Falcon
Homeless & Community Support

UNDERSTANDING THE BARRIERS TO SEEKING TREATMENT FOR ADDICTION

RESEARCH INSIGHTS
FINDINGS FROM QUALITATIVE AND QUANTITATIVE RESEARCH

2023

FALCON SUPPORT SERVICES E.M LTD IN PARTNERSHIP
WITH KAREN KELLARD, LOTUS SOCIAL RESEARCH
REGISTERED CHARITY 1103101

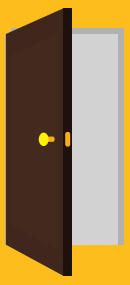
RECOMMENDATIONS

01
INCREASE AWARENESS OF SERVICES WITH EFFECTIVE COMMUNICATION

02
FLEXIBILITY WITH SERVICE TIMINGS

03
REVIEWING SERVICE LOCATIONS

04
DROP IN STYLE INTERIM SUPPORT SERVICE



05
EXPANSION OF PEER SUPPORT AND MUTUAL AID PROGRAMMES

06
INCREASED ABSTINENCE-BASED SUPPORT

07
INTEGRATED SERVICE TO MENTAL HEALTH SUPPORT

08
NEVER GIVE UP APPROACH

Falcon

Homeless & Community Support

UNDERSTANDING THE BARRIERS TO SEEKING TREATMENT FOR ADDICTION – RESEARCH INSIGHTS

FINDINGS FROM QUALITATIVE AND QUANTITATIVE RESEARCH

FALCON SUPPORT SERVICES AND
KAREN KELLARD, LOTUS SOCIAL RESEARCH SERVICES

AUGUST 2023

Contents

1. Summary

1. Background

This research was commissioned by the Public Health department within Leicestershire County Council who wished to explore barriers to treatment services for drug and alcohol users who do not currently use services to inform their future strategic planning and commissioning.

The aim of the research was to better understand and meet the needs of vulnerable and priority groups by identifying:

- Inequalities
- Reasons for non-engagement in treatment
- Gaps in provision
- Recommendations for improving the pathways

1.2 Methodology

The research was conducted by Falcon Support Services, a well-established Leicestershire based charity, who targeted those that are the hardest to engage including people experiencing rough sleeping and homelessness, vulnerable priority groups including sex workers, drug users who are not in contact with treatment services and young people not accessing services.

The report presents the findings of qualitative and quantitative research completed with:

- 73 anonymous participants with lived experience via surveys
- 68 anonymous professional via surveys
- 12 participated in focus groups
- 22 in depth interviews with participants with lived experience
- 6 in depth interviews with professionals

Those that participated in the research were self-selected, all aged over 18 years old. Confirmation was confirmed prior to engagement.

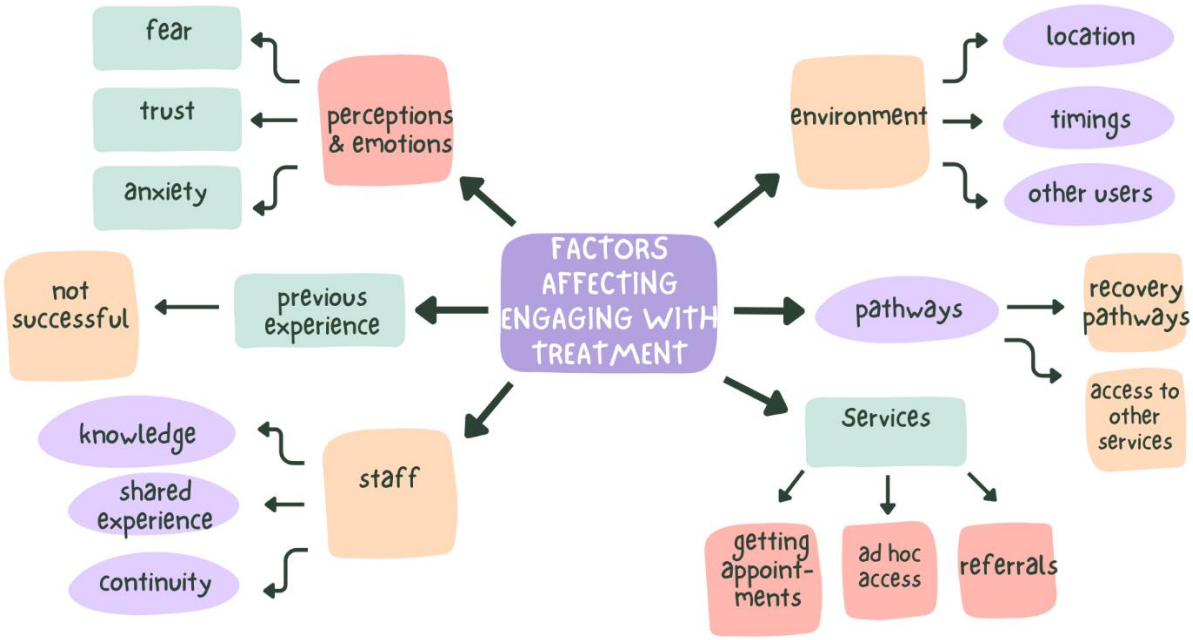
Findings

The report identifies six key themes affecting engagement:

- Perceptions and Emotions: Fear, trust, anxiety, stigma
- Environment: Location, timings, other users
- Services: Referrals, getting appointments, ad hoc access, information

- Staff: Knowledge, shared experience, continuity
- Pathways: recovery pathways, access to other services
- Previous Experience.

Figure 1 Summary of factors affecting engagement with treatment services



This study has identified a number of defining features that appear to be beneficial for clients accessing addiction treatment services. These include:

- Positive consistent relationships with workers in a face-to-face capacity. Participants benefitted from trusting relationships with consistent workers. Many felt the ability for workers to be psychologically and trauma informed, welcoming and non-judgmental contributed to their success.
- Peer support. Participants found inspiration and a wealth of knowledge in those who had lived experience. Peer support was instrumental in someone's recovery long term.

This study has identified a number of defining features that appear to be gaps in service provision:

- Universal mental health support,
- Limited access to detox and rehab
- Prevention work

Recommendations

Based on the findings of this study, the following recommendations are made for improving addiction treatment services:

- An effective communication at a local level to raise awareness of the service offer and processes,
- Increased prevention work in schools, colleges, youth settings and training for workers of educational establishments,
- Review of the current offer to ensure services are delivered flexibly with regards to location, environment, and timings,
- A ‘drop in’ interim support service to meet the needs of the individual either whilst they wait to be allocated a worker or in between contacts with their worker,
- Investment in the recovery community, strengthening the Peer Support programme and use of mutual aid meetings,
- Development of an abstinence-based offer,
- A whole systems approach for those facing addiction with mental health difficulties,
- A “Never give up” approach.

Whilst we acknowledge the limitations of the studies, these recommendations are based on the experiences of participants with lived experience and professionals, which is intended to improve the quality and accessibility of addiction treatment services. By implementing these recommendations, we can help more people achieve long-term recovery from addiction.

1. Introduction

This research was commissioned by the Public Health department at Leicestershire County Council and carried out by Falcon Support Services. The report presents the 18-month project and findings of qualitative and quantitative research to explore barriers to treatment services for drug and alcohol users.

1.1. Background to the research

Public Health wished to have a greater understanding into the reasons people don't engage in the commissioned Integrated Substance Misuse Treatment Service (ISMTS) to inform their future strategic planning and commissioning.

The research was commissioned to target those that are the hardest to engage including people experiencing rough sleeping and homelessness, vulnerable priority groups including sex workers, drug users who are **not** in contact with treatment services and young people not accessing services.

This would be achieved by engaging with participants with lived experience within community settings such as the Falcon Centre, Exaireo, Carpenters Arms, Nottingham Community Housing Association (NCHA), The Bridge (East Midlands) street outreach, needle exchange and treatment houses as well as mutual aids meetings including Narcotics Anonymous (NA) and Alcoholics Anonymous (AA). Unfortunately, due to the confidential nature of the meetings we were unable to access mutual aid meetings as part of this research.

1.2. Research aims and objectives

It is believed that there are a number of residents within Leicestershire with a need for substance misuse support that are either not receiving it or receiving support from other sources rather than the Integrated Service; this is believed to potentially be via sources such as treatment houses, Alcoholics Anonymous, Narcotics Anonymous, private rehabs centres or hostels. This project is to understand and ensure that Public Health are meeting the needs of vulnerable groups by identifying:

- Inequalities
- Reasons for non-engagement in treatment

- Gaps in provision
- Recommendations for improving the pathways

Project Timeline

During the period of the project, Phase 1 included the pre-research literature review, including building a knowledge base, identifying partners to take part in the research, exploration of bias and ethics considerations, creation of surveys, interviews and focus group questions.

Phase 2 included the dissemination of the survey, sourcing and completion of interviews and focus groups.

The final Phase 3 included the analysis of the research, report write up and recommendations.

Pre research literature review

The pre research literature review (Appendix A) was developed to understand the landscape of those accessing treatment for substance misuse and reviewed the scope nationally and locally, furthermore reviewed research informed the development of evidence for the research proposal, methodology and ethics.

Ethical Considerations

Work has been undertaken to ensure that bias was explored in all areas of data collection and a fair representation has taken place.

- Respect for autonomy: Research participants should have the right to make voluntary and informed decisions about whether or not to participate in research.
- Beneficence: Researchers should strive to maximise the potential benefits of their research while minimising the potential risks.
- Non-maleficence: Researchers should avoid causing harm to research participants.
- Justice: Research should be conducted in a fair and just manner, and the benefits and burdens of research should be distributed equitably.

Research has been conducted in a responsible and trustworthy way with GDPR compliance and full consent (Appendix B). Given the nature of the research participants it was important to protect the rights and welfare of research participants, and to promote the public good.

Methodology

Research design

The research used a mixed-method approach, which included a survey of participants with lived experience and professionals working within the services. Focus groups and in-depth interviews were self-selecting participants recruited through the online survey.

Service user perspective questionnaires on barriers to seeking treatment for addiction Completed:	73
Professional's perspective questionnaires on barriers to seeking treatment for addiction completed:	68
Service user in depth interview on barriers to seeking treatment for addiction completed:	22
Professional user in depth interview on barriers to seeking treatment for addiction completed:	6
Focus Group 1 on barriers to seeking treatment for addiction total participants:	5
Focus Group 2 on barriers to seeking treatment for addiction total participants:	7

1.3. Survey

A self-completion survey was circulated to the participants with lived experience and professional participants via survey monkey. The initial online survey was an invaluable tool, not only because it was quick to answer but it was instrumental in getting people interested in taking part in the in-depth individual research interviews. The outcomes of the online survey also informed the discussion guide for the in-depth individual interviews. Paper copies of the online survey were also provided to gain a larger reach and engagement in the survey. A copy of the questionnaire is in Appendix C.

Surveys were anonymous and it is not clear if those that completed a survey attended focus groups or interviews; therefore, comparisons have not be made and all surveys, focus groups and interviews have been analysed in insolation.

1.3.1. Recruitment and sample details

Housing and substance misuse services working in Leicestershire were contacted by email to publicise the research project and recruit participants. The organisations contacted were:

- Turning Point
- Exaireo
- The Bridge East Midlands
- John Storer House
- East Midlands Housing Association
- Carpenter's Arms
- Rough Sleepers Initiative (RSI) Outreach Team
- District Councils
- Drug rehabilitation centres
- Treatment houses
- Prisons
- Mutual Aid groups

In-person events including treatment programme graduation ceremonies were attended to discuss the research project and gather interest in taking part.

Two focus groups were held with participants with lived experience to provide an alternative method to capture peoples' thoughts and experiences.

1.3.2. Recruitment and sample details

Focus group one comprised five participants, three females and two males, ranging from aged 31 and 52 at the time of the fieldwork. All participants had been engaged with the commissioned service previously; three were in established recovery and no longer engaged with the commissioned service or their aftercare programmes; two participants were currently engaged with their aftercare programme.

1.3.3. Focus Groups

Focus group two comprised seven participants, three females and four males, ranging from aged 22 to 53 at the time of the fieldwork. All participants had engaged with the commissioned service at some point previously: three participants had refused to engage with the commissioned service again; one participant was still engaged with the commissioned service and three participants were engaged with their aftercare programme.

1.4. Qualitative in-depth interviews with participants with lived experience

Qualitative methods of research provide the best vehicle to explore complex problems and can better examine the interwoven reasons why a person may not access a commissioned substance misuse service. In-depth individual interviews were chosen as the method to engage this cohort due to their vulnerabilities, hard to engage and the need for flexibility. This method provided the participants with the opportunity to engage and express their views and experiences in a safe and confidential space.

The interviews were conducted in either the office building of the organisation they were being supported by, a local community building or in a place of the participants choosing. A £10 voucher was paid as an incentive to each participant.

1.4.1. Recruitment and sample details

A total of 25 respondents were recruited to take part in the interviews but three withdrew before the interviews were completed. 22 participants took part in the individual in-depth interviews; six identified as female and 16 as male. Four of the participants with lived experience were also working in the sector, either for the commissioned service or for a support agency. Participants received a voucher of £10 as a thank you for being part of the research. All participants signed a consent form, which outlined the purpose of the research, and its confidential nature.

Five of the 22 participants were recruited at the commissioned service and were interviewed at the premises; one additional interview was organised by the commissioned service. The remainder were recruited through the self-selection questionnaire as they were asked to indicate if they would be willing to take part and through the housing and support agencies contacted.

Of the 22 participants:

- 8 were Falcon Support Services residents or Drop In users
- 1 sex worker
- 9 had experience of rough sleeping
- 7 were noncommissioned service users
- 1 was a relative of a 13-year-old accessing the commissioned service.

1.5. Qualitative in-depth interviews with professional participants

Six in-depth interviews were conducted with staff working in the sector; two had experience working for the commissioned service, the remainder worked in homelessness services. The purpose of these interviews was to compare the experiences of the professionals with those participants with lived experience and to identify similarities and differences. This followed on from the self-completion questionnaire as there was a noticeable difference in the opinions of the professionals working in the sector to those using the services.

1.6. Analysis approach (use of transcripts, thematic coding etc)

The data collected via the self-completion questionnaire was entered into Excel and are presented in charts in this report to provide quantitative context to the qualitative data.
The qualitative data from the focus groups and in-depth interviews was transcribed verbatim and then reviewed to identify themes and sub-themes across the domains of interest.

Data was then coded thematically to those themes:

- Pre-contemplation - where there is no intention of changing behavior; the person may be unaware that a problem exists. [1]
- Contemplation - The person becomes aware that there is a problem, but has made no commitment to change.
- Service

[1] Prochaska, J.O. and DiClemente, C.C., 1986. Toward a comprehensive model of change. In *Treating addictive behaviors: Processes of change* (pp. 3-27). Boston, MA: Springer US.

- Expert by Experience.

Direct quotations (anonymised) from participants have been used throughout the report to illuminate the findings. In some cases, words have been added to improve the readability of the quotation – these are identified in [square brackets]. Furthermore, ellipses (…) have been used where text has been removed from a part of speech as it was not relevant for the point being made. However, the quotations themselves have not been changed and reflect the direct speech of participants with lived experience.

Quotation sources may be identified as follows:

- FG 1 or FG2 = participants with lived experience focus group one or participants with lived experience focus group 2
- IDI xxx = participants with lived experience in-depth interview
- PP xxx = professional participants in-depth interview.

1.7. Report structure

The remaining sections outline the main findings from the research:

- Section 3 describes participants' circumstances at the time of fieldwork, in relation to their substance misuse
- Section 4 outlines participants with lived experience's journeys to treatment services including pre-contemplation and their preparation in taking the first steps to recovery
- Section 5 describes their experience of accessing treatment services
- Section 6 draws on those experiences to provide a greater insight into the barriers and facilitators to accessing treatment services
- Section 7 reflects on the findings to provide a summary and consideration of implications for both policy and practice.

2. Participant circumstances

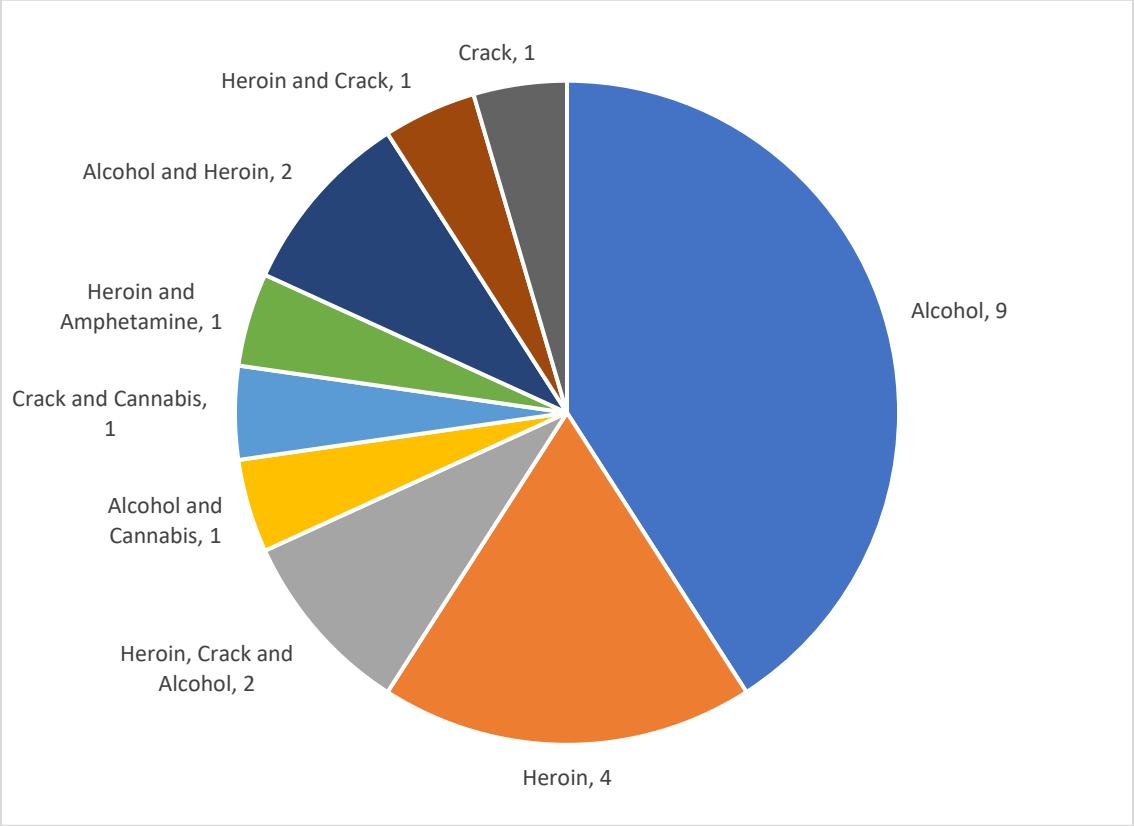
2.1 Drug and alcohol use

In Focus Group One, three participants' choice of substance was alcohol and for the remaining two it was multi-drug use. In Focus Group Two, two participants' substance of choice was crack-cocaine and heroin use, one was cocaine, one alcohol, and two were abstinent from alcohol.

Among the cohort interviewed individually, over a third identified alcohol as their main substance of choice (see Figure 2), with the remainder identifying heroin or crack only, or a combination.

Of the 22 participants interviewed in-depth, nine had been involved in the criminal justice system and associated drug/alcohol treatment (none had become abstinent through this route).

Figure 2 *Participant's substance of choice (self-identified)*



n-22

3. Journeys to treatment services

For many participants, the journey to treatment services began with both an acknowledgement of needing help, and a willingness or ability to seek out help before their journey to recovery could commence. Participants spoke about this 'pre-contemplation' phase followed by the subsequent contemplation and preparation for taking the first steps to treatment, and the fears and concerns that they felt at that time.

3.1 Pre-contemplation

The pre-contemplation phase – an inability to see how their usage of drugs and/or alcohol is problematic, or unable to recognize the impact or implications of their actions – was often discussed among participants as their first step in their journey to recovery. Many spoke of being referred to services previously or being persuaded by a family member or partner to see help, but not being 'ready' to commence until they acknowledged to themselves that they needed help and did not want (or could not) sustain their lifestyle.

> *I wasn't interested in that I went once just for someone, I went because she wanted me to go (IDI 101)*

> *Over the many years I was in and out of treatments with my substances and I was almost pushed from parents. I wasn't ready myself … (IDI 108)*

> *I wasn't really accepting that I was an addict … no matter how much you try and help somebody if they're not ready to help themselves, you can't (IDI 109)*

> *But you've got to do it yourself. You can't do it for your partner. You can't do it for your, You can't even do it for your kids. You got to do it for yourself. (IDI 103)*

> *But when I finally, finally, finally surrendered and admitted verbally my problem and went to a Turning Point… because I wanted to get better (FG1)*

This is reflected in the survey data (Figure 3 and

Figure 4); for participants with lived experience in particular feeling that they could manage their circumstances without help, and not thinking of themselves as an 'addict' were identified as key barriers to accessing help, and staff also noted the importance of participants with lived experience recognising that they had a problem and needed help.

Figure 3 *Attitude on use at the pre-contemplation stage (comparison of professional participants - staff views and participants with lived experience perspectives - service users) This was compared to understand the differences in perspectives.*

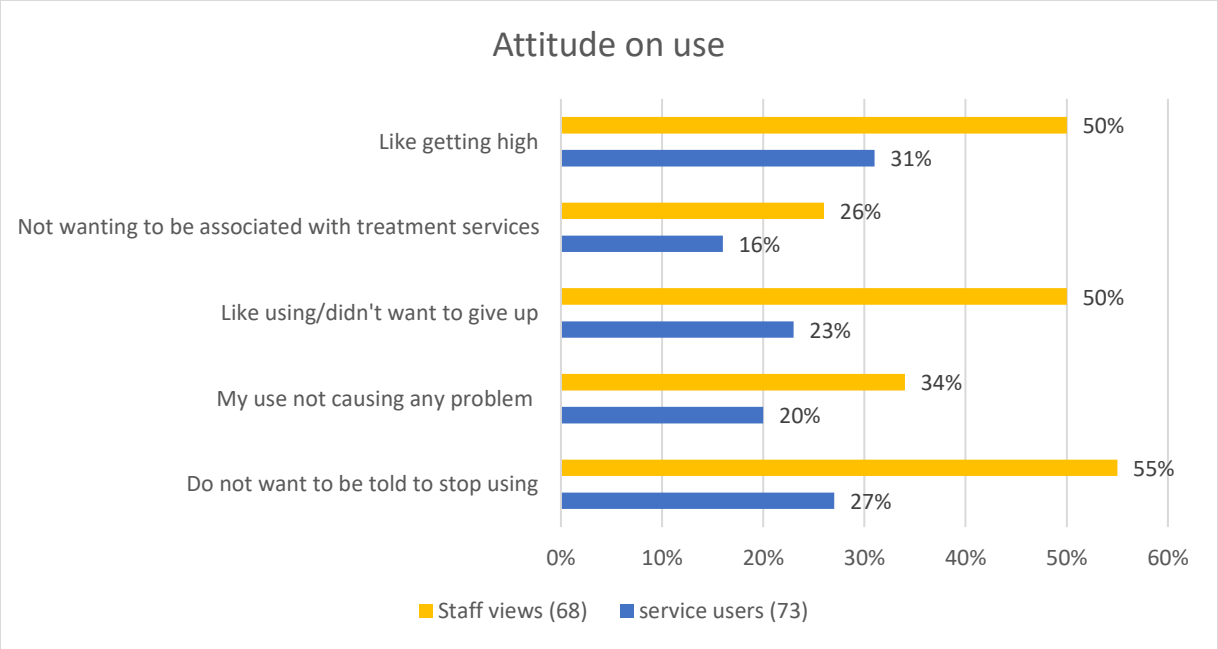
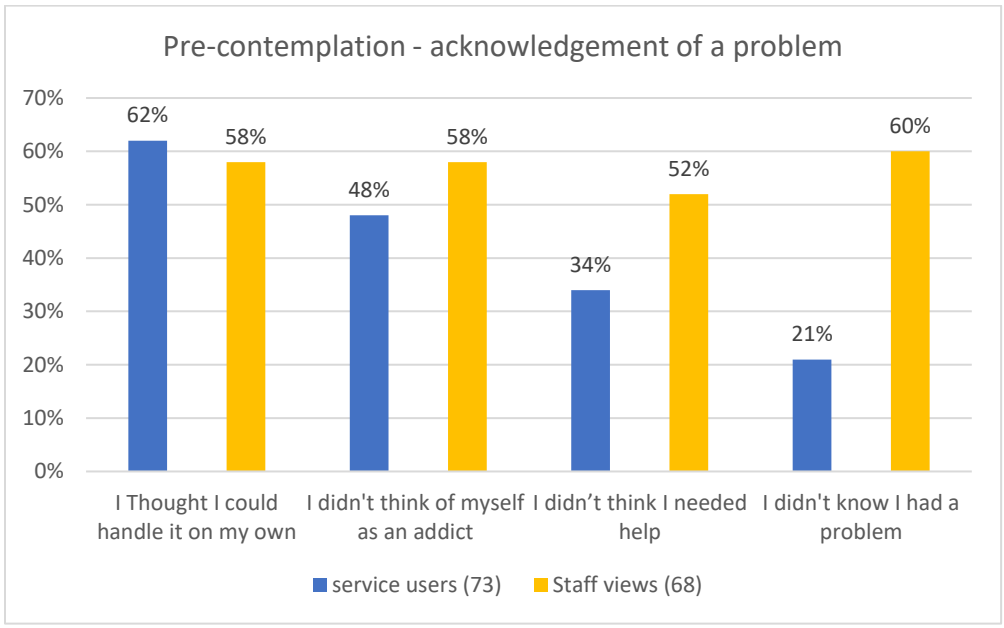


Figure 4 *Acknowledgment of a problem (comparison of professional participants - staff views and participants with lived experience perspectives - service users)*



For many participants, this recognition was often triggered by a particular event in their life, such as a family or partnership breakdown or a period of poor health/hospitalisation.

> *I tried to stop, didn't realise that stopping drinking would end up killing you. I walked to work one day showing these massive withdrawals, end up having two seizures and … I was in the hospital, they referred me to a Turning Point (IDI 102)*

> *It was Dr. [name] and he just said 'oh you'll' be all right, come on, y'all pull through because you're alright' and that was it. And then he just put me on antidepressants. So, Prozac which made me worse. ended up … had to go hospital (IDI 105)*

For others, seeking help reflected a realization that they no longer wanted the type of life that they had been leading, but were instead aspiring towards stability, their own home/stable accommodation, better health, improved relationships and general improvements to their lifestyle and social environment.

3.2 Contemplation and preparation for accessing treatment services

In their journey toward receiving support, participants often highlighted their concerns and fears about accessing help. For some, these fears and concerns delayed seeking treatment.

3.2.1 Fear and anxiety about the 'unknown'

Once they had made a decision to seek help, many then reported that they felt fearful or anxious about the first step. Participants spoke of anxiety about the 'unknown' of how they would be received at the service, and how they would be treated by staff.

> *the doubt was always there, isn't going to work. Am I going to be able to do it? The fear of like the unknown a lot of what, what, what happens there (IDI 104)*

I, myself, arrived at Turning Point very nervous, very frightened, apprehensive and walked in. It was a big building (IDI 108)

Other fears related to the effects of stopping or reducing drug or alcohol use, and the associated withdrawal symptoms.

I mean, everyone's terrified of withdrawal. Do you know what I mean, every user of every type, shape or form is terrified of stopping anything, you know what I mean? (IDI 102)

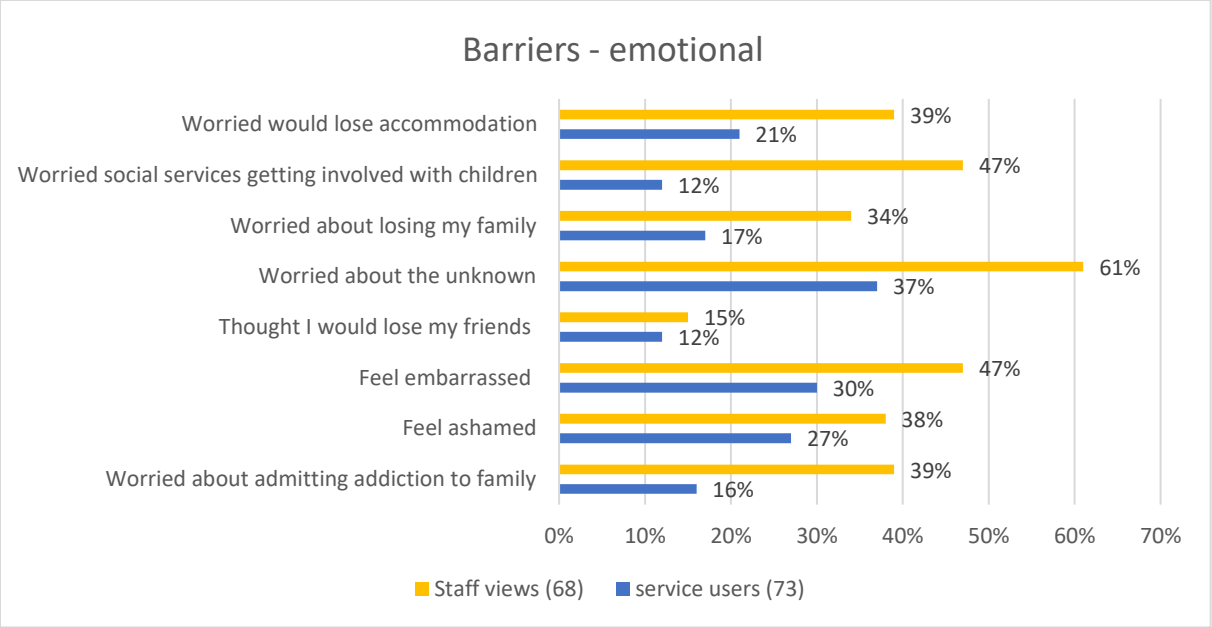
3.2.2 Concerns about impact on the family

A few participants with lived experience highlighted their initial fear of having their children removed from their care, which was allayed once they had contact with the support service.

my biggest fear of what I was always panicking about was my daughter be taken away which they never made me feel that was gonna happen (FG1)

The survey data also highlighted these initial fears and concerns. From both service user and professional perspectives, the biggest concerns were related to acknowledgement of the problem (and the feelings associated with that such as shame or embarrassment) as well as a general fear of the unknown (Figure 5).

Figure 5 Barriers to seeking support (professional participants - staff views and participants with lived experience perspectives - service users)



3.3 Taking the first steps

Participants discussed when they finally took the first steps to receiving support, having acknowledged that they had needed help and that there was no turning back.

> *I think for me back then I was ready. So, it didn't bother me because I knew I'd hit my rock bottom. So for me to attend, was what I needed to do it. So I don't think it even played into, I don't even think I questioned it. I just went (FG1)*

> *I need help and I need them and I've got to do it now and I'm ready to do it (FG1)*

Some discussed the concern they had prior to presenting for treatment in relation to actually turning up at the service, standing outside the door and ringing the bell or buzzer and a few participants recalled the visceral response they experienced at that time.

> *Standing outside and press that buzzer almost felt like I failed by going, in but then it was like, come on, it's not failing and it's the opposite (FG2)*
> *My very first experience was really scary. I went in very overwhelmed, very anxious, frightened because I'd expose myself, I knew for many years I was a*

an addict, but for me to actually finally go into a treatment place and go into somewhere for accessing help was it was really scary. And I walked in and I remember going to the counter and speaking to the receptionist who, she was lovely, but I then sat down and I was like a rabbit in headlights because I just didn't really know what to do and what, I'd got there on time for my appointment, but it felt like I was sitting there for hours (FG1)

For most, despite these fears the actual event of their first attendance at the service had been positive, reinforced for some by the presence of others in similar circumstances.

It was just the fear of the unknown. And most like they explained to me what my options were. I was quite happy, relaxed with them (FG1)

Well, I when, I went first time and yeah, they went, they're good in reception. Just sat with other people who were obviously in the same situation. No one spoke to each other, just look at each other, like I know what you're here for [laughs] but that's a good thing. (FG2)

However, there were a couple of examples provided by research participants where they had less positive experiences including feeling unsupported, or feeling confronted by other service users.

they was like so judgmental towards me when I'm saying, I have a problem with cocaine and they said you will be back on it in a week. So, I don't really want that sort of advice. I need advice to help me out. Not to tell me I am going to be back on it again (FG2)

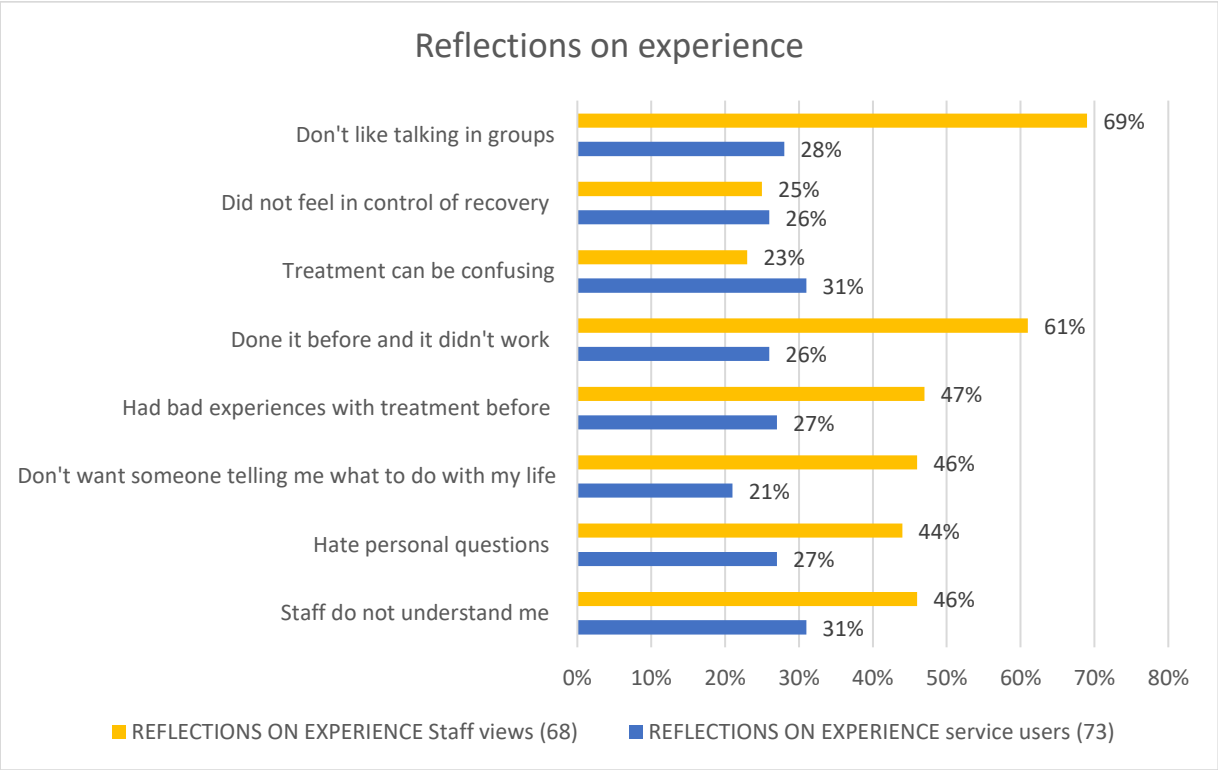
there were a lot of homeless people in there, not experienced homelessness myself. So that was quite scary. There were a lot of vocal people in there who were shouting (FG1)

Staff interviewed acknowledged the initial concerns participants with lived experience could experience, and the importance of them feeling welcomed when they first attended as well as being treated with respect and dignity.

> *I think that people really need to feel warm and welcome when they first present that first contact with the treatment services is vital (PP 102)*

From the survey data, it was evident that previous experience influenced participants with lived experiences' attitudes, including feeling that treatment was confusing, treatment having not worked previously, and feeling that staff did not understand them.

Figure 6 Reflections on experiences (professional participants - staff views and participants with lived experience perspectives - service users)



3.4 Experience of accessing treatment services

Most of the participants with lived experience interviewed had a relatively long history of accessing services and support, and their experiences were varied in terms of what services

they accessed, where and for how long. Furthermore, for some, their experiences of past services and support were hazy given both the passage of time and their circumstances at those times. Nonetheless, there were some common threads of experience that were recalled by participants including:

- The environment – the building or centre itself
- The location
- The staff (including peer support)
- Getting appointments was difficult and not at the time I needed them.
- Getting support for multiple issues/dual diagnoses
- Alcohol dependency treatment
- Access and referral to other services and support, and
- Communication between different services. Feeling like they had to repeat their issues and not being heard

3.5 The staff

Views of staff were often recalled when participants were discussing their experience of accessing support services – these were both positive and negative and consequently appeared to have a significant impact on whether or not a participant with lived experience continued to engage with the service.

3.5.1 Conversations with workers

A positive experience commonly mentioned by participants with lived experience was feeling that they were really being 'listened to'. Participants with lived experience highlighted their experiences of being able to have full, meaningful in-person conversations with workers – to be able to talk in depth about their circumstances, their history, past trauma, potential triggers and so forth - beyond the presenting issue of drug or alcohol misuse. Positive mentions were also made where staff seemed genuinely interested and concerned about the participants with lived experience lives.

> *I think it's just about being able to talk to somebody who understands the situation … So yeah, it's just about talking to someone who understands and just a bit of encouragement as well. (IDI 115)*

They are helpful and very compassionate. They show a lot of empathy (FG1)
She, she was a help. I mean, she was a person to talk to you and I felt like I was doing something positive for myself. (IDI 106)

Oh and the staff were extremely friendly as well. I could have a conversation with them and open up (FG1)

Melton's All right. But I think it was more to do with, like, I would turn up for the appointment, then that's it. You know, it's not like sit down and talk to them how you are and yeah, you know, so but over here, and then I started speaking to [Harm reduction Worker]. Yeah, me, [Harm reduction Worker] delved into my past. Why, how old when I started taking drugs and glue sniffing when I were younger. So yeah. seems more, more concerned. (IDI 105)

Where participants with lived experience felt that the staff were less interested or engaged with them during discussions contributed to reduced engagement with the service.

I always find it seven out of 10 you know, most of the time, they'll just go hiya, have a little interview and that's it. I won't, don't want to see them again. You know, if you know what I mean, … If you don't feel right you know, you don't feel right do you. but if you feel good with that person, you feel good. You know, you can sense you want to stay with that person. (IDI 101)

And on that first time, I just thought like, because I'm always very open about my life and what I've done and you know, because I want help really and I just felt like it was, I was very like, she was really quite condescending she was like 'When will you learn that drugs are not the answer' and I'm like, thank you for that [laughs]. You know what I mean, you know, I'm trying to spill my heart out here and it just made me think I'm not telling you anything next time. Like why would I Why would I be open and like really vulnerable?... And it made me feel like I couldn't come back in and be honest (IDI 110)

I'd likely them to try and help more, because at the minute, I just feel like a number, I don't feel that there's a personal thing between me and the worker, There's no rapport, There's no bonds there, So if I felt as if they actually got to know you, what's causing it, you'd be more willing to engage in actually trying these steps that they print off. (IDI 117)

Amidst the desire for personal and in depth conversations, some reported that their experience of phone conversations was less positive, primarily due to it being harder to engage by phone, and more difficult to have in-depth conversations.

Because it's all done over the phone not like saying that's a bad thing because it can be quite convenient but because it's done over the phone, it does feel a bit like impersonal … So sometimes for me, I I benefit more face to face, on the phone I kind of switch off [laughs] Because there's other things around me and I always asked, Can I do this in person (FG2)

That's the problem with the phone as well. I was trying to make notes and I wasn't really listening they did say can you like wait a second, well, can you repeat that kind of thing? And I just felt like maybe if there was a transcript option that could be sent to me that would be nice. Or if they suggested doing something to either send, sent it to like by email. It's not really a physical thing, But I benefit from more physical stuff (FG2)

Some experienced many different workers and a few reported that speaking with several different workers was not helpful in terms of building relationships or staff getting to know participants with lived experience.

I'm forever like changing worker so you have to constantly keep telling them what you want to achieve and all that. Yeah, it's a pain in itself (IDI 118)

3.5.2 Staff knowledge and experience

Participants with lived experience also highlighted their experiences of staff's knowledge in relation to supporting people similar to them, and their understanding of the complexity around drug/alcohol misuse. Unsurprisingly, experiences were much more positive where participants with lived experience felt that the staff had substantial experience (or 'lived experience') than where they did not appear to have this.

> *So she's only temporarily but I prefer to work with this lady. I think she's a bit more experience. Plus, she's very emphasized. She's there with you. you know, she's really good. And sometimes you get put on to people who have no experience … I felt like I was telling them, I felt like I was teaching them my sort of addiction (IDI 101)*

> *I do like workers like [worker] you know, has been through it before. I sort of get that, I appreciate they sort of know where you're coming from, lived experience. that did always, When I was ordered to do it. I always p***ed me off a bit, That they're sort of telling you what to do, but they've not been through it themselves (IDI 119)*

However, there were also examples of experiences where they felt that the worker did not have the expertise in the field so was unable to engage in a meaningful way.

3.5.3 Peer support and mentoring

Participants with lived experience who had accessed peer support spoke positively of their experiences, highlighting the value and importance of having a support worker who had been through a similar experience to them. This, they felt, helped them to feel reassured that there was someone at the service who had a lived experience of their situation, their addiction and the emotions that they might be going through.

> *I had an appointment and I went in and there was very fortunate that there were peer mentors there and a peer mentor came over and saw my vulnerabilities and sat and spoke with me and told me I'd made the right decision by going to Turning Point he'd been through Turning Point himself, hence why he was peer*

mentoring and offered support. To this day, I'm still actually in contact with this person. So with that, it's it was very fortunate (IDI 108)

Among those who had experience of peer support workers, the role was identified as critical, because they had been through a similar experience and were able to be a support for the participants with lived experience in a way that others may not.

there was a peer mentor that came over to me and reassured me that I was in the right place. And I'll never forget that peer mentor, that peer mentor was just fantastic and we're still we're friends now. And this person has been with me throughout my journey from accessing turning point to where I am now. (FG1)
The phone call check ins me peer support workers always, when they say they're going to ring they ring. They're always open if you need to phone them and to contact somebody to call you back. (FG1)

Furthermore, some mentioned that the peer mentor role indicated to them that a pathway to recovery was possible.

*That's inspirational to me, because it gives you the thought processes, like you know, it ain't the end, you know, I mean, it doesn't mean that's the rest of my life, you know what I mean, there is f**king a way out of it. And like he's is very much like, I'm still an addict, I've still have my s**t days, you know what I mean, you still f**kin get tempted. And if you can sit there and watch someone from your peer group. Do that. You know what I mean? More [of that], that would definitely go a long way. (IDI 102)*

Several participants with lived experience interviewed had become peer support workers whilst in their recovery, and all of them spoke of the benefits of doing so in their recovery.

Well, [they said] you'd be great at it, then like agreed to do it started off as a volunteer and then when I gotten on the next peer mentor course, so then went and I've done that, but yes, it helped me a lot because it's built my confidence

up, obviously gave me new skills too it's a great, you know, like learning opportunities and things like that (IDI 122)

The day that I signed off with them [Turning Point] I filled straightaway the paperwork and go on to look at going on to doing peer mentoring… I even graduated when I finished my peer mentoring … all the people that had supported me all came along and it was it was actually really special (FG1)

There were also several positive mentions of the value of the role of the recovery navigator, as someone with a lived experience and notable skills in terms of engaging with participants with lived experience and offering support. The Recovery Navigator role is an lived experience employee funded externally through the Exaireo Trust and Falcon Support Services.

I now wish there was more people like [recovery navigator] , he is one in a million we need more people in that community (IDI 103)

I've known him long a long while, [Recovery Navigator] is like, I heard he was clean. He was clean. I didn't believe it to be fair and just start thinking no one get clean, no one gets clean, is like just resigned to the fact that you will end up using all your life, and I heard he was in recovery and I knew he was in the services right here. Working in the services, doing the doing good stuff (IDI 104)

I've seen the likes of [recovery navigator] and you know, spoke to them and heard about their experience and their journey. You know, I knew they could do it, There was very good chance that I could do it, you know, because they were people that used a lot heavier than me. You know, they'd done it, got clean, stayed clean (IDI 111)

3.6 Appointments

Being able to get an appointment quickly was a common desire expressed by participants with lived experience, both at the point of entry into support as well as in times of crises or specific

challenges. However, many participants with lived experience reported some difficulties with being able to access timely appointments and experienced some difficulties as a result of that.

> *As I was struggling with my depression and homelessness at the same time. I got told to go back to me, Is it an administration interview? Where I have to go back in like two weeks' time. Around that time, I felt uneasy with that because it's, I want things to be quicker (IDI 101)*

Other participants with lived experience related to appointments were around concerns about remembering the time and day of appointments, and wanting to be prompted in advance so they did not miss appointments (and hence be at risk of consequences of that such as difficulties in getting access to related services such as a script). This concern appeared to be exacerbated among those with comorbidities, particularly mental health.

> *Like with my anxiety. I really need to build up. If I I need to know the day before… you can't text me 20 minutes before like, my head at that point. I'm overwhelmed. Scrambled. It's too much for me. And I said, you know, I'm really sorry. I'm gonna need more warning and I said Please, can you make a note in my notes and let the nurse prescriber know that I wasn't able to attend? Because I don't want it looking like I just didn't bother to turn up and …. She didn't do that (IDI 110)*

3.6.1 Accessing workers outside of appointments

Participants with lived experience also raised their experiences of being able to contact someone outside of their appointment times, and where they were able to do this, it appeared both welcomed and beneficial in relation to their progress and recovery.

> *She was very knowledgeable, and she, the relationship that we had, I could pick the phone up I could phone her, and I could have that contact. But I wanted to get better and for me, I think because I worked hard; I recognize that support was there. (IDI 108)*

Though I could even access a meeting if I needed to see my recovery worker or see a recovery worker. They were always open on Saturdays as well. They were open from nine to one so, but I had enough support which I was okay with that. (FG1)

Even those who had not required these ad hoc appointments or conversation, felt reassured that the option was there should they need it.

My experience has been very positive. I think that just knowing that somebody was going to phone me and also said that, you know mine's quite recent, so you know, But it was nice to know that there was somebody out there who cared. Yeah, just one person that, you know, she's like, you know, you can phone me anytime, obviously, you know, within reason but you know, might not always be able to answer but you know, I'll get back to you. I've not had to, but it was just, just to hear those. Just hear those words with that, you know, and for me that's meant a lot. (FG2)

I believe the one in [area] for is Monday to Friday, isn't it, Yeah, that yeah, that worked fine with me because I was preoccupied with my daughter on the weekends and it wasn't too bad generally. So I had enough support from them and if I needed [to] call, they were fine with that (FG1)

3.7 Experiences of support for dual diagnosis

Another common experience for those with a dual diagnosis, or multiple addictions, related to holistic or combined support and treatment. Participants spoke of feeling as though treatment services were directed at one addiction or were not available for their specific, often complex, underlying issues. This appeared to be particularly the case for mental health issues; experiences of those who had been unable to access different relevant services appeared to fare less well than those who had been able to access support for their mental health or psychological well-being.

Working with a worker, it might help have helped this time because a lot of my issues are with mental health as well. I was actually using alcohol as a self-

medication. So, this time with the mental health and having a CPN and then being with Turning Point has been a lot more positive. And I'm having interactions more with my worker. It's not all centered around, you know, go to AA. And just a little bit more understanding I think this time so yeah, so that's pretty much where I am (IDI 114)

The problem with me weren't the actual substance you know, you could have took the heroin away and all the other drugs and I would have found something else to become addicted to you know, I mean, I don't think the substances are the issues it's it's also the what's happening internally. You know, when I realized that, you know, that what needed fixing, it just becomes so much easier. You know, but I've never been kind of made aware of that before. You know, like, I say with Turning Point. All I ever got from them where you know, we'll put you on X amount of methadone and you know, we'll we'll take the off and stuff like this, but it never kind of worked because I've still got all this internal stuff. I've got trauma that haven't been dealt with and stuff (IDI 111)

Those who had been able to access more holistic support reported positive experiences including helping them to work through issues related to their past, and hence being better able to make progress around their drug or alcohol issues.

I think because of you know, one being an addict, having mental health issues as well. So she, because one of my biggest things is just going outside you know, or calling up to, like rearrange an appointment. I find that really difficult, easier now I'm [at supported accommodation] so much easier. I feel so supportive being here, that even when I'm struggling by myself, I know that there's always someone else who can help me with it. Whereas before, everything was just so overwhelming that I just couldn't tackle anything. (IDI 110)

Because sometimes you speak some people, like helpful always they're offered help in other fields of things as well. Like they asked me if I smoke cigarettes

and I said yes and they said would you like to stop that at the same time, but they didn't force me I wasn't ready at that point. (FG2)

3.8 Signposting other services

Positive experiences were also reported of staff who were able to refer service users to other services (including making appointments on their behalf), or advise them of other sources of support that they may benefit from.

But as far as myself when I was allocated with a key worker who, for me, she was absolutely fantastic. She was incredibly supportive. She put me in contact very early on with different mutual aid that I could engage with, she was very good at signposting. (IDI 108)

I think like what you said they have a good guidance of knowledge they had a lot of, plethora of contacts that can help me with what I needed. And were able to actually put it forward for me, very understanding (FG1)

I would see [commissioned service worker] every two weeks but she would check in with me every week. She put me on focus groups, she put me in alcohol awareness groups. She got all my GP's appointments sorted, and I worked hard with my GP as well. (IDI 108)

Being able to access services such as needle exchange was also spoken of positively.

The needle exchange and stuff like that, that were invaluable. You know, because obviously without stuff like that, you know, we've all been out there using dirty kit, and we wasn't have made to feel, you know, what's the word? What's the word I'm looking for? judged Or anything like that. We were always treated with respect and you know, dignity kind of thing. (IDI 111)

3.8.1 Referral to detox or rehab

Several participants with lived experience outlined their experiences of being referred to treatment services in the form of detox or rehab, citing these as a major contributor to their recovery.

> *It's a struggle, I knew I had to get off it. I mean, I prayed about it and I just thought if I don't get off this I'm gonna die. Yeah. And I knew the only way to do it was to just go bang off all the drugs because I was desperate wanting to get off it, the lifestyle didn't suit me at all. …so I had to get real and I never looked back once I went to rehab…your drug workers need to be encouraging people to go to rehab and want to go to rehab and it needs to be moving quicker. (IDI 112)*

> *I went into rehab the first time around, managed to get eight months clean, but I come out and like, even though I was clean, nothing that kind of changed internally, I'd not done enough work on myself, so I ended up relapsing. And then I'll come back in a second time, you know, fortunate enough that they gave me another chance and another stint in there so I did the full 12 months this time, you know, actually did the work did the steps got more you know, more involved in my, we do a lot of therapy in there and stuff like that. I did a lot of internal stuff and managed to stay clean and I've come out now. I celebrated 18 months clean a couple of weeks (IDI 111)*

Others mentioned that no one at the commissioned service never mentioned to them the option of accessing a detox or rehab facility. Several of the participants had only found out about the possibility through support workers at other services or through a chance conversation elsewhere.

> *There was never once mentioned [at the commissioned service] about going to rehab. Nobody ever mentioned anything, any other services that I could attend... [discussing accessing a support service] on Sunday morning, I knocked on the door. And the Support Worker let me in. …and I just collapsed and started crying and she's asked what had happened and I said well I've*

done such and such as I'm not gonna lie all I want is a bit of charge my phone so I can go and get some more drinks. So she charged it up for me sat me down, got my coffee, got me some tea… she was the one goes "have you thought about rehab?" and I was like, not really, and she said you know there is one in [area]? … She did my application form with me (IDI 103)

A few of these participants mentioned that for that reason, they would never return to the commissioned service as they felt that their focus was too narrow on managing the drug issue rather than looking holistically at factors that attributed to drug misuse.

3.9 Alcohol dependency treatment

For the participants with lived experience interviewed who were dealing with alcohol dependency, some felt that this could be given a different – even lesser- priority than other addictions or required staff who were more specialised in that area to help them such as helping them to understand their consumption and how to reduce it.

They don't really support you as much when it's alcohol, then what to do with the methadone scripts, I don't think and I've spoken about a lot of users, and they say the same. It just seems like they're offer you detox and you take it or you leave it, So yeah, or they just tell you to cut down percentages and stuff (IDI 118)

However, others reported more positive experiences with specialist staff, who were able to work with them to help them to understand and manage their intake by breaking down their consumption through monitoring and recording.

This next thing I want to do and they'll say break down my intake so it was more manageable. So it didn't seem like such a big hill like that. We went through the math and all the units I was taking in, which was good when they said so this is how many units and that's equal to blah blah blah glasses of like beer or wine or whatever. So it was quite good to see it there on paper. (FG1)

Yeah, like, they gave me booklets on what damage it does to you. because it wasn't so much the drugs. It was more to do with the alcohol. And they got me to do these every week. how many cans have you had? how many units and are you off the 9%? I was down to drinking; I think it was the 4% and 5% ones. Yeah, so I was actually like progressing (IDI 106)

3.10 Communication between different services

There was some evidence from participants with lived experience that there were times when communication issues occurred between different agencies or service providers, which mean that they as the service user did not always know what was happening. An example of this is given by a participant with lived experience who completed a course of treatment for Hepatitis C but was still waiting to hear whether they were clear or required further treatment.

the nurses from [hospital] come over to work with Turning Point to get you the medication, they're good, … Turning Point did the test, but the nurses did the medication, and when the medication was running out the nurses would get in contact with you, they were really good. So I've took the course, but I'm still waiting, I had a blood test took to see if it been cleared or I need more medication and I'm still waiting for the result and that's been about three months and I keep asking and asking is it clear, Is it clear, have I still got it or do I have to take more medication and it's like I'm banging my head against a brick wall. I just want to like know, if it is gone or not. because if it has, I want to start more medication to get rid of it. But no one's told me whenever it's cleared or not. (IDI 118)

Other examples were given in relation to poor communication from the commissioned service about the type of other support services available to them.

it seems like there's just kind of like, the missing bit is the communication and transparency between Turning Point and everywhere else (IDI 104)

There was some suggestion that the reason for limited advice about other services was related to funding, and the risk of losing funding if their own services were not used to capacity.

> *Sometimes services don't go on to other services because they are scared of losing your your attendance in their services, sort of thing, keeping them in jobs, they're scared to like pass you on to other services and pass on information and stuff and give you information that there's more help out there or that sort of thing, as that sort of barrier, they don't give you information about what they can offer and what's on offer out there (FG 2)*

3.11 The environment

Participants often spoke of the environment for treatment services and how it had influenced their experience of seeking support, both positively and negatively.

Factors that contributed to a positive environment included feeling safe, having a friendly welcoming atmosphere, having quiet surroundings, being able to get a cup of tea or coffee, and having enough space for people not to feel crowded.

> *You always got welcomed in. Yeah, you know, nice reception staff, and yeah, call you by your name (IDI 101)*

> *when I did go there the one time You know, everyone seemed friendly. and, you know, it was it was a nice, it was a reasonable environment in that respect, (IDI 114)*

> *But the other thing that was really important was when he actually made you feel safe and comfortable and relaxed. (FG1)*

> *just just being treated like a human being was nice. Yeah, because there are a lot of fear around it before I went. , I mean, you've seen you see it in the Hollywood films, you know when people are going to these places in they are made to standing a queue, You know, It can put the fear of God into you, but*

no, the service is not like that at all. You know, there are always privacy. (IDI 111)

Negative experiences highlighted included not feeling safe, feeling the environment was impersonal (the use of screens was mentioned here), having to access premises through a door with a security buzzer, feeling that the office or premises were dark or 'dingy', and finding the premises to be too small to the extent that some clients needed to wait outside until there was enough space for them to be accommodated in the office (which in itself was a concern where mentioned, particularly in relation to being seen by passing members of the public).

it's a place of service where it's very sensitive some people have massive fears about going to this sort of place and it's like to be met by, a door, a security door is very it's yeah, it's yeah, not good. (FG1)

Many participants had experienced different treatment services over time and they acknowledged that there was considerable variation in different services' premises.

Depending on where, which areas and it's like the [area] one was chaotic, it wasn't safe. The [area] one felt more like I was pressing buttons to get in and out to be let in. And then we sit in the holding room. It was very, very loud, very chaotic. The [area] one where I've been back to recently was very quiet, very well managed. clean, bright, welcoming, very relaxed. So yeah, just depending on whatever it is. (FG1)

3.12 The location

Experiences of the location of the service were also raised, with having somewhere that was accessible also highlighted as important including being within walking distance or easily accessible by public transport; mention was also made where the location of the service was less than ideal.

what worked well for me, is the locality personally for me localities ace … Location for where I was as well as really easy. I could walk there or I could just like park around the corner, it's good (FG1)

[discussing a previous service] I mean, that was that was vile, absolutely vile. You know, you're not in a very nice place in [the area] at all. And you know, you walk in there and you know, there's empty bottles of alcohol and joint stubbs, and needles and all sorts. So yeah, it I suppose, as well, you know, for me, it's not, I don't have to go massively far. But, you know, I'm a woman on my own, and I certainly would not want to be walking into [the area] in the dark, On my own or into those areas (IDI 114)

4. Factors affecting accessing treatment services

Drawing primarily on the evidence from the participants with lived experience interviews who shared their views and experiences of accessing support and treatment services, there are some clear themes identified in relation to what affects access, both positively and negatively. These can be grouped across four main domains:

- Staffing issues (staff knowledge/expertise, availability, continuity etc)
- Service delivery issues (environmental issues, access to services/appointments, modes of service delivery etc)
- Perceptions (perceived stigma, others' experiences/views, service reputation etc)
- Fear (loss of employment, impact on the family/children, fear of withdrawal)

Furthermore, as outlined in Section 4, being 'ready' in oneself to actively pursue treatment was recognized as a prerequisite to receiving treatment.

4.1 Staff issues

Access to knowledgeable, experienced and supportive staff is identified as a primary factor on service users' engagement with support and treatment services.

4.1.1 Experiences with staff

Where participants with lived experience reported a positive experience with staff, they appeared more likely to return to the service, but where the engagement was less positive this could have a negative impact on their willingness to engage in the service. Positive experiences included feeling as though they were being treated as an individual who needed help, and receiving praise when they made progress,

> *But yeah, can you know, just feels like you're just, you're speaking to authority rather than speaking to someone who relate to you. So that certainly could feel like that as well. So can just sort of like make you feel a bit uncomfortable. not judged, but sort of misplaced? Like it's wrong to be an addiction rather than I need help out this addiction (IDI 101)*

> *People with drug addictions drink or whatever, they thrive off stuff like that. I'm 40 years old. I still like being told well done. Yeah. You know what I mean? I don't take no shame in saying that, I buzz of it (IDI 102)*

Where participants with lived experience felt that workers took a genuine concern in them and their lives was also a contributory factor to engaging with services, and them feeling as though they could trust their worker. Receiving advice on different services and supporting them in accessing those services (such as accompanying them to visits) was also a positive factor in engagement.

> *It good having all the flyers and stuff, but flyers don't get read, … So when people go up, you need to be able to physically takes someone, if that makes sense? , just so that bit of hand holding Yeah, like lets go for a coffee, while you're walking around just oh look at that place did you you know that places is rehab, Walk past it. Yeah. Or, or you can go and get food bank from here. Walk past it. The shop on side the John Storer storehouse, which I found out from the Falcon (IDI 103)*

> *You know, if you're, if you're somebody who's got experience, you can talk it out. You can you know, you can share feelings and you know, you could have*

that you can start building a relationship with that person and building trust. That's the main thing. Trust. don't just tell anybody random about your life do you? You know, you build that relationship first, and then believe it happens both ways. (IDI 101)

Where this relationship was less positive, participants with lived experience felt they may be more likely to disengage. One commonly mentioned example of this was around scripts, and the perceived 'threat' of losing their script if they missed appointments or failed a drug test. A few felt that if this occurred, their drug use would increase (along with disengagement from the support).

she said if you fall off again, I'm not putting you back on it… she really she called me on a Friday afternoon, say Oh, and there's a note on your script saying that you need to come in for a drug test. And if it's, if it's positive, you're gonna get your meth put down 20 mil. And this happened three times. And for me, that made me suicidal…. And just said, I don't understand like it feels like you work with punishments (IDI 110)

4.1.2 Expertise of staff working in support services

Staff knowledge of services and support (beyond what was available in their own service) was also noted as important in service engagement. Some also commented that support services worked best when the staff had real expertise, and even experience, in drug and alcohol issues. Where participants with lived experience felt that a worker did not have the experience or expertise appeared to lessen their propensity to engage in services.

It's very hard to to really get if you haven't had to go through that. Not that I want people to but you know like when I went to my first rehab everyone there even the chefs and things they were all in recovery. Yeah. And they got it. You know, and I think that's the big difference. Because when I went to Turning Point in [area] my worker she was lovely, but I could tell she didn't get it. (IDI 110)

I've seen things, things have moved on and Turning Point those kinds of places, Do they know the score? I don't know. How clued up are they would they know what fentanyl was we didn't know what you know. You know, experience the difference between chasing the dragon in injecting it or whatever, you know, it's surely some of them would but…. (IDI 106)

Access to peer support was a positive factor effecting service engagement (see Section 5).

most people that I speak to that are drug users they rather talk to someone who's been in that position themselves, through it and are like peer mentors, rather than someone reading out of a book. (IDI 118)

have a peer mentor from that initial walking through that door to be greeted with a success story. And for somebody that can explain you do have to work hard, because this isn't it walking through the door is that is that first point. And if you can be greeted with somebody who is there not a recovery worker who is there to just fill the paperwork in and that side, but somebody with that lived experience. Somebody that can hold your hand, somebody that can just give that initial encouragement because you walked through the door (IDI 108)

peer mentoring … life experiences of addiction, and just to give the people hope that that you can get clean, and that you can do it, to support you, as an addict. I am not a professional, I've worked in services. I think that's a massive thing (IDI 104)

4.1.3 Continuity in staffing

Turnover of staff was also mentioned by participants with lived experience as a frustration. A few also noted difficulties in filling vacancies in support services which could impact negatively on service delivery, particularly in more regional locations.

and they're not advertising (support services), You know, and what is the reason why they're not advertised and is it because you haven't got the staff? They've got I know I do believe they've got a high turnover staff a really high

turnover staff. Yeah. Because the jobs, there's always jobs going a Turning Point. (IDI 108)

sometimes, you will get a new worker without them even telling you, you get a new worker, it's just like oh, this is such and such and they're gonna be your new worker, and it's like why am I getting a new worker, then you've got to explain everything all over again. It's like, not another one [laughs]. Since I've been a here I have been through four workers as it is in a year (IDI 118)

4.2 Service delivery issues

How, when and where services were available or delivered to service users was also evidently a significant factor in engagement with treatment services. This included access to appointments, access to services and support (including referrals to treatment and recovery services), access to services for mental health, and environmental factors (such as location and the presence of other service users).

4.2.1 Ability to get initial appointments.

Delays in initial appointments was identified as a potential barrier.

Yeah. So it was through [support service], So saw [harm reduction] first, she referred me to turning point, it took ages to come through, I went in to do my initial interview process, few different tests. And after that took a couple of months I think for the first interview appointment. And then that was pretty useless. There's pretty much print something off a computer and say follow this. (IDI 117)

I got in with Turning Point eventually that took about four weeks after doing an open group session similar to this in a way and then I got appointed a worker who was only working so many hours a day within the area, and I actually fit my working, at the time I was working, so had to fit my working day around what those appointments were. And I couldn't always make them because she got stuck at work with overtime or it was busy, so you would ring up and say sorry, I

can't make it. This is a reason why. Right? Well, I'll have to remake one then you've got to wait three or four weeks to make another appointment. (FG2)

There were also a few examples given by participants with lived experience of the initial online referral process being time-consuming, and of online referrals submitted but then needing to be chased up to progress.

The online referral is a bit tedious because I got referred by the hospital for a Turning Point never actually got back, from when the hospital did it so I end up having to refer myself to do it. So it was very tedious to do online. I spent about 40 minutes doing it (FG2)

Well originally I was told school was going to refer him, that didn't happen, But then we was told that is mental health worker was going to refer him, that didn't happen. Then we were told by his psychiatrist that we should self-refer him, So we tried to do that online. And it said that family could do that, but when we went online to do it, it gave a drop down section as to who was referring. There was no part for family. It was all professionals on the drop down and unless you ticked one of those boxes, you couldn't go on to the next part, so not helpful. So that caused a bit of a problem in getting a referral in and so that's why we're just hanging then in reception, to try and find out what we've got to do where we've got to go (IDI 121)

It took six weeks for me to get the referral. Once you made that first step and you've referred yourself to them and then if you want somebody there, even if it's just a phone call to say right okay, we'll get it sorted, but six weeks by that time you're back on the alcohol and you are knocking it back. And then six weeks down the line. I say oh yeah, we can see you in a week's time, well that's nearly two months. I was ready to do this X amount of weeks ago and it's taken that long to get it sorted (FG2)

4.2.2 Ability to get ongoing appointments

Participants with lived experience commonly reported that the frequency of appointments for treatment services was insufficient and this could be a barrier to accessing support, or a reason for disengagement. Examples were given of appointments being every two weeks, or occasionally monthly, which they felt was not sufficient for them to progress, and could be demotivating as so much could change in the intervening period.

> *But I don't see them every it wasn't once a week, it was only every couple of weeks or it was on a regular basis. should be more regular. (IDI 103)*

> *[appointments] should be at least once a week, once every two weeks, because once more could have done anything in that month, It's a long bloody time (IDI 117)*

A few participants noted that support workers appeared to have high caseloads, and that impacted on their ability to support their clients to the extent they needed.

> *I think their caseloads are too high. They've some of these recovery workers got 70, 70 cases to a worker. That's an awful lot. And if they see somebody once every two weeks and some of these people will only be over the telephone. But if they are vulnerable and they are high risk 70 to a caseload is an awful lot to manage (IDI 108)*

> *So, I've been stuck, I've been sat on 30 mil for three months and I got told it would only be a six week waiting list and she's [recovery worker] never in. I see Dr. [name] to sort it out, she said I'll sort it, But [recovery worker]'s never in. (IDI 113)*

> *But I think sometimes the waiting list, to get actually into Turning Point can, I've found in the past can be long. I don't know if there like understaffed or I think it's the staff issue. I think they've got too many clients with too many, what they are working with. Yeah, too big of a caseload (IDI 118)*

There was also mention of limited opening times for services.

> *They don't open their doors until this particular time. They close their doors at one o'clock. They won't answer the phone. prescribers are very difficult. It's very difficult from that element. (IDI 108)*

> *Especially on the weekend because you feel like you're going to use again on that weekend because it's party and party time, It's, everyone's is, everyone's going to. So on a Friday or Saturday when you feel like you're going to do it. They're the best people you want to talk to but they're never open to speak to you. (FG2)*

For some, delays in getting appointments could result in disengagement from seeking help; because it could take several weeks to get an appointment, that felt that it indicated that they were not seen as a priority, or needing recovery and that consequently their needs were not going to be met.

> *So with that waiting and waiting, I could just think, Oh, well, they don't really want to know if they really wanted to know that helped me straightaway. But in the back of your head, you're thinking well, I don't really want to know because you will have seen me by now and they wouldn't give me a two-week appointment down the road. So oh, why not use? Just what you know why bother? Yeah. And I think that's probably, probably why a lot of times I have turned my back to Turning Point… that two weeks of waiting that could be the most crucial point your life you know. (IDI 101)*

> *in the past, I've learned that waiting period affects my ability to get clean, I've just started using again (FG2)*

4.2.3 Rescheduling appointments

Some of those had work-related commitments reported that it could be difficult to attend appointment times during the working week, or to attend when appointments got rescheduled by

the service. Others with family or other personal commitments also noted that at times they needed to miss appointments or reschedule with limited notice, and it could be difficult to reschedule.

> *They just don't seem to understand that people have got lives outside of going to Turning Point. And life happens day in day out and you can't always make it you can't always get to an appointment. If you just don't turn up and you haven't rang them or you've not messaged them or whatever, then you haven't turned up but if you've let them know in enough time and they're quick enough then to (take you off the books)(FG2)*

As noted previously, a few participants with lived experience mentioned the perceived implications of missing an appointment (such as withholding a script), and felt that there was a lack of understanding about the complexity of the service users' life.

> *Do not dare step out of line. Because scaring people into it isn't ever going to happen. People don't just like, that, We're not turning up for appointments, there's reasons behind that. You know, don't just do something to punish us for it. Let's look at the reasons and see if there's anything we can do to make them better (IDI 110)*

> *Turning Point that kept .. altering the, these appointments my first one, and I couldn't get my head around things and it was too much for me. When it comes to [missing] the first one, they really weren't very helping at all, Which I've spoke to [support service] and everything else about the because I was on their system … to do that someone that's autistic and dyspraxia, someone who can't focus on a timescale I think that's bang out of order. (FG 2)*

4.2.4 Accessing staff outside of appointment times

A further factor affecting engagement with a service was identified from the participants with lived experience interviews as not being able to access help when they needed it (and where they were able to do so, this appeared as a positive impact on service engagement). A few

made comparisons of other support services that could offer this service, which was very much welcomed.

> *You know how the drop in is at the Falcon? Yeah, today if you could facilitate Turning Point office in there. Yeah. Know that you got [Harm reduction staff member]? They work in the office there. But if you, say the drop in has like a Turning Point, say someone goes to an appointment there and they can use to drop in as well. That's that kind of environment [that would be good] (IDI 101)*

> *No crisis team [there] now don't think, a lot of the time when I have rang up before, like for me appointments. They say oh no ones in today (IDI 105)*

There were also a few mentions of the difficulties in getting access to a support worker through a centralised call centre (some of which was said to be automated) which was felt to be impersonal and the response times for a return contact could be weeks, again acting as a potential barrier to seeking support.

> *Through to the central one it's almost like someone is just pressing too many buttons, and you might get a message four weeks later. (FG1)*

> *Through a central number and then you actually explain who you were and go through it all again to a central number to someone that could have been in Glasgow, they could have been in Wales, Birmingham wherever they have got back office, because you couldn't get hold of the person that was your worker. (FG2)*

4.2.5 Insufficient services and support

Some participants with lived experience also perceived that there was a shortage of support services and interventions, beyond medication, particularly for alcohol misuse.

*There's nowhere near enough programs offered. You know, I mean, like a few years ago, it used to be S***loads. Enhance ETS enhancing thinking skills, not I mean, and booster courses. There was always that s**t there (IDI 102)*

[at appointments, I] ..speak to them and tell them how much I have been drinking, they ask if I have reduced any, Then to say what can we do? print something off a computer basically. Say try and reduce it like this, if this don't work try and reduce it like that. Pretty crap. It's the honest answer. it's nothing I didn't already know, It's literally just a sheet you'd be able to find on the internet and print it off yourself. Speak to you for 10 minutes about a load of crap. They don't really seem interested to be honest. (IDI 117)

For those who lived in smaller towns, it was noted that services were even more limited, and often inaccessible for those who did not have their own transport.

But Turning Point, especially out in the more remote areas, there's no signage for them, I know people are aware of Turning Point in areas, but they don't again, they don't have a hub. Yeah. And I think they're some of the problems, Hinckley have only just got a hub (IDI 108)

Some participants with lived experience also felt that some of the group services were unsuitable for them, and they were reluctant to engage in this type of service.

These meetings that I've been to on numerous occasions just frustrated or annoy me, the group meetings they frustrate and annoy me to hell. I've [not] got the patience for them. It just frustrates the hell out of me. Primarily because the people that go there half the time are the ones that you see scoring 10 minutes later, with a preaching the Bible to you one minute next minute they're sitting in the pub with all the drunks. (IDI 120)

But with my mental health issues, because it's possible that I'm on the autistic spectrum. I do find it very difficult to be in groups. Certainly, to talk about myself

to open up, I find that very difficult and I know a lot of people will find that difficult anyway. But I would always find that, to the point where I almost came out the meetings and I wanted to go and have a drink it was too painful and too uncomfortable (IDI 114)

4.2.6 Understanding of recovery journeys

Another factor that appeared to be influential in accessing treatment services was having an understanding of what a treatment pathway or progression might look like for a service user. A few mentioned that, until it was presented to them, they had no concept of a recovery pathway, and others felt that there was a lack of proactivity in treatment services to help them to move off a script.

Having a clear understanding of the treatment journey or 'pathway' for service users was highlighted by participants with lived experience as important, in terms of knowing what the pathway might be for them, and how the different services or interventions would work, and for staff 'signposting' different supports or services.

but in terms of what your recovery is going to be in them setting out a direction. I don't think that's made clear. I think it's very much one step and we'll see what comes next kind of thing (IDI 102)

So what works well, treatment pathways I think are excellent. Because they do have the understanding of which were to signpost people. So with that they've got, I was alcohol, they've got non opiates and they've got opiates. So they were understanding and they will guide with that (FG 1)

This links to the pre-contemplation issue of fear of the unknown (see Section 4)
Some also felt that there was minimal effort on the part of treatment services to reduce script amounts, particularly for methadone.

I thought my life would just gonna be a methadone script. And that'd be it. You know, with kinda using, you know. Work was out of the question, a career out of the question. Yeah, I just felt completely trapped (IDI 111)

It's just that they want to keep you on methadone. If it's because then they obviously they make money off it, But I just want to, if I'm not using and I just want to get off the methadone and get off everything completely. (IDI 118)

4.2.7 Lack of awareness of services

Some participants highlighted a barrier to accessing services was a general lack of awareness of what was available, such as Turning Point. They noted the relative absence of flyers or information in commonly used public places as such as GP surgeries, pharmacies, police stations, community venues, courts, pubs, food banks, places of worship or public notice boards (such as those often installed in supermarkets or libraries). Many participants mentioned that they had known people who had not heard of such services, and others commented that they did not see much information about services (with word-of-mouth seemingly the more common way of finding out about services).

For those who went through rehab, it was notable that they had generally found out about this through support services rather than via a treatment service (and there was a perception among a few that rehab had been discouraged by the commissioned service, or advised that they were not 'ready' for rehab).

[I felt] ready to go into treatment. You know, I've got this place. It's a beautiful rehab, you know, all the support there kind of thing, but Turning Point just didn't, didn't seem to want me to, you know, to do that. (IDI 111)

A few other participants who had not accessed such services indicated that they did not think they would be eligible, or could not afford such treatment.

You know, that to me wasn't, didn't seem like it was an option. I don't have like a celebrity, You know they can pay their 10, 10 grand a week and go off and you know and get a nice hotel where they're going to be looked after a support and everything else through however long the process takes Yeah, I don't think and I'm pretty sure that that isn't an option when you're looking at the NHS (IDI 109)

4.2.8 Difficulties in getting referrals

General Practitioners (GPs) were highlighted by many as a main referral route, and the effectiveness of this route was evidently variable depending on the GP. Some reported excellent signposting and referral from their GP, but others reported that there was minimal help through this route.

> *So mine was just GP I had a fantastic fantastic GP who was just amazing. With regards to substances she was she was fantastic (FG1)*

> *wasn't until the fourth time that doctors was like yeah and they gave me a pamphlet for Turning Point, but that wasn't until the 4th time (FG2)*

There was also mention of the general difficulty in getting a doctor's appointment post-COVID, particularly face-to-face (which appeared to be preferred to telephone).

> *And like you can't even getting the doctors now. You can't even get to see a doctor. What can you do over the phone? There's nothing you can't say why, how you feel and that over the phone. Yeah, it's [the appointment] got to be face to face (IDI 105)*

Some participants recalled that their drug or alcohol misuse had commenced at a very early age (whilst still at school) and that at that time there was no awareness or knowledge of support or treatment services for children.

> *People don't actually realise you can have addictions at that age. And they're the worst types and you growing up with it and then you don't realise you can get help and just carried on to your 30s and then you feel that life's done for you sort of thing (FG2)*

4.2.9 Lack of mental health support

Many research participants raised the issue of getting access to mental health support, and it was often highlighted that mental health issues were often the trigger for the alcohol or drug

misuse. The difficulty of getting mental health support alongside drug or alcohol treatment was highlighted as having an impact on the service users' recovery.

> *I don't know of anybody. Just drugs, and no psychological issues. How many people going through the psychological services actually have substance abuse, might be legal and it might be called alcohol (IDI 109)*

> *if you don't treat it as a whole, it's never gonna happen. It's never going to happen. It's like it's telling somebody that's got back pain, well come off your Ibuprofen, because your back hurts, well, you might be able to for a few days, but actually that pain still gonna be there. You know, it's not addressing the issue behind it in the first place (IDI 114)*

> *they suggested Turning Point for the alcohol side, but in a sense, the alcohol abuse that I had was sort of linked to like, a mental thing that but they weren't dealing with one, they sort of were dealing with one thing separate from another, (FG 2)*

Some mentioned being denied access much-needed mental health support until they ceased drinking or taking drugs but felt that it was their mental health issues needed addressing before they could stop their substance misuse.

> *But there's no one who's a trained therapist and can't help me with my psychology. I can't get help with my drugs without getting help with my psychology. It's a massive crutch …They've then accepted a referral for psychological treatment… I'm now on a waiting list for a clinical psychologist. And 18 months later, I'm still waiting (IDI 109)*

4.2.10 The service environment and location

As noted in Section 5.7, the environment of treatment services was a factor that influenced participants' experiences and one that could potentially deter them from attending, or from fully engaging when they did attend. Having a welcoming, calm, friendly but professional environment was a positive influence on accessing support.

Go straight, have a cup of tea. Sit down, you know have that friendly atmosphere around you, you know, people approaching you making you feel like change is possible. Make you feel comfortable. So the next time we go back in, you're looking forward to going back in, Because it's a warm environment. You feel like there's a possibility you know, you know, and support. (IDI 101)

You know, Pictures on wall had been there 20 odd years or something, you know, that, that sort of thing. And they were quite off putting I'd of thought, you know, we've mentioned in the past the area, if people are outside Turning Point, it can be off putting going in there going in there, especially the first time they've never been in the services before the fear of like hang on a minute, I am not going in there, you know (IDI 104)

I would have it warm and welcoming what not, you know, nice colors. Nice three-piece suite. Something nice, so people don't get put off. offered a cup of tea as soon as you walk in because that'll make them come back if you are nice to them, they will come back. If the put off first impression. They won't come back (IDI 105)

Distance and proximity was also cited as making it harder to engage with services, particularly if they were not easily accessible by public transport.

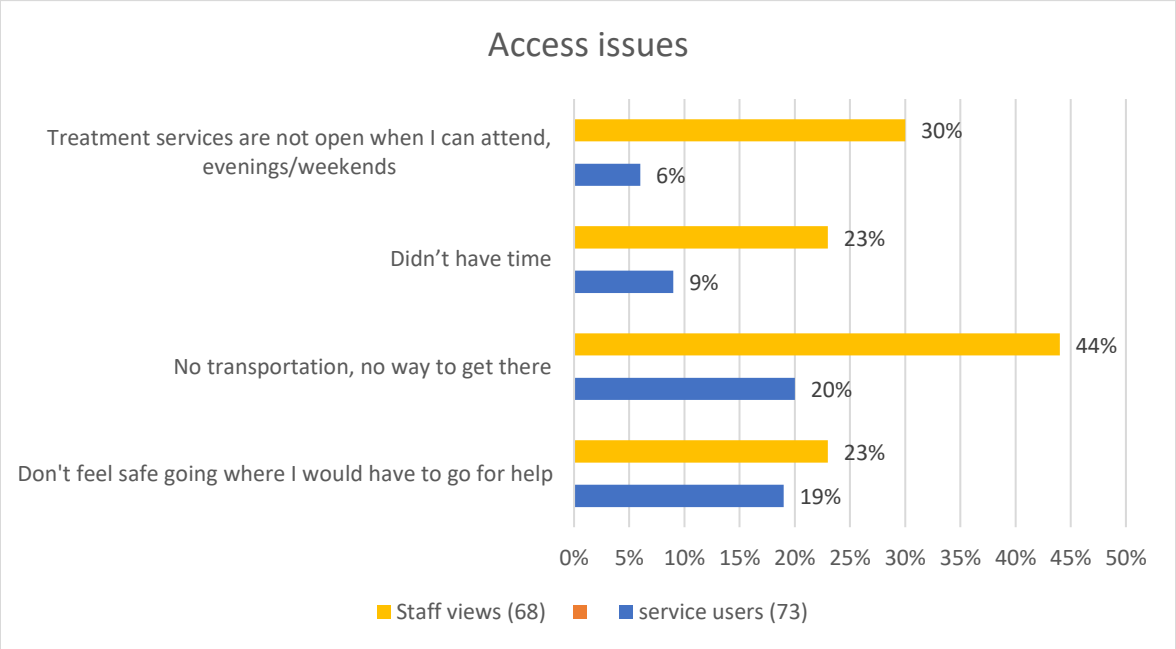
Another factor identified as a potential deterrent to engagement was the other clients at a service.

Maybe it could be temptation. When you get in? You know, maybe well, you're trying to change your life, next minute you see someone sitting opposite you, and your thinking lets go for a drink. You know, what you doing after here, however long got 10 minutes. Yeah, you know, so you're organizing what you're doing before even see worker (IDI 101)

[Why couldn't they help you?] Because I smoke a little bit of weed and I don't want to sit there in a room with another 10 heroin addicts (IDI 109)

These findings are also reflected in the survey data, particularly in relation to transport issues and not feeling safe (Figure 7).

Figure 7 Access and location barriers (professional participants staff views and participants with lived experience perspectives service users)



4.3 Perceptions

Perceptions of how they may be viewed by others was also mentioned by a few participants with lived experience – a fifth (20%) of survey respondents also identified this is as a barrier. In part, this appears to be related to the stigma they perceived was in place around people who had drug or alcohol addiction problems.

It's there's too much stigma about, it is this dirty, horrible thing to admit. I don't think people realize that there are the services out there (IDI 114)
I don't know I find its attached to that bit of sordidness you know what I mean, a bit stigma (IDI 122)

Negative views of some treatment services were also mentioned.

> *I do think that the stigma that they just need to be lifted around Turning Point and negativity that people will will put out there, and it's like, myself and I do think that is the positive feedback and the positives. What people talking about services out there. They will jump on board into it. Someone's said don't go to that chip shop it's awful. I'm not gonna go. And it's the same sort of thing. It's the same sort of thing (IDI 104)*

4.3.1 Experiences of others

Some also recounted negative experiences of others that they knew who were receiving support; whilst there was no direct evidence that this impacted on their own engagement in support, it may have negatively effected their views on the helpfulness of the service. For example, one participant was disappointed that when their partner cancelled appointments with a support service, there was reportedly no follow up as to why (and by association, how they could support them in other ways if they were unable to attend their appointment due to a crisis or poor mental health). In two other examples, frustration was expressed where appointments had been missed by other service users, and consequentially their prescription was withheld. Whilst undoubtedly the details of these individual circumstances are unclear, it would seem that it resulted in a negative view of a service.

> *No, you're not allowed, not until you have had an appointment and then they called up the pharmacy and said if [Name] comes in he not allowed his meth….. like how we then going to be able to trust that (support) person. Engage with that support person when you just feel like at any point, they're just going to do something like that? (IDI 110)*

> *I've actually lost a friend, he was doing well and then he missed a couple of appointments and they took him off his script and then we started using heroin again and that's when he OD for the last time and I think that was disgusting of the other services to just take them off the script and drop him because he's missed a couple, couple appointments because he's had to go be somewhere else, like a job or go see his kid or stuff like that happens every day (FG1)*

4.4 Fears

Some of the fears expressed by participants with lived experience about participating in treatment services reflect their concerns outlined in earlier in the report, in relation to pre-contemplation and contemplation (Section 4.1 and 4.2). For some if these fears were not allayed, they could lead to the withdrawal from support or disengaging from the services.

4.4.1 Worries about impact on employment

Those participants with lived experience who were working expressed some concerns that their employer (or co-workers) may find out that they are in treatment. One potential barrier raised was needing to attend appointments during the working day, but being unwilling to disclose the appointment to their employer for fear of losing their job.

> *they would say tell your employer and I didn't feel comfortable telling my employer because like I thought it was going to jeopardize my employment. So, the fact is like, here's these appointments, tell your employer and then they must let you go and I'm like, well, you can't make me do that because, you know, I didn't feel comfortable doing that. And they didn't take that one to account (FG2)*

Another example was given in relation to having their driving licence taken away by DVLA, which would impact on their employment.

> *Because of the fear of if they do that, is that their main source of income because they drive to their jobs? (IDI 108)*

5. Conclusion

This research sought to identify, engage and interview participants with lived experience of addiction to discover the barriers which stopped them from accessing commissioned substance misuse services. It should therefore be noted that the majority of participants with lived

experience had a history of complex trauma which in some cases led to their addiction, or they were still in active addiction with a chaotic lifestyle. Many of the people approached to take part have a natural distrust of people asking questions and therefore, were reticent in engaging with research such as this. Due to their previous trauma and/or their current active addiction it was necessary to be mindful not to create a retraumatizing environment and be mindful to reassure that sharing their experiences were of value to the research.

Due to the sensitivity of the research and the cohort we wished to engage it was important to spend time building relationships by visiting organisations to gain their support with the project. This theme of relationship building and relationship consistency flowed through the whole research project and was one of the key findings as an important factor in successfully entering into and maintaining a recovery pathway. As part of relationship building it was strongly evidenced that the peer support programme was a key area providing inspiration and a demonstrable positive impact on all addiction treatment services.

There were many positives about the current available services that came out of the interviews with many of the key themes for reducing barriers to services considered adjustments rather than a whole service review. The ability to access addiction treatment services in a mainstream capacity as opposed to attending a building associated with addiction was an important factor for a number of participants. Whilst these are specialist services it was noted that having them embedded in GP surgeries and community settings would reduce a number of barriers to people taking the initial step to making contact. This theme linked with the stigma that many people spoke about therefore integrating services into the wider offer for health and not segregating them out would be beneficial particularly for those maintaining their employment and family life.

5.1 Limitations

There was an under-representation of individuals in this research due to access difficulties which included those attending AA and NA meetings and ethnic minorities groups. Due to the confidential nature of the mutual aid groups the researcher was not allowed to attend these meetings therefore, was unable to build relationships. Similarly, there was little opportunity to gain access to those experiencing addiction from a more diverse ethnic groups.

5.1.1 Strengths

This study has identified a number of defining features that appear to be beneficial for clients accessing addiction treatment services. These include:

- Positive consistent relationships with workers in a face-to-face capacity, Participants benefitted from trusting relationships with consistent workers. Many felt the ability for workers to be psychologically and trauma informed, welcoming and non-judgement contributed to their success.
- Peer support, participants found inspiration and a wealth of knowledge in those who had lived experience. Peer support was instrumental in someone's recovery long term. A recommendation would be to strengthen and enhance the Peer Support programme, use of mutual aid meeting and recovery support groups.

6. Recommendations

Recommendation 1

We recommend that Public Health review and build on effective communication at a local level to raise awareness of the service offer and processes.

Participants spoke of the fear of the unknown and lack of awareness of local services. It was reported that people felt the website was hard to navigate and there was a lack of local social media presence and information in public places. A suggestion of creating "what to expect" guides or videos from recovery and treatment services would be beneficial.

Recommendation 2

We recommend reviewing the current offer to ensure service timings are flexible to meet the needs of service users.

Participants spoke about the opening hours acting as a barrier and suggested increased opening hours to provide better coverage around people's commitments such as work.

Recommendation 3

We recommend reviewing the current location points to ensure that they meet the current requirements of service users.

Participants spoke about the location of the service acting as a barrier and would prefer substance misuse services in GP surgeries or community settings where service users feel comfortable.

Recommendation 4

a) **We recommend a 'drop in' style interim support service is made available to those individuals whilst they wait to be allocated a worker.**

b) **We recommend that there is an option to allow additional support as required in addition to scheduled meetings between service users and their worker.**

Recommendations 4a and 4b relate to participants perceived lengthy waits with the registration and assessment process after making the decision to reach out for help and felt a more responsive and reactive service would remove barriers to accessing support.

Recommendation 5

a) **We recommend further investment in the recovery community, strengthening the Peer Support programme.**

b) **We recommend an increased use of mutual aid meetings.**

Recommendation 5a and 5b relate to participants finding inspiration from those with lived experience and the positive interactions and activities, including resilience workshops, education and learning throughout the whole journey of recovery, including the pre-contemplation stage, supported people to engage and maintain their journey.

Recommendation 6

We recommend a clearly communicated offer focused on supporting people to an abstinence-based point.

Participants spoke of a perceived feeling that the focus of their support programme was based on maintenance rather than recovery and abstinence. Although participants were aware of detoxes and rehabs, they felt there was not a clear offer communicated to support them to get to an abstinence base and felt they would have benefited from more focus on this alongside quicker access.

Recommendation 7

We recommend a whole systems approach for those facing addiction with mental health difficulties.

Participants spoke of mental health as a barrier to accessing and maintaining treatment. It was reported that people felt they needed a better pathway or integrated service to mental health support that operates in parallel with their addiction support.

Recommendation 8

We recommend a "Never give up" approach and non-engagement processes are reviewed and action taken.

Participants spoke of a perceived need for services to better understand people will not always be successful first time, and may fail, and require another opportunity. People felt a strict three strikes and your case is closed does not work for this client group and wanted to have an agreed plan on engagement, such a text reminder and what should happen if they disengage to help them re-engage.

7. Appendix

7.1 Appendix A Literature Review.

Literature Review on understand the barriers to seeking treatment for addiction.

To deliver this research project it is imperative to look at the current landscape of those accessing treatment for substance misuse addiction and review research in the area. This document will then outline its proposal, Ethics, Consent Form and a timeline for completion.

The Scope

Statistic trends by Notational Statistics show treatment numbers of 130,490 adults entered treatment between April 2020 and March 2021, a small rise compared to previous years of 275,896 adults in contact with substance misuse services between 2020 and 2021. Comparing to previous research Opiate use remains the large substance group in treatment with 51% (140,863) adults in treatment for opiate related drug misuse. The second largest group being those in treatment for alcohol related substance misuse, 76,740 (28%). Furthermore, statistics show a decrease in seeking treatment for Crack-Cocaine use of 21,308 this is the lowest number since statistics in 2016-2017. From 2011 there has been a yearly increase with cocaine related treatment, this decreased in 2020-2021 by 10% with 19,209 people starting treatment. 27,304 people sought treatment for cannabis use, 4,321 for benzodiazepine, 1,444 for ketamine use. 82,613 of people accessing treatment stated they had mental health treatment needs also. 22,493 people accessing treatment stated they had housing needs. Of 110,095 people who exited a treatment service in 2020-2021 50% were successful in completed their treatment programme and non-dependent on substance, a 47% rise from the year before. There were 3,726 deaths of people in treatment, a 27% increase from the year previous [(1)]

National Statistics also show statistically significant increase in alcohol related deaths was seen in 2020 compared to years 2012-2019, 8,974 deaths were recorded in 2020 with over 50 percent of the deaths being male [(2)]. In 2021 4,859 drug related deaths were recorded of this 63% (3,060) are registered as drug-misuse deaths; with over half of the deaths being related to opiate use. 3,275 deaths are registered as male and drug misuse deaths being highest among those age 45-49, closely followed by those aged 40-44. 258 deaths were related to psychoactive substances and rising for the 10th consecutive year; 840 deaths were involved cocaine. The number of deaths related to drug use is the highest since records began in 1993[(3)].

Locally, there is limited available information on drug use and treatment tends in the Leicestershire Area, However, the National Drug Treatment Monitoring System allows the ability to review the number in treatment and those exiting treatment in Leicestershire:

Total Exits Year to Date (YTD): Leicestershire												
Apr21 - Nov21	Apr21 - Dec21	Apr21 - Jan22	Apr21 - Feb22	Apr21 - Mar22	Apr21 - Apr22	Apr22 - May22	Apr22 - Jun22	Apr22 - Jul22	Apr22 - Aug22	Apr22 - Sep22	Apr22 - Oct22	Apr22 - Nov 22
Opiate	145	160	173	194	213	19	37	61	-No data available	100	126	141
Non-opiate only	112	127	134	148	157	12	28	42	-No data available	73	86	97
Non-opiate and alcohol	152	170	190	202	223	13	33	57	-No data available	92	102	113
Alcohol only	469	512	561	601	658	49	142	196	-No data available	290	345	405

Number in Treatment: Leicestershire													
Oct20 - Sep21	Nov20 – Oct21	Dec20 - Nov21	Jan21 - Dec21	Feb21 - Jan22	Mar21 - Feb22	Apr21 - Mar22	May21 - Apr22	Jun21 - May22	Jul21 - Jun22	Aug21 - Jul22	Sep21 - Aug22	Oct21 - Sep22	Nov21 - Oct22
Opiate	1119	1115	1111	1114	1101	1091	1082	1087	1078	1074	-No data available	1073	1074
Non-opiate only	202	219	221	224	213	221	224	220	217	210	-No data available	199	199
Non-opiate and Alcohol	321	319	318	315	314	310	324	326	326	314	-No data available	299	294
Alcohol only	968	981	983	987	971	978	989	1001	1015	1009	-No data available	994	1007

NDTMS - Monthly - Adults[4]

Reviewing the tables in the data above there is 2,600 people in treatment between April 2021 and March 2022 is 2,600 in Leicestershire. Evaluating the exits from April 2021-March 2022 to demonstrate a full year review of exits is 1,145 for the year. The National Statistics [1] stated above that 50% of their cohort had exited the service positively, if this is applied to the local statistics, it equates to 572 people for Leicestershire. Therefore, if 2,600 are in treatment between April 2021 and March 2022, and 572 exited the service completing treatment this would be 22%. Although this is ambiguous as the statistics above do not specify that people sought and exited treatment within the year timeframe. However, it does allow us to have an understanding of what is happening in treatment services in the Leicestershire area compared to the nationwide.

Research Review

Reviewing research that has been completed on barriers accessing treatment for substance misuse key themes have been noted. First the stigma around accessing treatment, UKDPC[5] focused their research on this theme and found that participants experience stigma in many different settings including pharmacies, Doctors Practices, hospitals, dentists, social services, employers, housing, criminal justice system and drug treatment services. Furthermore, relatives of the person seeking treatment and medication related stigma were specified in the research. It was noted that there is often a dispute between staff and client when it comes to

reducing methadone scripts, the client feeling listened too or valued often embodying itself as disempowering and withdrawing from service, whilst the staff member is following procedure to prevent relapse. A significant note when reviewing the scope above that 51% of those in treatment are using opiates. Overall, the research suggests that often services such as the police, doctors, drug treatment may unintentionally exhibit attitudes of stigma and training should be put in place to address this. There are also barriers discussed such as legislation, criminal records and administrative which contribute to the stigma.

Bogaers et al[6] also found stigma to be an influence in their research in the military. The research aimed to find barriers for military soldiers seeing treatment for mental health and substance misuse using three focus groups. The outcome highlights that soldiers were concerned about stigmatising attitudes from their seniors that could impede their career development, peer and community rejection and themes of toxic femininity and masculinity with the workplace culture. Recommendations suggest that leaders should intervene before a soldier reaches 'crisis' and that the military culture needs to promote awareness of both mental health and substance misuse, offering guidance and appropriate treatment, to reduce the taboo subject and create a supportive environment to seek treatment.

Roberts et al[7] conducted research over 4 focus groups and structured interviews with service users, service providers and service commissioners to analyse access to alcohol treatment and the relationship with alcohol related hospital admissions, noting a continuous rise in alcohol-related hospital admissions since 2012 and acknowledging a decrease in people accessing community based treatment. Roberts et al breaks down her findings into two strands: service related and individual related. Once more a theme of stigma in this research, particularly from General Practitioners from service users and service providers. Furthermore, budget cuts to reduce public expenditure is highlighted as a contributory factor for people not accessing treatment, suggesting that collaborating large local authority areas to one single access point is inconvenient for those who do not live locally, explaining that it can be costly and time consuming for people to access. There was also concern raised about contracts being up for tender, the risk of losing employment for employees and the therapeutic relationship for those who are engaged in treatment, confusion from clients' perspectives of name and location changes. a lack of treatment services available outside of working hours or weekends, a group engagement expectation was daunting for service users, a lack of understanding about pathways and expectations and an absence of promotion and information about services for those seeking treatment.

Professor Dame Carol Black [8] carried out a review commissioned by Department of Health and Social Care in 2021. The research was carried out in two parts, the aim of part one was to understand the demographics, demand and market of drug-use in the UK. The second part aimed to set recommendations for the government to reduce demand for illicit substances. In the Forward the report highlights "currently each £1 spent on treatment will save £4 from

reduce demand on health, prison, law enforcement and emergency services". Ultimately the review set out 32 recommendations expanding across many government departments to create a cohesive response to reform. First Dame Carlo Black outlines the increase for funding, the need for improved capacity and quality of specialist services for treatment and to put policy into practice to ensure local government use the allocated funds for treatment and for it not to be funnelled into other local priorities. The review sets out a need for a national quality standard agency to ensure quality across regions; and a need to rebuild the workforce and training for staff to improve quality and moral of services. The review also recommends that efforts and funding needs to be put in the revolving door offenders who need treatment over criminal intervention. The review highlights areas of support needed in financial stability and meaningful use of time, the need for suitable treatment services for rough sleepers, suitable housing and the importance these influences have on maintaining recovery.

From reviewing the above research common themes have emerged:

- Stigma: from services and staffing attitudes.
- Advertisement of services: promotional information on services is limited.
- Service expectations: unclear pathways and group settings prospects.
- Logistical needs: access to the services, location of services, and changes in services.

Proposal

Aims of the Research

- To understand inequalities in accessing treatment for addiction.
- To understand reasons for non-engagement in treatments.
- Identify gaps in addiction treatment provision.
- Provide recommendations for improving the pathways.

Participant Group

This research hopes to capture a broad and varied participant group, including those who are hardest to engage:

- People experiencing rough sleeping and homelessness.
- Targeting vulnerable and priority groups, including sex workers.
- People who are using substances such as crack cocaine and heroin, who are not engaged in treatment.
- Young people who are not accessing treatment.
- People who have been successful in treatment and now in recovery.

Methodology

The research will be carried out in two phases, first we will be completing a small quantitative questionnaire of 5-10 questions. we intend to distribute this questionnaire, through our internal

Harm Reduction Team who work within the community, through our accommodation services. Furthermore, we will be creating the same questionnaire of on surveymonkey.com so the survey can be shared on Falcon Support Services social media, sent to organisations such as supported accommodation services, treatment centres and street outreach to gain a baseline understanding of participants perspectives. An example of the quantitative questions:

Do you feel there is stigma attached to accessing treatment for addiction?

☐ Yes ☐ No

Have you ever felt stigmatised by the following services for having an addiction?

☐ Pharmacies ☐ GP Surgery ☐ Hospital ☐ Drug/alcohol treatment services

☐ Dentists ☐ Social Services ☐ Police ☐ Housing Services.

☐ Employment (Employers, Colleagues, Job centre) ☐ Local Authority (council)

Are you currently receiving treatment for an addiction?

☐ Yes ☐ No

Have you tried to access treatment before?

☐ Yes ☐ No

How many times have you tried to access treatment for addiction?

☐ Once ☐ Two to Three times ☐ Three to Five times ☐ Five to seven times

☐ Seven to ten times ☐ Ten times or more.

The questions are in development; and will be workshopped with professional who work on the frontline. To inform our survey we will be developing questions from Miller et al (1995), The barriers questionnaire work [10]. The questionnaire will allow us to catch a snapshot of perspectives from the target group which will allow us to develop the process for the second phase, In-Depth Interviews (IDIS). Falcon Support Services will also be conducting a survey on professionals who are working in partnership with treatment services for their service users, this will allow for comparable data.

IDIs have been chosen as the most appropriate form to gather the information as the research topic is complex, emotive, personal and unique. Moreover, the individual's perspective are important in understanding the topic and this method allows us to be flexible in the interviews. A discussion guide will be developed, with open questions on topics and prompts which will be developed from phase one. This will promote keeping the participant on topic yet allow them to discuss their perspectives freely. The interview will be audio recorded and transcribed to allow the interviewer and participant to engage fully in the interview. The structure of the interview will be:

Introduction	Welcome, names, offer of refreshments, discuss purpose of interview, discuss confidentiality and consent.
Practicalities	Discuss breaks, toilets, fire-alarms, duration, Phones on silent.
Warm Up Questions	A light general question asking to encourage participants ease into the exploratory questions such as 'do you live locally', 'have you always lived around here?' 'how are you today?'
Exploratory Questions	Themes and prompts around key topic of interests.
Debrief and Close	Summarise the interview, offer time for participant to ask questions or add comments, reminder of confidentiality and consent, Thank you's, gift card and aftercare leaflet.

We intend to hold between 1-3 focus groups to generate discussions and debates around the subject following the same discussion guide. Falcon Support Services will also conduct IDI's with professionals to allow an understanding from this perspective. We will then be able to draw comparisons on the IDI data.

<u>Recruitment</u>

As stated above we hope to circulate phase one's quantitative questionnaire through networking with supported accommodation services such as internal accommodation at Falcon Support Services and external such as Exaireo and Bridge Street. Treatment houses such as Carpenters' Arms, out-reach such as satellite drop-ins across Leicestershire. Furthermore, we can network the survey through an email using SurveyMonkey.com and on social media. The Survey will also offer the participants to express their interest in taking part in phase two.

Further recruitment will take place for phase two which will include networking in the above services, to attend team meeting, resident meetings, group meetings to promote the interviews. Furthermore we can reach out through posters in these services and sharing the information through social media.

Ethics

Ethical Considerations will need to be managed to ensure the research has a code of conduct to adhere too, this will support the researcher's integrity and reduce the potential harm to participants.

Ethical issue	Management
Voluntary participation	This will be explained to the participant at the beginning of each IDI. The participant will be given an aftercare sheet at the end of the research with information on how to contact the research group should they wish to withdraw at a later date.
Informed consent	An information sheet will be developed to be distributed at the recruitment phases, this will also be front page of the phase one and discussed at IDIs in the introduction.
Anonymity	An information sheet will be developed to be distributed at the recruitment phases, this will also be front page of the phase one and discussed at IDIs in the introduction.
Confidentiality	Once interviews are completed they will be coded with no significance to the person themselves. Recording will then be destroyed once transcripts are received.
Potential for harm	Interviews could be potentially re-traumatising for participants. An aftercare sheet will be developed to distribute after interviews which will include, how to withdraw, services to speak to such as Samaritans, satellite drop-ins, AA and NA meeting dates, times and places.
Results communication	The outcomes report from the research will be from analysing the data collected from this participant group. If comparisons are made to other literature, APA referencing will be used to acknowledge the work of others.

Ethic's guidance from scibbr[9]

Reference List:

1. "National Statistics", (25th November 2021) Adults Substance Misuse Treatment Statistics 2020 to 2021: report. Retrieved from Adult substance misuse treatment statistics 2020 to 2021: report - GOV.UK (www.gov.uk)
2. "Office for National Statistics", (7th December 2021). Alcohol-specific deaths in the UK. Retrieved from Alcohol-specific deaths in the UK - Office for National Statistics (ons.gov.uk)

3. "Office for National Statistics", (3rd August 2022). Deaths Related to drug poisoning in England and Wales. Retrieved from Deaths related to drug poisoning in England and Wales - Office for National Statistics (ons.gov.uk)
4. "ADTMS" (5th December 2022) Community adult treatment performance reports – Leicestershire. Retrieved from NDTMS - Monthly - Adults.
5. "UKDPC", (December 2010). Getting Serious about Stigma: the problem with stigmatising drug users. Retrieved from UKDPC » Getting serious about stigma: the problem with stigmatising drug users
6. Bogaers, R., Geuze, E., Van Weeghel, J., Leijten, F., Van Fe Mheen, D., Varis, P. Rozema, A. and Brouwes, E. (2020) Citation: Barriers and Facilitators for treatment-seeking for mental health conditions and substance misuse: multi-perspective focus groups study within the military. BJ Psych Open, 6(6) DOI: 10.1192/bjo.2020.136
7. Roberts, E., Hillyard, M., Hotopf, M., Parkin, S. and Drummond, C. (2020) Citation: Access to specialist community alcohol treatment in England, and relationships with alcohol related hospital admissions: qualitative study of servce users, service providers and service commissioners. BJPsych Open 25;6(5) DOI: 10.1192/bjo.2020.80.
8. "Gov.uk", (25th November 2021) Independent review of drugs by Professor Dame Carol Black. Retrieved from Independent review of drugs by Professor Dame Carol Black - GOV.UK (www.gov.uk)
9. Bhandari, P. (2nd December 2022) Ethical Considerations in Research: Types and Examples. Scribbr, Retrieved from: Ethical Considerations in Research | Types & Examples (scribbr.com)
10. Miller, W.R., Tonigan, J.S., Miller, W.R., Sovereign, R.G. and Krege, B., 1995. The barriers questionnaire. Journal of Consulting and Clinical Psychology, 70, pp.1182-1185.

7.2 Appendix B Consent Form.

Consent Form for Participants with Lived Experiences

Interview Consent Form

Research project title:

Research investigator:

Research Participants name:

Falcon Support Services have been commissioned by Public Health Leicestershire to facilitate research in understanding the barriers to seeking treatment for addiction. Thank you for agreeing to be interviewed as part of this research project.

The interview will take one hour, you have the right to stop the interview or withdraw from the research at any time, an information leaflet will be given to you to provide details on withdrawing from the research.

Ethical procedures for research undertaken require that interviewees explicitly agree to being interviewed and how the information contained in their interview will be used. This consent form is necessary for us to ensure that you understand the purpose of your involvement and that you agree to the conditions of your participation. Would you therefore read the accompanying information sheet and then sign this form to certify that you approve the following:

- the interview will be recorded and a transcript will be produced
- the transcript of the interview will be analysed by the research team.
- Transcripts will be anonymised and coded once transcribed.
- Access to the interview transcript will be limited to the research team at Falcon Support Services.
- Any summary interview content, or direct quotations from the interview, that are made available through publication or other professional outlets will be anonymised so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed.
- The actual recording will be kept for 8 weeks after interview for transcribing purposes.
- The transcribe of the interview can be kept for up to five years.
- Any variation of the conditions above will only occur with your further explicit approval

Quotation Agreement

I also understand that my words may be quoted directly. With regards to being quoted, please initial next to any of the statements that you agree with:

I wish to review the notes, transcripts, or other data collected during the research pertaining to my participation, if I wish to do so I must request these within one month of my interview date in writing.	

I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	
I agree that the researchers may publish documents that contain quotations by me.	

All or part of the content of your interview may be used;

- In papers, policy papers or news articles by Falcon Support Services or Public Health.
- On Falcon Support Services or Public Health website and in other media that may be produced such as spoken presentations
- On other feedback events

By signing this form I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time;

2. The transcribed interview or extracts from it may be used as described above;

3. I have read the Information sheet;

4. On completion of my participation I will receive a £10.00 gift voucher.

5. I can request a copy of the transcript of my interview within one month of my interview date and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality;

6. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

Printed Name of Participant	--
Participants Signature	--
Date	--
Researchers Signature	--
Date	--

Consent form for Professional Participants.

Professional Interview Information Sheet and Consent Form

Research project title: Understanding the barriers to seeking treatment for addiction.

Research investigator:

Research Participants name:

Falcon Support Services have been commissioned by Public Health Leicestershire to facilitate research in understanding the barriers to seeking treatment for addiction. Thank you for agreeing to be interviewed as part of this research project.

The interview will take one hour, you have the right to stop the interview or withdraw from the research at any time, an information leaflet will be given to you to provide details on withdrawing from the research.

Ethical procedures for research undertaken require that interviewees explicitly agree to being interviewed and how the information contained in their interview will be used. This consent form is necessary for us to ensure that you understand the purpose of your involvement and that you agree to the conditions of your participation. Would you therefore read the below information and then sign this form to certify that you approve the following:

- The interview will be recorded, and a transcript will be produced.
- The transcript of the interview will be analysed by the research team.
- Transcripts will be anonymised and coded once transcribed.
- Access to the interview transcript will be limited to the research team at Falcon Support Services.
- Any summary interview content, or direct quotations from the interview, that are made available through publication or other professional outlets will be anonymised so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed.
- The audio recording will be kept for 8 weeks after interview for transcribing purposes.
- The transcribe of the interview can be kept for up to five years.
- I understand that information which suggests that there is risk of serious harm to myself or other cannot be kept confidential and a joint decision will be taken regarding who to tell.
- any variation of the conditions above will only occur with your further explicit approval.

Quotation Agreement

I also understand that my words may be quoted directly. With regards to being quoted, please initial next to any of the statements that you agree with:

If I wish to review the transcripts or other data collected during the research pertaining to my participation, I must request these within one month of my interview date in writing.	
I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	
I agree that the researchers may publish documents that contain quotations by me.	

All or part of the content of your interview may be used:

- In papers, policy papers or news articles by Falcon Support Services or Public Health.
- On Falcon Support Services or Public Health website and in other media that may be produced such as spoken presentations.
- On other feedback events.

By signing this form I agree that;

1. I am voluntarily taking part in this project. I understand that I do not have to take part, and I can stop the interview at any time;

2. The transcribed interview or extracts from it may be used as described above;

3. I have read the Information sheet;

4. I can request a copy of the transcript of my interview in writing within one month of my interview date and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality.

5y78. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

Printed Name of Participant	--
Participants Signature	--

Date	--
Researchers Signature	--
Date	--

7.3 Appendix C Questionnaire's and findings.

Questionnaire for Participants with Lived Experience.

<u>Barriers to Seeking Treatment for Addiction Questionnaire.</u>

<u>Demographics for research:</u>

AGE:	☐ 18-24 YEARS	☐ 25-34 YEARS	☐ 35-44 YEARS
	☐ 45-54 YEARS	☐ 55-64 YEARS	☐ 65+ YEARS

GENDER:	☐ MALE	☐ FEMALE	☐ NON-BINERY
	☐ MY GENDER IS NOT LISTED HERE	☐ PREFER NOT TO SAY	☐
LOCATION LOCAL AUTHORITY:	☐ CHARNWOOD	☐ MELTON MOWBRAY	☐ HINKLEY AND BOSWORTH
	☐ RUTLAND	☐ NORTH WEST LEICESTERSHIRE	☐ BLABY
	☐ HARBOROUGH	☐ LEICESTER CITY	☐ NOT A LEICESTERSHIRE BOROUGH.

Are you currently receiving treatment for an addiction?

☐ Yes ☐ No

Have you tried to access treatment before?

☐ Yes ☐ No

How many times have you tried to access treatment for addiction?

☐ Once	☐ Two to Three times	☐ Three to Five times	☐ Five to seven times
	☐ Seven to ten times	☐ Ten times or more.	

<u>Question Option Two:</u>

A series of statements where participants can tick as many as apply to them, example:

Barriers to treatment for me are

- ☐ I didn't know I had a problem.
- ☐ I thought I could handle it on my own.
- ☐ I didn't think of myself as an addict.
- ☐ I was concerned of what others may think of me if I asked for help.
- ☐ I was too ashamed.
- ☐ I was too embarrassed.

- ☐ I didn't know where to go for help.
- ☐ I didn't want to be told to stop using.
- ☐ I couldn't afford to pay for help.
- ☐ I had no transportation, no way to get there.
- ☐ I didn't have time.
- ☐ I was afraid I would be put in hospital.
- ☐ I didn't think I needed help.
- ☐ I hate being asked personal questions.
- ☐ I didn't want someone telling me what to do with my life.
- ☐ I have had bad experiences with treatment before.
- ☐ Somebody I know has had bad experiences with treatment before.
- ☐ I was afraid of what may happen in treatment.
- ☐ My use was not causing any problems as far as I could see.
- ☐ I don't like to talk in groups.
- ☐ I liked using and didn't want to give up.
- ☐ I thought I would lose my friends if I went for help.
- ☐ I liked getting high.
- ☐ I didn't feel safe going where I would have to go for help.
- ☐ I have done it before, and it did not work.
- ☐ Treatment can be confusing.
- ☐ Staff in treatment services do not understand me.
- ☐ I did not feel in control of my recovery.
- ☐ I did not want to be associated with the treatment service.
- ☐ Fear of the unknown.
- ☐ I was worried I would lose my accommodation.
- ☐ I was worried about admitting to my family about my addiction.
- ☐ I was worried about loosing my family.
- ☐ I was worried social services would get involved with my children.
- ☐ Treatment services are not open when I can attend, evenings/weekends.
- ☐ Other

Questionnaire for Professional Participants

Professionals Perspective on Barriers to Seeking Treatment for Addiction Questionnaire.

Please return to robyn.edwards@falconsupportservices.org.uk

Demographics for research:

AGENCY	☐ DRUG AND ALCOHOL TREATMENT SERVICE	☐ HEALTH SERVICE	☐ ADVICE AND GUIDANCE SERVICE
	☐ HOMELESSNESS OR HOUSING SERVICE	☐ MENTAL HEALTH SERVICE	
	☐ OTHER (PLEASE SPECIFY):		
WHICH LOCAL AUTHORITY DO YOU WORK IN:	☐ CHARNWOOD	☐ MELTON MOWBRAY	☐ HINKLEY AND BOSWORTH
	☐ RUTLAND	☐ NORTH WEST LEICESTERSHIRE	☐ BLABY
	☐ HARBOROUGH	☐ LEICESTER CITY	☐ NOT A LEICESTERSHIRE BOROUGH.
	☐ LEICESTERSHIRE WIDE		

Question Two:

Please select all statements which you feel are barriers for Service- Users accessing treatment for addiction:

- ☐ My Service Users do not feel they have a problem.
- ☐ My Service Users feel they can handle it on my their own
- ☐ My Service Users did not think they needed help
- ☐ My Service Users do not think of themselves as an addict
- ☐ My Service Users have done it before and it did not work
- ☐ My Service Users did not want to be told to stop using
- ☐ My Service Users do not like talking in groups
- ☐ My Service User liked using and didn't want to give up
- ☐ My Services Users are worried about the unknown.
- ☐ My Service User liked getting high
- ☐ My Service Users are embarrassed
- ☐ My Service Users felt they did not have the time
- ☐ My Service Users have had bad experiences with treatment before
- ☐ My Service User finds staff in treatment services do not understand them
- ☐ My Service User felt their use was not causing any problem as far as they could see
- ☐ My Service Users do not like being asked personal questions
- ☐ My Service Users feel ashamed
- ☐ My Service Users had no transportation, no way to get there

- ☐ My Service Users are worried they would lose their accommodation.
- ☐ My Service Users did not know where to go for help
- ☐ My Service Users are afraid they would be put in hospital
- ☐ My Service Users know somebody who has bad experiences with treatment before
- ☐ My Service Users are afraid of what may happen in treatment
- ☐ My Service Users do not feel safe going where they would have to go for help
- ☐ My Service Users are worried about admitting to their family about their addiction
- ☐ My Service users are worried about losing their family
- ☐ My Service Users are worried social services would get involved with their children
- ☐ Treatment services are not open when my Service Users can attend, evenings/weekends
- ☐ My Service Users could not afford to pay for help.
- ☐ My Service Users did not want someone telling them what to do with their life
- ☐ My Service User did not feel in control of Their recovery
- ☐ My Service Users finds treatment can be confusing
- ☐ My Service Users do not want to be associated with the treatment services
- ☐ My Service Users are concerned of what other may think of them if they asked for help
- ☐ My Service Users thought they would lose my friends if they went for help
- ☐ Other (please specify)

COMPARISON OF QUESTIONNAIRE DATA FROM LIVED EXPERIENCE PERSPECTIVE AND PROFESSIONALS PERSPECTIVE.

LIVED EXPERIENCE PERSEPCTIVE (73)	PERCENTAGE	PROFESSIONAL PERSPECTIVE(68)	PERCENTAGE
PRE- CONTREMPLATION			
I Thought I could handle it on my own	62%	My Service Users feel they can handle it on my their own	58%

I didn't think of myself as an addict	48%	My Service Users do not think of themselves as an addict	58%
I didnt think I needed help	34%	My Service Users did not think they needed help	52%
I didn't know I had a problem	21%	My Service Users do not feel they have a problem.	60%
EMOTIONS			
I am/was worried about admitting to my family about my addiction	16%	My Service Users are worried about admitting to their family about their addiction	39%
I was/am too ashamed	27%	My Service Users feel ashamed	38%
I was/am too embarrassed	30%	My Service Users are embarrassed	47%
I thought I would lose my friends if I went for help	12%	My Service Users thought they would lose my friends if they went for help	15%
I am/was worried about the unknown.	37%	My Services Users are worried about the unknown.	61%
I am/was worried about losing my family	17%	My Service users are worried about losing their family	34%
I am/was worried social services would get involved with my children	12%	My Service Users are worried social services would get involved with their children	47%
I am/was worried I would lose my accommodation	21%	My Service Users are worried they would lose their accommodation	39%
ATTITUDE ON USE			
I don't/ didn't want to be told to stop using	27%	My Service Users did not want to be told to stop using	55%
My use was not causing any problem as far as I could see	20%	My Service User felt their use was not causing any problem as far as they could see	34%
I like/ liked using and didn't want to give up	23%	My Service User liked using and didn't want to give up	50%
I did/do not want to be associated with the treatment services	16%	My Service Users do not want to be associated with the treatment services	26%
I like/liked getting high	31%	My Service User liked getting high	50%
REFLECTIONS ON EXPERIENCE			
Staff in treatment services do not understand me	31%	My Service User finds staff in treatment services do not understand them	46%
I hate being asked personal questions	27%	My Service Users do not like being asked personal questions	44%
I didn't want someone telling me what to do with my life	21%	My Service Users did not want someone telling them what to do with their life	46%
I have had bad experiences with treatment before	27%	My Service Users have had bad experiences with treatment before	47%
I have done it before, and it did not work	26%	My Service Users have done it before and it did not work	61%

Treatment can be confusing	31%	My Service Users finds treatment can be confusing	23%
I did/do not feel in control of my recovery	26%	My Service User did not feel in control of Their recovery	25%
I don't like talking in groups	28%	My Service Users do not like talking in groups	69%
REFLECTION ON OTHER EXPERIENCE			
I was concerned of what others may think of me if I asked for help.	20%	My Service Users are concerned of what other may think of them if they asked for help	33%
Somebody I know has had bad experiences with treatment before.	13%	My Service Users know somebody who has bad experiences with treatment before	41%
KNOWLEDGE OF SERVICES			
I didn't know where to go for help.	31%	My Service Users didn't know where to go for help	31%
I couldn't afford to pay for help.	17%	My Service Users couldn't afford to pay for help.	34%
I was afraid I would be put in hospital.	10%	My Service Users are afraid they would be put in hospital	19%
ACCESS TO RESOURCES			
I didn't feel safe going where I would have to go for help.	19%	My Service Users do not feel safe going where they would have to go for help	23%
I had no transportation, no way to get there.	20%	My Service Users had no transportation, no way to get there	44%
I didn't have time.	9%	My Service Users felt they didn't have the time	23%
Treatment services are not open when I can attend, evenings/weekends.	6%	Treatment services are not open when my Service Users can attend, evenings/weekends	30%
OTHER COMMENTS:		OTHER COMMENTS:	
• Felt that because i have been in before they didn't want to give me another chance • Support groups were not beneficial as people would get drunk whilst there. The detox that I had was beneficial • I just want help • never received any • never received any • They cannot support me with a safe space to practice my religion or faith • Not having a clear understanding of what treatment entails • all of the above over the past 15 years. • All the above apply to all addicts, it's a sickness.		• Many of my service users with alcohol addiction feel treatment services (Turning Point) don't help as much they would with drug addictions. Many believe this is due to the better funding for drug addictions. • Very little help for people with alcohol use. • My Service Users are worried about admitting to themselves about their addiction, My Service Users do not want to have to do anything beyond what they usually do, My Service users just want a prescription without being in treatment • they felt they were not given enough time and were not listened to. they felt their views/opinions were not considered at all! as	

	an organisation i have found it difficult to build a good professional relationship with TP. we have found them very difficult and in my opinion have done a lot of damage. • Difficult to keep appointments due to chaotic lifestyle, service users not sure if they can get help for cannabis/coke etc as TP associated with heroin/alcohol • The service isn't flexible enough for the chaotic nature of the service users • The treatment centre would not listen to what they wanted

7.4 Appendix E Discussion Guide Example

Discussion Guide Interviews	
Introduction	Welcome, names, offer of refreshments, discuss purpose of interview, discuss confidentiality and consent.
Practicalities	Discuss breaks, toilets, fire-alarms, duration, Phones on silent.
Warm Up Questions	A light general question asking to encourage participants ease into the exploratory questions such as 'do you live locally', 'have you always lived around here?' 'how are you today?'

Exploratory Questions	ACCESS TO RESOURCES: • Can you tell me about the first time you accessed Turning Point or a treatment Service? • How did you know where to go for help? • Does going to Turning Point feel safe? • What is your access like to Turning Point? Local, Bus, hot-desk visits? • Are the Services open when you need them? • Where have you seen turning point advertised? TREATMENT SERVICE PERCEPTION: • Do you remember the first time you went to turning point, what was that like? • What are your thoughts on turning point? • What is your understanding of the treatment pathways? • What works well at turning point? • Are you currently with Turning Point? If So do you know what your next stages are on your pathway? • Do you feel that you get to make contributions to your pathway? SELF-PERCEPTION • How do you feel about attending Turning Point? • How do the Staff make you feel? • Did you have any worries before going to turning point? **What would you like to see improved with treatment services** **Demographics: please try to take age, gender and substance use information**
Debrief and Close	Debrief Lunch: Summarise the interview, offer time for participant to ask questions or add comments, reminder of confidentiality and consent, Thank you's, gift card and aftercare leaflet.