CoCreate

Access to Healthcare Research for Community Action Network and Public Health Dorset

Conversations Through Theatre

A CoCreate Project, using Forum Theatre to explore
the reasons people with poor mental health may DNA,
and ideas for solutions.

November 2023 – February 2024

This report was written by CoCreate Dorset CIC - Feb 2024

'Did Not Attend'

A new short play by CoCreate Theatre Group

CoCreate Theatre group are excited to share with you a new informal theatre performance & open conversation called 'Did Not Attend'.

CoCreate Theatre group is comprised of people with lived experience of mental illness, and poor mental health. Together we've been working on a short 'Forum Theatre' performance that we'd like to share with other groups with similar lived experiences.

Image - Excerpt from flyer advertising our
Short Forum Performance – "Did Not Attend"

Contents

Appendix

1. Barriers by theme from research discussions
2. Solutions suggested through forum theatre performance and discussion
3. Our volunteer researcher priorities
4. The Play
5. Participant Data – CAN forms
6. Case Study

Section 1

What are the barriers to people attending NHS appointments in Dorset?

We explored this question in two different ways

1. With our volunteers, at the start of the project in a two-hour session & throughout the workshops as we developed a creative response.
2. With people attending the performance as audience members through discussion

We heard an incredible range of detailed, in depth, and often emotional responses for reasons that people with poor mental health might miss appointments; some we expected, and some less obvious.

After reviewing the data, we feel the reasons could be broken into the following themes, with examples provided.

A full list of the reasons we recorded is attached to this document. **Appendix 1.**

Inequity of Access / Discrimination

"There is stigma around mental health, people don't take you seriously"

Many of the reasons we heard centred around inequity of access for reasons related to both mental health, and also including ethnicity, physical disability, learning disability and neurodiversity.

There was an overwhelming consensus that the current system wasn't able to accommodate people's access needs effectively and/or consistently and this was a significant barrier to accessing healthcare.

Some people felt unable to safely communicate their access needs, others had experiences where they had asked for adaptations, however they weren't accommodated, or taken seriously by staff.

We recognised that the current system often requires you to be a strong self-advocate regardless of your status, but that for many people with access needs this additional burden can be even more challenging, tiring, or overwhelming, especially when it needs restating at many points of contact.

"They treat you differently if you're from another country"

A small number of people we spoke to were recent immigrants or had experience navigating the system when English is a second language.

We heard about a lack of understanding of what the system is, what you are entitled to, what you can ask for. We heard about difficult / discriminatory experiences with reception staff, and a feeling of being unsupported and unwelcome.
In one incidence, we heard about someone waiting a long time for an appointment only for there not to be a translator there to support the communication on the day.

"8am call times don't work, I'm too sedated in the morning"

"Reception staff aren't very welcoming.
Waiting too long anywhere makes me anxious"

We heard a huge deal of frustration around the difficulties in the differing systems for making appointments, lack of flexibility in the system, and waiting room experiences that negatively impacted people's mental wellbeing.

We heard concerns about navigating travel to and from the appointment, and fear around not knowing what to expect from the appointment in advance.

We recognised that for people with poor mental health, support to reduce anxiety and overwhelm is vital to improve the likelihood of attendance. The lack of flexibility doesn't allow people to have their access needs met well.

Health Needs on the Day

This theme highlights the challenge of living with a fluctuating condition, and the impact of having a bad day on the day of an appointment, as well as the realities of managing daily tasks when living with poor mental health.

"Sometimes I just forget"

"If my paranoia is playing up, it's hard to leave the house, or get on a bus. I'd need someone to go with me"

The reasons we heard in this theme reflect issues around the impact of poor mental wellbeing might have on organisational skills (to remember appointments), but also the

impact of mood on the day making travel difficult or low mood impacting motivation to attend.
We heard about people not being able to face calling to change or cancel appointments as they couldn't face the long wait on the telephone / couldn't find an easy way to contact the service and how this can then result in care being removed without any further follow up.

Negative Self-Beliefs

"Needs to be a more individual approach to support those with low self-esteem, not getting seen quickly adds to feelings of worthlessness, not important enough to be seen, not worth it"

This recurring theme centres on people's own beliefs about their health, their ability to get well, and their right to do so. We discovered that many people with poor mental health, may also have very low self-esteem, or self-beliefs that impact how they engage with the NHS.

"You think you'll waste your time, all this journey, this effort, nothing will get better"

Often this leads to feeling like they're not deserving of treatment, there's no point in engaging, there's no hope of things getting better; this impacts the motivation to attend, or to reschedule missed appointments.

It feels important to note that some of these beliefs are interrelated in the reality of poor past experiences with NHS services, and reinforced by a system that often feels unwelcoming or reassuring from the first contact and throughout (as commented on below).

"You might open a can of worms"

Conversely there was also a fear of getting better, which recognises a fear for some people with poor mental health, that the changing of a delicately held equilibrium can feel difficult to manage regardless of the direction of travel.

NHS – Previous Poor Experience

A number of people raised a sense of hopelessness around engaging with health services rooted in poor past experiences, especially including a lack of continuity of care, and/or a lack of a clear mental health recovery plan and/or a lack of being understood and taken seriously.

We heard from lots of people feeling like they hadn't been followed up or had been dropped from services without discussion, people struggling to access the right care at the right time, including waiting a long time for medication reviews and changes – a sense that the NHS "isn't supporting me even though I'm asking for what I need and trying to self-manage my health".

"If I'd asked for that support because I'd had a heart condition and it was related to that, I think they would have taken me seriously"

We heard about a lack of understanding and/or not being taken seriously around stated mental health needs, when accessing care for a physical health problem; a frustration that as the patient-expert they weren't able to be heard fully in conversations around their care and what was best for them, an assumption this was because it was related to mental health - the practitioners involved didn't have enough understanding of how to support patients beyond the physical health concern.

The consequences for physical health here feel very clear, if people can't trust their mental health needs to be met whilst obtaining care for their physical health, it negatively impacts mental health, causing distress or worsening of symptoms, this may result in them disengaging from health care in order to prioritise safeguarding their mental health.

The NHS System - Communication

"Why is it that it's a generally understood joke that the receptionists - the way we portrayed some of them in the play *[as hard to get hold of, cold, unhelpful]* ***– all the audiences recognised them. It's a mindset, it's a culture, it could change."***

This theme acknowledges the systems within the processes of making and attending an appointment that people found challenging; poor methods of communication, as well as a perceived culture that often lacks care and empathy.

There was a clear sense that a one size fits all approach needs to be replaced with a more tailored and personalised approach for people with support needs.

Many people acknowledged that they felt it was less the fault of existing staff, who they respected as doing their best in difficult situations, and that underfunding, and lack of staff created a system that was problematic.

Overall, how the NHS **communicates** with people, at all points of contact was identified as a considerable barrier to engagement.

"A culture of poor comms, from the start of the journey onwards….
Better be nice or else''

We heard about the frustrations of long waiting lists, and unclear communication during that period about expectations of when appointments might happen. This can result in people attending A&E instead.

We heard about multiple communications from different services feeling confusing e.g. texts and letters. Many people questioned why communication methods couldn't be more personalised and recognise some people prefer letters/texts/emails, and that would improve their ability to receive and remember appointments.

"It's an old-fashioned system – I mean who sends letters anymore?
Everything is on email, or in my google diary."

We heard about the difficulty in changing and cancelling appointments, especially when trying to contact a service by telephone. A system that decides when you come, rather than a two-way communication that finds an appointment with you or asks you to confirm you will attend.

Some people noted that it wasn't clear what the NHS (and other support services that could be signposted) offered, and the difference of the offer between different GP practices.

For example, good practice conversations highlighted services such as GPs with a mental health specialism / or practice mental health nurse they could access and feel safe with, but some people said they only became aware that these things were possible by asking – it wasn't offered.

Some of the people we spoke to were unclear about the mental health telephone services available and retreat spaces. We wondered if there was better support available, but it wasn't clear how to access it across the system.

People highlighted a lack of clarity on the broader services that were now available to self-refer to, or what the processes were.

People can't choose what they don't know exists.

Making appointments wasn't easy, long hold times and the 8am for appointments system that has been adopted in many places came up often.

"Early calls don't work for people on sedating meds. It needs to be more inclusive to enable access for everyone. It didn't used to be this way."

And why some services could be flexible in offering face to face, telephone, or video call appointments, and others couldn't.

"Can they make it more inclusive e.g. could it be done on the phone, online. How to promote access for all. Accessibility needs to be more fluid."

Computer systems are poor, and there were many examples of issues with repeat prescriptions and long-term management of a condition – for example not being notified directly that a check-up will be required before the next repeat is issued which then caused issues for self-management.

There were a couple of discussion points raised around GDPR concerns, and accessing your records both by request and via an app – these were negative experiences.

Many people felt frustrated by the amount of information you needed to provide at every contact. It feels like another barrier, and in public spaces like waiting rooms, some people didn't feel comfortable sharing their personal information when booking in.

The way in which people are communicated with also frequently came up, and a sense of culture that needed to shift:

"Communication, is even more important for people with mental health. Staff attitude - there's a culture, people say 'I understand how you feel' all the time, it infuriates me!
No, you don't [you don't have my health condition]*!*
No ownership of mistakes, people need more training or even different staff."

"The first thing you hear when you call up is a warning not to abuse staff
- it sets the tone, it's the wrong tone."

"There's a common theme that the NHS is overwhelmed, in crisis - it not a good start.
You expect it to be shit. You don't expect quality.
We don't hear the good stories."

Receptionists as unhelpful gatekeepers: *"They forget they are there to serve you, not the other way around".*

Other External

The weather, costs related to travel, other unanticipated life events preventing attendance.

What people think could be done to address these barriers?

A list of notes from our conversations is provided in **Appendix 2**

> **"The big issue here is that whatever we feedback, we can't change it. Everyone knows that the NHS is underfunded, if the issue is long waiting lists, then we can't change that, they're here to stay, it doesn't matter if we highlight it 300 times it's not going to have any effect."**

We share the ideas we heard for solutions, whilst recognising the reality of an overburdened and underfunded system.

We hope that this report meets the people who can meaningfully support change to happen, people who will listen to our views and act on our ideas.

We recognise that there are some areas where change would be significant and take time, others could be implemented more easily.

Prioritise Equity of Access

Ask people with lived experience to support you with making things better as consultants and advisors. They are uniquely placed to provide you with knowledge and information about what is challenging and what best practice could look like.

Undertake an Access audit – ask how accessible is your service (across the journey) to people with poor mental health, as well as other disabilities? What could change now? What could you work towards in the future?

Recognise that what's accessible for one person, might be a barrier to another person. Try to be flexible and adaptable with the resources you have to improve things.

Improve mental health awareness training, especially in relation to patient experience. Include all staff especially receptionists and administrators.

Create a culture that is always thinking about access by embedding it as a theme at meetings, in reporting, in the design of communications, or change of the way services are delivered, as well as other internal processes.

Small changes can contribute to reducing big barriers. To understand more of the experience of someone experiencing poor mental health it's important to recognise that attending an appointment is likely to trigger a series of stressors. However small each of these might seem individually, all these factors can build into an insurmountable obstacle, if people feel safe, supported and understood they are more likely to engage. Many of these factors are within the control of NHS.

Stressors could include; struggling to feel worthy of help, struggling to navigate the phone system, being on hold for a long time, being unsure what service to access, remembering the appointment, planning the travel, paying for the travel, getting dressed, leaving the house, worrying about the outcome, being spoken to rudely, waiting a long time, waiting in a overstimulating environment, being unclear on expectations, unexpected changes, not feeling heard, seeing a new practitioner, having to explain your story again, not being given enough time to process or ask questions, being unclear what happens next…

Personalised Care at every point of Contact

Personalised care extends to every part of the journey – inclusion and access means more space for flexibility, adaptation and empathy from first phone call or letter, to discharge.

When we asked people about solutions, many people cited examples of services that had specialist staff who could offer extra support as part of a care co-ordinator type role.

A role that provided additional support, a friendly and empathic response, someone who was able to triage and spend more time to better understand issues and work together on solutions that best met a patient's individual needs.

This role was cited as a person who could reduce DNA's especially those related to people in poor mental health / approaching crisis states, as they could reassure and support a patient, as well as advocate on their behalf and work towards solutions with them. They could also facilitate simple things like reminder messages or phone calls, and support with planning transport.

This was a role that had time to value people, to encourage people to attend appointments, and talk through what to expect, reducing anxiety. They might also have the power to support self-referrals, have a knowledge of other services that could support a patient, and provide a more wrap-around, holistic service to meet the access needs of the individual.

This was also a role that could reduce pressure on reception staff, and would have more specialist communication skills and knowledge, to build better relationships.

We understand from our audience conversations that Dorset Mind have previous experience in offering this type of service in some places. Could this be a way of working to develop as a standard offer?

Alongside a skilled care co-ordinator role, there was discussion about using volunteers in waiting spaces, someone who could act as a befriender.

Continuity of Care is really important, we already know this. For people with more than one health need it could reduce DNAs (and improve outcomes). We wondered if people with higher support needs could be identified, and then prioritised towards receiving more continuity of care through seeing the same practitioner/s as routinely as possible?

Listen to people and act on what they're asking for, you will enable people to take better care of their own health.

Communications

Methods of communication were a key theme for improvement; the system would work better and DNAs would likely reduce if the methods of communication were fit for the 21st century.

Services need to be more flexible in the ways they are contacted and communicate out from, and for communication to be more two-way.

This might look like:

- Being able to state your communication preferences, and enabling face to face, phone, text and email as well as letter as options for people to choose from.
- Making better use of email more generally.
- Asking for appointments offered to be replied to as accepted (RSVP), as standard practice, e.g. reply 'YES' Text to accept this appointment.
- Make 'choose and book' appointment-making the norm.
- Ensuring information is available in different languages and formats

Call patients you don't hear from, or who miss appointments to find out why, instead of removing from waiting lists automatically, and without understanding the situation fully.

If you use a 'call at 8AM for appointments' system, please offer a 1PM equivalent for people who need it for access reasons.

Hold times are often very long, telephone systems exist which ‘call back’ when an operator is free, rather than leave you on hold. Can we adopt these?

Better information about what services are provided, this might look like:

- Better leaflets and ‘take home’ signposting for other services e.g. MH phone lines
- Clearer information about how to request and access support within a service
- A place or places where you can understand the maze of services and different entry points, e.g. you can now self-refer to physio, steps2wellbeing – how do people know this? What else can you access?

‘Culture’

Could we improve the attitude of staff and the culture within services by initiating things like ‘the most welcoming GP receptionist award’.

Ask everyone to consider a more positive welcome to their service – change negative phone messages, look at the tone of communications.

Think how the same messages can be delivered differently and in ways that are more positive, friendly, and welcoming.

People experiencing poor mental health need other people to understand they may be thinking or acting out of character, and they need meeting with empathy and support. This isn’t always the experience they receive.

Understand that patients observe other interactions with patients in waiting areas, if these are negative or challenging interactions, they also impact on sense of safety and welcome.

More patience, compassion and understanding would help.

Celebrate the good news stories, and work to challenge low expectations of the NHS.

More staff.
More training for staff.
Different staff.

Make health records work better

Can the system support access, and other relevant information, better.

This would reduce the need for people to continually be explaining themselves and asking for their needs to be met.

This could look like an access needs plan which flags when the patient record is accessed on databases, it could have different levels of information for different groups of staff.

It might include things like;

- I find mornings difficult, please find me an afternoon appt
- I find waiting in reception areas difficult, please can my appointment time be prioritised, or an alternative waiting (quiet) space provided.
- I can become agitated when anxious.
- I may need the option of phone or video appointments
- If I miss an appointment – follow up with me as I need more support.
- I prefer to receive information by text and email

Develop a system to make sure this data is captured in a timely way from the people who could benefit from it. Remember that access information needs regularly updating.

Can we promote better use NHS numbers to reduce the amount of personal information provided over the phone/ checking in?

The Appointment

It was noted that there was a lot of good practice during the pandemic. Can we return to some of the ways of working established in this period?; Triaged well, good use of phone/video call, waiting times kept short at face-to-face appts.

Waiting spaces and the time spent in them are off-putting. How can resources be used differently, and new services designed more accessibly?

This might look like;

- Sensory hours (like supermarkets offer) with low light and noise stimulation
- Clearer expectations on wait times when you book in to reduce anxiety,
- Options to come back in XX minutes if the wait is considerable.
- Screen booking in optional – ensure face to face welcomes are there for those who need them
- Quiet spaces made available as standard.

- Flexibility to move around, go outside etc. if wait time is long and not worry about missing being called
- A volunteer or staff member whose role is to offer support

Support with preparation for the appointment, including navigating new buildings or spaces, and what to expect your experience to be like.

More flexible appointments

Face to face appointments, telephone and video appointments should all be available options. Home visits can also be a solution.

More time at appointments. Less rushing.

Consider if tests can be done through the post, rather than having to make a visit.

Volunteer Performer-Researchers in role as parents in Sarah’s Story

Section 3

About the Project

CoCreate worked with new and existing participants, using forum theatre as a way to explore the questions as part of this research. We then performed a short play to four audiences and recorded their ideas around what changes would support access to health care.

The scenes we created were rooted directly in the experiences of the people taking part in the workshops. We were careful throughout to check that our creative decisions of characters and their stories were truthful, and reflected real life accurately.

We tried to demonstrate different barriers, based around the themes we'd identified at the start, so we could explore a range of different needs and solutions.

A summary of the action, or script for each of the three scenes is in **Appendix 4 .**

In this project we defined three roles for the people we worked with

1. **Volunteer Performer/Researcher**
   This role enabled some of existing theatre group members to use and improve their performance and creative skills by devising and performing a short play.

   In addition, they contributed to the early planning and discussion around barriers, and brought their own lived experiences to shape the work we presented.

   They also took part in 30-minute sessions to help project manage the tour, helping with ideas for places to perform, people to contact, taking responsibility for sourcing costume or props, etc.

   In a final session we discussed what we'd learnt from the conversations, and what we felt was collectively important to feedback in this report **(Appendix 3)**

2. **Workshop participant**
   This role enabled new people, with less confidence, to take part in the theatre workshops. There was no commitment to attend all sessions.
   This role enabled us to widen the reach of the project, and gather more ideas and feedback in an active creative way. It also enabled us to offer creative opportunities to people with lived experience.

3. **Audience**
   This role was to attend and watch the forum performance, and the then participate in a facilitated / active discussion where we looked at ways we could improve the outcome. We marketed the show explicitly to audiences with lived experience, and people interested in the research.

We worked with 8 people as **Volunteer Performer/Researchers**, of which 5 completed the project.

NB Of those that left, 2 were for health reasons, 1 was related to employment.

We worked with 3 people as **Workshop Participants**, with 4 workshops attended.

We had conversations with 35 people as part of our **Audience.** We performed at community venues in West Howe & Boscombe (2 performances) and Weymouth.

Sessions Delivered

We delivered a total of **10 sessions,** and **4 performances**, with a total **reach of 46 people.**

We collected 28 completed activity evaluation forms - for data see **appendix 5**

Activity	Who was involved
Planning and research session (2 hours); what are the barriers?	Online. Volunteer Performer/Researchers
Workshops 1, 2, 3 (2 hours)	Boscombe. Volunteer Performer/Researchers, Workshop Participants
Workshop 4 – dress rehearsal (2 hours)	Boscombe. Volunteer Performer/Researchers, Audience
Project Planning Sessions (30 minutes) x 4	Boscombe, Volunteer Performer/Researchers
Performances x 4 (60-90 minutes)	West Howe, Boscombe, Weymouth. Volunteer Performer/Researchers, Audience
Reviewing the data – evaluation for reporting session (3 hours)	Boscombe. Volunteer Performer/Researchers

Other Project Outcomes

Participant benefits

In addition to the research outcomes, the participants were able to use the opportunity to find support for their mental health through meaningful, creative activity, and improve their skills as performers.

A more complete report on the creative and wellbeing outcomes will be available via our website late March 2024.

Volunteer feedback on the experience was very positive and included:

'I need this group to be healthy'

'If I had a magic wand, I'd put more money into this '

' A family of friends, knowing we're not alone in this.'

' Really, really, helped me with my mental health'

'Great to have peer to peer support with similar lived experiences'

‘Felt confident about being a real actor – would like to take on more. ’

Supporting the Creative Health workforce

This project enabled us to work with a young theatre graduate and emerging artist as an assistant facilitator, in a mentee role. This provided an opportunity to develop their understanding and skills in working alongside people with lived experience of mental health.

Other Outcomes

As part of the legacy of this project, we plan to

- Use the thank you fund to offer a further 8 weeks of performance skills development to the group

- Apply for further funding to develop another performance, based in issues that matter to the group, to perform locally

- Continue working with our assistant facilitator to further develop his skills

- Begin to embed the role of volunteer in our work more deeply, in particular with one volunteer who will help guide what this could look like, with a view to setting up a volunteer advisory group

Local Press

Our performance in Weymouth was covered by Dorset Echo.

Available at [https://www.dorsetecho.co.uk/news/24102043.short-play-lantern-trust-weymouth-focus-mental-health/]

Volunteer performer-researchers in role as 'Billy' and his friend

Appendix

1. Barriers
2. Solutions
3. Our volunteer researcher priorities
4. The Play
5. Participant Data – CAN forms XLS
6. Case Study