



“VOICE OF THE VOICELESS” DESTIGMATISING THE PHARMACY EXPERIENCE FOR PEOPLE WHO RECEIVE OPIOID SUBSTITUTION TREATMENT

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PHD RESEARCH

Open Access Article

Should I Stay or Should I Go? A Qualitative Exploration of Stigma and Other Factors Influencing Opioid Agonist Treatment Journeys

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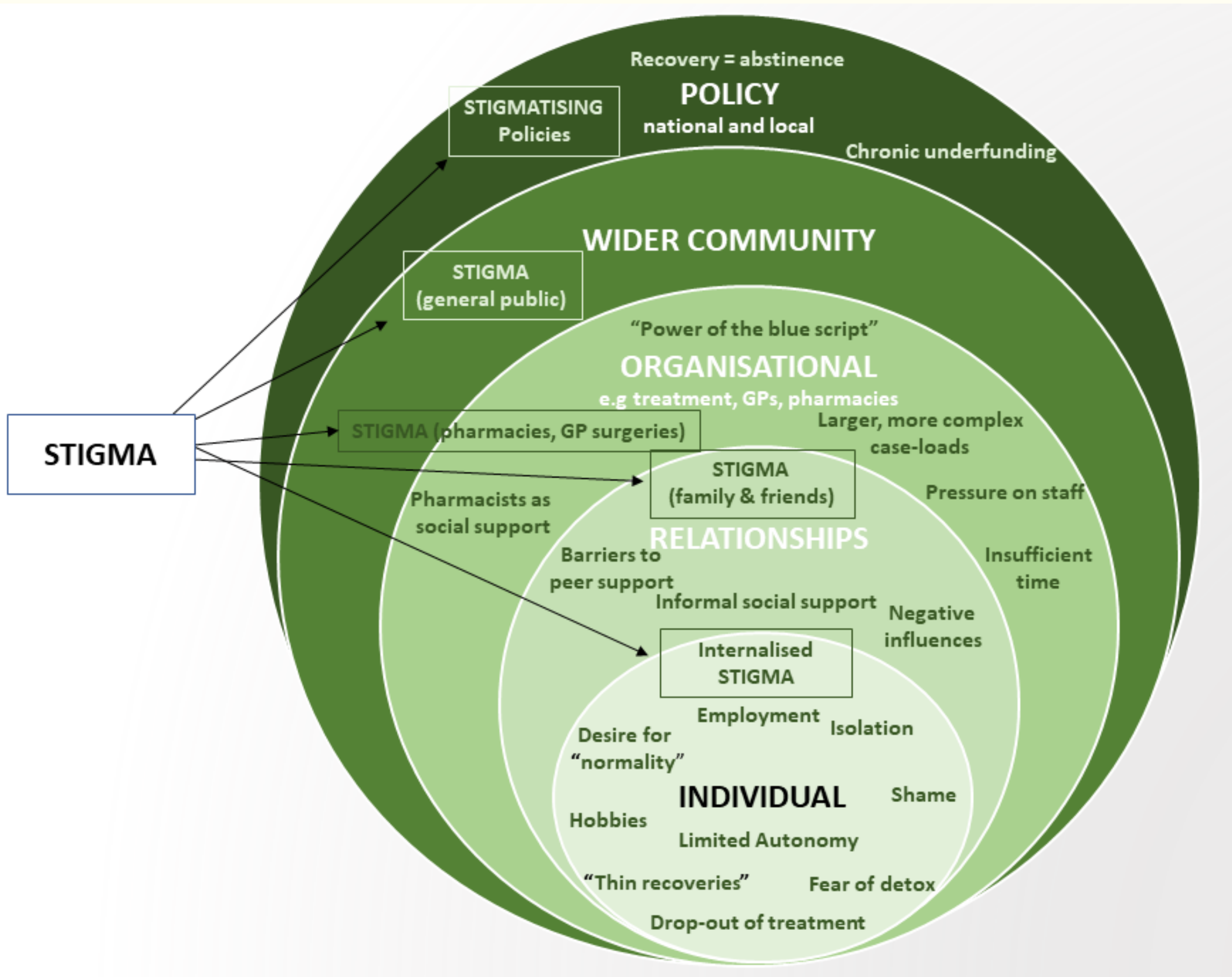
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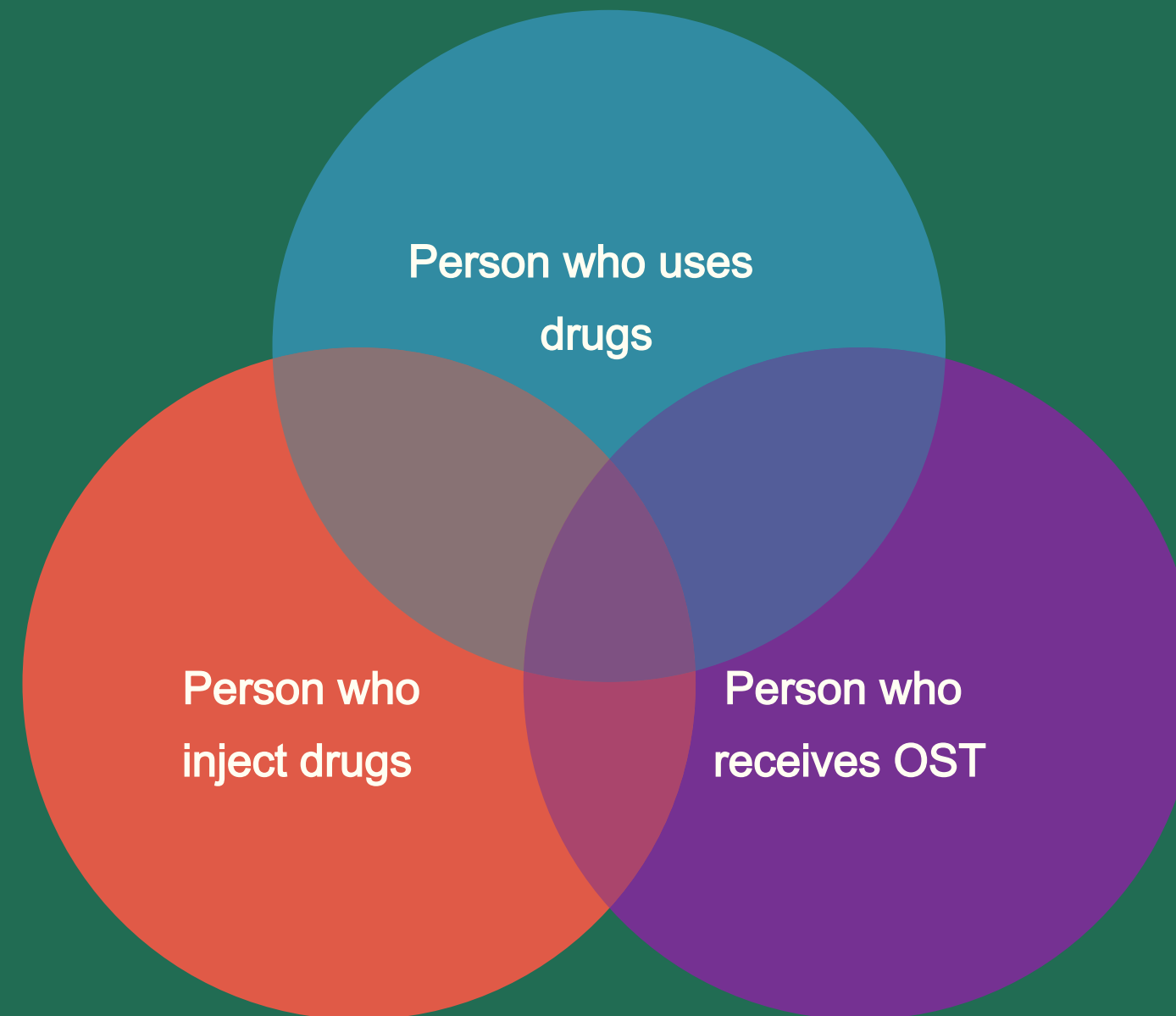
Review Reports

Versions Notes

Highlights



INTERSECTING STIGMAS



Other stigmatised identities that may intersect:
Gender, class, race, disability.

1. STAKEHOLDER WORKSHOP

Funders: Research England, Briggstow
Institute



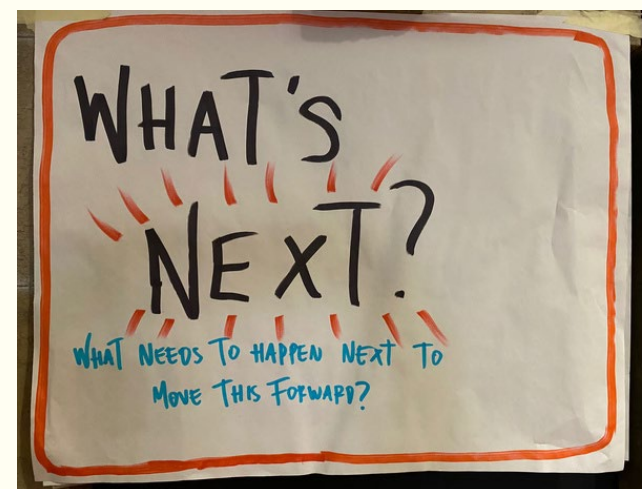
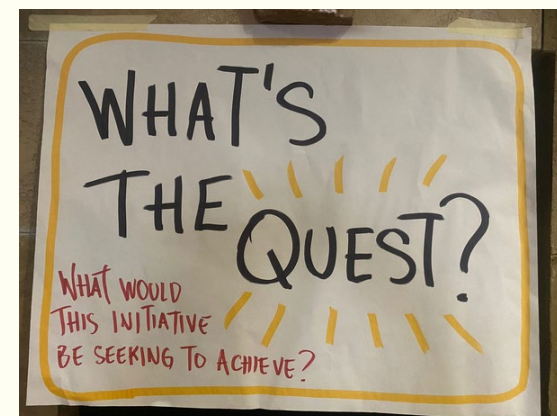
To identify policy, practice & research needs in relation to stigma towards people who use drugs & OST

13 people with lived experience, 14 professionals, including pharmacy, OHID, police, HMP, academics, BDP, DHI, Bristol City Council, Anyone's Child, EuroNPUD




Pharmacies were a key focus

- particularly for those with lived experience of receiving OST





WHY STIGMA AND WHY PHARMACIES?

- Pharmacies cited as key source of stigma for people who receive OST (Carlisle et al., 2023; Harris & McElrath, 2012; Madden et al., 2021).
 - Experiencing stigma is inherently **de-humanising** ; it **marginalises** people, worsens **social isolation** , increases perceptions of **chronic pain** and severely limits wellbeing and life chances (Broman et al., 2023; Carauna, 2024)
 - ==> drop out from treatment ==> Undermines harm reduction aims of OST, leaving people vulnerable to overdose, death and complications associated with injecting drug use, e.g. HIV, Hep C, skin infections.
 - Pharmacists are **uniquely placed** to be a source of valuable support for people who receive OST (Carauna 2024; Scott & Carlisle, 2021) as they see them frequently - often on a daily basis.
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2. CO -PRODUCTION WORK: 'Voice of the Voiceless'

Funder: University of Bristol's Participatory Research Fund

Building on the previous workshop, we narrowed the focus to the experience in pharmacies...

5 people with *living* experience of OST, 3 people with former experience of OST & 3 UoB academics (including a pharmacist), 1 pharmacy assistant, BDP, DHI, Bristol City Council, Harm Reduction Mother2Mother



2. CO -PRODUCTION WORK

Funder: University of Bristol's Participatory Research Fund

Our pharmacy experience

By people who receive opioid substitution prescriptions

In this booklet we highlight the good and bad experiences people who receive opioid substitution prescriptions have with pharmacists – however, we hope that in the future this work will make bad experiences much less likely.

Rights

for service users:

- You have the right to be spoken to and treated with respect.
- You have the right to judgement-free treatment.
- You have the right to discuss and review your script with your drug service staff. This includes frequency of collections and any issues with your pharmacy.

You have the right to be treated like anyone else visiting the pharmacy.

You have the right to privacy and confidentiality. You may not wish to use the private consultation room, but it should always be your CHOICE.



What pharmacists want service users to know

- Understand that buprenorphine and methadone are **controlled medications**, which means that pharmacists have to work within the law and government guidelines. Not doing so is a criminal offence.
- Controlled medications like methadone and buprenorphine come with additional paperwork and procedures, so can take some time to prepare. Your pharmacist may be very busy, and you will sometimes need to wait.
- Understand that pharmacists and pharmacy staff are **human** and might just be having a bad day.
- **Don't judge** your pharmacist/ pharmacy staff based on previous experiences in your current or previous pharmacy. It can take a little time to build a good relationship with each other.
- Wherever possible, positively influence others by demonstrating a **respectful attitude**.

What service users want pharmacy staff to know

- Never underestimate the importance of remembering people's faces, using people's names and asking how they are today. Remember that you might be the person who we have the most interaction with on a daily/weekly basis and you have the power to have a positive or negative influence on our lives and **sense of self-worth**.
- Remember that you are very important to your OST customers – you probably know them better than most other professionals and see them more frequently
- Don't assume that we have complete flexibility with collection times – **we do work, have childcare and other commitments**. The start and end of the day may be the only time that we can collect medications.
- Always offer people **'the power of choice'** where possible. Having autonomy over our day to day lives is very important to us.
- Please remember that we may have been receiving our medications for many years and are **experts in our own bodies**. If we tell you something doesn't feel right or we need help, you should signpost us to where to go for support.
- Understand the considerable impact that **issues with methadone/ buprenorphine scripts** have on our lives and well-being. It is likely to cause a large amount of stress, particularly before weekends/bank holidays, because we are dependent on these medications. **Being sent away without a script could risk our lives**.
- Understand that we are **human** and might just be having a bad day.

Voice of the Voiceless

About us

We are a collective of people who use(d) drugs and receive methadone or buprenorphine; Bristol City Council; Bristol Drugs Project; Developing Health and Independence; Harm Reduction Mothers2Mothers; and academics from the University of Bristol.

We are committed to tackling the stigma that exists in relation to using drugs and receiving methadone and buprenorphine treatment. Through our work, we hope to put the power back into the hands of the oppressed and give the voiceless a voice.



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2. CO -PRODUCTION WORK

Funder: University of Bristol's Participatory Research Fund

My pharmacy experience

Simon's story

I was living in London in 2001. In June I had gone to the park with a friend and our children. I felt my chest becoming more painful, I assumed I was getting a cold. At the time I was on a daily methadone regime at a local chemist, I had to drink it on the premises. I progressively got more ill over the next 24 hours; I could barely drink by the morning.

When I went to the pharmacy that day, the pharmacist saw I couldn't drink the methadone and really impressed on me that I must see a GP at once. He allowed me to take my methadone so I could sip at my pace, as my throat seemed to be closing. I was coughing constantly. I went to the GP who gave me large antibiotics that I would never have been able to swallow, then went home.

Later that evening I couldn't drink a drop of water. I could barely move so I gave in to pressure and got a cab to hospital.

Again, a doctor tried to send me home with the same antibiotics, but a nurse insisted I stay as I needed intravenous fluid.

The next morning on the ward round the group of doctors, students etc heard me cough, came straight to my bed. After hearing me cough I was gently told I'd be more comfortable in ICU. I later discovered the doctors thought I'd live 4 hours. I was in ICU for 6 weeks then on a ward for another 6 weeks. If my chemist hadn't been so concerned, kind and insistent, I would not have sought treatment thinking I could deal with it.

I have had positive and negative experiences with chemists, it really makes a difference to how I feel as a person.

Simon's story



11

My pharmacy experience

Katrina's story

I've accessed chemists for nearly 20 years for opioid substitute. I've had a lot of good and bad experiences. Good, as in I might not be here now writing this. Bad, as in being told loudly in a busy chemist that I was banned as my then boyfriend had shoplifted there. Because of that I was also going to be put on a rapid reduction of my 90mls methadone script. At the time I was homeless, my script had been the one positive in my life.

I was humiliated, confused, angry, felt powerless and mostly scared of being ill from losing my script, which made no sense to me.



13

10

OTHER RELEVANT RESEARCH

NATIONAL STIGMA INDICATORS PROJECT

Funder: OHID

Working with academics across the UK to adapt existing Australian e-learning modules for UK Healthcare setting to address addiction stigma

DEVELOPING INNOVATIVE, INCLUSIVE, AND DIVERSE PUBLIC PARTNERSHIPS

Funder: NIHR

Working with NHS & Academics in West Midlands to develop partnerships with people who use substances and experience multiple disadvantage, including stigma and shame

MOVING ON UP: STIGMA & HOUSING

Funder: Bristol City Council

Focus group study to understand the role of stigma in people failing to move on from supported housing locally.



THANKS FOR LISTENING



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