Personality Disorder Improvement Programme

Working in partnership to design mental health services:
NHS Lanarkshire and Scottish Recovery Network

The Personality Disorder Improvement Programme (PDIP) is working in partnership with health boards and health and social care partnerships across Scotland to highlight examples of good practice of service provision for people who have or may attract a diagnosis of personality disorder.

This case study looks at an example of collaborative working with NHS Lanarkshire, Scottish Recovery Network and people with lived experience.

This case study summarises the partnership working experience of NHS Lanarkshire and Scottish Recovery Network in completing their 'Moving from consultation to co-design' project.

We will highlight areas of good practice in their engagement process and learning points for connecting services and people. This shared learning hopes to inform how other groups can take forward collaborative working in their mental health service design.

The content of this case study is gathered from the project's final report, summaries, and presentation shared at the PDIP Webinar on 7th November 2022. It includes perspectives from people with lived experience, third sector organisations, and health and social care staff.

Involving lived experience and the third sector in designing mental health services

Background

The NHS Lanarkshire Personality Disorder working group formed in 2018. Its remit is to review and coordinate care for people who may attract a diagnosis of personality disorder within their health board locality.

- As a multidisciplinary working group, scoping was completed to ensure representation across health and social care fields was present.

- Early recognition on the impact of including lived experience in their work led to the group approaching other health boards to hear their experiences.

- The group also approached Scottish Recovery Network, leading to the undertaking of this project in collaboration with people with lived experience.

In 2022 the NHS Lanarkshire Personality Disorder working group, Scottish Recovery Network, and people with lived experience worked together in 'designing a mental health service.'

The project widened its audience beyond people who have a diagnosis of personality disorder to also include people who have complex mental health problems and/ or who have experienced trauma.

The project's service was aimed for 'people with complex mental health problems who may attract a diagnosis of personality disorder' in Lanarkshire.

The use of 'personality disorder' in this case study reflects discussion and consensus of diagnostic labels by Mind and the British and Irish Group for the Study of Personality Disorder.

We aimed to write this case study using language that is non-stigmatising. However we are aware that language tends to evolve rapidly and reflect societal attitude changes towards mental health.

If people read this in the far future, we hope they consider this and take into account our good intentions in using the most widely used and recognised terms available to us at the time.

Tools for collaborative working

This project uses the method of 'co-design' to involve people with lived experience in work that usually is completed mostly by NHS staff.

There are different definitions for the term co-design. Most people and organisations define it as a method where people work together towards a mutual goal with a shared power balance.

This means that decision-making is collaborative, and people who may usually not participate in these decisions have a voice on topics that affect them.

Service users

Service providers
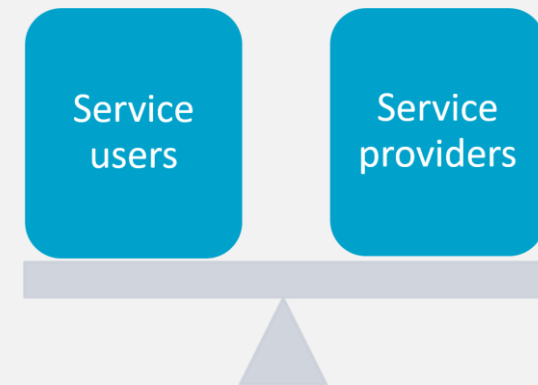
Barriers to lived experience and third sector engagement were identified early at the project information session. We recommend reading the detailed summary of these findings on the project's final report (pp.5-6).

This influenced the Scottish Recovery Network's decision to use their Recovery Conversation Café Toolkit as a tool for engagement.

This toolkit aims to support people and organisations to engage people in a meaningful way to hear what is important to them.

A variety of resources from Scottish Recovery Network is available via our Resources page to support teams to use this model - including guides, templates, and exercises.

"The ability to engage with third sector organisations and hear about community resources was highly valued…"

NHS Lanarkshire representative, Final Report pp.16.

Project journey

1

Connecting through conversations

Initial engagement used a mix of approaches to hear people's views and experiences
- Two conversation cafes and a number of one-to-one interviews were completed.
- Local organisations were supported to engage their members.

2

Collaborative working through 'co-design'

Participants then came together to identify key themes, plan engagement, and agree on report
- Two co-design sessions (one online and one in-person) led by group feedback were facilitated by Scottish Recovery Network.

3

Review and reflection

Final discussions on report to ensure it reflects agreed opinions, reflecting on key learning
- Two review sessions offered to facilitate reflection: one for lived experience participants on their experience, and one for the NHS Lanarkshire group on their learning.

"Empower people, give them choice, it should be client led…"

Project participant, Final Report pp.12.

Person-centred approach

Engagement findings

The importance of delivering a truly person-centred approach within mental health services is highlighted as one of the key themes from discussions.

Participants shared that they can feel judged by their diagnosis and are given limited support to avoid reliance on services.

- **Support should be flexible** and based on what the person needs at that time, it should not be dependent on someone's history or diagnosis.

- **Consistency and human relationships** help people's recovery as it can help people feel less excluded from the care and support they need.

- **Support should be offered on a consistent and ongoing basis** to reduce the potential of 'cycle of referrals' and help people to have a better relationship with services.

Overall, developing care planning to be more holistic and collaborative is recommended by project participants to achieve person-centred care. People feel they should be part of decision-making bout their care.

Recommendations

Enabling people with lived experience to create a more holistic care planning document in collaboration with their NHS service providers is recommended.

- ✓ **Care planning led by the person with lived experience** to empower people and give them choice in their care.

- ✓ **A flexible approach to support** allows for meaningful collaboration on the care planning process and regular updating.

- ✓ **Being supported to make informed decisions** about their care is important, and this approach can reduce the feeling of exclusion from services and support.

- ✓ **Peer workers** can be implemented as a support to enable this process.

"I don't want to 'return to the person I was before', I want to heal and live my best life as this new version of myself. The service would be helping with that; teaching ways to cope with setbacks and triggers, not just focusing on a quick fix or coping mechanism – but actually helping people to heal."

Project participant, Final Report pp.8.

Trauma-informed care

Engagement findings

In sharing their views on what matters most to them and how a new service could promote recovery, participants noted the impact of services providing trauma-informed care.

Making a shift to collaboration and trauma-informed communication could improve experiences and outcomes for people accessing services.

- **Working in collaboration** can empower people and feel able to use their own experiences to make informed decisions regarding their care.
- **Feeling of safety** can be increased when steps are taken to avoid re-traumatising people when accessing services.
- **Acknowledging** the history, complexities and stigma of the 'personality disorder' label as part of trauma-informed practice is important.

Overall, project participants identified that mental health services should be informed by trauma and the experiences of people who access these services. Staff should receive training to enable this approach.

Recommendations

The development of short training course on trauma-informed care is recommended. This training would be designed and delivered by the NHS health board in partnership with people lived experience.

- ✓ **Increasing staff understanding of trauma and how people can present when they are in crisis** would be the main goal of this training.
- ✓ **Staff wellbeing and emotional resilience focused modules** would be included in recognition of the role compassion fatigue and burnout can play on staff attitudes.
- ✓ **Producing the training in collaboration** with people with lived experience gives a voice to what does and does not work for them when they access mental health services.

"An on-going service that is a constant in someone's life would be helpful, as at the moment people are passed pillar to post and having to re-tell their story through multiple assessments can be re-traumatising."

Project participant, Final Report pp.9.

Whole person, whole systems

Engagement findings

The positive impact of a 'whole person whole systems' approach which includes connection and inclusion was shared by engagement participants.

Accessing further services such as third sector is recommended as a complementary element to clinical support, to help people receive the care they need.

- **Peer support** through connection with people with similar experiences can help recovery in a supportive environment.
- **Family, friends, and carers** are integral to this approach as supportive relationships can improve connection to services.
- **Improving connections to other services** can positively impact social, emotional, and financial support by increasing range of options available.

Overall, improving connectivity is key theme highlighted throughout the project's findings. Project participants suggested better co-ordination and connection of support would improve their experience of accessing services.

Recommendations

One approach recommended to improve connectivity is creating a 'drop in' wellbeing hub hosted by the health board.

- ✓ **Partnership working** between the wellbeing hub and local third sector organisations offers a variety of support and signposting.
- ✓ **Peer workers** based within these hubs can help promote recovery through connecting with other people with similar experiences.

Introducing the role of 'peer navigators' to mental health services may improve people's experiences in accessing services and support.

- ✓ **Peer navigators** would be an allocated and trained person for support.
- ✓ **Navigators connect service users with complimentary support** in the community.

"We should take a collaborative approach to find out what support people want and what they want to achieve. We find out what they want from the care and take it from there. It's not one size fits all."

Project participant, Final Report pp.12.

Tips for designing mental health services collaboratively

Connecting through conversation
"It's good to have representation from both NHS and third sector organisations at the sessions. Representation matters, and it can help to bridge the gap between our ideas and what is possible", shared by a person with lived experience (Final Report pp.15).

Creating the environment
Provide time before starting sessions to allow people to chat, connect, and create a more relaxed and trusting environment.

Let the audience lead discussion
Use findings from initial discussions to help focus conversation on the goal of planning services – focusing on the identified outcome without controlling the narrative.

Good facilitation matters
"It was really good to hear things from the patient's perspective and the group that I joined was facilitated very well, it really felt like a safe space", shared by a NHS Lanarkshire representative (Final Report pp.15).

Useful tools
Introduce visual aids as tools when doing online sessions as well as in-person as this can helps focus discussion on the task at hand.

Resources

British & Irish Group for the Study of Personality Disorder (BIGSPD). BIGSPD Values and Philosophy [online]. 2022. [cited 2023 Jan 12]. Available from: https://bigspd.org.uk/bigspd-values/

MIND. The Consensus Statement for People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorder [online]. 2018. [cited 2023 Jan 12].

Scottish Recovery Network. Moving from consultation to co-design – report [online]. 2022. [cited 2023 Jan 12].

Scottish Recovery Network. Moving from consultation to co-design – resources [online]. 2022. [cited 2023 Jan 12]. Available from: https://www.scottishrecovery.net/resources/moving-from-consultation-to-co-design/

Scottish Recovery Network. Recovery Conversation Café toolkit [online]. 2022. [cited 2023 Jan 12]. Available from: https://www.scottishrecovery.net/resources/recovery-conversation-cafe-toolkit/

> " [This experience has enabled NHS Lanarkshire staff] to hear the views and opinions of people who we might not have heard from otherwise, and to reflect on the services currently provided.
>
> NHS Lanarkshire,
> Final report pp.16.