one system – making information sharing quicker and easier to benefit the individual.

Improving communication

The whole approach should 'be human' and this should influence how professionals communicate as well as how the system works. User-friendly language is important.

Running training

Individuals should feel safe and supported. There should be less stigma and more respect for individuals presenting with addiction. Every service should have a better understanding of mental ill-health and have a mental health first aider/champion.

More training is needed, especially in mainstream services around addiction and mental health, and for new professionals, as they can be seen as judgemental and dismissive.

> “There's a lack of motivation and re-assurance, a lack of being human. There might be no-one else around in your life to give this.”

> “I don't want to keep going over my story, it's traumatic.”

Think about how to incorporate self-statements

Space for your ideas

“I don’t want to be judged for being homeless. I don’t want to look homeless.”

“Having support, including CPN and Psych, come to you at the hostel, hotel, or supported accommodation works better.”

Think about ways to remove barriers to access.

The access theme looks at different types of access to services and facilities.

Overall findings show an inconsistency in how individuals are able to access support and facilities. For example, one individual was fast tracked for support due to homelessness, whereas another wasn’t referred by a GP due to not knowing which area the individual would be living in.

Key priorities:

Being more flexible

Make services and systems more flexible. Give choices of in-person or digital appointments (building on some flexibilities which have come during Covid-19). The ideal appointment plan looks different for every person. Same day appointments, non drug options, drop-ins and stopping punishments for missing appointments were suggested.

Getting medication

Option for prescriptions and medication to be sent to where an individual is staying or where it can be easily accessed (e.g. to a service or pharmacy). Options for services or pharmacy to hold medication to support medication management. Have options for minimal safe dosage of medication for short periods when needed. (This links to the time theme and the impact of COVID-19 too.)

Access to other facilities supports mental health

To have clinic rooms for physical health at hostels. To have safe spaces to have private (e.g) phone conversations in centres or services. Better regular access to IT is needed so key online forms can be completed (e.g. housing bids).

Having regular access to facilities like showers, washing machines and dryers is important to avoiding feelings of judgement and improving mental health. Access to cooking facilities, equipment and healthy food are important to improving mental health by build bonds and feeling like you’re moving on.

Space for your ideas

Our research shows how time can go missing, be inconsistent, or not be long enough.

Key priorities:

Being flexible

To have the time each individual needs in each appointment and to meet at the preferred location of the individual (e.g. at temporary accommodation) or opportunity for digital appointments.

Impact of Covid-19

The professional experience questionnaire reports how Covid-19 has led to more flexibility in terms of time. For example, psychiatrists have been more available on the phone, there’s been more time for team discussions, and a streamlining of GP services with same day phone appointments and prescriptions and medication delivered

Stop losing time

Some individuals felt like they’d slipped off the radar and that too much time had passed between appointments and referals.

> “OD’d months ago and no follow up support.”

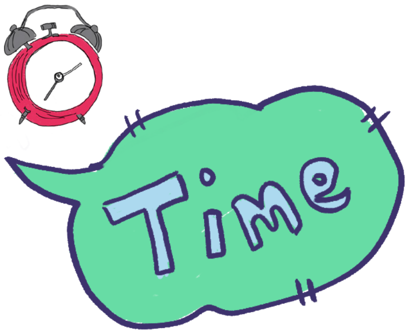
> “After seeing GP, you’re in a wilderness.”

Needing an advocate

To have someone to talk through things properly (e.g. as part of the medication journey) is important. This is sometimes referred to as the ‘human’ aspect — it is about having consistent support outside of treatment.

Having consistency

The time spent with GP’s and other professionals can be inconsistent because of not knowing who you are going to see in the appointment. The preference is to have consistency, as for example, seeing the same GP for a long period of time helps to build up trust.

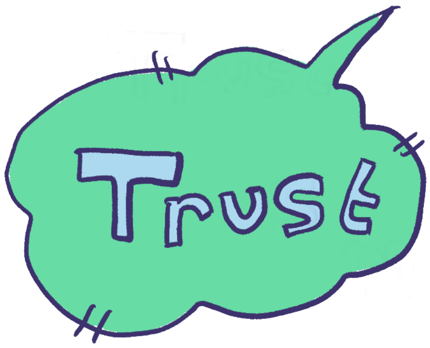


> “Seeing a different Psych every time isn’t helpful.”

> “When I’m well I can navigate the system, but not when I really need it. I need people to take over when I’m at 50%.”

Think about ways to achieve continuity in support.

Space for your ideas



Trust underpins all of the themes which can be seen in our research.

Often there is a lack of trust that the medication prescribed is the best option. This can be seen as a result of a few things:

- Feeling ignored when speak out and worry about punishment if do (e.g. withdrawn support)
- Expectation of being judged
- Side effects can be really bad – some professionals don't seem to want to talk about side effects
- Conflicting professionals' opinions makes it hard to know what to do
- Lack of trust that alternatives to medication – such as cognitive therapies and social prescribing – will be thought about

Findings show that medication can give a quality of life which some participants feel they wouldn't have without them. Alongside this, there is often worry about dependency, consequences of missing medication and side effects.

Pre COVID-19 often pharmacies were more respected and seen as being more supportive than GP's. COVID-19 appears to have increased some trust in GP's with a move to being less risk averse e.g. weekly or fortnightly methadone instead of daily.

Key priorities:

Consent and communication

Individuals should be given the full and necessary information, for example about their diagnosis and medication so they can make an informed choice . This includes being more open about pro's and con's.

Things which individuals want to know:

- How long will I be taking the meds for?
- Will taking the meds fix the problem or make it easier to live with?
- What's in the meds and what are the side effects?
- What are the long term health implications?
- What are the alternatives?
- Why can't some substences be legalised?

> “It's like GP is going down a list, throwing meds at you... going down a list of things to try.”

> “Stuck with a legal drug habit. I don't want to be taking tablets the rest of my life.”

> “I didn't know about Alzheimers for the meds I've been on for 15 years.”

> “It's about taking the least worst meds (re side effects).”

> “GP's argue with you, they judge and underestimate you.”

As part of this, one participant mentioned how a booklet with common mental health diagnosis and shared lived experiences about medication would be helpful.

Think about language, behaviour and approach.

More training

More training for professionals around listening to an individual’s experience of medication. More support to be offered for individuals to feel confident that speaking up won’t result in punishment or support being withdrawn. Some individuals reported how it sometimes took stopping meds to be listened to.

Professionals can be seen as too specialist in their mental health knowledge, as well as not specialist enough in their knowledge around mental health and homelessness.

In the professional experience questionnaire, more training and information was wanted:

- Very localised training, for example, on homelessness service needs in the local area and practical support (what’s needed and what’s available)
- The most common meds and how they are used for mental health
- About prescribing medication for and with addiction
- Moving away from judgements that an individual with addiction can’t be supported

Thinking about and doing research

Some professionals want more research into how well medication works and potential side effects alongside other substances.

Others mention how we need to re-look at past research to see who did the research, who wrote about it and how it was presented — for example, thinking about biases.

Space for your ideas

“Meds are pacifying and ineffective.”

“I don’t want to be zonked out by my meds.”

“It seems like everyone is scared of taking responsibility.”

“Need to fight for rights. If I don’t chase around nothing happens.”

Think about ways of being more empowering and inclusive.

As a theme responsibility features in our research in a few different ways.

1. Individuals with lived experience are often taking personal responsibility: in particular, by researching their diagnosis, prescribed meds and side effects as part of looking for alternatives. There is often an expectation that if an individual doesn’t chase appointments, information or referals (etc) that nothing will happen. This links to the trust theme.
2. Professionals can be seen as not taking enough responsibility for supporting individuals. Note: Professionals who took part in our research, were keen for more training and creating more opportunities to support individuals with lived experiences.

Key priorities:

Improving communication

Getting access to support and medication can be hindered by delays, errrors, miscommunications and confusions, so improving communication between teams and services is very important.

More training and support

Some medications aren’t safe when homeless, for example medications which are sedating. Professionals need to be aware of this when prescribing or supporting and also communicate this to individuals.

Provide access to free face-to-face training for individuals on how to manage their medication and also provide easy access to blister packs.

Note: From our lived experience questionnaire we can see that individuals had their own routines and safe places to manage their meds, with several individuals using blister packs and others relying on a trusted person for support.

Keeping things simple

Make processes and systems simplier. For example,

> “Prescriptions can be confusing… need to order all at different times, it’s hard to keep track of too many tablets.”

Make it easier to manage prescriptions and give support around this.

Making sure an individual knows their rights

When processes and systems are complicated it’s even more important for individuals to know their rights. Knowing your rights is often see as a way to improve how you are treated and your treatment.

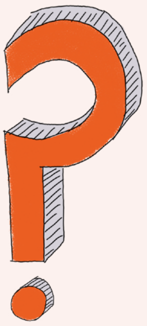
Being involved in decision-making

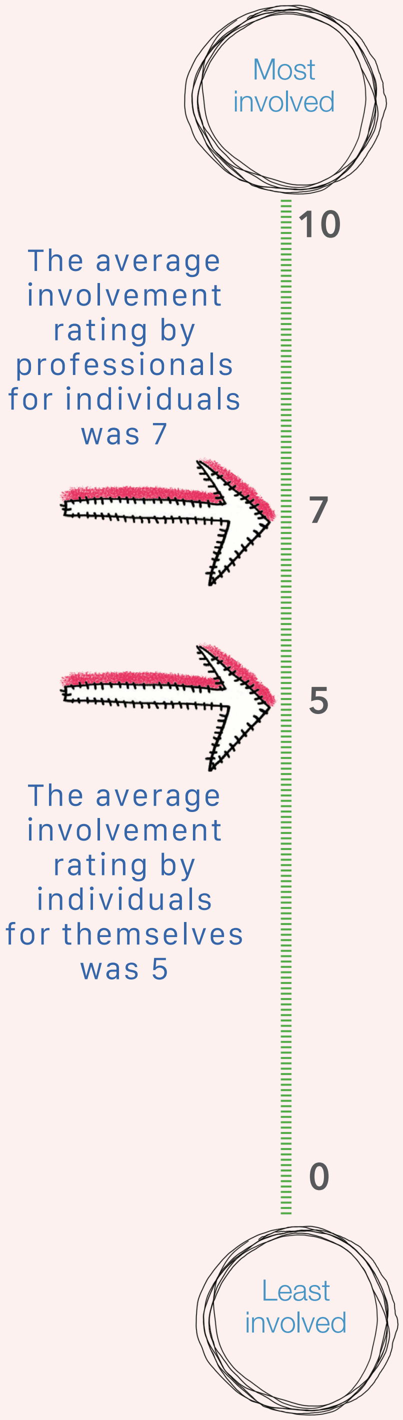
> “If all people involved worked together, it might be different.”

The quote above was about probation and improving support for mental health, but it also applies to other findings generally about teams and services needing to work better together, and individuals being involved more in decisions made about their wellbeing.

In both the lived and professional experience questionnaires we asked about the level of involvement individuals with lived experience have in decision-making about their medication and mental health. Have a look at the findings --->

How involved are individuals with lived experience in decision-making about their medication and mental health





The average involvement rating by professionals for individuals was 7

The average involvement rating by individuals for themselves was 5

Space for your ideas

> “Asking for my own TV, but I’m told I’m not ready. It’d make it feel more like home. I want to get used to coming home, but it’s an empty room.”

> “Don’t want to go to bed every night, because people are on spice.”

> “Trying to sort out getting a place for mum when she leaves prison, she’s got no home to go to and I’m anxious about this.”

> “In jail people become mentally unwell.. need more support in jail and make sure when leaving, people are in the right place to get help.”

Moving on is an important theme, it is thinking about the future and how to get there.

Here are some things which need to change to help with improving mental health and moving on – medication is only part of this.

Key priorities:

Help creating a home

Individuals want to create a feeling of home in temporary places to feel safer, avoid feelings of isolation and to support their mental health.

Feeling safe and supported

Individuals want to feel safe and supported.

Some individuals wanted changes to the visibility and accessibility of illegal substences in hostels, hotels and supported accommodation.

Some individuals are clean when they arrive and shared how it can be difficult to stay clean.

> “Was clean when I arrived, but it’s all around... dealers line up at the front door.”

Moving on, or trying to move on can cause anxiety due to:

- Feeling like there’s nothing happening
- Feeling like there isn’t the support needed
- Feeling anxious about living alone. This can be about money worries and also about living alone after a long time living with more people (e.g. care, prison and in temporary accommodation)

It is a priority that changes are made when in and moving on from prision. There is a lot of anxiety for self and loved ones connected to this. This anxiety adds to the already negative effects of prison and homelessness on mental health.

Access to things that help mental health

Improve opportunities to try and do other things which support an individual’s mental health – asking each individual what works for them.

Our research showed that therapy can be seen as having the biggest impact upon mental health.

Volunteering

Individuals with lived experience shared how volunteering is a good way to keep busy and feel useful – which helps with mental health. For some individuals, volunteering was about having chance to support others.

> “Use volunteers better in centres, so people can talk to them.. be more like counsellors and not just cleaning plates and stuff.”

In our lived experience questionnaire individuals shared what else helps mental health:

- Volunteering 100%
- Music 100%
- Having own place 67%
- Talking therapies 67%
- Reading 67%
- Learning new things 67%
- Exercise or sports 67%
- Art 50%
- Meeting up with friends 33%
- Gardening 17%

Technology

Although already mentioned in the access theme, technology features again in moving on – trying to move on isn’t helped by limited access to computers.

Ongoing support for mental health

Make sure the support which is in place whilst homeless, doesn’t all disappear when no longer homeless. Our lived experience questionnaire shows how some people weren’t able to get support because they are no longer homeless.

Consistency with reviews is needed to make sure that individuals are getting the support needed on an ongoing basis. (This links to a person-centred approach) ●

> “I want to do good, be more than what I’m doing right now.”

> “Sat all day waiting to use a computer to get on Manchester Moves to bid for a place. Need to make it fairer.”

Think about people’s changing circumstances and life goals.

Space for your ideas

Afterword: what now?

By Paul Pandolfo and Tess Tainton (retiring co-chairs of the Manchester Mental Health Action Group)

To start with a massive thank you to everyone who contributed to 'It's My Medication', particularly those who shared their personal experiences in the hope they might prevent others facing what they went through when systems failed them.

Our main ask is for you to help us live up to their expectations.

The idea for this report came from a forum close to our hearts, the Manchester Mental Health Action Group (MHAG), part of Manchester's Homelessness Partnership.

For 6 years we co-facilitated this group, inspired by the dozens who joined it along the way; from people living on the streets, to front-line staff and volunteers, to those holding the levers of power in health, housing and homelessness organisations.

This diverse and passionate group had a strong common belief, that a fairer society is possible if the double challenge of homelessness and mental ill-health attract more attention and innovative thinking.

Over one of MHAG's regular lunch-table meet-ups (note: the best ideas come over a shared meal and brew) there were strong feelings in the room about how complicated people's medication journey can be when they are homeless. And that those with a mental health diagnosis requiring prescribed treatment often experience multiple barriers and a lack of continuity of treatment.

Despite a high level of passion and campaigning zeal in the room there were reservations about taking on the subject in a piece of research.

These concerns ranged from fear about it being a 'wicked problem' that was too big and complicated to resolve, to a degree of resignation that prescribed treatment systems will always be designed towards those with homes.

We knew though from our earlier work,

'Cause & Consequence', that real change is possible when you bring people together around a common social justice cause.

Our approach to community-led research might appear unconventional but it works. As do the creative research methods taken to explore people's 'snakes and ladders' experience of mental health and homelessness systems.

It's incredibly important that we find new ways to listen to people in the greatest need and examine what is being faced by those facing repeated barriers and broken safety nets.

People feel their right to public services enjoyed by the majority can melt away due to circumstances beyond their control – the lack of a home and poverty.

It's an unfairness that shouldn't be tolerated.

And so as we wind up our work, we have both now moved on to other roles, we really wish that others take on the baton of the MHAG, and our approach to participation and involvement.

There's so much more still to do ●


If all people involved worked together, it might be different

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