Healthcare Improvement Scotland

ADP and Homeless Programme: Reducing Harm Improving Care

Understanding the experiences of people who require access to homelessness, alcohol, and drug services

September 2022

NHS SCOTLAND

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Executive summary

Introduction

In 2021, we sought to understand the experiences of homeless people that require access to drug and alcohol services, recognising the current challenges faced across the system and the high numbers of drug and alcohol related deaths across Scotland. The aim of speaking to people who use services was to understand the current levels of integration across homeless and alcohol and drug services and the extent to which people can have their needs met in the current system.

We engaged with over 70 people, and it was clear that there was a shared experience of accessing services with many people reporting that they felt they needed to be at crisis point before receiving the care and support they need. In addition, the current system set up means that people are often required to identify their own care needs and navigate a complex and disjointed system to have their needs met in a coordinated way.

People reflected on the lack of choice and control in decision making around their care needs with family members having little or no input into supporting their loved ones to access the care and support they require.

From listening to people using services, we heard that lack of coordinated care is contributing to people feeling that no one is managing their care and support needs. This means people can fall through the gaps in service provision resulting in disengagement with services and critical health and wellbeing needs being unmet. People reported the prevalence of long-term health conditions alongside their addiction and mental health issues with people feeling that they are left to prioritise one need over another.

Delivering holistic care for people in a changing and chaotic situation is difficult to plan for. To improve access, care and treatment for people, we must take a holistic view of the range of needs people have and design services that are coordinated and able to meet the needs of people at different times in their journey.

This report sets out the key findings from our engagement with people with lived and living experience of homelessness and/or alcohol and drugs and identifies the areas that should be considered to ensure that future services are designed around the needs of the people using them.

Summary of key findings

Feedback from all our engagement activities has identified nine key themes that should be considered as we look to design services that support people to have their needs met in a coordinated way.

A one-page summary of the findings from our engagement work can be found here.

Analysis of the findings from our engagement activities identified that:

There is an urgent need to improve access to services

- In general people report spending a long time without access to services and feel that they *'need to hit rock bottom before they are offered support'*. Therefore, for some people it is *'easier to stay on drugs than to get help'*
- Even if they manage to secure an appointment, stigma is the second biggest barrier mentioned in terms of service accessibility. People told us that *'when I went to addictions, I felt, just looked at me as if I was a junkie, and I didn't like that, because I was begging for help, so I basically, I just felt pushed away constantly'*
- There are also practical concerns which need to be considered in order to make it easier for people to attend appointments. Service providers should ensure people are physically and financially able to attend appointments and understand the reasons for non-attendance at appointments.

People want joined up services which can coordinate care

- People reported experiencing a continuous chain of referrals, with many services unable to provide direct access often requiring referral from other services before being accepted into the new service. This was most evident when people require access to both mental health and addiction services, this situation makes people feel that they are offered *'leaflets instead of support'* and that they are being *'passed from pillar to post'*
- Participants described the need for increased levels of support during transition periods, such as when being discharged from hospital, being released from the justice system, or moving into new housing
- In addition to housing, addiction, and mental health services, people also require support with day-to-day tasks such as cooking, budgeting, setting up bills and help with house decoration
- People reported positive engagement with third sector support organisations, which offered a 'one-stop-shop' for support.

Make person-centred service delivery a reality and offer people more choice and control

- Most of the people we engaged with expressed anger and frustration at the fact that they were not offered choices in terms of their treatment and housing options and felt that *'we're just a number to them'*
- People felt they were placed in harm's way by not having a say regarding the area in which they would live
- People reflected on their negative experiences of accessing opioid-substitution treatment, with reports of not feeling safe during pharmacy pick-ups and of limited engagement with medical professionals who *'just want to give me a prescription, they don't want to ask me what I've got wrong with me'*
- People also expressed a strong preference to talk to people with lived experience. They were seen as trustworthy contacts and could support navigation of the system from a service user perspective.

Why are we doing this work?

Scotland continues to face significant challenges relating to harms caused by drugs and alcohol, including rising numbers of drug and alcohol related deaths. The National Records of Scotland Drug Related Deaths report identified 1339 drug related deaths in 2020, the highest number ever recorded and 3.5 times higher than our European counterparts.

Further analysis undertaken by National Records of Scotland showed that in 2020, 59% of deaths amongst people experiencing homelessness were drug related, a 5% increase from 2019. In addition, 1190 alcohol specific deaths were recorded in 2020, evidencing a 16% increase from 2019.

These figures highlight the need for a better understanding of the models of care and level of integrated working across these systems. In response to these challenges, the Scottish Government launched a new national mission in January 2021 to reduce drug and alcohol related deaths and harms.

To support this work, Healthcare Improvement Scotland (HIS) were commissioned by the Scottish Government and the Convention of Scottish Local Authorities (COSLA) to deliver an improvement programme, Reducing Harm, Improving Care, which engages homelessness and drug and alcohol services, alongside the people who use them to:

- Improve access to services
- Develop integrated, joined up services
- Provide greater choice and control

To ensure a full understanding of the current system and the needs of those using services, it was critical we sought the involvement and participation of people with lived and living experience of homelessness and alcohol and drugs, alongside families and carer's and third sector support staff involved in providing care and support.

The Charter of Patient Rights and Responsibilities states that people have the right to be involved in the development of the health and social care services they access. This supports our understanding of involving people with lived and living experience in the design and delivery of services they use. Together with the publication of the Medication Assisted Treatment (MAT) standards: access, choice, support and the Drug Death Task Force Changing Lives – Final Report, this provides support in the work we want to achieve.

Engagement approach

Method

To ensure that we captured the views and experiences of people using services, a number of engagement activities were undertaken:

- Scottish Drugs Forum (SDF) and Homeless Network Scotland (HNS) supported peer researchers to undertake 53 peer led one to one interviews with people experiencing homelessness and alcohol and / or drug issues
- Engagement with Scottish Families affected by Drugs & Alcohol (SFAD) to understand the experiences of family members and carers
- Engagement with Simon Community's Harm Reduction staff and women accessing their service
- An online survey issued to voluntary and third sector organisations

A summary of the activities undertaken is included in Figure 1 below and a full report detailing our engagement approach and the learning gained from this can be found here.

Data collection

- Peer researchers were recruited by SDF and HNS and carried out one to one interviews with people with lived and living experience of homelessness and drug and / or alcohol use either via telephone or in person between October and December 2021. A copy of the discussion guide used is included at Appendix 1
- The interview recordings were transcribed by a third-party service and analysed by Healthcare Improvement staff
- We worked with the Simon Community Scotland to gain feedback from Harm Reduction Staff through 2 Google Meet discussions, as well as the Women's Harm Reduction Coordinator, to gain feedback from women who access Simon Community services. 10 women participated in discussions which were facilitated by the Women's Harm Reduction Coordinator
- We engaged with SFAD family support organisations from each HSCP area involved in the programme. A group discussion was held with 5 staff members and a volunteer and followed up with individual meetings with staff members to understand what the challenges, barriers and enablers were for people they support in helping a loved one's access to services. We also spoke with a volunteer on 3 occasions to create a case study

- on her experiences of supporting a loved one to access services. A copy of the case study can be found here
- An online survey was distributed to third sector organisations that support people with homelessness and alcohol and / or drug issues. 18 responses were submitted which were analysed by Healthcare Improvement Scotland staff

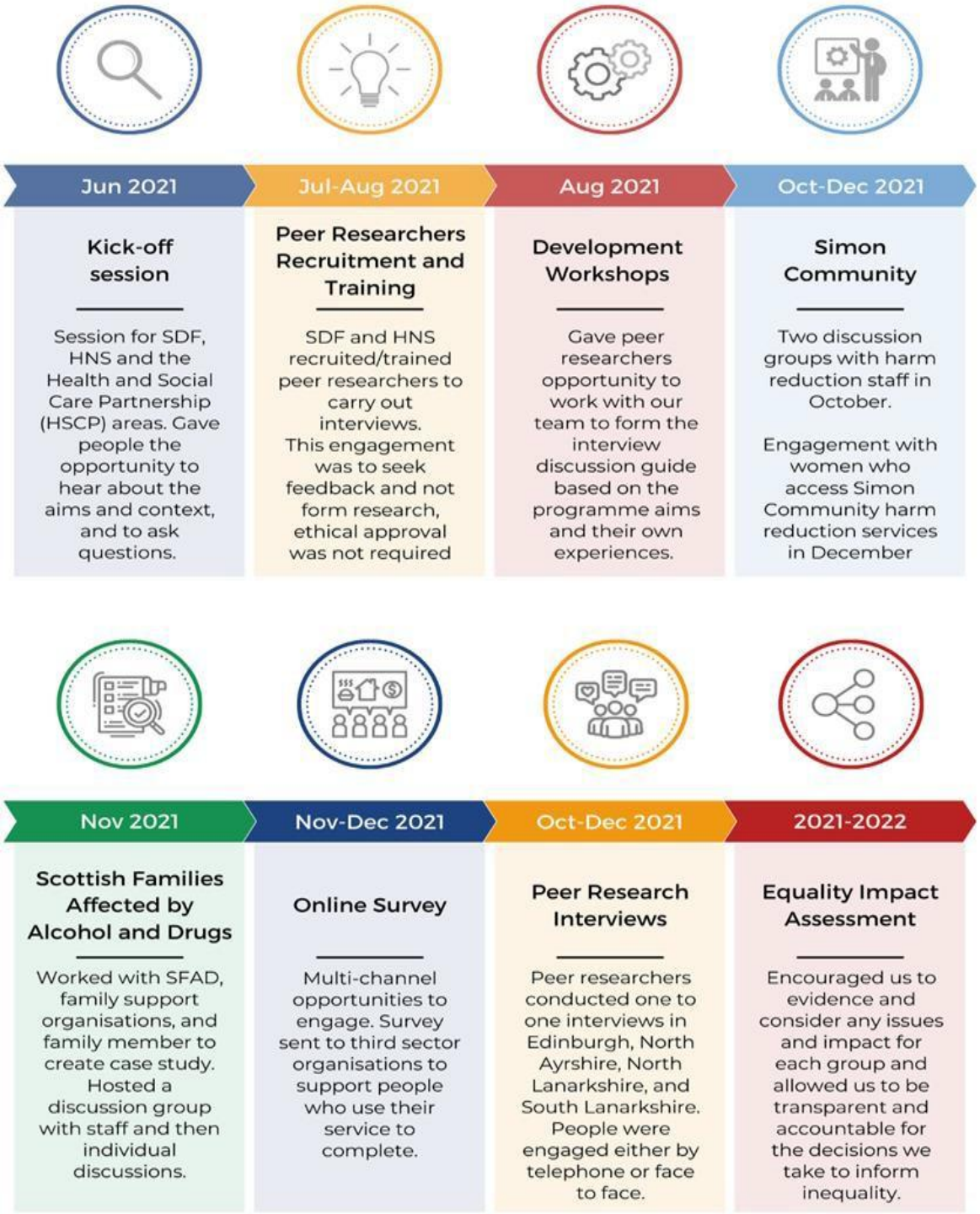


Figure 1: Summary of engagement approach

Analysis

Peer interview transcripts were anonymised, and the data coded and categorised by Healthcare Improvement Scotland. Thematic analysis was carried out to identify the key themes including those based on feedback from the Simon Community, SFAD and our online survey.

The themes identified were validated with the peer researchers who carried out the interviews to ensure accurate reporting of people's experiences. We have used direct quotations in the text below to illustrate all main themes and findings from the overall engagement work.

Results

Demographics

Peer interviews

Peer Researchers completed a total of 53 interviews which the aim of capturing a representative picture of those who access alcohol, drug and homeless services. Figure 2 displays demographics data split by age and gender.

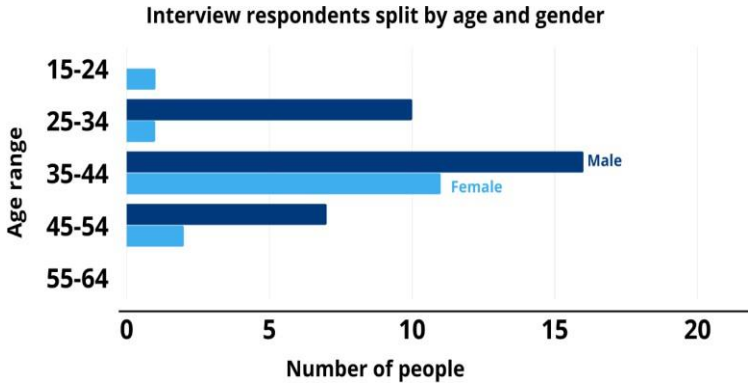


Figure 2: Demographics of interview responders

Online survey

In relation to the online survey, 71% of respondents were male, 29% female and 50% of people considered themselves to have a disability. Please see online survey demographics below.

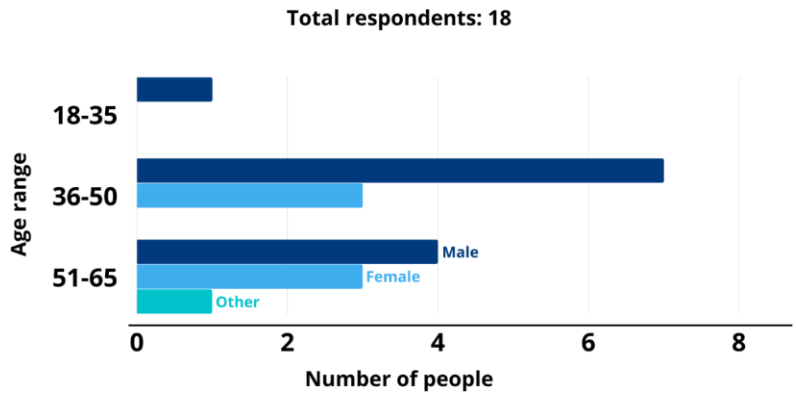


Figure 3: Demographic of online survey responders

Simon Community Harm Reduction Services

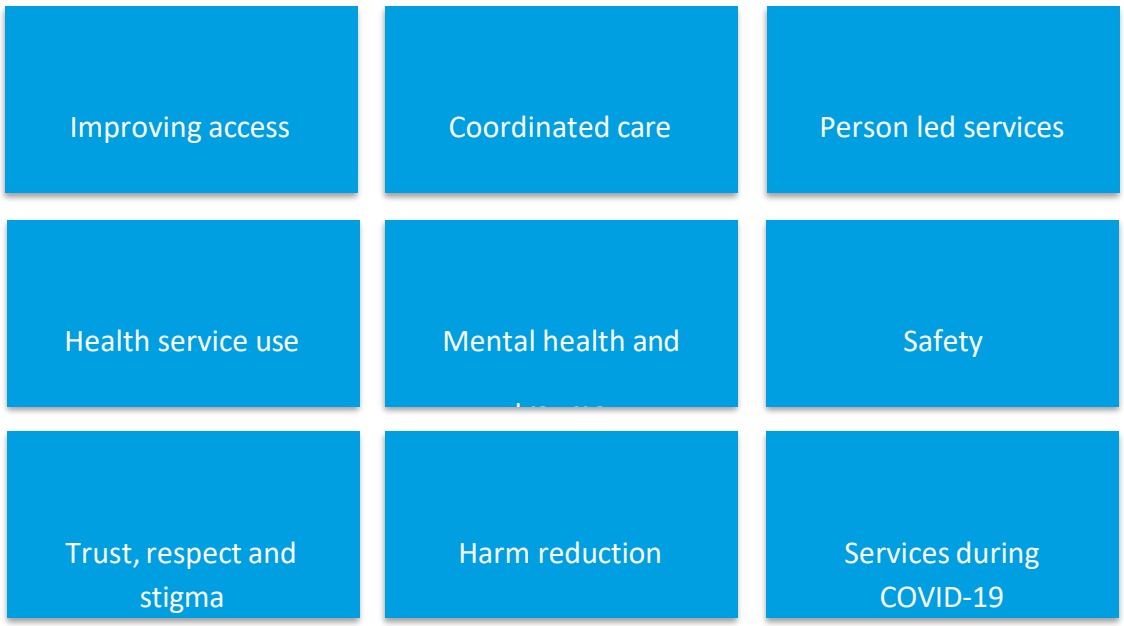
In response to the peer led interviews and online survey, we additionally engaged with 10 women who access Simon Community services.

Findings

Nine key themes were identified. Some of these themes were directly related to questions asked during the peer research interviews and third sector engagement, on the topics of improved access, coordinated care, person-led services, harm reduction, and services during COVID-19. Themes around health service use, mental health and trauma, safety, trust, and stigma were identified through thematic analysis of the interview transcripts and other third sector engagement.

Findings relating to each theme are below. As well as highlighting the challenges people faced, we look at what support could be implemented. Table 1 highlights further quotes from the peer led interviews for each theme.

Themes:



Improving access

- People were often not clear on how they became linked with a particular service as they had multiple entry routes such as through the justice system, social workers, peer support networks, professionals working in other fields or directly from third sector outreach services
- We heard that there were long waiting times for access to housing services (with the exclusion of homeless accommodation provision such as temporary B&B accommodation), addiction services, primary care practices and mental health support
- Women who accessed services told us there were long waiting times to have their own accommodation, this can also have an impact when they have caring responsibilities

'I was getting moved about all the time, from hostel to hostel, I wasn't happy about that. I wasn't getting anywhere moving towards my own house. I don't know why they were moving me'.

- Statutory services are mainly available between normal office hours Monday – Friday. However, several people highlighted that they would have benefited from a 24-hour access system, since in some cases they were escaping domestic violence in the middle of the night or were forced to find emergency temporary accommodation during the weekend
- Service access was made difficult by issues such as: 1) a lack of local connection meant that some people were relocated to areas where they originally came from and where they did not feel safe; (2) people with mobility issues were not offered travel support;
- (3) people often lacked the financial means to use public transport as they could not afford the bus fare, nor had been provided with a bus pass for free; (4) appointments were made at times, or locations, that were unsuitable for individuals. For example, morning appointments are described as more difficult to attend than afternoon appointments, while some individuals found set appointments difficult to attend

- People expressed a need not to be automatically cut off from support services if they missed appointments. Participants described having reminders, or support workers accompanying them to appointments as helpful

'People with complex needs are not in stable recovery (3 strikes and you're out), people are missing out on services, need to look at the wider picture to why people miss appointments'.

- Staff working in the third sector highlighted that mental health should be considered alongside alcohol, drug and homeless needs.

''When services do not work together, people fall through the gaps'.

- People valued when professionals actively sought to support them, for example, when an outreach worker checked on their safety when they were sleeping rough. Our feedback shows that this can be a motivational boost for a person in need, who might then start engaging with a larger range of services.

- Throughout our engagement we heard that, at times, people had to reach crisis point and be a danger to themselves before being offered support or an intervention from service providers.

'But you have to get to the bottom of the barrel before there was help out there, and you have to, you have to get to the bottom of the barrel and then it's, they should be intervened a wee bit sooner, definitely'.

- When a family member is supporting a loved one to access services, we heard that family support is not seen as a priority and people do not feel listened to by services, which is a barrier to involving family members in a loved one's care and treatment.

'Partnership working isn't there, people don't think families need support in their own right. Family members get stuck and are not listened to, it would be useful for them to listen to the families'.

- Family member and carer support is needed to help loved ones to navigate a complex system to access the services they need. Statutory services should consider the benefits of involving family members in a loved one's care and treatment and create mechanisms to support this.
- Services that have a heavy focus on abstinence-based recovery make people who are using drugs and alcohol feel like they are being punished when they are accessing services, or they can feel scared to access them.

Coordinated care

- People spoke of a continuous cycle of referral. Some people described how they actively sought to serve a prison sentence to get access to coordinated addiction treatment
- People described the need for increased levels of support during transition periods, such as when being discharged from hospital, being released from the justice system, or moving into new housing. People reported having negative feelings when transferred to new accommodation with no support in place. Specific examples included:
    - When leaving the hospital, participants described the challenges around securing necessary appointments with clinical specialists or picking up prescriptions
    - People reported leaving prison on a Friday afternoon at 5 pm and struggling to find a temporary bed for the night. Some also said that they had to live without access to opioid substitution therapy for several weeks, until a prescription was transferred from the prison health system to local pharmacy care

    - People spoke of feelings of isolation and loneliness when they were offered new accommodation. This is often exacerbated by the lack of support to develop independent living skills such as cooking budgeting and cleaning
- Some people interviewed spoke of difficulties when accessing benefits, while those who had assistance from support workers welcomed this help
- Often, family members and carers are left to coordination of care across a range of services and find this difficult to achieve
- There were positive examples of service engagement, especially for those who could access a 'one-stop-shop for services', usually through a third sector organisation. Using this approach, one support worker managed all appointments, made referrals, and helped the individual attend meetings as needed. People preferred to have one main point of contact who would then pass on their information and advocate on their behalf to other service providers

'I had people advocating for me and helped me access the services I required'.

'I got that through, when I came in here at first I didn't have a doctor, dentist, chemist, anything, so they sorted out doctors, dentists, chemists, addiction workers, health workers, nurses, so they put all that in place for me'.

- People discussed the challenges with accessing services which were often not coordinated, leaving them to retell their stories and navigating a complex system

'I couldn't understand why they all fought for you to come to my service, we're better, come to mine, and I thought how do you not all work together, because this is people's lives, it's not about who's service is better than who, and I think it's beginning to, look all you are

interested in is getting names on sheets, names on seats, and getting funding, that's how it's coming across to me, I don't know why you aren't all working together now'.

- Staff from third sector organisations were able to provide support for people to access the services they needed, with the most effective family support being provided through third sector organisations, this includes support for children, younger adults, and older family members

'The day I wanted to change my life and decided to stop using drugs all together, the staff helped me by getting me local recovery meetings'

Person-led services

- Some people involved in our engagement were not aware of what person-led services meant for them. In some cases, this was due to terminology, as people recognised the term once explained. Some people described the challenges they had faced with services in relation to specific, personal needs

'We're just a number to them like we're just a number to them, the one day I couldn't get the bus home, because the buses and that were off, and basically they gave my room away

- Often, people we spoke to expressed frustration at a lack of choice in terms of their treatment, care, and housing options. For example, a lack of choice in terms of
- accommodation location was a barrier in some people's recovery journey. While some people wanted to be near friends and family, others wished to be housed out with their normal locality. This links with support in recovery and the requirement to be in a geographical setting which facilitates recovery, away from the structures which may potentially cause relapses

'There's no a mass of nice houses, but if you're going to put somebody who's riddled with addiction in a block of flats, with other people who are riddled with addiction, without giving them some sort support to help them stay in that flat, being around they people that are riddled with addiction, then they're not going to be able to get better, so it's pointless putting them in it, because they're eventually they're going to end up in jail for selling drugs, or using'.

- People described services as not being person-centred when: they had difficulties in accessing support and appointments, were offered a limited choice in their care and treatment options and felt that staff were too busy and did not understand individual circumstances
- Family support services expressed the need for a whole family approach to service provision with an understanding of the challenges family members face. They need to be an equal partner
- Participants housed in temporary accommodation described the short timelines which they were given around moving accommodation, often being told on the day that they had to move
- There were several good examples of person-centred care including where people were involved in decision making, being informed of their treatment options and involved in decisions and pace of changes in their care and treatment. This happened when people had good relationships with services, including third sector services providers, were in control of harm reduction decisions, could determine the pace of recovery and had access to a range of support activities. The key being that they were asked what their goals and aspirations were, and then were enabled to achieve them

'Everything is done on my terms and at a pace that is comfortable for me and all the reviews are led by me which means I have full control over my care plan and my move on plan'.

- People also expressed a preference to talk to people with lived experience. They were seen as trustworthy contacts and could support navigation of the system from a service user perspective

'I'm a firm believer that people that treat us as alcoholic things, you know, people in recovery, should be people that have been through it, I'm a firm believer in that, because

*they, they understand you a lot better than somebody who's just went up the ranks through college and stuff like that, I've had a couple of people like that, and I'll be honest, I've sat there, and I've not took in a f******word that they've said to me, because I know that they hadn't been through what I've been through'.*

Health service use

- People described long waiting times to get access to treatment, not being given treatment options, as well as experiencing long term physical health issues alongside their mental health and addiction issues. However, some people told us that once mental health services were accessed, the support was good

- Participants described challenging relationships with some health professionals, with some describing the negative consequences of this for future engagement and treatment choices

'Want to give you a prescription, and that's it, that's how I feel the doctors' with me, just want to give me a prescription, they don't want to ask me what I've got wrong with me'.

- Issues around accessing opiate substitution treatment were also raised by the those we spoke with:

- Several participants described the process of prescription pick up as stigmatising, because people were often asked to use separate counters which would allow other customers to identify their health issues
- One person told us they were reluctant to complain about the service received as they feared *'being whipped off their script'*. Some people felt that their needs were not being listened to when they were trying to negotiate either an increase or a decrease in dosage. Some participants described instances where they felt empowered and in control when they were offered choices in terms of their opiate substitution therapy

- We heard that people felt that they *'were tied to a chemist'*, as once on methadone, routes to different care and exit plans weren't always clear

> *'I thought they're getting to choose over my life, they get to pick what I've to be on, and why could they not just even have done that with what I've said to them, given me a detox, in the hospital, come off the drugs and then I could go back outside and live my life with being drug free and I was told no, they can't do that, you'll just have to go on the methadone, and be tied to their methadone, tied to their chemists every day'.*

Mental health and trauma

- The majority of people we engaged with spoke about a need for mental health support

- People spoke of issues such as: anxiety, depression, suicide thoughts, psychosis, and PTSD. Some people reported having a combination of mental health and other health related issues, some of which were ongoing, and some were experienced in the past

> *'You need more rehab, you need more counsellors, you need more, everyone is dealing with mental health, that's the only reason they're taking drugs, is to cover their mental health, and the poverty, there's a lot of different issues that's gone on'.*

- People reported experiencing significant levels of trauma leading to issues with mental health and wellbeing.
- Participants discussed experiencing low levels of self-esteem and the confidence to access services. In some cases, this included suicidal thoughts and feelings of worthlessness.

'Yeah, the doctor just saying right, here's some medication and I'm telling them look, I don't want to be here anymore and stuff, and he, if he referred me that day to the CPN, I wouldn't have tried to commit suicide'.

- People told us that it was upsetting to have to repeat their story, and potentially relive their trauma, due to the lack of continuity in support workers or because they needed to access a different service. Most interviewees had previously agreed to have their data shared between different service workers. In some cases, we heard reports of people being frustrated that their case report was not read in full, even though the professional interviewing them had access to the data

*'I said to my Doctor, I said I don't like meeting other workers, I said they don't even take the time to read your file, I said, so you go in there, and you've got to explain it all, because they're too lazy to pick up the file and actually f****** read it'.*

- Participants described the benefits of having someone who they felt would take the time to listen, e.g. support worker, peers, or accommodation staff during periods of instability
- People appreciated having recovery cafes and outdoor activities to attend, as this appeared to improve overall wellbeing

'It's alright, it's, I think everybody is in the same boat the now, they're all depressed, and I suffer from all that stuff, anxiety, depression, bipolar and that, I've got all that stuff, but I still try and get out every day and make sure life's a better day, do you know what I mean'.

- Planning for the future was seen as a positive motivator for people in their recovery journey. This included one person being involved in decisions around reduction of dosage that would allow her to go on holiday with her family
- People spoke of the need for support staff to be trauma informed, leading to a more person-centred and understanding approach
- There is a need for carer and family member wellbeing support from services. The impact for family members, including their mental health, should be considered by service providers
- The most effective family support is provided through third sector organisations, this includes support for children, younger adults, and older family members

Safety

- People told us that they often did not feel safe, particularly when accessing temporary accommodation and collecting prescriptions at pharmacies
- Hostels were often seen as unsafe environments, as individuals may be in a shared room with someone they do not know and have little control over personal living arrangements
- People told us that if they were trying to be abstinent, other residents drinking, using, or selling drugs could jeopardise their recovery. Some people said that they felt safer in prison, or being homeless, compared to a hostel
- We heard that hostels were often the places where people started using drugs if they were not already doing so

> *'Well I would say that if they listened to the people, to where they do and don't want to go, for example, my housing officer keeps trying to put me in areas I don't want to go for my safety, or my daughter's safety and they don't listen, they just pap you about, if that makes sense'.*

- When people could move to a location that met their own needs and circumstances, they felt safe in their home. While some people prefer to be housed near family and friends for support, others prefer to be housed in a new area, away from the people who may impact a return to drug and/or alcohol use

> *'Well I feel with the housing, I've had a say all the way, so I have, housing have been there, they've listened to me, they've actually done everything they can, they've put me into places where I actual feel at home and I feel safe, I'm in my actual own town again, and I feel so safe it's unbelievable, so I do'.*

- People spoke about being targeted by those selling or using drugs in the pharmacy queue as well as being exposed to negative behaviours from peers
- People spoke of similar experiences when coming and going from drop-in clinics and day centres

> *'Where I have to go to pick up my prescription, and I said to them many times, I don't want to be coming here, there's a drug dealer on the corner of the alley that you go in, waiting'*

- In the peer led interviews, women spoke of domestic violence being a route to their homelessness
- Safety is an issue for some women, including when accessing services used by men; women need offers of housing in appropriate areas where they feel safe and away from triggers
- People wanted a feeling of safety to be extended to their family. We heard examples of people living in temporary housing who reported a lack of access to a safe space, in which they could see their children

Trust, respect, and stigma

- We heard that stigma is one of the biggest barriers for people accessing services
- Some people described feeling worse after engaging with services such as
- GPs, drugs or housing services. People described feeling judged, being treated as they were a *'hindrance to their day, their shift'*, treated as *'just a number to tick off'*, and even seen as *'junkies'* unworthy of support.

> *'When I went to addictions, I felt they just looked at me as if I was a junkie, and I didn't like that, because I was begging for help, so basically, I just felt pushed away constantly'.*

- People told us they felt embarrassed and ashamed that they were homeless and used drugs and alcohol and described the negative impact of stigma, leading to a reluctance to access services in the future
    - Third sector partners told us that
- people who access services experience stigma and that services should take a non-judgmental approach when engaging with people who access services

> *'People do not present themselves at the GP or health professional because of the associated stigma, people just need to hear one negative comment and all trust/relationship building is lost'.*

- People told us that service providers did not always understand addiction, for example not understanding the full range of physical symptoms related to withdrawal

> *'Imagine I went in with a broken ankle, right, they wouldn't put a plaster on it and say to me, right, we'll no see you again, because it'll come off itself, but they do that with us, oh you've got a drug and alcohol problem, there's a couple of Valium, a drip and get to ****, there's no follow up'.*

- People had positive experiences when they were offered long-term, consistent contact with the same case worker, as this created trusting relationships

> *Referring to a case worker: 'She has always known me, and she's always treated me like, she never treated me like s*** she just treated me normal, she's just treated me like a friend and that's what I like about her'.*

- People spoke positively about engagement with healthcare professions where they were treated with empathy and compassion and took the time to explain how a specific service worked, and the care a person would expect to receive

Theme 8: Harm reduction

- Some people had been trained to administer naloxone and were carrying naloxone kits (Naloxone can reverse the effects of an opioid overdose and thus is a potentially lifesaving intervention)
- Some people had experienced an overdose themselves or had friends or family who had overdosed
- People told us that they had access to blood borne virus and HIV screening
- People valued having access to clean injection equipment as needed

> *'No, there's no excuse not to have clean tools, because there's, you can go into a chemist and the drug councils have got a wee card that you go in and pass over your card and get your condoms and that on the quiet'.*

- Some people indicated they would benefit from the use of safe injecting rooms
- We heard that support and interaction with third sector services such as the Simon Community had a positive impact on harm reduction
- Third sector staff highlighted the lack of integration and communication between services makes it difficult to embed a harm reduction approach

Services during COVID-19

- People spoke of a decrease in their quality of life during the COVID-19 lockdown
- There was reduced contact with services during COVID-19, this led people to experience a decline in their mental health, which resulted in increased take-up of support from third sector organisations such as the Simon Community

'Women were having less contact with care managers and there was a lack of accountability for meetings to take place, we started to offer emotional and practical support and relationships and trust were really built upon'.

- COVID-19 resulted in the loss of face-to-face support; participants described negative consequences in relation to their mental health because of this change. The frequency and satisfaction with telephone support during the pandemic varied. People worried that their health was deteriorating, but that nobody could observe this change via telephone.

'The doctors and that, they'll need to open up again a bit more, and see people instead of all this phone consultations and all that, it's a lot of rubbish, how can you see a doctor, see me

*I've lost about 4 or 5 stone right, how, see the doctor, he doesn't even notice that he's not seen me, because he's on a f*****g phone'.*

- We also heard that people received infrequent calls and were often given helplines as support systems
- Some people described waits of several weeks for support
- As a result of reduced service contact, people felt an increased sense of isolation, with some saying that they had become demotivated to engage in further social activities or services
- Some people who accessed video meetings said that they felt that they were *'repeating themselves online'* or that they felt it was hard to open up to people on a screen

'Many were closed, or unable to access as I do not have equipment to access online appointments. Most organisations were only offering online appointments. But the nature of those in drug and alcohol recovery is that many of us do not have access to computers. Also, I, like many, find speaking about issues on the telephone too hard'.

- Those who valued access to online meetings and WhatsApp support groups set up by third sector organisations, often reported that they did so because they already knew some of the attending members

'When I went onto 1 Zoom, I noticed 5 or 6 faces from a group that I had joined in the Royal, the new fellowship, so that made me join that group, and I'm still a member of that group, in fact I'm the secretary on that group now, so, but don't get me wrong, I, I felt with Zoom right, I've got to, I can't just go now and sit and talk to them right'.

- Some people spoke of the lack of online access, Wi-Fi or the appropriate devices to access appointments digitally, however others liked the fact that they were given access to a tablet with internet access, as this allowed them to connect to online services that were available and increased their level of digital inclusion
- The number of people experiencing homelessness increased due to relationship breakdowns and third sector staff observed an increase in benzodiazepine use
- Two services set up during COVID-19 were valued by people but have now stopped:
    - Access Practice ran drop-in sessions for same day opiate treatment
    - Prescription delivery service was welcomed, and its removal has left people feeling stigmatised with the trust placed on them during Covid-19 removed

Key areas for consideration

These findings highlight the experience and insights of people who access alcohol, drug and homeless services across four Health and Social Care Partnership areas, Edinburgh, North Ayrshire, North Lanarkshire and South Lanarkshire.

We heard from people who are trying to navigate a complex system to access the services they need, who often have experience of trauma, the prison system or rough sleeping.

Many of the people we spoke to were trying to have their housing, mental health and substance use needs met, with some people being either in permanent accommodation, in a longer-term recovery programme or actively engaged with third sector organisations.

Across all our engagement, people had a shared experience of trying to access services to have their health and wellbeing needs met. The following section of the report details the key areas that require to be considered in the future design and delivery of services.

Improvement activities

Improved access

The way in which people with varying needs access services was viewed as complicated, often requiring referrals and lengthy waits for support. Often the coordination of care is left to family members and carers.

People require an immediate response when seeking support. The engagement highlighted that people should have access to a range of services, joined up support and care coordination as they need and request it, without the need for referral to more appropriate services. Services must have the capacity to adapt and meet the care needs of people at different points in their journey.

To support improved access, services should:

- Not exclude people from services if they do not attend appointments
- Understand the reasons for non-attendance
- Work with people, including family members and carers, to support them to be able to attend
- Ensure that family members and carers have access to the right care and support
- Be trauma informed and non-judgmental to reduce stigma and remove barriers to access
- Consider providing 24/7 services that support people at weekends and after 5 pm

Where services are no longer offered in person, people should be supported with:

- Access to digital devices, either as personal devices or communal devices in trusted community spaces such as libraries, accommodation providers and community centres

- Access to data and the internet
- Adequate support to build confidence in using digital devices, including ongoing technical support through Digital Champions
- Safe, private spaces to access services confidentially

Digital access requirements differ depending on the person's housing situation:

- People living in temporary furnished flats require access to their own device, data and internet and the ability to access support in the community
- People living in temporary / shared accommodation sites require access to communal devices, data and internet and should be supported by key workers to help facilitate access to services

Coordinated care

People described interactions with multiple agencies for various aspects of support, such as for housing, healthcare, alcohol, and drug use needs. Long waiting times were seen as the ‘norm’, which led to increased frustration and in some cases, worsening of the person’s condition. Our engagement identified that people appreciated a coordinated approach to having their health and wellbeing needs met.

Care coordination can support people to have their needs met at the point of contact. Each person requiring support should have a single coordinated care plan, accessible by every agency providing support:

- This should include a personal care and housing plan
- The plan needs to be owned by a key worker in a lead agency with the autonomy to make decisions around that person's care needs
- The care plan should be developed in collaboration with the person
- Family members and carers should be involved in the development of the plan
- Efforts should be made with relevant services and agencies to generate where possible, direct access to services without the need for referral
- Where direct access is not available, services should work together to prioritise people with the most complex needs, avoiding where possible long waits for access
- Mental health should be considered alongside alcohol and drug issues to ensure a coordinated approach to both
- Plans should include support with advocacy and help with day to day living tasks such as cooking, budgeting and cleaning
- Staff supporting care planning should be trauma informed with an awareness of addiction

Insights from support staff identified the need to create pathways exclusive to women and especially younger women who are vulnerable, isolated or do not have access to services, a support network or at present a 'local connection'. Thought should be given to understanding the needs of women to develop services that are safe and provide women with the ability to care for their children whilst in recovery.

Where possible, care planning should include the involvement of people with lived and living experience to generate trusting relationships leading to greater engagement in services.

Choice and control

Our engagement highlighted that people have little choice and control over the care and treatment they receive. It was clear that people are often not aware of the treatment choices available to them.

To increase choice and control:

- People should be informed of the available treatment options on offer and be supported to make decisions on what is best for them. This should include the involvement of family members and carers to support decision making and access to services and treatment
- Support with advocacy should be seen as part of an integrated approach to meeting people's needs and future services should be designed to ensure adequate resource is available to support people with their advocacy needs
- Offers of accommodation need to consider proximity to supports that can aid recovery whilst being mindful of placing people in areas where they can be exposed to harmful behaviours such as violence, drug and alcohol consumption and drug dealing. While housing options may be limited due to availability, these factors are important considerations especially if someone is returning to the community from a care setting, prison or hospital
- People should be involved in decision making about management of opiate substitution treatment, including the increase and reduction of dosage
- Create safe spaces for women and families to care for their children
- Support should be tailored to meet a person's individual needs and this should be considered for any care planning and coordination

Harm reduction

People reported positive experiences of accessing harm reduction services. Services should be aware of existing harm reduction services and ensure people are supported to access these services including:

- Blood Borne Virus screening
- HIV screening
- Safe injecting equipment
- Naloxone provision and training

These interventions were widely valued and helped reduce harm associated with drug and alcohol use.

Conclusion

The findings from our engagement with people reflect published literature, as detailed in the evidence review carried out by the Reducing Harm Improving Care team, and echo the recommendations recently published in the NICE guidelines on Integrated health and social care for people experiencing homelessness.

Our engagement illustrates how people with lived and living experience of homelessness, and who use alcohol and/or drugs can experience a range of difficulties in accessing, engaging with, and staying in services, which often requires support from family members and carers.

Evidence of successful access and engagement included a person-centred approach to treatment and recovery; a trusting relationship with a supportive and consistent key worker; and the use of holistic support to coordinate people's varying needs such as housing, substance use and wider social and living needs.

The recommendations contained within the Drug Death Task Force Changing Lives – Final Report support the findings contained within this report and provide a structure upon which to design and deliver services that meet the needs of the people using them.

Acknowledgements

We would like to thank our third sector collaborators, the peer-researchers and the people with lived and living experience who took time to give us their feedback. This work would have not been possible without them. We would like to thank our Healthcare Improvement Scotland colleagues from the Reducing Harm Improving Care team and the Evidence and Evaluation for Improvement team for their support in this programme.

We aimed to write this report using language that is non-judgement and non-stigmatising. However, we are aware that language tends to evolve rapidly and reflect societal attitude changes towards homelessness and substance use.

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Table 1: Example quotes illustrating the material used in underpinning the analysis themes

Theme	Example quotes
Improving Access	'They don't particularly get in touch with you very often, you know what I mean, I've been homeless for 4 months now, and I've spoke to my housing officer 3 times, you know what I mean, so it's no exactly the greatest'.
	'They usually give you leaflets and that, do you know what I mean, they used to say to you there's leaflets outside, but like basically nobody, you're sitting there rattling, or your sitting there dying, screaming out for help, nobody's really wanting to read a leaflet, do you know what I mean'.
	'It's just the travel all the time to, like half an hour just to walk up to the chemist, and it's a fair walk, do you know what I mean, it's about 20 minutes, so I tried to get a bus pass, but I asked the housing worker, and she said aye, and I asked the doctor at Caly Court, and they said aye, but I still didn't get it, that was months ago'.
Coordinated Care	'I just feel as if I'm getting knocked about between a chemist to a doctor to a psychiatrist'.
	'When my support worker phoned, she'd left, she didn't even phone me to tell me that she was leaving and she was passing my medical records onto somebody else, so I was quite upset with all that, because it's been a very long progress for me'.
	'I'm sitting in my living room and I've got, somebody put my window in, when I was in the hostel, well about a month ago, and I was sitting with a broken living room window and I'm, it was just getting passed from pillar to post and this one to that one, to that one. That's how I ended up in hospital, do you know what I mean, sitting in the living room with a fucking, with a bit of board in the full window is out, it's f******g, it's freezing'.
Person-led service	'No, there was no plan, I went in and I told them that I'd used or whatever, methadone was instantly going up, but there was never any, any plan as to how long I was going to be on it or a reduction plan or anything'.
	'They never even, I was never even given the choice of was it methadone I wanted to be on, or was there any other options'.

	‘The drug support, the drug support was s***e, I felt at the beginning, I never ever wanted to go on methadone, because I didn’t see the point of replacing one item with another item, there wasn’t much point in that, and she said, oh no, I’ll just be a temporary thing and then I got put on it, and never ever seen the worker again’.
	‘All these years I’ve been on a script, I haven’t had a doctor once say to me, how do you feel about getting clean’.
Health service use	‘I’ve had GP’s that are, I feel they’re talking down to me, as if I’m just nothing but a, sorry to use this word, but like a junkie’.
	‘I think some of the, some of the doctors should really sit and look in the mirror and say, think about the way they’re speaking to the person, because when you leave the, the office, the only word for it I can say is you feel soul destroyed, like you’re getting nowhere’.
	‘I think they kind of, they see you as a hindrance, instead of somebody who’s not well, they don’t see you as somebody who’s ill, the see you as somebody who’s self-inflicted, whereas we know it’s an illness, they’ve no got a clue about this illness, and they’re medical professionals, they don’t even know it’s an illness that matters to that’.
	‘I don’t, I think they’re really good people at the NHS, I think that they look at people with addictions and it’s basically a nuisance, and they’re just like so happy to get rid of you, rather than like help point you in directions like, there’s no connection, in my personal experience’.
Mental health and trauma	‘Well see when I was homeless, I just wanted to drink and black out, like blank things out, because I thought to myself, I’ve no got a future here, I just want to die, I just want to die, so I thought to myself, if I just drink and drink and drink, I might just die in my sleep’.
	‘I was at my mums, maybe like a year ago, when I was still taking the street diazepam, and my mum could see that I was having, nearly having a breakdown, and I was nearly in tears, because I felt I’d no help from nowhere’.
	‘I’ll walk round the streets half the time while I’m waiting to come back in here, and I’m just thinking about things in the past, and thinking about my kids and that, and I can feel myself welling up nearly crying, breaking down as I’m walking down the street, you know what I mean,

	I've got to fight that back, and then it's like I do need to get help with my mental health, I really do, because it's deteriorating badly'.
Safety	'Like you're sending people there to go and come, get over their addiction yet you've got a dealer on, right outside'.
	'I've spoke to my worker about trying to get out of where I'm at, because I don't feel safe for that people, people buzzing my door to get in to my house to use drugs, and I'm, I'm trying to come away from that, I'm just getting fed up with it'.
	'I got a flat down in Airdrie, next, it's down next to the street, and there was a heroin dealer that stayed in my close and I couldn't get peace from them, buzzing then early in the morning to get in to go and get their stuff'.
Trust, respect and stigma	'These text book people, you need to have people like yourselves, that know what it's like to be on something, no these people that are reading from a book, like the social worker that phoned me, right away I could tell she wasn't a mother, she's a text book, I'm like that, I can't, I can't, you can't come down to my level, you're looking, judging me from the minute, from the minute I've met you, you're judging me'.
	'I feel like sometimes in hostels, some of the workers just don't care, they feel like oh they're a f*****g junkie, and alchy, do you know what I mean, that's the way we see them, and it's so sad'.
	'when I went to addictions, I felt, just looked at me as if I was a junkie, and I didn't like that, because I was begging for help, so I basically, I just felt pushed away constantly'.
Harm reduction	'I've done my naloxone training, I've got, I carry naloxone, my friend, people on the street before overdosed'.
	'No, there's no excuse not to have clean tools, because there's, you can go into a chemist and the drug councils have got a wee card that you go in and pass over your card and get your condoms and that on the quiet'.
	'R: So what does substance, what does reducing harm in relation to substance use mean to you? M: What do you mean by that?

	R: So basically have you heard of naloxone, has that been, have you, has that been mentioned to you before? M: No'.
Services during Covid-19	'I mean during Covid it was phone calls, which was fine, but then you go out and about go and see the people, and sit down face to face, and have a talk, but through lockdown it was really a phone call and never got out the door, it was a hard on your mental health, you know'.
	'I felt like a prisoner and that, that made my kind of mental health and depression like even worse, it really, I didn't know anybody, I didn't know where to go, it was, it was really quite scary'.
	'A lot of people ended up dying because of they were isolated, and they were taking drugs in their house themselves, and I lost a few pals to addiction'.

Appendices

Appendix 1: Copy of interview schedule

Service User Interview
Peer Researcher Questions

Remind the participant that the interview is being audio recorded but that they will be kept anonymous and non-identifiable. Questions in italics are prompts to be used as needed to gain more information.

Section 1 – Demographic information

- How would you describe your gender?
- What age are you?
- What area do you live in?

Section 2 – Improving access

- What services have you used?
  Are these Addiction and/or Homelessness services? When did you use these? If you've used before and since Covid-19, how have the services changed? Has the change been good/bad? How long did you use them for?
- How did you find out about these services?
  Did someone tell you about them? Were you referred by a worker? Did you self-refer?
- What motivated you to access these services when you did?
- Was it easy to access them when you needed/wanted them?
  Were there any barriers to access? Did you need any support to attend? Did you get this support? What else might have helped?
- Did the services you used meet your needs?
  How did they do this? Interventions? Assessments?
- When you accessed the services did they explain what would happen with your data/information and how this may help you?
- Do you feel Addiction and Homelessness services work together?

How do they do this? How could they do this more?

- What is the most accessible/best service you have used and why?
- What is the most challenging service you have used and why?
- Are there any other local support services you are aware of but have not used/mentioned so far?

Section 3 – Reducing Harm

- What does reducing harm in relation to substance use mean to you?
  E.g. reduction/increase in substance use, prescribed MAT, Naloxone, BBV testing, Injecting Equipment Provision (IEP)

- What does reducing harm in relation to homelessness mean to you?
  E.g. supported accommodation, Housing First, own tenancy?

- Have you experienced harm reduction efforts/interventions from services?
  What were they? Were they effective for you? What else might have been helpful?

- Do the harms with substance use and homelessness impact each other?
  Do services support with this? How could this be done better?

- How can housing allocations best be used to reduce harm?

Section 4 - Better (Person-Led) Services

- What does the phrase 'person-led service' mean to you?
  Would you say services you have accessed match up with this definition?

- How much of a say did you have in your treatment/care at these services?
  Were you given choice in interventions (e.g. type of MAT, accommodation)? How was this choice explained/offered to you? Did you ever feel you didn't have a choice? What did that feel like?

- How would you describe your experience with the service staff?
  Did they involve you in your treatment plan, etc.? Did you feel respected and listened to? Were they skilled in treatment provision you needed?

- How did the services communicate with you?
  Was this good? How could it have been better?

- Would you be willing to share your information with all services that may be able to support you?

Appendix 2: Copy of online survey

ADP and Homeless Programme: Reducing Harm, Improving Care Online survey participant information:

By completing this survey, you are consenting to Healthcare Improvement Scotland using the information you provide for the purposes stated in the survey introduction. Any personal information that you give us will be kept confidential and will only be used for the reasons that have been specified in this survey. We will not give your information to outside organisations (apart from organisations processing the information on our behalf) unless you have given us your permission. Whenever we intend to give your personal details to other organisations we will ask for your permission first.

The findings from the survey will be analysed by Healthcare Improvement Scotland, Scottish Drugs Forum and Homeless Network Scotland and written up for a report which will be shared with The Scottish Government and services/organisations across Scotland. Your name or any identifiable information will not appear in the report or in any presentations.

We may use quotes you give when reporting but all quotes will be anonymised. It will not be possible for anyone to link anything in the report to you.

When you have completed this questionnaire to your satisfaction, please click "Finish Survey" at the bottom of the final page.

Healthcare Improvement Scotland is a national NHS organisation which has been asked by the Scottish Government to develop a programme to improve the quality of care people receive from services, and to achieve better health outcomes for people who experience homelessness and use drugs and/or alcohol. Healthcare Improvement Scotland is working in partnership with Scottish Drugs Forum and Homeless Network Scotland to speak with people with lived and living experience of drugs, alcohol and homelessness in four Health and Social Care Partnership areas, these are North Lanarkshire, South Lanarkshire, North Ayrshire and Edinburgh.

We want to understand the experience people have when they access alcohol, drug and homeless services, and to gather thoughts of how it could be improved. Feedback will inform our understanding of alcohol, drugs and homeless services, and the challenges,

barriers and enabler's people have experienced. Feedback will help shape and design future alcohol, drug and homeless services.

If you want to find out more about this survey and the ADP and Homeless Programme: Reducing Harm, Improving Care, please contact his.housing@nhs.scot.

For further information, you can also visit ADP and Homeless Programme: Reducing Harm, Improving Care.

Improving Access Questions

1. What services have you used in the last 2 years?

Before Covid 2019/20

☐Alcohol and drug services

☐ Homeless services

☐ Mental health

☐ Other

Other (please specify):

During Covid – from March 2020

☐Alcohol and drug services

☐ Homeless services

☐ Mental health

☐ Other

2. How do you think services changed during Covid?

2a. Alcohol and Drug services:

2b. Homeless services:

2c. Mental health:

2d. Other:

3. How did you find out about the services you require access to?

Before Covid 2019/20

☐Word of mouth

☐ Referral by a service

☐ Self-referral

☒ Other

During Covid – from March 2020

☐Word of mouth

☐ Referral by a service

☐ Self-referral

☐ Other

During Covid – from March 2020

Other (please specify):

☐ Yes
☐ No
☐ Don't know

4. Did you face any barriers in accessing services?

Before Covid 2019/20

☐ Yes
☐ No
☐ Don't know

5a. If yes, can you tell us what those barriers were?

5b. What do you think would have helped overcome the barriers?

5c. If no, what helped to make sure there were no barriers in place?

Reducing harm questions

5. Thinking about a time when you have needed help, what intervention(s) have helped/would help the most?

Person-led service questions

Person Centred services treat people who use services with dignity and respect and involve them in decisions about their own health, putting them at the centre of their care.

6. Reflecting on your experience of services –

Do you think the services you use are person centred?

Before Covid 2019/20

☐1.Very person centred

☐ 2. fairly person centred

☐ 3. Not sure

☐ 4. Sometimes person centred

☐ 5. Not at all person centred

During Covid – from March 2020

☐1.Very person centred

☐ 2. fairly person centred

☐ 3. Not sure

☐ 4. Sometimes person centred

☐ 5. Not at all person centred

7. What was it that made the service(s) person centred?

8. In what way was the service(s) not person centred?

9. Reflecting on your experience of services –

a) Do you feel like you were involved in decisions around your care and treatment?

Before Covid 2019/20

☐ Yes

☐ No

☐ Don't know

During Covid – from March 2020

☐ Yes

☐ No

☐ Don't know

Additional comments:

10. Reflecting on your experience of services, could you tell us what a good service would look like for you?

Equality monitoring questions

How old are you?

☐ 18-35

☐ 51-65

☐ 36-50

☐ Over 65

- I do not wish to disclose this

What is your sex?

- Male
- Female
- I do not wish to disclose this
- Other:

Please select the option which describes your ethnic origin:

- White
- British
- Scottish
- English
- Welsh
- Any other white background
- Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background
- Mixed
- White and black Caribbean
- White and black African
- White and Asian
- Any other white background

- Black or Black British
- Caribbean
- African

- Any other black background
- Other Ethnic Group

- Chinese
- Any other Ethnic Group

- I do not wish to disclose my ethnic origin

Please select the option which best describes your sexual orientation:
Do you consider yourself to have a disability?

- Yes
- No
- I do not wish to disclose this

Please indicate your religion or belief:

- Atheism
- Buddhism
- Christianity

- Islam
- Jainism
- Sikhism

- Hinduism
- Judaism
- No religion

- I do not wish to disclose this
- Other:

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