13.0 Views of people who use the services

NHS Lothian Department of Public Health and Health Policy, and the Edinburgh Access Practice for homeless people sought the views of people using services in two separate pieces of work.

13.1 People in recovery and current injectors attending different services (NHS Lothian Department of Public Health and Health Policy)

Participant characteristics

Of the 29 people interviewed six were women, five as individuals and one as part of a couple, with her male partner. Fewer women were available to interview at the locations attended. Many of those interviewed had been in custody and /or prison, including people not actually seen in either of these settings. In total, over half had experienced prison, some several times. At least 16 people described themselves as currently homeless, either living in a B & B or a hostel, staying with friends or actually on the streets. In addition, two of the men interviewed in prison expected to be homeless on their release.

The youngest person interviewed was 22 years old and the oldest 56. Many described a drug habit stretching back over many years, with some having started at 11, 12 or 13 years old. This was not universal – at least 2 respondents (one in his 20s and one in his 40s) said they had only used for 2 years, were currently on methadone and determined to stop at this point in time. Actual injecting of heroin tended to come later on in the drug taking career. It was not the first type of drug, nor route for most of those interviewed. Injecting was often initiated when the person was seeking a bigger hit and influenced to do so by injecting peers.

Views on current services

Most though not all respondents were aware of specialist services available, such as the Spittal Street Centre, the Edinburgh Access Practice and the different Recovery Hubs, whether or not they made use of them all. Some did not identify with the concept of the recovery hub and referred to them as just another service they would go to get their needles.

Respondents were generally unable to suggest any extra services they would like to see, but did have some comments about current organisation and delivery.

Several people talked in negative terms about what they perceived as a lack of control over how and when they could access services. They disliked for example, the fact that there were designated hours for certain things (e.g. what time they could come in to get their methadone at Spittal Street) or that some services offered a drop-in rather than an appointment system, because this might mean not being seen at all if all available slots were already taken. At the same time, most of those

interviewed freely recognised that they often found it very difficult to keep appointments, for a variety of reasons.

Three people were interviewed in a pharmacy but others also spoke about their experiences of getting methadone from their chemist. A positive experience often seemed to depend on a good relationship with particular members of staff. Many were described as friendly and welcoming although others were less so, even in the same shop. One respondent, who had difficulty in remembering and keeping appointments, said that his local pharmacist would remind him when he needed to see his community psychiatric nurse to get a new prescription. Another contrasted the attitude of the new manager at his local chemist with the previous owner, whom he had known for some time:

'*They dinnae speak to you. The old chemist, they'd speak away to you, really nice.'*

He further complained that the new manager had instituted time constraints on when methadone users were allowed to come in, and felt this very keenly as unjustified discrimination.

This perception of being seen and treated as a 'second class citizen' was reiterated many times; a number of respondents felt they were looked down on and made to wait so other shoppers could be given preference. However, the partitioned section at the back of one pharmacy which reinforced this feeling for several respondents was, on the other hand, seen as privacy and a positive advantage by others. A key issue appears to be whether or not people feel that as methadone users they are explicitly singled out, with no other option but to be visible. One respondent described a situation which he perceived as unnecessary and degrading, where he was required to use a different door, clearly signed, and wait outside on a busy shopping street, sometimes for up to 20 minutes.

Feedback about staff encountered in specialist services was generally positive. Several respondents referred to specific workers by name, although they were sometimes unclear about their precise role and remit. Clearly what matters to people is a good relationship and the level of support received rather than knowing the precise professional term for the worker who provides it. In particular the capacity to work with and across a variety of services is valued, because recovering addicts need help in so many different areas. One respondent said that he didn't know how he would manage the demands of daily life without his key worker. Another, about to be released from prison, commented:

I've got Lifeline picking me up, I've got a Lifeline worker they are taking me out picking me up from the gate, taking me to sort out my prescription, job centre, doctor everything like that so I have somebody there that is going to help me.

Integrated and intensive support of this kind is even more crucial for people with poor literacy skills. One of the prisoners interviewed said that he was unable to read or write. This was not specifically raised by any other respondents but is likely to be an issue for a number of drug users, given literacy rates across the general population. This needs to be borne in mind in relation to conveying any kind of information.

Many respondents used the Edinburgh Access Practice for health care but some were registered with other practices across the city. While some felt that GPs needed to be better informed about addiction and relevant services, others (mostly in areas with a high number of drug users) described a very positive relationship with their doctor.

There was positive feedback from several respondents about peer led support, both in terms of groups as well as the potential for informal one-to-one contact, perhaps in a waiting room. One interviewee felt this provided the opportunity for better conversations with professionals; he suggested that he would find it easier in the first instance to confide in a peer supporter, who would then help him relay the information he wanted. The most enthusiastic proponents of peer support were possibly those who had found help in this way in the past, and were now peer supporters themselves.

There were widely differing views on Narcotics Anonymous; some clearly felt the meetings had been, quite literally, a lifeline for them, but others disliked the religious overtones:

'Like NA? Shit. Well no not shit that's a lie. But they do try and put the bible in your hands.'

A number of respondents expressed a preference for one-to-one support over groups. However, some peer supporters expressed the view that with increasing confidence many recovering addicts might progress to finding groupwork both possible and helpful, and had observed this transition. The structured groups or classes focussed on specific activities offered at Spittal Street Centre were very popular with a number of respondents. One long term injector was not keen to access groups but it seemed that he was unaware of what the focus of the group could or would be. He referred to diversionary activities that he had attended when he was young and would be interested in doing as an adult that involved mechanics and fixing old cars and motorbikes.

Respondents were asked specific questions on blood-borne virus testing, overdose, experience of naloxone and access to clean works. Most had been tested for Hepatitis and HIV and knew their status, although some individuals had 'not got round' to finding out the result. There was no clear evidence of widespread reluctance to take up treatment for hepatitis C, apart from the perennial difficulty of

keeping appointments; one person said they had been deterred by anxiety about side effects.

For those who were interviewed in prison it seemed that the prison setting provided a welcome opportunity for them to get tested and that is where they had received their previous tests each time they were in custody.

Respondents who had experienced an overdose – some three or four times – were frequently not very clear about the circumstances, the aftermath or the kind of support they had been offered afterwards. A few described coming round and leaving before or as the ambulance arrived. Naloxone was almost universally approved of as a good idea, although not all had been offered it. Some were resistant to use it for fear of the consequences of 'ruining someone's hit'. They felt that the person they were administering it to might have been angry and become violent with them, although they did accept how important it was to have it on their person. Those who had been taken to hospital stated that they signed themselves out as quickly as possible and were not interested in speaking to staff.

No interviewees said they had ever encountered difficulties in getting hold of clean works, except for one on one occasion late at night. Indeed several voiced quite strong disapproval of people who sometimes didn't have enough clean works and consequently shared needles, with comments such as 'there's no excuse' and 'they're just lazy.'

Respondents were also asked their views on safe injecting rooms and heroin assisted treatment but there was no consensus regarding either of these approaches. There was greater support for safe injecting rooms, with most seeing potential benefits especially for people living and using on the streets, or in public. Dissenting voices suggested that people on treatment or considering stopping would be encouraged to start using heroin again, and many thought that the police would just 'hang around watching for people.' The concept of heroin assisted treatment was clearly new to many people and they were unsure as to what they thought. Some felt that harm would be reduced because heroin is easier to come off than methadone and the drug would be quality controlled. Others saw no benefit, they considered that heroin was in itself 'a horrible drug' that people should not be maintained on.

The main issues

Clearly respondents views on services and how helpful they found them were informed by their own experiences and those of people they knew. A number of recurring themes emerged from the interviews.

Lengthy assessment period for OST

A major issue raised was the difficulties posed by a lengthy assessment period, that is, the waiting time between first presenting for treatment and actually getting a methadone prescription. A number of respondents suggested that 8-12 weeks is not unusual. The effect of this was eloquently described by one respondent:

'I just had to deal with it on my own. There's nothing, I mean people can say stuff, say that they're there, to talk to us, like that. But talking doesn't get rid of withdrawal symptoms. Every day I still had to, I mean I had that in the back of my mind, you know, (date I can start, date I can start), but every day, you know, also another voice in the back of my head that said, you need to, you know, you're withdrawing, you're going to start being sick, and stuff like that, Each hour that passes you need to make money or you need to go out and get drugs, and I knew, from the first day that I came here, that it was kind of like a death sentence, well not a death sentence if you know what I mean, it was kind of like a prison sentence in that I knew when I was getting the help, when it was starting, but the fact that it was so long (lengthy pause) away. I mean you say 2 months, it's not a long time but you know when you're sick of living, the way I was living. And you come in here, wanting help, and it's like you're ready, right there and then, for the help, but it's in 2 months time. A lot of things could've happened to me in 2 months. I could've been caught shoplifting in those 2 months and been sent to prison, which woulda thrown all this out the window.'

The consequences of delay could be significant. Another respondent, back in custody after being released two days previously, commented:

'The problem is I always get put on a treatment order from court, but in the meantime what are you meant to do to feed your habit? So I'm still committing the crime to feed my habit. So I can never get on to the treatment order if you know what I mean……..It's not like fast enough to help you out, if you know what I mean.'

Respondents generally felt that they were treated with consideration in custody and helped, through receiving medication, to cope with the effects of their withdrawal while being held. One reflected that if it were possible to do this for people in custody he didn't understand why there could not be ways to help people waiting to start treatment.

Recovered addicts were also critical of such long delays. There was a view that facilities on offer, such as support groups or opportunities to talk for example, were not something that people would be able to access in any meaningful way at this particular juncture, or could really help them through the wait before starting treatment.

Methadone programme

A second common theme was the ambivalence that many respondents expressed about methadone, or its substitutes, as a treatment option. One respondent acknowledged that:

'It's put me back on my feet. It means I can get up and go to work every day.' but added that methadone '…builds in another step to getting clean.'

Other respondents queried the wisdom of replacing one addictive drug with another. There was evidence of a deep seated fear about coming off methadone, as withdrawal was perceived to be much worse than with heroin. There was also a widely held view that health professionals are reluctant to help people reduce their methadone or come off it.

'Cos you're on it for life, they dinnae want to take you aff it, know what I mean.'

Although it was recognised that some people may be happy to stay on methadone more or less indefinitely, several respondents expressed anger that addicts in recovery are not more actively supported and encouraged to move onto the next stage i.e. a lower dose or complete recovery.

There was a view that treatment options are limited and inflexible. One respondent talked about his partner who experienced difficulties ingesting liquid methadone but was offered no alternative, although he felt sure that one existed:

'*They should, I dinnae mean this place but like the pharmacist or the doctor or whatever should accommodate to that individual persons needs….Instead, you just - oh, they're all fucking smackheads, they're all taking methadone, that's it, they're all getting methadone, and that's it.'*

Clearly there may be clinical reasons why an individual needs to be on a particular dose which can't be reduced and it is possible this is not always well understood, especially in relation to injecting use 'on top'. Individual respondents also recognised that although they disliked the loss of autonomy inherent in the treatment programme, for example with daily supervision, it had benefitted them.

Nonetheless, anger about a perceived dismissal of people who inject drugs as simply 'junkies' and by implication undeserving of help, not only by the general public but also sometimes extending to service providers, was strongly expressed.

Mental health

A number of respondents expressed feelings of embarrassment and shame about their drug use and consequent behaviour, such as begging or selling sex, often alongside anger about what they perceived as unfair or denigrating treatment. They

were aware that injecting drug users are judged harshly by society in general, and several distanced themselves from those they considered to be 'real junkies', by way of a defining type of behaviour that they themselves professed to be above, for example, people who leave used needles in places 'where bairns can pick them up.'

Such lack of self worth, combined with the implacable need to meet the demands of their addiction, resulted in poor physical as well as mental health. Loss of weight due to poor diet was commonly mentioned, alongside some of the more direct effects of injecting, such as wounds. Most respondents were smokers with a significant number suffering from Chronic Obstructive Pulmonary Disease (COPD). For some, this affected their ability to get to services as walking and breathlessness was a problem.

Most respondents described feelings of anxiety and depression with several on medication, and a few specifically referred to stays at the Royal Edinburgh. Some had overdosed on prescription drugs in an attempt to commit suicide and self harm was mentioned specifically by those in prison. In addition, several respondents talked about very traumatic events in their lives such as childhood abuse, parents being in abusive relationships, losing contact with family, losing friends or a partner through drug use and in some cases actually finding or being present with the person who overdosed and died.

Several respondents said that it was during periods of feeling very low, or after a difficult or sad experience, that they tended to relapse back into drug injecting. Some identified a viscious cycle of drug use and depression which prevented them from engaging with available services. They were interested only in picking up their injecting equipment or their prescription without having to speaking to anyone, including workers.

The focus group participants, all of whom had been 'clean' for a number of years, strongly emphasised the need for addicts in recovery to develop new ways of coping and thinking. Those currently injecting or on treatment concurred with this, inasmuch as the reasons given for wanting to stop were often expressed in terms of total weariness with themselves and their existence, and a strong desire to stop living in a way that was completely and utterly controlled by their drug habit. As one respondent put it:

'*I wasn't eating at all because I never had any money. Any money that I got, you know if I got £5, I never looked at it, as sort of £5, I could spend that on food or electricity or whatever, all of that, it's….oh that's half way towards getting a £10 bag of heroin, I'm half way there already, I just need to make another £5…..Every day, when I was using heroin, every day I would like, when it got to a certain point in the day when I'd had enough heroin to, to, you know, for my addiction so that I wasn't withdrawing any more and stuff like that I'd make plans for the next day. And then*

they plans would go out the window the next day as soon as I woke up and I was withdrawing because first thing on my mind was right I need to get money, and if I have money right I need to get drugs.'

Some respondents described very positive experiences of counselling and psychological support, which had helped them to understand and begin to address some of their difficulties. This was accessed from different sources, for example, their community psychiatric nurse, or while in prison. Others felt they needed more help, particularly at vulnerable points such as release from prison, or leaving hospital. One or two respondents described strong feelings of being completely abandoned and let down by services at this point.

Support networks

When asked about what had finally brought them to the stage of seeking treatment, respondents typically made comments along the lines of being 'sick of living', that their life had become 'unmanageable' or fear that if they continued on their current course they would end up dead. Two men specifically referred to not wanting to be perceived by their children as addicts as the decisive factor in their decision. However, motivation to sustain recovery could be sorely tested by staying or being returned to accommodation in an area where they had been known as an addict, and it was consequently very easy to slip back into networks of fellow drug users, many of whom had been friends.

Some also felt threatened and described being hassled and pressurised to buy drugs and return to their old ways; one man said he had been assaulted on the street near his home when he refused to buy drugs. The willpower required to withstand this kind of 'persuasion', whether friendly or otherwise, must be considerable and can propel people into situations of extreme isolation. Several respondents talked about spending a lot of time alone or seeing only one or two trusted contacts. As one man put it:

'I just go to the gym and stuff every day eh. Keep myself to myself.'

For some, isolation can be exacerbated by a fear of going out due to anxiety or depression.

People observed in the premises and waiting rooms of different services appeared, unsurprisingly, to know many of those also attending; it is likely that individuals may build up alternative networks of support with others on treatment.

However problems clearly remain for many who wish to stay in a familiar community they like but where recovery is impeded by other peoples' previous perceptions of them. Those about to be released from prison were fatalistic about their chances of

sustained recovery and felt they would inevitably lapse back into addiction, unless they received a great deal of help.
In conclusion, these interviews were held with people who inject drugs or are on methadone treatment, to gather their views on general and specialised health and drugs services. Interviewees were at different stages of their treatment and the findings reflect this. Service providers were not interviewed at this point in time.

Respondents recognised themselves that drug addicts are not always the easiest or most straightforward people to interact with. One participant specifically referred to seeing fellow clients behave rudely and aggressively to pharmacy staff, and those in recovery described addicts as being adept at manipulation. Some individuals also remarked that they had been upset and angry about a key workers decision, for example instituting daily supervision, but were subsequently able to see the benefits.

It seems undeniable that balancing the individual service user's need for autonomy and control with the necessity to impose constraints on their access to and use of drugs, if they are to successfully recover, is a specialist negotiation that requires skill and knowledge. The researchers acknowledge that it is also a role of which they have no direct experience. While being unconnected with any of the services may have been advantageous in encouraging respondents to be more open in certain respect, it also seems clear that some were less than candid about all aspects of their current drug use.

Nonetheless, the views expressed and the experiences described indicate some clear findings and areas for consideration.

13.2 People attending the Edinburgh Access Practice for the homeless

Participant characteristics

Semi- structured interviews were carried out by one interviewer with 30 participants. Ages ranged from 36-62 with a mean age of 46. Twenty two of the participants reported injecting in the last six months while all participants reported injecting use previously. Twenty one participants were currently homeless or living in homeless accommodation while nine had their own home but had been homeless in the past.

Views on current services

Some respondents were positive regarding services in Edinburgh for drug users and couldn't suggest areas for improvement. Some considered Edinburgh to be better than other cities they had lived in or reported they had witnessed services developing over time.

'They're (services) pretty good here with the access practice and all the services that come with it. It makes such a difference having all the services in the one place.' (Current Injector)

A number suggested increased outreach services or a mobile unit that would attend different locations to provide services.

'More doctors and that at the places where people are rough sleeping. Or even to go to like the night shelters. Maybe in a van or something coz these people are the ones who need help most from doctors and nurses but their lives are so chaotic they aren't able to go get it themselves.' (Current Injector)

One respondent suggested improved communication between prison and primary care was needed particularly in regard to scripts of opiate replacement.

'Leaving prison there has to be more support. For scripts especially like methadone...They leave you waiting and that's how most people end up back on the tools.' (Previous injector)

The main issues

Naloxone

Of the 22 who were injecting, only six currently had a naloxone kit. No participants had used their kit before. Of the 30 participants, 19 had previously had an overdose but none had been injected with naloxone by a non-medical person.

Public injecting

Of the 30 participants, 24 (80%) had injected in a public place at one point in their lives. Immediacy was a common theme with users feeling the need to use soon after purchasing drugs due to withdrawal (rattling):

'For quickness – I was rattling and needed a jag.' (Current Injector)

Others identified that due to homelessness there was nowhere else to go apart from public place:

'Well I'm staying in a tent so there's no' really anywhere to go. I hate it and it's so stupid doing it outside but I have no other option.' (Current Injector)

Safer injecting facilities

When asked specifically about use of Safer injecting facilities (SIFs) the majority said they would use SIFs if available:

'*Aye – the safety and cleanliness of the environment. All the tools and staff on hand to help me if I was to go over.' (Current injector – public in the last 4 weeks)*

However many reported that given the choice between a private place or a SIF, they would rather inject in a personal place due to privacy and comfort.

13.3 Key findings: Service user views

Service providers

- Good relationships with professionals really matter, and integrated care and support provided by one key worker is highly valued.
- Staff in specialist services are generally perceived as supportive and helpful; this extends to some but not all providers in other services, such as some pharmacies and GP practices.
- Peer support is valued, informally as well as in groups, although some prefer a one to one approach. Activities based groups were positively commented on.

Services

- The lengthy assessment period between presentation and starting treatment is a major issue for service users, with potentially serious consequences.
- Respondents generally felt that the range of services currently available met their needs, but some were not aware of all the specialist services on offer.
- There was no consensus on the need for safe injecting facilities or heroin assisted treatment. The majority of people interviewed at the Edinburgh Access Practice indicated they had injected on the street and would consider using such facilities; although many indicated that given the choice they would prefer to inject in a personal place. The views of people (of which 55% were homeless) interviewed in other settings included concerns about efficacy and uptake.

Naloxone

- Among the people interviews at the Edinburgh Access Practice, 6/22 had a naloxone kit and 19/30 had previously experienced an overdose.

Mental health

- Poor mental health, often linked with traumatic events prior to or arising from their drug use, was identified by almost all respondents, and their need for ongoing help.
- Some felt they needed more support with mental health issues; however not all would or had accessed support offered.

Times of transition

- Critical transition points, or times of greater vulnerability to relapse were highlighted – release from prison or hospital, assessment period, return to previous social/community networks.

Sampling

- Recruitment of people for interviews was through services. Therefore, women and other groups with low levels of service engagerment were under represented in these interviews. Any future assessment will take steps to rectify this bias.